Integrated HIV Prevention and Care Plan

including the Statewide Coordinated Statement of Need

State of Maine • 2022

Department of Health and Human Services

A collaborative effort of:

Mainers living with diagnosed HIV/AIDS
The State of Maine Infectious Disease Prevention Program
The State of Maine Ryan White HIV/AIDS Part B Program
The State of Maine's Ryan White HIV/AIDS Part C Programs
The State of Maine's AIDS Education and Training Center
Key stakeholders, including State and community partners

Submitted by the State of Maine's HIV Prevention and RWHAP Part B

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Section I - Executive Summary

Maine faces unique challenges, being geographically larger than the five other New England states combined, but with a total population of only about 1.3 million (roughly the same as San Diego, California). Maine has disparate rural and urban populations and the highest median age of all U.S. states at 45 years of age.

The past three years have created significant challenges across the state and nationwide due to the COVID-19 pandemic as well as the emergence of the monkeypox virus epidemic. It has changed how communities live, behave, and seek health care and supportive services. It has changed how health and support services providers serve people in Maine. The pandemic has also greatly shifted the workforce within Maine's Department of Health and Human Services (DHHS).

Due to these extenuating factors, this plan may highlight service provision and innovations before 2020 and since the start of the pandemic. There will be some data and surveillance trends that address the years 2015-2019, as that was the latest period for which comprehensive data were available. When more current data are available, they are used within this document. The Epidemiologic Snapshot section of this plan and the *State of Maine Epidemiological Profile* provided in Appendix B are the most recent full snapshots available.

Compared to most other states, Maine has a low prevalence of HIV. At the end of 2021, there were 1,802 individuals living with diagnosed HIV in Maine. Of these 1,802 individuals, 72 percent identify their race as white, 79 percent were assigned male at birth, 55 percent are between the ages of 45-64, and 55 percent identify as men who have sex with men (MSM).

Over the last five years, the prevalent population has not changed significantly in terms of race/ethnicity, sex at birth, or route of transmission. The biggest shift has been in age groups, reflecting Maine's aging population. The six-year median of new cases (2016-2021) follows a demographic distribution similar to the overall prevalence.

At the end of 2021, 75 percent of all people living with HIV/AIDS (PLWHA) in Maine were virally suppressed. Although this is a marked increase from 61 percent in 2014, it represents a decrease from the high of 79 percent in 2019. Since the onset of the COVID-19 pandemic, there has been an increase the percentage of PLWHA who have not had timely viral loads (i.e., at least one in any given year). Notable negative disparities in viral suppression exist within the following groups: Black/African Americans, Hispanic/Latinx, PLWHA ages 13-44, and people who inject drugs (PWID).

Annually, more than $31 million is spent on HIV, STD, viral hepatitis, and tuberculosis prevention and care in Maine. More than half of these funds are directed toward pharmaceutical assistance for PLWHA, which contributes to Maine's overall high rate of viral suppression and low number of new cases diagnosed per year. It also includes nearly $1 million per year in housing specifically for PLWHA and more than $26,000 per year in medical transportation for PLWHA, addressing two of the most-identified needs.

Currently, about 60 percent of PLWHA in Maine are enrolled in Ryan White HIV/AIDS Program Part B (RWHAP Part B) services. In 2021, 86 percent of RWHAP Part B enrollees were virally suppressed. About 20 percent of RWHAP Part B enrollees are considered New Mainers (i.e., individuals born in countries other than the United States, regardless of immigration status), who often face immigration, cultural, and language barriers. Appendix Q is a detailed report on issues experienced by New Mainers whose applications are processed through the Boston Asylum Office.

Executive Summary of Integrated Plan and SCSN

Maine's 2022-2026 Integrated HIV Prevention and Care Plan, including the Statewide Coordinated Statement of Need (herein together known as the "Integrated Plan") is based on data specifically collected for the planning process as well as on reports released by other community and governmental agencies regardless of their affiliation with the planning process. The text of the Integrated Plan itself is largely novel. Section III: Contributing Data Sets and Assessments is the only part of the plan that serves multiple functions as it contains text directly from the State's most recent HIV Epidemiological Profile (which is included in its entirety in Appendix B).

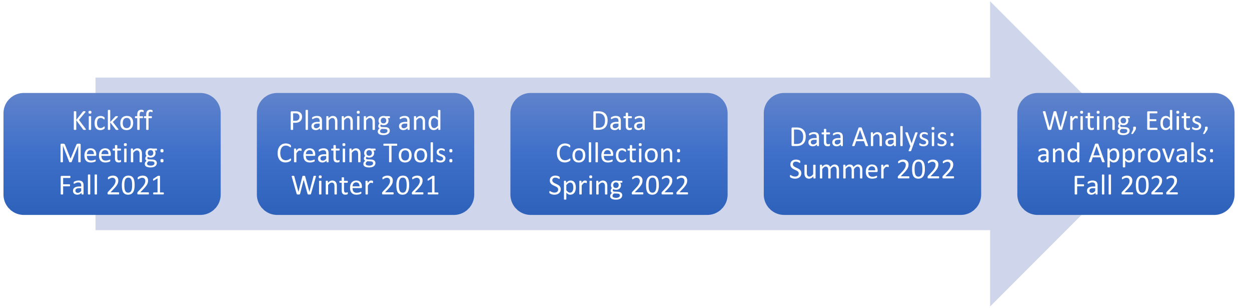
The current 2022-2026 Integrated Plan builds on the 2017-2021 Integrated Plan by continuing the successful activities and strategies that resulted in high overall rates of viral suppression and satisfaction ratings while maintaining low rates of new HIV infections.

Approach

In the fall of 2021, select members of the State of Maine's Infectious Disease Prevention Program came together to develop the framework for the Integrated Plan. Included in this Integrated Planning steering committee were the following individuals, who met bi-weekly from October 2021 to December 2022:

- **Infectious Disease Prevention Program Director** – Lauren Gauthier
- **HIV/STD Prevention Program Manager** – Max Reinhold, then Kiara Caraballo
- **HIV/STD Prevention Health Educator** – Alyssa Farmer
- **RWHAP Part B/ADAP Program Manager** – Margaret Reynolds
- **RWHAP Part B Program Assistant** – Trina Sirois-Bealor
- **RWHAP Part B Data and Quality Specialist** – Tara Thomas

The Maine HIV/AIDS Advisory Board (MeHAAB) was originally established as an integrated planning body for all HIV prevention and care services for the development of the previous Integrated Plan. The steering committee assessed the current membership of MeHAAB in November and December of 2021. To ensure a wide variety of partners were present, the committee reached out to prospective partners via personal calls and emails to request their participation in the planning process. Following recruitment, the steering committee worked with MeHAAB's co-chairs to host a kickoff meeting. In this November 2021 meeting, MeHAAB identified emerging issues among PLWHA and those at higher risk of contracting HIV. The group also developed an actionable timeline for the plan's year-long creation, which took the following form:



As outlined, the steering committee spent two months after the kickoff meeting gathering existing data reports from MeHAAB partner organizations. Simultaneously, the committee developed various needs assessment surveys and a questionnaire for interviews. After edits, beta testing, and approval from MeHAAB, the committee used these tools to collect and analyze data. The steering committee then presented its synthesized findings to the larger planning body, and the advisory board spent its next two monthly meetings setting goals and objectives to address the barriers, gaps, strengths, and opportunities identified in the analysis.

Finally, the steering committee completed a draft Integrated Plan and shared it with MeHAAB. After the group had approved the document, the steering committee disseminated it to the Director of Maine Center for Disease Control and Prevention (Maine CDC), Nirav Shah, JD, MD; the Associate Director for Maine CDC Division of Disease Surveillance, Ann Farmer, MS; the State Epidemiologist for Maine CDC, Isaac Benowitz, MD. Final approval came from Maine's Commissioner for the Department of Health and Human Services (DHHS), Jeanne Lambrew, PhD.

Documents submitted to meet requirements

Maine's 2022-2026 Integrated Plan outlines the goals, objectives, and strategies to address the HIV epidemic in the state. All goals fall within the categories created by the U.S. Centers for Disease Control and Prevention (US CDC) vis a vis *Ending the HIV Epidemic: A Plan for America* (EHE). To inform these goals, the State's steering committee created three needs assessment surveys that were distributed to RWHAP Part B enrollees, PLWHA who were not enrolled in RWHAP Part B, and those at risk of HIV/STDs. Members of the steering committee also conducted a small focus group among PLWHA in northern Maine and 22 one-on-one interviews with people living with or at risk of HIV. The surveys, interviews, and focus group provided invaluable data on the lived realities of people using HIV prevention and care services in Maine.

The following reports examine the data collected specifically for the Integrated Planning process:

- Detailed Resource Inventory (Appendix C)
- *State of Maine Infectious Disease Prevention Program 2022 Workforce Survey Report* (Appendix E)
- *State of Maine 2022 HIV/STD Prevention Needs Assessment Survey Report* (Appendix G)
- *State of Maine 2022 Needs Assessment Survey Report: People Living with HIV/AIDS* (Appendix H)
- *State of Maine RWHAP Part B 2022 Needs Assessment Survey Report* (Appendix I)

- *State of Maine Infectious Disease Prevention Program 2022 Interview Summary Report* (Appendix V)

These reports were created independently of the Integrated Planning process but contributed valuable data nonetheless:

- *State of Maine Epidemiological Profile, 2020* (Appendix B)
- *Maine Shared Community Health Needs Assessment Report 2022* (Appendix D)
- *Office of MaineCare Services HIV/AIDS Waiver – 2020 Provider Survey Analysis* (Appendix F)
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- *Syringe Service Programs in Maine 2021 Annual Report* (Appendix R)
- *Vulnerability Assessment for Opioid Overdoses and Bloodborne Infections Associated with Non-Sterile Injection Drug Use in Maine* (Appendix S)
- *Maine Opioid Response: 2021 Strategic Action Plan* (Appendix T)

A table that outlines the major themes of these documents can be found in Section III.

Section II - Community Engagement and Planning Process

From summer 2021 to winter 2022, the State's steering committee worked with MeHAAB to recruit and engage a diverse cross-section of stakeholders. To ensure the planning body prioritized the needs of those most impacted by HIV, recruitment focused on engaging organizations and individuals who could represent priority populations and speak to their most pressing concerns. Immediately upon coming together for the first time in November 2021, MeHAAB identified emerging issues, trends, and priority populations which were used to inform the creation of needs assessment tools during the data-gathering process.

Section II details Maine's planning process, including the makeup of MeHAAB, how PLWHA were engaged in the planning process, emerging issues identified by the body, and how these issues resulted in the goals and objectives set forth in this plan.

Jurisdictional Planning Process

In summer of 2021, the State's steering committee established hour-long, biweekly planning meetings. The initial meeting was three hours long and was held to develop a 2021-2022 timeline with clear deadlines for recruitment, data collection, data analysis, writing, and approval processes. In the month that followed, the State's team more thoroughly reviewed the newly released federal guidance, Maine's 2017-2021 Integrated Plan, and goals set forth by both EHE and National HIV/AIDS Strategy (NHAS). While Maine is not an EHE priority location, the team still utilized EHE and NHAS goals as general guidance for prioritizing objectives and strategies. These strategies, detailed in Section V, were used to create a foundation on which to build the Integrated Plan.

In its second meeting, the committee evaluated and assessed current and former MeHAAB membership to create an updated list of stakeholders. Using the "Examples of Key Stakeholders and Community Members" in Appendix 3 of the Integrated Plan Guidance, the group identified gaps among existing MeHAAB participants. After creating a final comprehensive list of potential and current participants, each State steering committee member reached out to prospective partners via email and phone. For partners who were required to engage in the planning process, the State outlined their responsibilities in an introductory email. Committee members also asked external partners to identify PLWHA or individuals at high risk of HIV transmission who would be interested in joining MeHAAB. For those representatives (PLWHA and those at higher risk), the State offered incentives in the form of grocery cards as compensation for the time spent in meetings. Finally, to assist external partners with client/patient recruitment, the State created marketing materials and social media content for partners to distribute. The recruitment flyer is included as Appendix U.

Once the initial recruitment phase was completed, the State's steering committee facilitated a day-long kickoff meeting. The meeting included the following components:

- Introductions
- Explanation of MeHAAB and participation requirements
- Overview of the Integrated Planning process

- 2020 data on HIV prevention and care in Maine
- Request for existing data
- 2021-2022 Integrated Plan creation timeline

MeHAAB met monthly after the kickoff meeting. All planning meetings for both the State's steering committee and the MeHAAB planning body were held virtually.

Entities Involved in Process

The following entities have been actively involved in the MeHAAB Planning Process:

MeHAAB Participants – Integrated Plan Planning Process	
Category	**Representation**
PLWHA	• Eight PLWHA
Substance use/PWID/PWUD	• Church of Safe Injection • Maine Access Points • MaineGeneral Syringe Service Program • City of Portland Syringe Service Program
Community-based organizations serving PLWHA, social services providers, mental health providers	• Frannie Peabody Center • Health Equity Alliance • Horizon Program at MaineGeneral Medical Center • St. Mary's Regional Medical Center • Healthy Living for ME®
HIV testing and outreach programs	• Frannie Peabody Center • Health Equity Alliance
STD clinics and programs	• City of Portland STD Clinic • Maine Family Planning
Housing services providers	• HOPWA Provider (Frannie Peabody Center)
State HIV/AIDS legislative advocacy	• HIVAC
Indigenous communities	• Wabanaki Public Health and Wellness
Medicare/Medicaid	• Office of MaineCare Services
RWHAP Part C	• Horizon Program at MaineGeneral Medical Center • Greater Portland Health • Regional Medical Center at Lubec
RWHAP Part F	• Gilman Clinic
Immigrant population	• Maine Access Immigrant Network
Other government offices/agencies	• Department of Education • Office of Behavioral Health • Maine CDC Rural Health and Primary Care Program
Non-RWHAP Part C HIV care clinics	• Gilman Clinic

	- St. Mary's Regional Medical Center
Universities	- University of Maine at Farmington

Role of RWHAP Part A Planning Council/Planning body

There are no Part A programs that serve the State of Maine.

Role of Planning Bodies and Other Entities

The role of the State's steering committee was to create a 2021-2022 progress timeline, recruit and retain MeHAAB members, request and compile existing data, collect new data, analyze all data, and draft the Integrated Plan.

As noted in the Executive Summary, six Maine CDC staff made up the State's steering committee. Collectively, these individuals administer Maine's cooperative agreements with US CDC for HIV and STD prevention and oversee all RWHAP Part B services, including the AIDS Drug Assistance Program (ADAP). The ADAP Coordinator and ADAP Eligibility Specialist also periodically attended MeHAAB meetings to provide their insight and expertise.

The role of the larger MeHAAB planning body was to guide data collection, provide insight into needs and barriers of priority populations, establish goals and objectives for the Integrated Plan, and approve the final plan. MeHAAB members also provided monthly updates from their organizations and discussed emerging issues, such as COVID-19 and monkeypox.

In addition, several MeHAAB members are also part of Maine's HIV/AIDS Advisory Committee (HIVAC), a group of PLWHA and organizational/governmental representatives who aim to create, champion, and change legislation to support the health and wellness of PLWHA. Having individuals who were both involved in HIVAC and MeHAAB created a symbiotic relationship between the groups via information and data exchange. The data MeHAAB collected and compiled has and will help HIVAC advocate for beneficial legislation.

Collaboration with the RWHAP Parts

In addition to the RWHAP Part B, Maine has three RWHAP Part C recipients:

- Horizon Program at MaineGeneral Medical Center (Augusta, ME)
- Greater Portland Health (Portland, ME)
- Regional Medical Center at Lubec (Lubec, ME)

Gilman Clinic is subcontracted by the Northeast AIDS Education Training Center (AETC) in Boston to provide Ryan White Part F services throughout Maine.

While the RWHAP Part B Program co-led the steering committee planning process with their US CDC-funded Prevention colleagues, the Part Cs and AETC contributed in two ways. First, they routinely participated in monthly MeHAAB planning body meetings. Second, they provided both the information needed for the Resource Inventories and any additional non-identifying data they collected over the previous year.

Engagement of People with HIV

PLWHA were involved in every step of the Integrated Planning Process. They will also be heavily involved in future implementation, monitoring, evaluation, and improvement processes of the Integrated Plan through participation in MeHAAB and needs assessments.

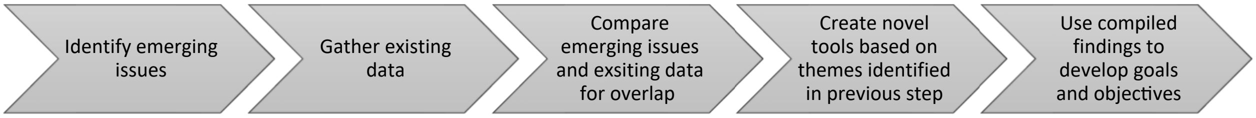
PLWHA were first brought into the planning process during the kickoff meeting. Over the next 12 months, MeHAAB continued to encourage unaffiliated PLWHA to attend MeHAAB meetings via flyers, social media posts, incentives, and personal outreach. By the end of the planning process, MeHAAB had eight PLWHA actively involved. These members represented a cross-section of demographics, including representatives from three primary risk populations--MSM, PWID, and females at very high risk (FVHR). Long-term survivors and members of populations with statistically significant viral suppression disparities in Maine were also represented.

By the end of the planning process, PLWHA had contributed in the following ways:

1. PLWHA attended all monthly MeHAAB meetings.
2. Per MeHAAB bylaws, a PLWHA co-chaired MeHAAB. This person was integral in crafting and approving agendas for each meeting.
    a. During the Integrated Planning process kickoff meeting, PLWHA helped to create a document identifying emerging issues in the following areas:
        i. HIV Care
        ii. HIV Prevention
        iii. Substance Use and Syringe Services
        iv. Miscellaneous
3. One member of the State's HIV/STD Prevention team and one member of the State's HIV Care team conducted 17 individual interviews with PLWHA. Two of the interviews were conducted with individuals who are also part of MeHAAB.
4. Four PLWHA participated in a focus group in northern Maine that focused on needs of PLWHA in rural areas, including case management, medical care, ADAP usage, and barriers to health.
5. PLWHA participated in two new needs assessment surveys created by the State's steering committee: one for PLWHA who are part of the RWHAP Part B Program (which received 446 responses) and one for PLWHA who are not clients in the RWHAP Part B Program (which received 21 responses).
6. In addition to their participation in novel data collection, PLWHA were represented via annual client surveys conducted by the Office of MaineCare Services, RWHAP Part B, and two RWHAP Part Cs (Horizon Program at MaineGeneral Medical Center and Regional Medical Center at Lubec).

Priorities

MeHAAB determined its priorities by comparing data collected before, during, and after the integrated planning process. The below graphic gives a high-level view of the process, and the following sections expand upon it.



Before Data Collection and Analysis

During the kickoff meeting, the steering committee facilitated a brainstorming activity to identify potential key issues around which to focus data collection. The results are noted in the table below. All bullet points came from PLWHA, people at risk for HIV, or key partners.

Emerging Issues for Mainers LWHA and Higher-Risk Populations

Compiled via a brainstorming activity in MeHAAB's Nov. 2021 kickoff meeting.

HIV Care	**HIV Prevention**
• Geriatric care (aging) • Co-morbidities with chronic/terminal diseases • Mental health needs (lack of accessible care) • Education - e.g. Providers aren't always accessing treatment guidelines, disconnection from specialists, don't know enough about long-acting injectables • Pandemic Issue - Disengagement with services • Concern around financial assistance program caps for the RWHAP Part B. • Definition of a family for eligibility purposes	• Education - Understanding HIV for Health Care Providers • PEP and PrEP knowledge - provider education and access • Late HIV diagnosis • Concern that people who believe themselves to have a low risk of contracting HIV means they are not being screened for HIV • PrEP uptake for injection drug users • General education for youth and young adults • PrEP and PEP laws: collaborative prepping for the impacts of new policies. • Creating a system of referrals
Substance Use and Syringe Services	**Miscellaneous**
• Issues specific to the COVID-19 pandemic: (1) Loneliness and isolation (2) Increasing stimulant use (methamphetamines and cocaine)	• Housing issues have been exacerbated by the COVID-19 pandemic and inflation. • Politics (who set policies) can and have impacted government, social, and medical programs

• Drug treatment systems are not geared to treat methamphetamines and cocaine, but we are seeing higher usage of those drugs. • Not enough gay and bisexual-focused programs surrounding use of crystal meth • More robust harm reduction offerings for people using stimulants • Dangerous result if we return to 1-1 exchange • Criminal penalties for syringe possession- new policy implications • Increasing diagnosis Hepatitis C	• Issues specific to the COVID-19 pandemic: (1) Barriers to internet and computer access, (2) telehealth opportunities, and (3) loneliness and isolation • Maine does not do a great job serving immigrants or those who don't speak English. We do not have enough diverse languages for materials and all organizations in the field need better cultural competency training • Food security • Lack of hygiene • Access to mental health care for those with MaineCare • Outreach to specific subpopulations, specifically Hispanic and/or Latinx

During Data Collection and Analysis

The steering committee reviewed and edited existing needs assessment surveys from prior planning processes and solicited from other jurisdictions, integrating additional questions based on the emerging issues identified above and other key points of interest, including:

1. Experiences of PLWHA in the health care system
2. Housing for both PLWHA and those at risk of contracting HIV
3. The state of cultural competency within support organizations (governmental, nonprofit, and for-profit)
4. Mental health for both PLWHA and those at risk of contracting HIV
5. Aging with HIV
6. PrEP and PEP
7. Injection drug use as it relates to PLWHA and those at risk of contracting HIV
8. Impacts of the COVID-19 pandemic on both PLWHA and those at risk of contracting HIV
9. Preventing HIV among high-risk young adults
10. Case management for PLWHA
11. State of HIV care for those living rurally (telehealth, travel time to care)
12. Specific needs of the New Mainer community (primarily immigrants and asylum-seekers from Angola, Burundi, Congo, Rwanda, and Sudan)

After Data Collection and Analysis

After all data (new and existing) were collected and analyzed, MeHAAB identified broad priorities based on the findings. These priorities were used to craft Maine's goals, and they included:

1. Mental health care
2. Access to health care
3. Communication from the State about HIV/HCV/STDs.
4. The discrepancy in perceived risk versus actual risk of an HIV, HCV, or STD infection

While not all priorities can be addressed within the timeframe of this Integrated Plan, they were all considered when goals and objectives were created.

Updates to Other Strategic Plans Used to Meet Requirements

This does not apply to the State of Maine.

However, existing strategic plans did inform the development of this plan, such as the *Maine Shared Community Health Needs Assessment Report* (Appendix D) and the *Opioid Response Action Plan* (Appendix T).

Section III - Contributing Data Sets and Assessments

This section contains a summary of the qualitative and quantitative data used to develop the Integrated Plan. Full data reports and detailed analyses are available in the appendices.

Maine's status as a low prevalence state with a handful of entities receiving direct funding from US CDC and the RWHAP enables it to more easily execute data-sharing agreements than larger jurisdictions, allowing for routine information-sharing and more integrated care.

In addition to the reports attached as appendices, quantitative service data were available from HOPWA annual progress reports, Ryan White Services Reports, and periodic data reports from EvaluationWeb and CAREWare. Qualitative data were collected via a small focus group and one-on-one interviews with PLWHA and those at risk of contracting HIV.

Data Sharing and Use

Data available to the jurisdiction for the purposes of this Plan included previously published data reports; HIV surveillance data housed in the Maine Electronic HIV and AIDS Reporting System (eHARS); service utilization and outcomes data related to contracted HIV/STD prevention partners through data entered in EvaluationWeb; service utilization and demographics within harm reduction services; and demographic, service, and clinical data entered into the statewide CAREWare network.

These data were used to generate the Care Continuum, the *State of Maine HIV and AIDS Epidemiological Profile* (Appendix B), and to identify trends in services to compare to the Resource Inventory and gaps/barriers identified in needs assessments.

There are longstanding data-sharing mechanisms in place that facilitate the routine exchange of client-level data to ensure continuity of care and monitoring of health outcomes.

The CAREWare network includes the RWHAP Part B and its subrecipients, two of the three RWHAP Part C recipients (Regional Medical Center at Lubec and Horizon Program at MaineGeneral Medical Center) and their subrecipients, and the Office of MaineCare Services. Access to the network is granted by data-sharing agreements. Demographic data, including ADAP and case management eligibility, are shared among all providers within the CAREWare network. Certain variables (such as housing status, poverty level, and lab data) can be set to extract the most recent value from any provider on the network in Custom Reports.

Maine CDC's data-sharing agreement with the Office of MaineCare Services (OMS) not only grants OMS access to CAREWare but describes how the two offices within the State's Department of Health and Human Services share eligibility, claims, and laboratory data.

Maine CDC's Infectious Disease Prevention Program conducts quarterly matching between HIV Care (RWHAP Part B) and HIV Surveillance. Surveillance uses these matches to update demographics and care status; Care uses them to import CD4 and viral load results into CAREWare. Because Surveillance and Care both fall within the Infectious Disease Prevention

Program, there is no data-sharing agreement in place. Instead, these data exchanges are governed by internal program policies and procedures and role-based access in the respective data systems.

Other data used to support planning include public disease surveillance reports published by Maine CDC's Infectious Disease Epidemiology Program, the Maine Shared Community Health Needs Assessment, and the Maine Integrated Youth Health Survey. These reports were used to identify health-related trends among the general population in Maine for comparison to needs assessment data among people living with or at risk of HIV.

Epidemiologic Snapshot

The following Epidemiologic Snapshot is excerpted from the *State of Maine Epidemiological Profile, 2020* (Appendix B), the most recently available epidemiological profile.

In 2019, Maine's population was an estimated 1.3 million. More than 36 percent of Maine residents lived in its two southern-most counties, York and Cumberland. 51 percent of Maine's population identified as female, and 93 percent of Maine's population identified as non-Hispanic White. Individuals of any race who identified their ethnicity as Hispanic/Latino made up approximately 2 percent of the population. Approximately one-third of Maine's population was over 55 years old.

During 2019, there were 29 newly diagnosed cases of HIV reported to the Maine CDC. Of those, 38 percent were cases of stage 3 HIV infection (AIDS). As of December 31, 2019, there were an estimated 1,757 individuals living with diagnosed and reported HIV disease (PLWHA) residing in Maine. Of these, 52 percent were infected with HIV (stages 1, 2 or unknown) and 48 percent were infected with AIDS (HIV stage 3).

In 2019, the estimated rate of reported HIV disease in Maine was 130.7 cases per 100,000 (95 percent CI: 124.6 – 136.8), an increase since 2010, when the estimated rate of HIV/AIDS in Maine was 108.2 cases per 100,000 (95 percent CI: 102.6 – 113.8). This increase in HIV prevalence may be due to several factors, including increased HIV testing, improved disease reporting and data collection, and longer lifespans among PLWHA.

In 2019, the majority of new HIV diagnoses were among males (72 percent). 78 percent of the total 1,757 PLWHA in Maine were male; 22 percent were female.

Approximately 59 percent of new HIV diagnoses in 2019 were among non-Hispanic White individuals and 35 percent were among non-Hispanic Black/African American individuals. 76 percent of new HIV diagnoses in Maine in 2019 were among individuals over the age of 30.

African Americans accounted for 19 percent of Maine PLWHA overall. Approximately seven percent of PLWHA in Maine were of Hispanic/Latino ethnicity. Approximately 18 percent of Maine PLWHA were born outside the U.S. In 2019, both Black/African American and Hispanic/Latino populations in Maine experienced a disproportionately high rate of HIV disease.

Among PLWHA in Maine, 53 percent were likely to have been infected through unprotected male-to-male sex, 8 percent through injection drug use, and 3 percent through a combined risk of male-to-male sex and injection drug use. Eleven percent of all known infections were likely transmitted via high-risk heterosexual contact; this was the most frequent mode of identified transmission for HIV-positive women (36 percent).

Thirty-seven percent of all Maine PLWHA were living in the Cumberland Public Health District (PHD) at the time of their HIV diagnosis. Additionally, 52 percent of individuals newly diagnosed with HIV in 2019 were residing in the Cumberland PHD.

Between 2010 and 2019, an estimated 220 HIV positive individuals died in Maine. Sixty-six percent of these deaths were due to causes other than those directly related to HIV.

Population level estimates of certain behaviors or diseases known to be associated with HIV transmission can assist in understanding trends and changes in HIV risk. These include HIV testing, sexual risk behaviors, sexually transmitted diseases, viral hepatitis, and injection drug use. According to the 2019 BRFSS, approximately 36 percent of Maine adults reported they had ever received an HIV test.

Advancing our focus to the intersection of HIV and other select STDs, in 2019 there were 3,989 cases of chlamydia reported to the Maine CDC for a rate of 296.8 cases per 100,000 individuals. Rates were highest among women, adolescents, and young adults. During the same year, there were 547 cases of gonorrhea reported to the Maine CDC and the rate was 40.7 cases per 100,000 individuals. Rates of gonorrhea were highest among men and young adults aged 20-29. There were 111 cases of syphilis reported to the Maine CDC in 2019, including 96 cases among males (89 percent). Approximately half of 2019 syphilis cases occurred among those reporting male-to-male sexual contact and a quarter were among persons coinfected with HIV.

Viral hepatitis shares common modes of transmission with HIV, and HIV-positive individuals are particularly at risk for viral hepatitis infection. In 2019, there were 59 acute cases of hepatitis C and 1,917 cases of chronic hepatitis C reported in Maine. The rate of chronic hepatitis C has been increasing in Maine over the past five years.

Injection drug use is a risk factor for acquiring and/or transmitting HIV. At the end of 2019, there were 135 Maine PLWHA who were known to have likely acquired the disease via injection drug use, representing 8 percent of Maine PLWHA. According to data from the Maine (DHHS), Office of Behavioral Health (OBH), 22 percent of individuals admitted to substance use disorder treatment in 2019 reported injection drug use. Of those, 39 percent disclosed sharing needles in the past six months.

Engaging in certain types of unprotected male-to-male sexual contact can place individuals at a higher risk for acquiring HIV from, or transmitting HIV to, sexual partners. MSM make up the majority of PLWHA in Maine and nationally. MSM also made up the largest proportion of cumulative new diagnoses of HIV disease in Maine from 2015 through 2019.

High-risk heterosexual contact can also place an individual at increased risk for HIV. In 2019, an estimated 11 percent of Maine PLWHA likely acquired the disease through high-risk heterosexual contact. High-risk sexual contact includes contact with a partner who uses injection drugs, is a bisexual male, and/or is HIV-positive. High-risk sexual contact was a more common mode of HIV transmission among female and Black/African American PLWHA in Maine.

Youth ages 13 to 24 are a population of special concern for HIV planning and prevention because they experience several significant risk factors related to HIV—including risky sexual behaviors, substance abuse, and lack of access to health care—at higher rates than other age groups. In 2019, 14 percent of new HIV diagnoses in Maine in were among this age group.

The number of HIV-positive individuals in Maine currently using illicit drugs is unknown. According to the 2018-2019 National Survey on Drug Use and Health (NSDUH), approximately 19 percent of Maine residents over age 12 reported using a least one illicit drug in the month preceding the survey, and 56 percent had used alcohol in past month. Young adults ages 18 to 25 had the highest rate of substance use in Maine.

In 2019, approximately 22 percent of Maine PLWHA were female. Female PLWHA in Maine were more racially diverse and were also more likely to have acquired HIV via high-risk heterosexual contact or injection drug use compared to male PLWHA.

Engagement in appropriate HIV medical care reduces morbidity and mortality among PLWHA. In 2019, more than 96 percent of individuals newly diagnosed with HIV were linked to HIV care within three months of their diagnosis. Among individuals diagnosed with HIV in Maine and living in the state as of the end of 2019, approximately 83 percent were in HIV care and 79 percent were considered virally suppressed.

Health care coverage is an important factor in receiving timely and appropriate HIV care. In 2019, approximately 63 percent of Maine PLWHA were enrolled in the State's ADAP Program. Of these enrollees, 92 percent had some type of health insurance coverage at some point during 2019.

Pre-exposure prophylaxis (PrEP) has been proven to reduce the risk of getting HIV from sex by 99 percent and reduces the risk of transmission through needle-sharing by at least 74 percent. National research shows an emerging association between PrEP use and declines in rates of new HIV infections. This is a topic for future exploration and study in Maine, as the impact of PrEP in the state is yet to be determined. Preliminary data from CDC in 2020 show that PrEP uptake is low for key populations, such as youth ages 16-24, Black, and Hispanic/Latino people when compared to all other age groups and racial/ethnic groups. Data from CDC show that in 2019 and 2020, 636 and 658 people were prescribed PrEP, respectively. This represents only 16 percent PrEP coverage, which is calculated as the number who have been prescribed PrEP over the estimated number of persons who had indications for PrEP.

The term "treatment as prevention" (TasP) describes the concept of HIV prevention through clinical treatment of PLWHA. For TasP to be effective, PLWHA must have a suppressed HIV viral load, at which point the risk of transmitting HIV to sexual partners is virtually eliminated.

Maine was recognized in the NASTAD 2020 data report for high rate of viral suppression among RW Part B enrollees. The high rate of access to care and viral suppression in Maine may be helping to prevent new infections in the state.

Despite medical advances and focused HIV prevention and care programs, HIV continues to have a harmful impact on the health and well-being of Maine people. New infections are occurring in Maine even as HIV-related deaths decline and HIV prevalence is incrementally increasing. Continued work in HIV prevention and care services remains vital in promoting the health of all Maine residents.

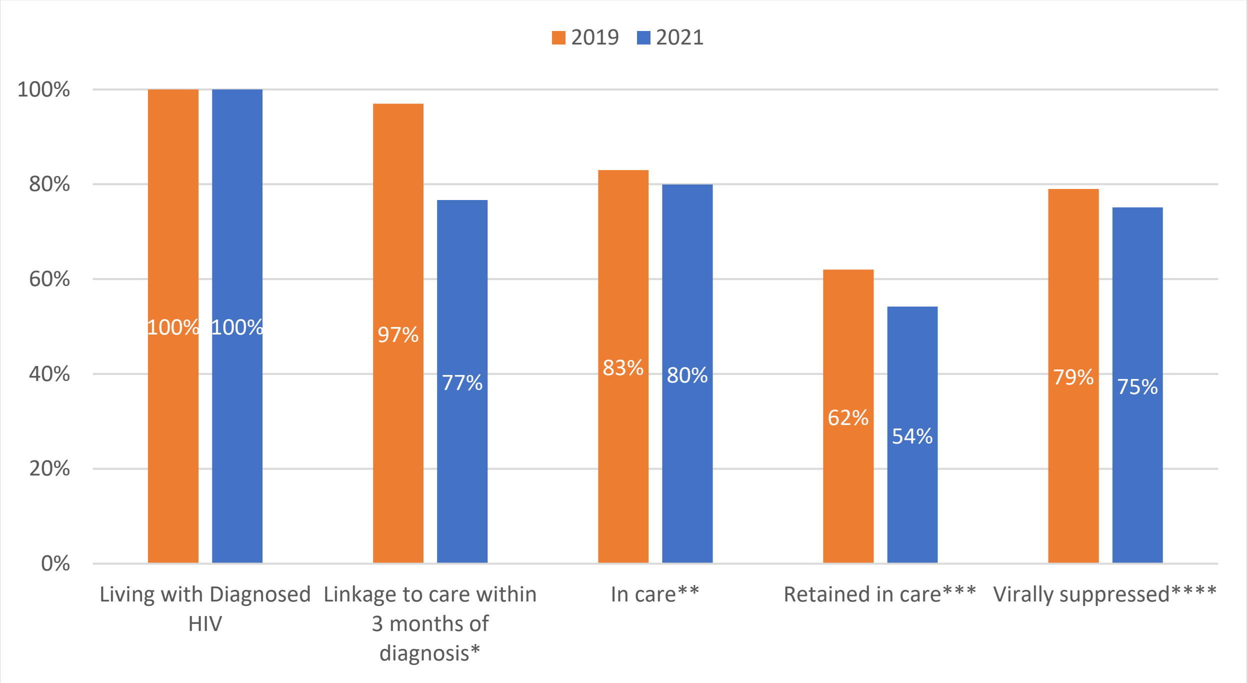
For more information, please see the *State of Maine HIV and AIDS Epidemiological Profile, 2020*, in Appendix B.

Continuum of HIV Care in Maine

The HIV care continuum describes a series of critical points for PLWHA in engagement in HIV care, with viral load suppression as a key goal to improve health outcomes and reduce HIV transmission.

As described previously, the COVID-19 pandemic has had an impact on health engagement and outcomes for PLWHA in Maine and around the world. Figure 1 below illustrates the HIV Care Continuum included in Appendix B (using data from 2019) alongside the most recent HIV Care Continuum (using data from 2021).

Figure 1. Continuum of care among individuals (age 13+) PLWHA in Maine, 2019 and 2021



Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

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[*] For individuals newly diagnosed in the calendar year (n=29 in 2019 and n=30 in 2021).

[**] Defined as the number of persons who had either ≥1 CD4+ or viral load test result during the calendar year.

[***] Defined as the number of persons who had ≥ 2 CD4 or VL at least 90 days apart in the calendar year.

[****] Defined as the number of persons who had suppressed VL (≤200 copies/mL) at most recent test during the calendar year.

HIV Prevention, Care, and Treatment Resource Inventory

More than $31 million per year is directed toward HIV, STD, viral hepatitis, and tuberculosis prevention and care services in Maine. The following organizations and agencies provide direct services related to HIV, STDs, viral hepatitis, and/or tuberculosis:

- **Office of MaineCare Services:** State Medicaid program, includes an 1115 Waiver to provide services to people living with HIV with an income up to 250 percent of the federal poverty level.
- **Maine CDC Infectious Disease Prevention Program:** RWHAP Part B recipient, US CDC grantee.
- **City of Portland Public Health:** Provides HIV/STD testing and syringe services with funding from Maine CDC and directly from US CDC.
- **Frannie Peabody Center:** HOPWA grantee and recipient of private grants. Community-based nonprofit that provides HIV prevention and care services in southern Maine. Contracted by Maine CDC to provide HIV prevention and RWHAP Part B case management services. Bills MaineCare for targeted case management and behavioral health services.
- **Maine Access Points:** Community-based nonprofit that provides harm reduction, syringe access services, overdose prevention education, naloxone distribution, peer support, and advocacy statewide. Recipient of private grants, contracted by Maine Department of Health and Human Services to provide HIV/hepatitis prevention, harm reduction, and substance use services.
- **Health Equity Alliance:** Community-based nonprofit that provides HIV prevention, case management, sexual health and wellness, and harm reduction services in northern Maine. Recipient of private grants. Contracted by Maine CDC to provide HIV prevention. Contracted by Regional Medical Center at Lubec to provide RWHAP Part C medical case management.
- **Regional Medical Center at Lubec:** RWHAP Part C recipient in northern Maine.
- **Greater Portland Health:** RWHAP Part C recipient in southern Maine.
- **Horizon Program at MaineGeneral Medical Center:** RWHAP Part C recipient in central Maine.
- **Gilman Clinic:** Contracted to provide AIDS Education Training Center services in Maine, including consultation with health care providers. Provides medical care for people with HIV and viral hepatitis.
- **Maine Family Planning:** Community-based nonprofit that provides reproductive health services. Contracted by Maine CDC to provide HIV/STD/hepatitis prevention services.

Figure 2 below shows total direct service dollars from public and private funding sources allocated by the organizations and agencies listed above to HIV, STD, viral hepatitis, and tuberculosis services by activity. (A more detailed table is available in Appendix C.)

Figure 2. Combined Resource Inventory, Maine

Activity	Total
AIDS pharmaceutical assistance	$16,372,041
Health insurance premium and cost-sharing assistance	$2,113,400
Other: Hospital and ambulance	$1,502,487
Case management (targeted, medical, non-medical)	$1,400,365
Naloxone distribution	$1,384,063
Syringe service programming	$1,252,900
Outpatient/ambulatory health services	$1,008,901
Housing	$999,613
Substance use/overdose prevention, outreach, education, and navigation	$961,332
HIV counseling, testing, referral services	$456,233
Home and community-based health services	$420,255
Other: Behavioral health clinician	$385,046
STD counseling, testing, referral services	$350,318
Oral health care	$337,617
Hepatitis counseling, testing, referral services	$321,813
Other: Nursing home & PNMI	$230,660
Mental health services	$218,192
Other: Fiscal employer agent	$213,251
Health education/risk reduction	$194,000
Food assistance	$179,000
Other: Community provider	$173,765
Other: COVID-19 STD Workforce Supplemental	$100,000
Other: COVID-19 and adult vaccination community education and linkage to care	$85,234
Early intervention services	$80,639
Other: Provider education and training	$65,432
Other: Durable medical equipment supplier	$40,707
Tuberculosis Control and Assistance	$38,000
Outreach and social marketing/communications	$36,807
Substance abuse outpatient care	$34,720
Medical transportation	$26,700
Emergency financial assistance	$23,000
Rehabilitation services	$16,340
Psychosocial support services	$15,000
Medical nutrition therapy	$11,050
Other: Optometrist and vision center	$7,410
Hospice	$6,947
Other professional services	$6,000
Other: Advocacy activities compliant with 501(c)3	$3,750
PrEP	$1,200
Grand Total	**$31,074,188**

Maximizing the Quality of Health and Support Services Available to People At Risk

Currently, Maine has two community-based HIV/STD testing partners and two clinical-based HIV/STD testing partners. Community-based sites offer rapid HIV and HCV testing in addition to condom distribution and educational outreach. Maine has an online ordering system for any entity to procure external and internal condoms, dental dams, lubricant, and educational brochures and flyers. Maine will use the distribution information to assess geographic reach and how best to increase access to educational and safer sex materials in the plan. Figure 3 below shows the number of safer sex materials (internal and external condoms, dental dams) distributed from 2018-2021.

Figure 3. Total Number of Safer Sex Materials Distributed in Maine, 2018-2021

	2018	2019	2020	2021
Number of Safer Sex Materials	83,025	83,818	34,375	142,265

Clinical-based sites offer confirmatory HIV, HCV tests, syphilis, gonorrhea, and chlamydia testing (including extragenital) and treatment services in addition to rapid testing and outreach. Maine CDC partners with funded and non-funded testing sites to provide outreach, education, and testing to people at highest risk for HIV/HCV/STD transmission. Maine CDC provides rapid HIV counseling, testing, and referral training to syringe service programs, clinical staff at FQHCs that are interested in expanding outreach, and racial/ethnic minority serving organizations.

As part of the goals and objectives described in Section V, Maine will continue to increase HIV/STD/HCV counseling and testing access through partnerships with MAT programs, rural health networks, and among youth. Figures 4 and 5 below describe the number of tests distributed from 2019-2021 by community and clinical providers. Figure 6 shows testing and linkage outcomes for key priority populations, including FVHR, MSM, and PWID from 2019-2021 who were enrolled in HIV testing program.

Figure 4. Total Number of HIV Tests Distributed in Maine, 2019-2021

	2019	2020	2021
Number of HIV Tests Distributed	1889	927	1347
Number Newly Diagnosed	6	1	6
Number linked to care	4	1	5

Source: EvaluationWeb; Maine Electronic HIV and AIDS Reporting System (eHARS)

Figure 5. Total Number of HIV Tests Distributed in Maine by Population, 2019-2021

Population	2019	2020	2021
FVHR	302	131	259
MSM	602	452	553
PWID	498	125	160

Source: EvaluationWeb; Maine Electronic HIV and AIDS Reporting System (eHARS)

Figure 6. Total Number of Clients Newly Diagnosed and Linked to Care in Maine, 2019-2021

	2019		2020		2021	
Population	No. New Dx	No. LTC	No. New Dx	No. LTC	No. New Dx	No. LTC
FVHR	0	0	0	0	0	0
MSM	5	3	1	1	6	5
PWID	1	0	0	0	0	0

Source: EvaluationWeb; Maine Electronic HIV and AIDS Reporting System (eHARS)

The COVID-19 pandemic created significant challenges to partner sites and client access as many sites were forced to limit their hours, testing, and outreach locations to provide services. There were fewer clients getting tested. To help address some of the pandemic-related issues, Maine redirected some federal funding from US CDC to support partner sites with at-home testing. Additionally, in 2020, Maine CDC established a partnership with NASTAD and Building Health Online Communities (BHOC) to support at-home HIV testing through social networking apps. Through both programs, Maine distributed 154 and 129 home tests statewide in 2020 and 2021 respectively. Maine will continue to incorporate at-home testing in its service provision and refine its process to improve linkage-to-care for self-tested individuals. Maine CDC has increased efforts to provide more at-home testing through partnerships with SSPs and organizations in rural areas.

Coordinating Substance Use Prevention and Treatment Services

Since 2019, Maine has seen a significant investment and increase in the provision of syringe service programs (SSPs). Maine had three certified SSPs across six sites prior to 2019. Maine now has eight partners across 21 sites, 17 of which are currently operating. With the increased financial investment and resources from the State of Maine there was a subsequent increase in the number of syringe program participants, number of syringes exchanged and disposed, and the diversity of referrals made. The Governor of Maine further expanded services for SSPs through emergency executive orders during the pandemic. Additionally, Maine decriminalized the possession of syringes which allowed for increased syringe access to people in Maine in 2021. More syringe program information can be found in Appendix R.

In 2019, a Vulnerability Assessment (Appendix S) was released showing the geographic areas where residents are at highest risk of opioid overdoses and bloodborne infections due to injection drug use. The most vulnerable areas are Kennebec County, Penobscot County, the Portland area of Cumberland County, Somerset County, and Washington County. The Vulnerability Assessment makes recommendations for interventions that strategically allocate resources to the highest-risk areas, including to support the opening of SSPs in the most vulnerable areas and expand the operating hours and staff at existing SSP locations. With this information, the

Infectious Disease Prevention Program began collaborating with the State Office of Behavioral Health (OBH) to support overdose prevention patient navigators in the five vulnerable areas to assist clients at risk of overdose and post-overdose with accessing support services.

Additional partnerships with OBH include hepatitis C linkage to care and treatment services conducted by five partner agencies across the state. Maine CDC and OBH staff meet regularly to discuss trends in service provision for substance use and viral hepatitis in populations at highest risk for HIV, HCV transmission, and opioid overdose.

The *Maine Opioid Response: 2021 Strategic Action Plan*, which describes the State's overall strategy for reducing the stigma associated with substance use disorder, building resilience across the lifespan, building and maintaining infrastructure, and implementing activities to reduce the negative health and economic impacts of opioid and other substance use disorders, is included as Appendix T.

Maximizing the Quality of Health and Support Services for PLWHA

About 60 percent of PLWHA in Maine are enrolled in RWHAP Part B services, which includes ADAP, financial assistance for dental, food, rent/utilities, and some case management. In 2021, 86 percent of RWHAP Part B enrollees were virally suppressed. Prior to the COVID-19 pandemic, viral suppression was 91 percent among RWHAP Part B enrollees; the decrease in viral suppression is mainly attributable to an increase in the percentage of people who did not have a viral load test in the reporting year.

Case management and linkage to support services is provided by community-based organizations including Frannie Peabody Center, St. Mary's Regional Medical Center, the Horizon Program at MaineGeneral Medical Center, Health Equity Alliance, and Community Health and Counseling Services. Services are primarily funded by MaineCare reimbursements for Targeted Case Management. Frannie Peabody Center (the state's HOPWA grantee) supports some case management through its housing grants. Regional Medical Center at Lubec also provides some funding for medical case management under RWHAP Part C to Health Equity Alliance and Community Health and Counseling Services. The RWHAP Part B Program supports non-medical case management for PLWHA who are not eligible for any other form of case management.

As the state's HOPWA grantee, Frannie Peabody Center provides rental subsidies and short-term assistance with rent, mortgage, and utilities to qualifying PLWHA statewide. The average wait time on the subsidy wait list is four to five years. Once a subsidy is awarded, finding a unit that meets Fair Market Rent standards has been a challenge, especially in the metropolitan areas of Augusta, Bangor, Portland, and in some parts of York County. Maine State Housing's 2020 Rent Affordability Index data found that only one of Maine's sixteen counties (Franklin County) was deemed affordable and 93,000+ households were unable to afford the median two-bedroom rent. The age of Maine's housing stock presents additional barriers for households with children under the age of six, whose families must consider lead paint/poisoning issues.

The Office of MaineCare Services, Regional Medical Center at Lubec, Horizon Program at MaineGeneral Medical Center, and RWHAP Part B all conducted satisfaction surveys with PLWHA which have comprehensive results reported in attached appendices J, L, and M. Data show that overwhelmingly PLWHA in Maine are satisfied with services they receive both in terms of quality and the category of health and support services currently available. Minimal access issues were reported or identified through needs assessments.

Strengths and Gaps

As stated above, data show extremely high levels of satisfaction with current services available for PLWHA. Most survey respondents did not identify unmet needs. Therefore, we would rely on securing new funds for any new or additional services rather than redistributing funding from existing services described in the Resource Inventory.

While housing was identified as a significant need in numerous assessments, this Integrated Plan does not specifically address the complex issue of the lack of affordable housing in Maine. As of April 9, 2022, HUD increased the Fair Market Rent for the Portland, ME, metro area. This change should increase the rental opportunities that can be used by HOPWA and work to address some of the housing needs identified.

Additional gaps become apparent when stratifying viral suppression data by different demographic characteristics. Maine modified the Disparities Calculator presented by the Phoenix EMA at the 2022 National Ryan White Conference and populated it with surveillance data to identify statistically significant disparities in viral suppression among people living with diagnosed HIV in Maine (see Figure 7 below).

Within RWHAP Part B enrollee data, it is clear that African Americans are less likely to be virally suppressed than Black New Mainers. Similarly, individuals identified as Native American only are less likely to be virally suppressed than those who identify as Native American and any additional race(s). Maine CDC’s HIV/STD epidemiologist position had been vacant for almost two years prior to the development of this Integrated Plan. Now that there is sufficient capacity, further analysis of nuanced surveillance data is possible, which will strengthen plans for delivering the most culturally competent services to those with the greatest disparities.

Added epidemiological capacity will also make it feasible to conduct specific data matches between surveillance and care to develop a profile of people living with HIV in Maine who are not enrolled in RWHAP Part B services in order to create more effective outreach plans.

Figure 7. HIV viral suppression in 2021 among Maine PLWDH age ≥13, by selected characteristics

Populations/Subpopulations	**Total**	**Unsuppressed**	**Suppressed**	**% Suppressed**	**Disparity**	**Sig Disparity**
All PLWDH ≥13 years	**1760**	**438**	**1322**	**75%**		
Male	1394	331	1063	76%	1.1%	Not Sig
Female	358	104	254	71%	-4.2%	Not Sig
Transgender	8	3	5	63%	-12.6%	Not Sig

By race and ethnicity	**Total**	**Unsuppressed**	**Suppressed**	**% Suppressed**	**Disparity**	**Sig Disparity**
American Indian/Alaska Native	10	3	7	70%	-5.1%	Not Sig
Asian	13	2	11	85%	9.5%	Not Sig
Black/African American	318	105	213	67%	-8.1%	Sig
Hispanic/Latino	122	53	69	57%	-18.6%	Sig
White	1256	270	986	79%	3.4%	Sig
Multiple races	31	4	27	87%	12.0%	Not Sig
Unknown races	10	1	9	90%	14.9%	Not Sig

By age groups	**Total**	**Unsuppressed**	**Suppressed**	**% Suppressed**	**Disparity**	**Sig Disparity**
13-24	28	12	16	57%	-18.0%	Sig
25-34	143	48	95	66%	-8.7%	Sig
35-44	290	91	199	69%	-6.5%	Sig
45-54	432	110	322	75%	-0.6%	Not Sig
>=55	867	177	690	80%	4.5%	Sig

By route of transmission	**Total**	**Unsuppressed**	**Suppressed**	**% Suppressed**	**Disparity**	**Sig Disparity**
MSM	970	203	767	79%	4.0%	Sig
IDU	121	53	68	56%	-18.9%	Sig
MSM and IDU	60	13	47	78%	3.2%	Not Sig
Heterosexual	190	51	139	73%	-2.0%	Not Sig
Other	419	118	301	72%	-3.3%	Not Sig

Capacity Building

Based on needs assessment data and in line with goals and objectives described later in this plan, areas that should be the focus for capacity-building include:

1. Health care provider education
2. Increased use of PrEP and PEP
3. Increased knowledge and access for injectable ART and PrEP

Approaches and Partnerships

MeHAAB includes all organizations and agencies that receive funding from US CDC and HRSA/HAB to provide HIV prevention and care services as well as other partners that provide complementary services.

During the development of this Integrated Plan, additional partners were brought to the table, including Healthy Living for ME (HL4ME), Maine's Community Care Hub offering evidence-based health and wellness programs, as well as social care coordination services through a network of partners. HL4ME® is currently a d/b/a of Spectrum Generations, central Maine's Area Agency on Aging.

All MeHAAB members were included in the development of the Resource Inventory above. A template was emailed to all MeHAAB members and partners, and responses were compiled into the table above. A more detailed table is available in Appendix C.

Needs Assessment and Approach

The table below describes the themes and highlights from the various needs assessments conducted and previously published reports used to develop this plan. More detail (including the approach and methodology for each needs assessment) is available in the referenced appendices.

Themes and Highlights

Report Name	Appendix	Themes/Highlights
Maine Shared Community Health Needs Assessment Report 2022	D	Top health priorities include: • Mental health • Social determinants of health • Access to care • Substance and alcohol use • Older adult health • Diabetes • Oral health • Cancer • Communication

Themes and Highlights		
Report Name	**Appendix**	**Themes/Highlights**

State of Maine Infectious Disease Prevention Program 2022 Workforce Survey Report	E	• HIV case managers are knowledgeable about the HIV treatment guidelines and ADAP/RWHAP Part B services and policies
		  ○ There has been improvement since 2017, despite significant turnover
		• Training preferences overlap between HIV case managers and prevention providers
		
		• Health care providers may need increased outreach and education, particularly in the areas of:
		  ○ Best practices and ways to access PrEP and PEP
		  ○ Best practices related to extragenital testing for chlamydia and gonorrhea
		  ○ Best practices related to routine HIV testing
		  ○ The U=U campaign
		  ○ Resources available from Maine CDC’s Infectious Disease Prevention Program
		
		Key informant data from HIV case managers and prevention providers identified the following:
		• Biggest challenges for clients:
		  ○ Housing (identified as the top unmet need)
		  ○ Financial stability
		  ○ Transportation
		  ○ Mental health
		• Reduce stigma and increase access to affordable housing to help clients become and stay virally suppressed
		• Increase outreach/education and promote/expand access to PrEP and PEP to prevent new HIV infections
		• Continued education/training to reduce disparities and health inequalities
		• Increased communication and integrated care settings to better coordinate services

Office of MaineCare Services HIV/AIDS Waiver – 2020 Provider Survey Analysis	F	• About one-quarter of providers indicate behavioral health conditions as the top barrier to patient adherence/compliance, a consistent finding for the past six years • 11 percent of providers indicated transportation was the top barrier to patient adherence/compliance

Themes and Highlights

Report Name	Appendix	Themes/Highlights
		• 55 percent of providers indicated that they had reviewed the HIV treatment guidelines in the last 12 months, down 15 percent from the prior year • 42 percent of providers were not at all familiar with Community Health Workers, but 68 percent would refer patients to them if available
State of Maine 2022 HIV/STD Prevention Needs Assessment Survey Report	G	• The most frequently reported types of discrimination were based on gender identity and sexual practices • There are clear indications of risk perceptions that conflict with behaviors ○ The most common reason respondents reported for not being tested for HIV was their perception that they were not at risk • Routine HIV testing does not appear to be offered by PCPs, even to those with reported risk behaviors ○ Of the 16 respondents who reported being diagnosed with HCV in the past two years, about half reported being tested for HIV since their HCV diagnosis • MSM respondents were the most likely to report having heard of, taken, or been refused PrEP • Very few respondents reported ever taking PEP • All groups had high proportions of respondents who reported symptoms of depression and anxiety in the 14 days before the survey • Most respondents did not indicate a need for social opportunities. This was consistent across risk groups. • Internet access – particularly by phone – was common among most respondents, except PWID. This may indicate needs for mobile-friendly Internet resources and to consider resources that are not online when outreaching to PWID.
State of Maine 2022 Needs Assessment Survey Report: People Living with HIV/AIDS	H	• The top six unmet needs were: ○ Eye care ○ Alternative therapies ○ Paying for housing ○ Paying for utilities ○ Mental health ○ Paying for food

Themes and Highlights		
Report Name	**Appendix**	**Themes/Highlights**
State of Maine RWHAP Part B 2022 Needs Assessment Survey Report	I	• Viral suppression is high even among those without stable housing • Those who have been incarcerated are more likely to be unstably housed, but still maintain high rates of viral suppression • There are clear indications of risk perceptions that conflict with known risky behaviors • About two-thirds of respondents have heard of PrEP and about two-thirds of those who had heard of it were comfortable speaking with partners about it • Most respondents indicated that they are comfortable with their health care provider and had seen them in the past year. Transportation was the number one factor for those who reported being able to consistently get to medical appointments. • Some respondents were confused by the terms "undetectable" and "suppressed," and there were some discrepancies between self-reported results compared to Surveillance records. This indicates a need for more client/patient education about what results mean. • 85 percent of respondents had seen a dentist in the last 18 months or reported having no teeth/dentures. Dental was the fourth-most identified unmet need. • Many reported of symptoms of anxiety and depression in the 14 days before the survey. • The most-identified areas of unmet need were: ○ Activities with other PLWHA ○ Food ○ Alternative therapies ○ Social retreats ○ More affordable Internet access ○ Paying for utilities ○ Dental care ○ Eye care ○ Paying for housing
MaineCare Services HIV/AIDS Waiver – Member Survey Analysis 2020	J	• Overall, members reported good physical health, good mental health, stable housing, and always getting the medical care and medication they need • About half reported experiencing food insecurity

Themes and Highlights		
Report Name	**Appendix**	**Themes/Highlights**
		• Three-quarters reported having case management and noted that it helped them find services they need
Designated Health Professional Shortage Areas Statistics, Second Quarter of Fiscal Year 2022 Designated HPSA Quarterly Summary	K	• Maine has more designated Primary Care Health Professional Shortage Areas than any other state in Region 1 • Maine has more designated Dental Health Professional Shortage Areas than any other state in Region 1 • Maine has more designated Mental Health Care Health Professional Shortage Areas than any other state in Region 1
State of Maine RWHAP Part B 2021 Satisfaction Survey Report	L	• Most members are satisfied with ADAP/RWHAP Part B and find it easy to access services • Members who have a case manager are generally happy with their case management service. Most who do not have a case manager do not want one. • Those who did not utilize RWHAP Part B services had high rates of viral suppression and did not identify specific barriers to accessing services.
Report on HIV Client Satisfaction with RWHAP Part C Services and Issues with Adherence (Regional Medical Center at Lubec)	M	• Satisfaction was very high (90-100 percent) for: ○ HIV physician care ○ Medical case management ○ Mental health counseling ○ Medication management • Ratings somewhat high (about 80 percent) for: ○ Dental care ○ Help with travel • Ratings not very high (about 50 percent) for: ○ Nutrition education and supplements
Maine Integrated Youth Health Survey *2019 State Snapshot for Maine 5th and 6th Grade Students*	N	• Highlights from the data that may suggest risky behaviors include: ○ 24 percent spend two or more hours at home after school without a trusted adult ○ 44 percent have ever been bullied at school ○ 6 percent ever drank alcohol ○ 2 percent ever used marijuana
Maine Integrated Youth Health Survey *2019 State Snapshot for Middle School Students*	O	• Highlights from the data that may suggest risky behaviors include: ○ 46 percent have ever been bullied at school ○ 25 percent have felt sad or hopeless for at least two weeks in the past year

Themes and Highlights		
Report Name	**Appendix**	**Themes/Highlights**
		○ 20 percent have ever seriously considered attempting suicide ○ 4 percent drank alcohol at least once in the past 30 days ○ 4 percent used marijuana at least once in the past 30 days
Maine Integrated Youth Health Survey *2019 State Snapshot for High School Students*	P	• Highlights from the data that may suggest risky behaviors include: ○ 23 percent were bullied at school ○ 32 percent have felt sad or hopeless for at least two weeks in the past year ○ 16 percent have seriously considered attempting suicide in the past year ○ 23 percent drank alcohol at least once in the past 30 days ○ 22 percent used marijuana at least once in the past 30 days
State of Maine 2022 Interview Summary Report	V	• Interviews with PLWHA: ○ Seventeen 60–90-minute interviews conducted ○ High satisfaction levels of medical care ○ High satisfaction levels of ADAP services ○ Complaints of too much paperwork and bureaucracy accessing care (medical, Ryan White services, Case Management) ○ High utilization of Case Managers to navigate paperwork and bureaucracy ○ Primary Care physicians are unfamiliar with HIV and aging while living with HIV. For minor, non-HIV related diagnoses (like a head cold), a patient's Primary Care Physician would commonly refer their patient to the patient's Infectious Disease physician. The Infectious Disease Physician would then refer the client *back* to their Primary Care Physician. This created cyclical ineffective care. ○ Need for better transportation to get to services; telehealth is beneficial, but patients wanted to see their doctor in person as well ○ Desire for alternative therapies (acupuncture, vitamins, etc.) to be covered by RWHAP Part B

Themes and Highlights		
Report Name	**Appendix**	**Themes/Highlights**
		○ Maine's immigrant population living with HIV expressed a desire for free or reduced cost legal help and individual lessons on American cultural norms. Doing so on an individual basis was important due to stigma in small communities. • Interviews with people at risk of HIV: ○ Five 60–90-minute interviews conducted ○ Low knowledge of free or low-cost HIV and STD testing services ○ Low knowledge of rapid HIV tests ○ Low knowledge that rapid tests are available in non-clinical settings ○ Desire for more easily accessible SSP locations and more locations around the state—those who need to access an SSP often do not have a car and are unable to utilize services ○ High satisfaction with services available and received at SSPs ○ Dissatisfaction with the one-for-one needle exchange regulations—this system makes it very difficult for people to get clean syringes after they are confiscated (by police or after rehab programs) ○ Desire for health care providers to be better at discussing sexual history, drug use, harm reduction practices, and HIV/STD prevention and testing options
Horizon Program Client Satisfaction Survey	n/a	• Provided raw data that showed generally high ratings across the following services: ○ HIV care ○ Case management ○ Mental health services ○ Peer counseling
Focus group for PLWHA hosted by Health Equity Alliance	n/a	• Four PLWHA attended and identified these areas for improvement: ○ Food assistance (specifically, they would like to have separate caps for RWHAP Part B food and housing assistance) ○ Communication ○ Durable medical equipment ○ More/better social opportunities

Themes and Highlights		
Report Name	**Appendix**	**Themes/Highlights**
Data from the Maine Integrated Youth Health Survey, 2021	n/a	• Observations from detailed reports of responses from middle and high school students: ○ 31 percent of middle school students and 77 percent of high school students indicated that they had ever been taught in schools about STDs or pregnancy prevention ○ 54 percent of middle school students and 54 percent of high school students indicated that they or their partner used a condom the last time they had sexual intercourse ○ 19 percent of high school students indicated that they drank alcohol or used drugs before they had sexual intercourse the last time ○ 13 percent of high school students who have ever had sexual intercourse have ever been tested for HIV ○ 16 percent of high school students who have ever had sexual intercourse have been tested for an STD in the last 12 months

Priorities

The broad priorities that were identified from the needs assessment process included mental health care, access to health care (including lack of providers, long wait times, insurance issues, etc.), and communication from the State about HIV/HCV/STDs. Another major theme was the discrepancy in perceived risk vs. actual risk of HIV, HCV, and/or STD infection. While not all these priorities will be able to be addressed within the timeframe of this Integrated Plan, they were core factors in how achievable goals were set for the Integrated Plan.

The State's steering committee has outlined strategies for addressing the following goals within each of the EHE pillars.

Diagnose: Increasing HIV home testing, increasing HIV/HCV/STD testing, increasing knowledge and awareness of free or low-cost HIV, HCV, and STD testing.

Treat: Increasing peer support opportunities, increasing viral suppression, decreasing time for linkage to care, and increasing access to prescription drugs for PLWHA.

Prevent: Increasing PrEP and nPEP usage, increase outreach and education on HIV, HCV, and STDs for priority populations and health care providers.

Respond: Collecting molecular sequencing data and creating and distributing an HIV/HCV/STD Outbreak Response Plan and facilitating tabletop exercises based on the Outbreak Response Plan.

Actions Taken

The State of Maine Infectious Disease Prevention Program has already increased the number of counseling, testing, and referral (CTR) trainings that it provides. This will increase the number of trained staff and volunteers who can provide rapid HIV and HCV testing to communities in Maine. Many of the new trainers work in organizations that serve PWUD/PWID, indigenous people, rural communities, and racial and ethnic minorities. Additionally, with the emergence of monkeypox virus, more outreach, testing, and education events occurred during 2022 to reach LGBTQ+ individuals who were at risk.

The RWHAP Part B Program has already taken action to address some of the priorities listed above. In 2022, the RWHAP Part B increased the income limit for food, housing, and dental assistance from 300 percent of the FPL to 350 percent; removed a monetary cap on dentures; started a biannual RWHAP Part B newsletter; simplified the Release of Information form; expanded the ADAP formulary; and translated all RWHAP Part B and ADAP program documents into the top three written languages that enrollees speak outside of English (French, Portuguese, and Kinyarwanda). Additionally, RWHAP Part B has implemented quarterly trainings for case managers (up from semiannual trainings), including trainings by guest speakers. In late 2022, these trainings will be expanded to include HIV/STD prevention partners to encourage more integrated services and collaboration.

The RWHAP Part B Program has also worked with Maine insurance providers, NASTAD, RWHAP Part C clinics, and the pharmaceutical company ViiV Healthcare to implement a strategy and guidance for the administration of long-acting injectable anti-retroviral drugs. As of October 2022, ADAP has developed a procedure to support patients who choose to move to long-acting therapies.

During 2022, Maine’s Infectious Disease Prevention Program in partnership with Maine CDC’s Communication Department and a marketing firm have begun planning a large-scale social marketing campaign around HIV, STD, and HCV awareness and education. The marketing team involved MeHAAB members in the planning and creation of visuals and themes for the campaign, which is set to be released in 2023.

Through legislative action taken in spring of 2021 to update the notifiable conditions rules in Maine, Maine CDC’s Infectious Disease Epidemiology Program can collect HIV molecular sequencing data from all laboratories. This is the first step in the process to collect and analyze genetic data to determine HIV molecular clusters. The analysis of these clusters will help Maine respond quickly to potential HIV outbreaks.

Section IV - Situational Analysis

The tables below outline the strengths and challenges from the previous five years (2017-2021). Four separate tables were created to address strengths, challenges, and identified needs by each of the EHE pillars. These identified needs were then used to guide the objectives, strategies, and activities detailed in Section V.

EHE Pillar	Strengths	Challenges
Diagnose	• Mainers adapted easily to at-home testing • Quick development and implementation of virtual HIV Counseling Testing and Referral Training • Provision of at-home tests • Partnered with external agencies to provide additional at-home tests via online social networking sites	• COVID-19 pandemic made Mainers less likely to go to the doctor's office to get tested • There is limited routine testing in Emergency Departments or Primary Care Facilities • A high proportion (around 1/3) of Mainers are diagnosed with HIV and AIDS simultaneously (late diagnosis) • The general population of Mainers have a low perception of risk of contracting HIV • A barrier to at-home testing is the paperwork that comes with getting the test
	Identified Needs	
	• More opportunities and availability of free or low-cost HIV testing services. • A more clearly defined response to at-home tests that are self-reported positives • Education related to risk perception, PrEP, free community resources and testing • Transportation to outreach events, support, testing sites, etc. • PCPs should incorporate HIV testing into routine bloodwork. • More comprehensive testing for HIV, STD (including extragenital) and HCV	

EHE Pillar	Strengths	Challenges
Treat	• High rates of medical insurance • Telehealth appointments • PLWHA are highly satisfied with their medical care. • PLWHA are highly satisfied with ADAP • The RWHAP Part B offers financial aid for areas that	• Previous data collection has limited nuance when it comes to race, ethnicity, and country of origin. • Transportation to care and support • Reengagement of people who fall out of care • The rural nature of Maine means that care is often difficult to access

	PLWHA have identified needs (food, dental, housing) • High levels of satisfaction with case management	• Lack of rolling Open Enrollment for marketplace insurance • The rollout, coverage, and administration of long-acting injectable pharmaceutical ART • Staffing across the State: specifically, the State of Maine has not been able to hire or retain an HIV Epidemiologist in just under two years. Therefore, the State has not been able to create a comprehensive unmet needs assessment. • Limited transportation for PLWHA to access care • Maine has more Designated Health Professional Shortage Areas (Healthcare, Mental Health, and Dental) than any other state in Region 1 (New England) • Lack of mental health services and worsening mental health due to the COVID-19 pandemic
	Identified Needs	
	• Transportation to care and support • Develop better surveillance regarding racial, ethnic, and country of origin differences among PLWHA • The creation of a Data to Care plan • Training for PCPs and other non-Infectious Disease providers on the following: o How to prescribe PrEP and PEP o Extragenital STD testing o Routine HIV testing o U=U o HIV treatment guidelines o Resources available to PLWHA o Aging with HIV • Community connection: activities for PLWHA • Mental health care • Increased communication from RWHAP Part B and case management agencies • There are unmet needs in the following categories: o Food o Housing o Utilities (including internet)	

	o Dental care o Eye care o Alternative therapies

EHE Pillar	Strengths	Challenges
Prevent	• Establishing PrEP 207, which is a website that has information about PrEP, how to initiate, and which providers to see. • Since 2019 Maine has added new syringe service providers in various locations across the state. • Maine passed legislation that decriminalized syringe possession	• Previous data collection has limited nuance when it comes to race, ethnicity, and country of origin. • The roll-out, coverage, and administration of long-acting, injectable PrEP • Getting more providers to offer PrEP • There are gaps in knowledge around PrEP and PEP among the general population and clinicians • Lack of perceived risk in at risk populations • Clients living with HCV not routinely tested for HIV • Geography and transportation to accessing SSPs
	Identified Needs	
	• More opportunities for community groups (peer support) for at risk populations • Need for mobile–friendly online resources and need for non-online resources for PWID • More SSP sites and removal of 1-to-1 syringe distribution policy • More education related to risk perception, PrEP, and free community resources and testing • Transportation to outreach events, support, testing sites, etc. • More comprehensive testing for HIV, STD (including extragenital) and HCV • Develop better surveillance regarding racial, ethnic, and country of origin differences amongst people at risk of contracting HIV • Training for PCPs and other non-Infectious Disease providers on the following: o How to prescribe PrEP and PEP o Extragenital STD testing o Routine HIV testing o U=U o HIV treatment guidelines o Resources available to PLWHA o Aging with HIV • More training for patients on U=U	

EHE Pillar	Strengths	Challenges
Respond	• On the state level, the Prevention team collaborates with the Maine CDC public health nurses • On the state level, the Prevention team collaborates with the Overdose Prevention Team at the Office of Behavioral Health • The State of Maine has a surveillance alert system in place to identify outliers. This potentially allows for early notification of an emerging outbreak.	• Previous data collection has limited nuance when it comes to race, ethnicity, and country of origin. • High rates of turnover and not enough staff in medical, case management, or governmental agencies.
	Identified Needs	
	• A more clearly defined HIV outbreak response plan to identify new cases. And, within this plan, the State must define a method to identify new HIV cases in vulnerable populations. • The ability to adapt the created outbreak response plan for other emerging diseases that have an impact on PLWHA or those at risk of HIV transmission, like monkeypox virus.	

Section V - 2022-2026 Goals and Objectives

Section V details the Goals and Objectives for each of the four EHE pillars; diagnose, treat, prevent, and respond. Maine's steering committee created the tables below to ensure that all objectives and strategies are feasible and beneficial to both Prevention and Care objectives.

Goals and Objectives Description

Diagnose

Goal: Diagnose all people with HIV as early as possible.

Objective 1: By December 31, 2026, increase the number home tests in Maine by 10 percent from 2022 baseline of annual home tests provided.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Have free at-home testing available at community-based organizations, clinics, and all funded partner locations.	CBOs Clinics Funded partners SSPs	CDC federal funds SAMHSA federal funds Maine State funds Harm reduction grants	Increase number of providers offering home tests. Increase in number of people linked to care.	TakeMeHome data Monthly reports from partner organizations HIV-funded testing data	Increase the number of Mainers who know their HIV status. Reduce the number of late HIV diagnoses in Maine.	MSM FVHR PWID BIPOC Individuals diagnosed with an STD in the last 2 years
Increase number of key partner locations who have staff trained in HIV CTR to offer home tests.						

Increase number of at-home tests provided within SSP outreach and services.			Increase testing in high-priority populations			Individuals who have ever exchanged sex for money/substances/goods Transgender, non-binary, gender nonconforming, and other gender diverse individuals
Provide accessible client-facing guide for linking to HIV care if positive.			Increase the number of at-home test kits used			
Create social media posts and printed materials with information on how to access free at-home testing.						

Objective 2: By December 31, 2026, increase routine testing in high impact settings in Maine as demonstrated by a 10 percent increase in the number of tests at high impact settings from 2022 baseline.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
HIVAC will work to pass legislation to ensure HIV testing is "opt-out" when Mainers receive routine bloodwork.	Emergency departments Primary care practices	CDC federal funds Maine State funds Other federal capacity-	Increase routine testing in primary care and emergency departments settings.	EMR data Surveillance data	Increase the number of Mainers who know their HIV status. Reduce the number of late HIV	New Mainers MSM FVHR PWID

Add HIV testing to lab order sets in electronic medical record systems.	Minor emergency clinics STD clinics Urgent care clinics FQHCs EMR RWHAP Part C and F providers	building grants			diagnoses in Maine.	BIPOC Individuals diagnosed with an STD in the last 2 years Individuals who have ever exchanged sex for money/substances/goods Transgender, non-binary, gender nonconforming, and other gender diverse individuals All individuals seeking health care
Work with public health facilities to increase frequency of HIV testing.				Legislative Tracking		
Trainings on HIV will be provided to PCPs around the state of Maine to increase knowledge on HIV, STD, HCV, and access to care.			Increase in knowledge of available resources and testing options. Increase in the number of comprehensive screenings (syphilis, HIV, HCV, and extragenital gonorrhea and chlamydia) offered to clients.	Pre- and post-tests on HIV diagnosis, treatment, and care Completion certificate EMR data Surveillance data		

Increase outreach and education on comprehensive testing for HIV screening and STD (extragenital), and HCV testing guidelines.			Increase the number of doctors providing HIV treatment to their clients. Reduce the burden on ID doctors and allow newly diagnosed individuals to get into care within 14 days. Decrease in HIV co-infections with STDs.			

Objective 3: By December 31, 2026, needs assessment data show an increase in knowledge and awareness of testing in Maine from 2022 baseline.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Provide cost and location(s) on social media applications, marketing campaigns/ pamphlets at key partner facilities.	Maine online PrEP resource Funded HIV/STD testing and outreach partners RWHAP Part C and F providers	CDC federal funds Maine State funds	Increase in knowledge of available resources and testing options. Increase in the number of tests. Increase in the number of Mainers who know their HIV status.	Activity reports on social media posts Monthly testing reports Surveillance data HIV-funded testing data	Increase the number of Mainers who know their HIV status. Reduce the number of late HIV diagnoses in Maine.	New Mainers MSM FVHR PWID BIPOC Individuals diagnosed with an STD in the last 2 years
Provide medical providers with educational information and training on HIV						

prevention and STD treatment guidelines	Sexual health clinics CBOs Tribal partners					Individuals who have ever exchanged sex for money/substances/goods Transgender, non-binary, gender nonconforming, and other gender diverse individuals All individuals seeking health care
Provide educational and outreach materials on locations where client can be referred to for low-cost to free HIV testing.			Increase in number of health care providers who offer testing to clients. Increase in number of health care providers who encourage clients to be tested. Increase in number of health care providers who know about available free and low-cost testing in Maine.	EMR data Surveillance data		

Treat

Goal: Treat people with HIV rapidly and effectively to reach sustained viral suppression.

Objective 1: By December 31, 2026, increase the number of peer support and community events for PLWHA in Maine by 10 percent from 2023 baseline.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Establish baseline of peer support and	MeHAAB	CDC federal funds	Baseline of existing peer	Annual needs assessment	Linkage to HIV medical care	All people in Maine LWH

community events for PLWHA scheduled for 2023.	Community partners	Ryan White funds Maine State funds	support and community groups established.	survey for MeHAAB participants	Increase in the number of people retained in medical care. Achievement and maintenance of viral suppression.	
Create a plan to increase the number of culturally appropriate peer navigators and mentors throughout the state in conjunction with key partners.			Create a plan to recruit and train culturally appropriate peer navigators and mentors. Increase in the number of peer support and community groups across Maine.			
Provide education and outreach to PLWHA about peer support and community groups in their region.			Increase in number of PLWHA who participate in community and/or peer support events. Decrease in reports of isolation and poor mental health in needs assessments.	Annual MeHAAB needs assessment survey for participants Post-event client satisfaction surveys		
Healthy Living for ME to provide leader trainings for partners' staff and volunteers to deliver community-based workshops	Healthy Living for ME	Federal Administration for Community Living funds	Work with health care and community-based entities to provide Living Well with HIV and/or Living Well for Better	Reports from Healthy Living for ME	Increase in the number of people retained in medical care.	

for the Positive Self-Management Program, branded as Living Well with HIV and Chronic Disease Self-Management Program, branded as Living Well for Better Health in Maine.			Health to at least 15 individuals annually.		Achievement and maintenance of viral suppression.	
Leverage Healthy Living for ME as an available partner to connect individuals to resources related to health behaviors (such as diet and physical activity/exercise), access and quality of care, transportation, housing, family and social support, community safety, and income to improve individuals' overall Social and Behavioral Determinants of	Healthy Living for ME	CDC federal funds Individual entities' funding streams	Work with health care, community-based, and state entities to provide social care coordination services/solutions.	Reports from Healthy Living for ME	All people in Maine LWH, will have equitable access to eligible resources and services to best meet their SBDOH needs, including caregivers/supports .	All people in Maine LWH and their caregivers/supports.

Health (SBDOH) outcomes.						
Objective 2: From January 1, 2022, to December 31, 2026, increase viral suppression rates by 5 percent from 2022 baseline data within subpopulations with statistically significant disparities.						
Key Strategies & Activities	**Key Partners**	**Potential Funding Resources**	**Outcomes**	**Monitoring Data Source**	**Expected Impact on HIV Care Continuum**	**Priority Population**
Hire a Data-to-Care Coordinator to work with Linkage-to-Care Coordinator to identify and link people who have fallen out of care or who have not yet been linked to care.	Maine CDC	CDC federal funds Ryan White funds Maine State funds	Increase the staff capacity dedicated to increasing viral suppression within the Infectious Disease Prevention program at the Maine CDC.	Human Resources Data	Linkage to HIV medical care Retention in medical care Achievement and maintenance of viral suppression	Black/African Americans Hispanic/Latinx Individuals aged 13-44 People who inject drugs
Hire a State of Maine Community Health Outreach Worker (CHOW) for those clients who do not want community-based Case Management.		CDC federal funds Ryan White funds State of Maine funding	Increase access to Case Management	RWHAP Part B annual surveys		Black/African Americans Hispanic/Latinx Individuals aged 13-44 PWID
Include a question about interest in Case Management on RWHAP Part B recertifications and surveys.						

Train and educate CHOWs who work with migrant farm workers, immigrant and asylum-seeking individuals, and other marginalized people on HIV testing, treatment, and retention in care.	Participating organizations in MeHAAB Maine Mobile Health Program Office of Population Health Equity	N/A	Increase access to Case Management Increase linkage to care Increase HIV testing in minority populations			PLWHA who are migrant farm workers (especially those who do not speak English and do not have permanent residence in one state)

Objective 3: By December 31, 2026, increase linkage to care within 14 days for those who have fallen out of care or who are newly diagnosed by 5 percent from 2023 baseline.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
By December 31, 2023, establish baseline data for clients who are rapidly linked to care.	ID specialty care clinics PCPs Community-based testing locations Clinic-based testing locations Emergency departments	Federal CDC funds	Increase in number of newly diagnosed PLWHA linked to care in 14 days. Increase in number of clients out-of-care that are reengaged in care.	Surveillance data	Increase in number of clients linked or reengaged to care. Decrease in average time it takes clients to be linked to care.	Houseless and unstably housed individuals Low-income populations PWUD New Mainers Newly Diagnosed individuals
Assess clinic readiness to provide rapid linkage to care.						
Assess Electronic Medical Records Systems (EMRs) in clinics to prioritize HIV care appointments.						
Within 14 days of confirmatory test						

results, Linkage to Care Coordinator will contact newly diagnosed PLWHA and link the individual to care.	Urgent care clinics Case managers FQHCs					
Distribute HIV Care and Treatment, and support service information to the public for display at high impact clinical and community settings.						

Objective 4: By December 31, 2026, Maine's HIV/AIDS Legislative Advisory Committee (HIVAC) annual strategic plans will include advocacy to increase the access of prescription drugs, including long acting injectables, for PLWHA and PrEP for those who are at higher risk of contracting HIV.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Assess existing prescription access for HIV medications.	Office of MaineCare Services Health care providers Pharmacies Insurance providers	N/A	HIVAC strategic plans for 2025 and 2026 will include a goal concerning expanded access to prescription drugs. Increased access to HIV medications.	HIVAC strategic plans in 2025 and 2026	Increase in number of people who are virally suppressed. Increase in number of people who are retained in care.	All PLWHA
Increase access to HIV medications for people with MaineCare.						

	Pharmacy board Maine Insurance Bureau Legislature Area Agency on Aging					

Prevent

Goal: Prevent new HIV transmission by using proven interventions including PrEP and SSPs

Objective 1: By December 31, 2026, increase the number of PrEP and nPEP users in Maine by 10 percent from 2022 baseline.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Create marketing campaign and distribute culturally appropriate information and flyers for PrEP and nPEP 101 that includes information around payment options.	Maine CDC funded HIV testing and outreach providers CBOs Clinical providers, including RWHAP Part C	Federal CDC funds	Increase in the number of PrEP prescriptions statewide.	Surveillance Data EMR data Prescription Data MaineCare Data	Decrease in number of clients diagnosed with HIV. Increase number of clients prescribed PrEP. Increase number of clients prescribed nPEP when needed.	New Mainers MSM FVHR PWID BIPOC Individuals diagnosed with an STD in the last 2 years
Move forward with rules for pharmacy-driven PrEP access in Maine.						

Maine CDC and RWHAP Part F will work together to provide training on PrEP/nPEP to health care providers	Maine CDC communications team Maine Pharmacy Bureau PCPs FQHC Maine CDC Emergency departments Pharmacies Drug assistance programs RWHAP Part F provider					Individuals who have ever exchanged sex for money/substances/goods Transgender, non-binary, gender nonconforming, and other gender diverse individuals Partners of PLWHA
Provide training and outreach educational materials on PrEP/nPEP to community members						
Maine CDC and RWHAP Part F will work together to provide training and education for emergency departments providers on supporting nPEP access and medication assistance (full dispensing of drug).						
Objective 2: By December 31, 2026, increase number of HIV/STD outreach and educational activities to priority populations within Maine by 10 percent from 2023 baseline.						
Key Strategies & Activities	**Key Partners**	**Potential Funding Resources**	**Outcomes**	**Monitoring Data Source**	**Expected Impact on HIV Care Continuum**	**Priority Population**

Baseline will be established from 2023 data collection.	Maine CDC	Federal CDC funds Maine State funds SAMHSA funds	Baseline dataset.	HIV Prevention Program Measures	Decrease in individuals diagnosed with HIV Increase linkage to care for individuals diagnosed with HIV.	Youth People at high risk for HIV PWUD PWID
Provide HIV/STD testing, PrEP, and HCV testing access in SSPs. Certify additional fixed and mobile SSPs sites in underserved locations.	SSPs Funded CBOs Funded clinics		Increase in SSP clients who access HIV, STD, HCV testing and PrEP			
Provide age-appropriate comprehensive sex education in schools.	SBHC PCPs Schools Department of Education		Increased awareness about HIV and STDs among school-age Mainers.			Youth People at high risk for HIV
Provide marketing campaign and materials on HIV, STD, and HCV transmission to key partners	PCPs Emergency departments FQHCs		Increased awareness campaigns targeting clinicians. Increase in HIV/STD/HCV screenings.			
Objective 3: By December 31, 2026, increase number of HIV/STD outreach and educational activities to Maine health care providers by 10 percent from 2023 baseline.						

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Baseline will be established from 2023 data collection of outreach and education activities offered to providers.	Maine CDC PCPs Emergency departments FQHCs Urgent care clinics CHOWs Office of Population Health Equity RWHAP Part F provider	Federal CDC funds Maine State funds	Increase in PrEP prescriptions. Increase in HIV/STD screenings. Increase in materials ordered by clinical providers.	Surveillance Data Prescription Data Maine CDC Program Data	Decrease in individuals diagnosed with HIV. Increase linkage to care for individuals diagnosed with HIV.	People at high risk for HIV/STDs
Maine CDC and RWHAP Part F will work together to provide educational and outreach materials on HIV and STD transmission to providers.						
Maine CDC and RWHAP Part F will work together to offer training to health care providers and nonclinical support staff on HIV/STD, PrEP, and HCV services.						

Respond

Goal: Respond quickly to HIV outbreaks to get viral prevention and treatment services to people who need them.

Objective 1: By January 31, 2023, the State of Maine will create a molecular sequencing data monitoring program to detect and respond to HIV clusters.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Collect genomic sequencing data for import into eHARS.	Maine CDC HIV surveillance Maine CDC informatics team	Federal CDC funds	Increase in molecular clusters identified	Surveillance Data Hospital EMR Data	Earlier diagnosis of HIV infection. Increased linkage to care of newly diagnosed individuals. Increase in PLWHA who are retained in care.	People at high risk for HIV
Train HIV Surveillance Staff on HIV-Secure TRACE to analyze molecular data and detect clusters.						
Create protocol to monitor molecular sequencing data.						

Objective 2: By May 31, 2023, the State of Maine will create and distribute a comprehensive HIV/HCV/STD Outbreak Response plan.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
Form the Outbreak Response steering committee.	CBOs Emergency departments	Maine State funds	Steering Committee established	Maine CDC Protocols	Earlier diagnosis of HIV infection Quickly linked HIV medical care	People at high risk for HIV

	RWHAP Part C providers FQHCs SSPs				Achievement and maintenance of viral suppression	
The Outbreak Response Steering Committee will complete the comprehensive HIV/HCV/STD Outbreak Response plan.	CBOs Emergency departments RWHAP Part C providers FQHC SSPs	Maine State funds	Comprehensive HIV/HCV/STD Outbreak Response plan created	Maine CDC Protocols	Earlier diagnosis of HIV infection Quickly linked HIV medical care Achievement and maintenance of viral suppression	People at high risk for HIV

Objective 3: By December 31, 2026, the State of Maine will facilitate routine tabletop exercises with entities included in the comprehensive HIV/HCV/STD Outbreak Response plan.

Key Strategies & Activities	Key Partners	Potential Funding Resources	Outcomes	Monitoring Data Source	Expected Impact on HIV Care Continuum	Priority Population
The Outbreak Response Steering Committee will recruit key stakeholders for participation in the tabletop exercise.	Maine CDC CBOs RWHAP Part C providers Other partner organizations	Maine State funds	Stakeholders in Maine will effectively respond to an HIV, HCV, or STD outbreak. Increase workforce available to assist in case of an outbreak.	Meeting minutes from tabletop exercises	Earlier diagnosis of HIV infection Quickly linked HIV medical care Achievement and maintenance of viral suppression	People at high risk for HIV

The Outbreak Response Steering Committee will facilitate the first tabletop exercise with key stakeholders.	SSPs FQHCs Maine hospitals Maine PCPs Maine universities		Host annual tabletop exercise related to HIV, HCV and STD disease clusters			
The State of Maine DHHS steering committee develop annual tabletop exercise plan with key stakeholders.						

Priority Populations

The Goals and Objectives tables above describe the priority populations for each strategy, including people at highest risk for HIV in Maine as well as those living with HIV who experience the greatest disparities.

Updates to Other Strategic Plans Used to Meet Requirements

The State of Maine is not using another strategic plan to satisfy this requirement.

Section VI - 2022-2026 Integrated Planning Implementation, Monitoring, and Follow-up

Successful implementation of the Integrated Plan will be facilitated by the State's steering committee. Before working to accomplish the plan's goals and objectives, the steering committee will first disseminate the contents of Integrated Plan and thank the individuals who contributed to its development by using a multi-modal approach to meet the interests, time constraints, and language levels of all individuals and organizations who contributed.

Approaches will include hosting drop-in presentations at organizations like SSPs, CBOs, and community centers. The program will additionally send highlights to RWHAP Part B enrollees in their winter 2022 ADAP/RWHAP Part B newsletter. Finally, representatives from the Care and Prevention teams will work together to send thank-you notes to all interviewees. Maine CDC will use social media and a marketing strategy to support these efforts.

In January of 2023, three subcommittees will be created to implement, monitor, evaluate, improve, and report on activities being conducted to address each of the goals and objectives outlined in Section V. The subcommittees will include a diverse group of individuals who are well-suited to help accomplish the goals as well as evaluate the success of activities and report on successes and challenges. Maine's steering committee will create templates for action plans and quarterly progress reports for subcommittees to use during this process. Subcommittees will be responsible for evaluating the success of their activities and making improvements as needed. Subcommittee heads will jointly create annual progress reports and the State of Maine's Infectious Disease Prevention Program Director will present the annual progress reports at MeHAAB and publish the reports on the State's website.

2022-2026 Integrated Planning Implementation Approach

The implementation, monitoring, evaluation, improvement, reporting, and dissemination processes will be facilitated by staff within the State of Maine Infectious Disease Prevention Program. All activities to accomplish these processes will happen on the annual cycle outlined below. These actions will be supported by reorganizing the way the planning body operates. In January 2023, MeHAAB will split into subcommittees based on the four pillars of the EHE.

To aid in the implementation of the plan, the State's steering committee will create the following tools for approval by MeHAAB: (1) subcommittee 2022-2026 action plan template, (2) subcommittee progress report template, (3) MeHAAB annual progress report template, and (4) an Infectious Disease Prevention embedded webpage where the Integrated Plan and associated annual progress reports are uploaded. The State will also use quarterly HIV/STD/HCV prevention and harm-reduction programmatic meetings to disseminate and request updates.

The Integrated Plan will be used as a tool to determine how to utilize existing resources and identify which objectives may require new funding. Until such funding becomes available, the State will continue to maximize actual assets. Maine CDC will also continue its annual practice of working within the Legislature's biennial budget process to propose new budget initiatives for underfunded programs and new projects.

2022-2026 Integrated Planning Implementation Approach

Month	Type of Meeting	Action
January	Full body	**Annually through 2026:** The State of Maine will release and present an annual progress report.
February	Subcommittee	
March	Subcommittee	
April	Full body	**2023 Only:** All subcommittee heads will present a 5-year detailed plan to accomplish objectives within their assigned goal/pillar in the G&O table. **2024-2026:** Subcommittee heads will present subcommittee progress reports **Annually through 2026:** The State of Maine will make updates to the Integrated Plan and re-distribute to the planning body and the public via the State's website. Revisions to the Integrated Plan will be based on data reported in the January annual progress report.
May	Subcommittee	
June	Subcommittee	
July	Full body	**Annually through 2026:** Subcommittee heads will present subcommittee progress reports and any changes made to their individual action plan based on the revised Integrated Plan approved in April. **Annually through 2026:** The State of Maine will electronically publish the annual progress report and the revised, approved Integrated Plan on their website. They will also disseminate the documents to Case Managers and highlight changes to the IP in the RWHAP Part B client summer newsletter. HIV/STD/HCV prevention and harm reduction partners will receive changes to IP via quarterly programmatic meetings.
August	Subcommittee	
September	Subcommittee	
October	Full body	**Annually through 2026:** Subcommittee heads will present subcommittee progress reports. **Annually through 2026:** Starting in October of each year, the State of Maine MeHAAB representatives will collect and evaluate data, then write the annual progress report to evaluate the effectiveness of their methodology.
November	Subcommittee	
December	Subcommittee	

Implementation

To implement Maine’s Integrated Plan, MeHAAB will divide into three subcommittees in January of 2023: Diagnose/Prevent, Treat, and Respond. Quality management will be a part of every subcommittee. Facilitation of each subcommittee will be led by a corresponding Maine CDC staff member:

- **Diagnose/ Prevent** - HIV/STD Prevention Program Manager and HIV/STD Public Health Educator
- **Treat** - RWHAP Part B/ADAP Program Manager
- **Respond** - HIV/STD Epidemiologist

Subcommittees will meet once a month, while the full MeHAAB group will meet once each quarter. To the extent that it is possible, each subcommittee will be comprised of a group representative of MeHAAB’s larger makeup. This includes:

- PLWHA
- A person at high risk of contracting HIV
- A Maine CDC representative
- One representative from another State of Maine Department or Office (MaineCare, DOE, DOC, OBH)
- Two or more representatives from community-based organizations
- A medical provider
- A RWHAP Part C representative
- A public health provider
- The RWHAP Part B Data and Quality Specialist (to focus on and track quality management)

The State’s steering committee will meet to create an action plan within six months of the Integrated Plan release which will be presented to the full MeHAAB group for approval. As a standing practice, the full group will continuously work on boosting membership by utilizing practices developed during 2023.

Monitoring

To monitor progress, MeHAAB will institute a series of reports based on templates created in the first quarter of 2023. Throughout the Integrated Plan’s implementation, one member of MeHAAB will stand as the group’s Monitor to ensure that these reports are completed and reviewed on time. Reports will include the following:

Reports to Monitor Maine’s Progress Toward Goals and Objectives				
Report	**Explanation**	**Submission Frequency**	**Responsible Party**	**Dissemination**

Subcommittee Action Plan	A one-time plan that shows how the subcommittee will accomplish the objectives within their assigned goal.	March 2023, then updated as needed	Subcommittee head	Subcommittee head will present on the plan in March 2023.
Subcommittee Progress Report	Report will follow a standardized template. It will be used to update the planning body on the progress each subcommittee has made to accomplish their action plan.	Quarterly though 2026	Subcommittee head	A representative from each subcommittee will present results at each full meeting.
Annual Progress Report	The report will follow a standardized template and will be released and presented annually. The report will describe annual progress using metrics identified in Section V: Goals and Objectives and will guide changes made to the Integrated Plan.	January 2024-2026	Subcommittee heads will work together each fall to create this	Infectious Disease Prevention Program Director will present on the report annually, in January. The report will be published to the State's website.

Evaluation

To evaluate if MeHAAB's activities are accomplishing the goals and objectives set forth in this plan, report templates (for both subcommittee actions and the annual report) will be created using data indicators set by the goals and objectives chart. All strategies and actions will be operationalized using a SMARTER approach (**S**pecific, **M**easurable, **A**chievable, **R**elevant, **T**ime-Bound, **E**valuate, and **R**eward). The templates will include deadlines, action items, and assignments detailing the entities responsible for carrying them out. The State of Maine HIV/STD Epidemiologist and the RWHAP Part B Data and Quality Specialist will review and finalize all templates.

In addition, each fall, subcommittee heads will work with the RWHAP Part B Data and Quality Specialist and HIV/STD Epidemiologist to complete their portion of the larger Annual Progress Report. This process will include data collection and analysis from sources both in and outside of the planning body. Any challenges or barriers to specific objectives or action items will be discussed at routine subcommittee meetings and provided to the larger group if continued challenges remain.

The RWHAP Part B Data and Quality Specialist will attend all subcommittee meetings to focus on and track quality management.

Improvement

Data collected will be determined both by the action plans set forth by each subcommittee and the goals and objectives described in Section V of this plan. Annual data collection will resemble a more limited version of that which was completed for this plan but will use the same strategies, including interviews, surveys, and required data reports.

After data are collected, subcommittee heads will analyze the results and create an annual report to be released in January of each year from 2024 to 2026. If updates to the Integrated Plan are required based on the data, the Infectious Disease Prevention Program Director will oversee their implementation. In turn, subcommittees will adjust their individual action plans.

Reporting and Dissemination

Each July, the State of Maine will release MeHAAB's Annual Progress Report and, if applicable, any changes to the 2022-2026 Integrated Plan via its website. Case managers and HIV/STD prevention partners will be notified either in their quarterly trainings or via an announcement made through email. All RWHAP Part B clients will receive news of implementation, monitoring, evaluation, and improvements in their biannual newsletter.

Updates to Other Strategic Plans Used to Meet Requirements

No other strategic plans were used to meet requirements.

Section VII - Letter of Concurrence

The State of Maine does not receive any Ryan White Part A or EHE funding. MeHAAB serves as the Integrated CDC Prevention Program Planning Body as well as the RWHAP Part B Planning Body.

The letter of concurrence signed by the MeHAAB chairs is included as Appendix W.

Appendix A: Terms/Acronyms with Definitions

The acronyms/terms used throughout this Plan are defined below:

Acronym/Term	Definition
AIDS	Acquired Immune Deficiency Syndrome
AIDS Drug Assistance Program (ADAP)	Under the umbrella of the Ryan White Part B Program, ADAP helps low-income people with HIV to afford health insurance and HIV-related medications.
AIDS Education and Training Center (AETC)	Funded under Part F of the Ryan White HIV/AIDS Program. Gilman Clinic is the subrecipient of the New England AETC.
AOA	Area Agency on Aging
ART	Antiretroviral Therapy
ARV	Antiretroviral - medication to fight retroviruses, including HIV
Behavioral Risk Assessment	A series of questions to document and/or a process of questioning used to identify behaviors or behavior patterns that increases the likelihood of a client acquiring or transmitting STDs, Human Immunodeficiency Virus (HIV), and/or HCV
BIPOC	Describes individuals who are Black, Indigenous, and/or People of Color
BRFSS	Behavioral Risk Factor Surveillance System, national health-related telephone survey data.
CAREWare	An electronic health and social support services information system developed by HRSA’s HIV/AIDS Bureau for Ryan White HIV/AIDS Program grant recipients and their providers.
Case	Clients with a confirmed STD, HIV, and/or HCV.
Case Management	A service that provides guidance and assistance in accessing medical, social, community, legal, financial, and other needed services which foster independence and in support of health outcomes.
Case Manager	A trained professional who provides direct service to individuals living with HIV and/or provides case management.
CBO	Community-based Organization
CD4	CD4 cells are a type of white blood cell. They're also called CD4 T lymphocytes or "helper T cells."
Client	An individual who receives services.
Client-centered	The concept of providing services that are respectful of and responsive to individual client preferences, needs,

Acronym/Term	Definition
	and values as documented by the Comprehensive Assessment and Care Plan.
Continuum of Care	The HIV care continuum is a public health model that outlines the steps or stages that people with HIV go through from diagnosis to achieving and maintaining viral suppression through care and treatment.
CQII	Center for Quality Improvement and Innovation (formerly National Quality Center)
Department	Maine Department of Health and Human Services
DHAP	U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, Division of HIV/AIDS Prevention
Diagnosed	A Laboratory-confirmed positive case of HIV, STD, or HCV.
Disease Intervention Specialists (DIS)	Public health professionals who perform HIV, STD, and HCV prevention-related activities, primarily through Partner Services offered to newly-diagnosed cases that have been reported to Department.
DOC	Maine Department of Corrections
DOE	Maine Department of Education
eHARS	Enhanced HIV/AIDS Reporting System, the surveillance database
Ending the HIV Epidemic (EHE)	The federal Ending the HIV Epidemic in the U.S. (EHE) initiative focuses on reducing the number of new HIV infections in the United States by at least 90% by 2030, which would be fewer than 3,000 per year.
EvaluationWeb	A web-based data system to collect HIV test-level data and other variables for activities funded by U.S. CDC.
Expedited Partner Therapy	The clinical practice of treating the Sex partners of patients Diagnosed with chlamydia or gonorrhea by providing prescriptions or medications to the patient to take to his/her partner without the health care Provider first examining the partner.
Females at Very High Risk (FVHR)	Females who engage in Sex behaviors that put them at disproportionate risk of acquiring or transmitting, including women who: a. Have had unprotected anal or vaginal Sex with a partner who is MSM and/or PWID; b. Have traded unprotected anal or vaginal Sex for money, goods, and/or survival needs; c. Are currently or recently infected with gonorrhea, syphilis, and/or viral hepatitis; and/or

Acronym/Term	Definition
	d. Have been Sexually assaulted within the past twelve months
FPL	Federal Poverty Level
HCV	Hepatitis C Virus or Hepatitis C
Health and Environmental Testing Laboratory (HETL)	The public health testing laboratory operated by the Department.
High-risk	A person who is disproportionately more likely to acquire or transmit HIV, STD, and/or HCV due to Sex and/or drug injection behaviors/behavior patterns, and/or prevalence within their demographic group.
HIPAA	Health Insurance Portability and Accountability Act of 1996
HIV	Human Immunodeficiency Virus
HIV Advisory Committee (HIVAC)	The HIV Advisory Committee was established in 5 MRSA §19202 to advise: "the Office of the Governor and state, federal and private sector agencies, officials and committees on HIV-related and AIDS-related policy, planning, budget or rules."
HL4ME®	Healthy Living for ME® is the Network Lead Entity of Maine's Community Integrated Health Network (CIHN) made up of local organizations, health systems, and volunteers who work together to empower individuals to take charge of their health.
HOPWA	Housing Opportunities for People with AIDS program through the U.S. Department of Housing and Urban Development. Frannie Peabody Center is the HOPWA grantee in Maine.
HRSA/HAB	U.S. Department of Health and Human Services, Health Resources & Services Administration, HIV/AIDS Bureau
Linkage/Linkage to Care	The process of assisting HIV, STD, and/or HCV-Diagnosed persons to enter Medical Care.
Maine CDC	Maine Center for Disease Control and Prevention
Maine HIV/AIDS Board (MeHAAB)	Integrated HIV Prevention and Care Planning Body for the State of Maine
Medical Care	Health care that is provided by a medically licensed professional within a clinical setting on an on-going basis.
Memorandum of Understanding (MOU)	A bilateral or multilateral agreement between two or more parties expressing a convergence of will between the parties, indicating an intended common line of action.
MSM	A man/men who has Sex with other men.
MSM/PWID	Men who have sex with Men and also inject drugs
NASTAD	National Alliance of State and Territorial AIDS Directors

Acronym/Term	Definition
National Epidemiological Database Surveillance System (NEDSS)	A data system that electronically transfers public health surveillance data from the healthcare system to public health departments and those health departments to CDC.
National HIV/AIDS Strategy (NHAS)	The National HIV/AIDS Strategy (2022–2025) provides stakeholders across the nation with a roadmap to accelerate efforts to end the HIV epidemic in the United States by 2030.
Navigation	Navigation involves assisting clients with finding community resources, making and tracking Referrals, empowering clients to take action to address their individual service needs, facilitating positive behavioral changes, and stigma-free education about HIV, STD and HCV prevention education.
New Mainer	A person living in Maine who was born in another country, regardless of immigration status.
Newly Diagnosed	Someone whose laboratory-confirmed Positive Result was unaware to the individual being tested AND was not previously existing in the surveillance data.
Non-Occupational Post-Exposure Prophylaxis (nPEP)	Any preventive Medical Treatment started after exposure to HIV to prevent the infection from occurring. Also known as post-exposure prevention.
NSDUH	National Survey on Drug Use and Health
OBH	Office of Behavioral Health within Maine DHHS
OMS	Office of MaineCare Services within Maine DHHS
Outreach	Services that support and promote HIV, STD, and Viral Hepatitis prevention, testing, and Referral to populations most at risk for acquiring or transmitting those infections. A coordinated activity that supports and promotes HIV, STD, and Viral Hepatitis prevention, testing, and Referral.
Partner Services	A public health intervention that reduces incidence, prevalence, and morbidity associated with HIV and STD infections. Partner Services is a process of assisting individuals newly-Diagnosed with HIV and/or STD(s) in notifying their Sex and/or needle-sharing partners of their risk of exposure to their infection, and to assist those partners in accessing testing services and/or Treatment services.
PCP	Primary Care Physician
PHI	Protected Health Information
PLWHA	Person living with HIV/AIDS
Pre-Exposure Prophylaxis (PrEP)	When people at very High-risk for HIV take daily medicine to prevent HIV. PrEP can stop HIV from taking

Acronym/Term	Definition
	hold and spreading throughout your body. When taken daily, PrEP is highly effective for preventing HIV from Sex or injection drug use.
Prevention Services	Services, such as counseling, education, and/or other activities, that reduce a client's risk of acquiring or transmitting HIV, STDs, and/or Viral Hepatitis.
Priority Population	A group of individuals, categorized by behavioral patterns or other factors, that have an increased risk of acquiring or transmitting HIV, STD(s), and/or HCV based on evidence and supported by state data.
Public Health District (PHD)	In 2008, the Maine Legislature in conjunction with the Maine Department of Health and Human Services (DHHS) approved the establishment of eight public health districts, using population size, geographic areas (county borders), and hospital service areas. In 2011, in collaboration with the five Maine Tribal jurisdictions, a Tribal Health District was established with boundaries determined by Tribal Health Center service areas and tribal jurisdictional boundaries. The districts are: 1. York (York County) 2. Cumberland (Cumberland County) 3. Western (Androscoggin, Franklin, and Oxford counties) 4. Midcoast (Waldo, Lincoln, Knox, and Sagadahoc counties) 5. Central (Somerset and Kennebec counties) 6. Penquis (Penobscot and Piscataquis counties) 7. Downeast (Washington and Hancock counties) 8. Aroostook (Aroostook County) 9. Tribal Health District (five Tribal Communities)
PWID	People Who Inject Drugs
PWUD	People Who Use Drugs (includes non-injection drugs)
QA	Quality Assurance
QI	Quality Improvement
QM	Quality Management
Rapid Test	A non-complex Screening test that, in under twenty (20) minutes, can detect the presence of HIV, syphilis, or HCV antibodies produced an infection that can be performed outside of a laboratory or clinical setting with a CLIA Waiver.
Referral	The process or documented act of assessing, providing information on Support Services, and/or arranging for

Acronym/Term	Definition
	provision of services that address and/or support a client's non-medical or medical needs
RFP	Request for Proposals, a competitive funding process
Ryan White HIV/AIDS Program (RWHAP)	A federal program (Parts A-D and F) that helps low-income people with HIV receive medical care and essential support services.
Ryan White Part B Program (RWHAP Part B)	Part B of the Ryan White HIV/AIDS Program provides grants to states and territories to improve the quality, availability, and organization of HIV health care and support services.
Ryan White Part C Program (RWHAP Part C)	Direct grants to primary care providers funded under Part C of the Ryan White HIV/AIDS Program. In Maine, these consist of Portland Public Health, Maine General Medical Center, and the Regional Medical Center at Lubec.
Screening	A cost-effective antibody test, usually performed in a general asymptomatic population, to identify those clients that likely have an HIV, syphilis, or HCV infection.
SCSN	Statewide Coordinated Statement of Need
SMARTER	Process used to clarify and define expectations for goals and objectives. It includes the following components: Specific, Measurable, Achievable, Relevant, Time bound, Evaluate, and Recognize achievements.
SSP	Syringe Service Program
STD/STI	Sexually Transmitted Disease(s) / Sexually Transmitted Infection(s)
Support Services	Any services that address and/or support a client's non-medical or medical needs to reduce their risks associated with acquiring or transmitting HIV, STDs, and/or viral hepatitis
TasP	The term "treatment as prevention" describes the concept of HIV prevention through clinical treatment of PLWHA
Training	A session offered by the Department or other technical assistance agency to enhance the knowledge, capacity, and skills of the Provider's staff.
Treatment	Medication that will reduce the symptoms of or eliminate an infection.
Undetectable=Untransmittable (U=U)	U=U is a campaign explaining how the sexual transmission of HIV can be stopped.
Viral Load Test	A laboratory test that measures the amount of HIV in a blood sample. Results are reported as the number of copies of HIV per milliliter of blood.

Acronym/Term	**Definition**
Viral Suppression	A very low level of HIV in the blood (less than 200 copies per milliliter).

State of Maine
HIV and AIDS Epidemiological Profile, 2020

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Infectious Disease Prevention Program
Division of Disease Surveillance
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LIST OF ABBREVIATIONS

ADAP	AIDS Drug Assistance Program
AI/AN	American Indian/Alaska Native
AIDS	Acquired Immunodeficiency Syndrome (HIV stage 3)
BRFSS	Behavioral Risk Factor Surveillance System
CDC	United States Centers for Disease Control and Prevention
CTR	Counseling, Testing, and Referral sites
DHHS	Maine Department of Health and Human Services
DIS	Disease Intervention Specialist
eHARS	Electronic HIV/AIDS Reporting System
FPL	Federal poverty level
HAV	Hepatitis A virus
HBV	Hepatitis B virus
HCV	Hepatitis B virus
HIV	Human Immunodeficiency Virus
HPSA	Health professional shortage areas
HRSA	Health Resources and Services Administration (US HHS)
IDU	Injection drug use
MeCDC	Maine Center for Disease Control and Prevention
MIYHS	Maine Integrated Youth Health Survey
MSM	Men who have sex with men
MUA	Medically underserved areas
MUP	Medically underserved populations
NCHSTP	National Center for HIV, STD, and TB Prevention (CDC)
NIR	No identified risk
NRR	No reported risk
NSDUH	National Survey of Drug Use and Health
PHD	Public health district
PLWHA	People living with diagnosed HIV/AIDS
PrEP	Pre-exposure prophylaxis
STD	Sexually transmitted disease
TasP	Treatment as prevention
WITS	Web Infrastructure for Treatment Systems

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EXECUTIVE SUMMARY

This profile was developed by the Maine Center for Disease Control and Prevention (MeCDC)'s Infectious Disease Prevention Program to assist Maine HIV prevention and care planners as well as others interested in HIV epidemiology. The profile focuses on three core questions:

1) What are the sociodemographic characteristics of the general population in Maine?
2) What is the scope of HIV in Maine?
3) What are the indicators of risk for HIV infection in Maine's population?

The profile additionally examines populations of special interest to Maine's Ryan White program and the continuum of HIV care in the state.

Due to challenges during the COVID-19 pandemic, the release of this profile was delayed. It includes all data available through 2019. When more current data was able to be found, it was included in this profile.

In 2019, Maine's population was an estimated 1.3 million. More than 36 percent of Maine residents lived in its two southern-most counties, York and Cumberland. Fifty-one percent of Maine's population identified as female, and 93 percent of Maine's population identified as non-Hispanic White. Individuals of any race who identified their ethnicity as Hispanic/Latino made up approximately two percent of the population. Approximately one-third of Maine's population was over 55 years old.

During 2019, there were 29 newly diagnosed cases of HIV reported to the MeCDC. Of those, 38 percent were cases of stage 3 HIV infection (AIDS). As of December 31, 2019, there were an estimated 1,757 individuals living with diagnosed and reported HIV disease (PLWHA) residing in Maine. Of these, 52 percent were infected with HIV (stages 1, 2 or unknown) and 48 percent were infected with AIDS (HIV stage 3).

In 2019, the estimated prevalence rate of reported HIV disease in Maine was 130.7 cases per 100,000 (95 percent CI: 124.6 – 136.8), an increase since 2010, when the estimated rate of HIV/AIDS in Maine was 108.2 cases per 100,000 (95 percent CI: 102.6 – 113.8). This increase in HIV prevalence may be due to several factors, including increased HIV testing, improved disease reporting and data collection, and longer lifespans among PLWHA.

In 2019, the majority of new HIV diagnoses were among males (72 percent). 78 percent of the total 1,757 PLWHA in Maine were male; 22 percent were female.

Approximately 59 percent of new HIV diagnoses in 2019 were among non-Hispanic White individuals and 35 percent were among non-Hispanic Black/African American individuals. 76 percent of new HIV diagnoses in Maine in 2019 were among individuals over the age of 30.

African Americans accounted for 19 percent of Maine PLWHA overall. Approximately seven percent of PLWHA in Maine were of Hispanic/Latino ethnicity. Approximately 18 percent of Maine PLWHA were born outside the U.S. In 2019, both Black/African American and Hispanic/Latino populations in Maine experienced a disproportionately high rate of HIV disease.

Among PLWHA in Maine, 53 percent were likely to have been infected through unprotected male-to-male sex, eight percent through injection drug use, and three percent through a combined risk of male-to-male sex and injection drug use. 11 percent of all known infections were likely transmitted via high-risk heterosexual contact; this was most frequent mode of identified transmission for HIV-positive women (36 percent).

Thirty-seven percent of all Maine PLWHA were living in the Cumberland Public Health District (PHD) at the time of their HIV diagnosis. Additionally, 52 percent of individuals newly diagnosed with HIV in 2019 were residing in the Cumberland PHD.

Between 2010 and 2019, an estimated 220 HIV positive individuals died in Maine. Sixty-six percent of these deaths were due to causes other than those directly related to HIV.

Population level estimates of certain behaviors or diseases known to be associated with HIV transmission can assist in understanding trends and changes in HIV risk. These include HIV testing, sexual risk behaviors, sexually transmitted diseases, viral hepatitis, and injection drug use. According to the 2019 BRFSS, approximately 36 percent of Maine adults reported they had ever received an HIV test.

Advancing our focus to the intersection of HIV and other select STDs, in 2019, there were 3,989 cases of chlamydia reported to the MeCDC for a rate of 296.8 cases per 100,000 individuals. Rates were highest among women, adolescents, and young adults. During the same year, there were 547 cases of gonorrhea reported to the MeCDC and the rate was 40.7 cases per 100,000 individuals. Rates of gonorrhea were highest among men and young adults aged 20-29. There were 111 cases of syphilis reported to the MeCDC in 2019, including 96 cases among males (89 percent). Approximately half of 2019 syphilis cases occurred among those reporting male-to-male sexual contact and a quarter were among persons coinfected with HIV.

Viral hepatitis shares common modes of transmission with HIV, and HIV-positive individuals are particularly at risk for viral hepatitis infection. In 2019, there were 59 acute cases of hepatitis C and 1,917 cases of chronic hepatitis C reported in Maine. The rate of chronic hepatitis C has been increasing Maine over the past five years.

Injection drug use is a risk factor for acquiring and/or transmitting HIV. At the end of 2019, there were 135 Maine PLWHA who were known to have likely acquired the disease via injection drug use, representing eight percent of Maine PLWHA. According to data from the Maine Department of Health and Human Services (DHHS), Office of Behavioral Health, 22 percent of individuals admitted to substance abuse treatment in 2019 reported injection drug use. Of those, 39 percent disclosed sharing needles in the past six months.

Engaging in certain types of unprotected male-to-male sexual contact can place individuals at a higher risk for acquiring HIV from, or transmitting HIV to, sexual partners. MSM make up the majority of PLWHA in Maine (56 percent). MSM also made up the largest proportion of cumulative new diagnoses of HIV disease in Maine from 2015 through 2019.

High-risk heterosexual contact can also place an individual at increased risk for HIV. In 2019, an estimated 11 percent of Maine PLWHA likely acquired the disease through high-risk heterosexual contact. High-risk sexual contact includes contact with a partner who uses injection drugs, is a male who has sex with men and women, and/or is HIV-positive. High-risk sexual contact was a more common mode of HIV transmission among female and Black/African American PLWHA in Maine compared to other genders and races respectively in the state.

The Ryan White HIV/AIDS Program (RW) works with states to provide services to individuals who do not have sufficient health care coverage or financial resources to cope with HIV disease. The State of Maine receives grant funding from the Heath Resources Service Administration (HRSA) to administer RW Part B services that cover core medical and support services for people with HIV/AIDS. HRSA has identified priority populations requiring special attention for RW program planning and resource allocation.

Youth ages 13 to 24 are a population of special concern for HIV planning and prevention because they experience several significant risk factors related to HIV—including risky sexual behaviors, substance abuse, and lack of access to health care—at higher rates than other age groups. In 2019, 14 percent of new HIV diagnoses in Maine in were among this age group.

The number of HIV-positive individuals in Maine currently using illicit drugs is unknown. According to the *2018-2019 National Survey on Drug Use and Health (NSDUH*), approximately 19 percent of Maine residents over age 12 reported using a least one illicit drug in the month preceding the survey, and 56 percent had used alcohol in past month. Young adults aged 18 to 25 had the highest rate of substance use in Maine.

In 2019, approximately 22 percent of Maine PLWHA were female. Female PLWHA in Maine were more racially diverse and were also more likely to have acquired HIV via high-risk heterosexual contact or injection drug use compared to male PLWHA.

Engagement in appropriate HIV medical care reduces morbidity and mortality among PLWHA. In 2019, more than 96 percent of individuals newly diagnosed with HIV were linked to HIV care within three months of their diagnosis. Linked to care is defined as the percent diagnosed in a calendar year who received a CD4 and viral load lab within 30 days of diagnosis. Among individuals diagnosed with HIV in Maine and living in the state as of the end of 2019, approximately 83 percent were in HIV care and 79 percent were considered virally suppressed, defined as having less than 200 copies/mL as of their most recent viral load test.

Health care coverage is an important factor in receiving timely and appropriate HIV care. In 2019, approximately 63 percent Maine PLWHA were enrolled in the State's AIDS Drug Assistance Program (ADAP). Of these enrollees, 92 percent had some type of health insurance coverage at some point during 2019.

Pre-exposure prophylaxis (PrEP) has been proven to reduce the risk of getting HIV from sex by 99 percent and reduces the risk of transmission through needle-sharing by at least 74 percent. National research shows an emerging association between PrEP use and decreases in rates of new HIV infections.

This is a topic for future exploration and study in Maine, as the number of individuals currently using PrEP is unknown and its impact in the state is yet to be determined.

The term “treatment as prevention” (TasP) describes the concept of HIV prevention through clinical treatment of PLWHA. For TaSP to be effective, PLWHA must have a suppressed HIV viral load, at which point the risk of transmitting HIV to sexual partners is virtually eliminated. Maine was recognized in the NASTAD 2020 data report for high rate of viral suppression among RW Part B enrollees. The high rate of access to care and viral suppression in Maine may be helping to prevent new infections in the state.

Despite medical advances and focused HIV prevention and care programs, HIV continues to have a harmful impact on the health and well-being of Maine people. New infections are occurring in Maine even as HIV-related deaths decline and HIV prevalence is incrementally increasing. Continued work in HIV prevention and care services remains vital in promoting the health of all Maine residents.

INTRODUCTION

Background

This epidemiological profile is designed to provide a comprehensive and thorough description of populations in the state of Maine infected with HIV or at risk of HIV infection. The profile was developed by the Maine Center for Disease Control and Prevention (MeCDC), Infectious Disease Prevention Program to assist Maine HIV prevention and care planners and others interested in HIV epidemiology. This profile was designed to serve as a planning tool to help identify present and future needs, set priorities for activities that support individuals living with diagnosed HIV/AIDS (PLWHA), and reduce HIV-related morbidity and mortality in Maine.

The goals of this profile, as suggested by the U.S. Centers for Disease Control and Prevention (CDC), are as follows:

- Provide a thorough description of HIV among various population groups within the state.
- Describe the current status of PLWHA in the state and provide some understanding of what the distribution of HIV in Maine may look like in the future.
- Identify characteristics of the general population and of populations who are living with, or at high risk for, HIV in Maine, and who may need primary and secondary prevention or care services.
- Provide information required to conduct needs assessments and gap analyses.

To meet these goals, the epidemiological profile is divided into three sections. Section 1 will address three essential epidemiological questions:

1. What are the sociodemographic characteristics of the general population in Maine?
2. What is the scope of HIV in Maine?
3. What are the indicators of risk for HIV infection in Maine's population?

Section 2 will address additional priority populations in Maine, focusing on an exploration of populations of special concern. Section 3 will provide an overview of the continuum of HIV care in Maine.

The following document is a five-year update to the 2015 Maine HIV Epidemiological Profile. It includes HIV data reported through December 31, 2019, unless otherwise noted.

Methods and Data Sources

This document relies primarily on disease data reported to the MeCDC by healthcare providers and laboratories in accordance with Maine's Rules for the Reporting of Notifiable Conditions. The document also considers local and national research concerning HIV risk behaviors and seroprevalence as well as U.S. Census data. Table 1 summarizes the sources of data used within this profile. A more detailed description of each data source is included in Appendix A.

Where possible, data are presented by sociodemographic characteristics and county and/or Maine Public Health District (PHD). MeCDC's current policy is to limit reporting where there are five or fewer individuals within a given group and the underlying population is less than 5,000. In these instances, individual cell numbers may be suppressed or categories and/or years may be combined to allow for trend analysis. Figures regarding HIV/AIDS prevalence and new diagnoses are based on data reported to MeCDC as of February 14, 2020.

Table 1. Data sources for the 2019 Maine HIV Epidemiological Profile

Section/Question	Data Source
SECTION 1/Question 1: What are the characteristics of Maine's population?	U.S. Census Bureau, American Community Survey 5-year estimates, 2015-2019
	U.S. Census Bureau, American Community Survey 1-year estimates, 2019
	U.S. Census Bureau, Population Division, Population Estimates Program, 2019
	U.S. Census Bureau, State and County Quick Facts
	U.S. Census Bureau, Census 2000 Summary File 3
SECTION 1/Question 2: What is the scope of HIV in Maine?	Maine electronic HIV/AIDS Reporting System (eHARS) database
SECTION 1/Question 3: What are the indicators of risk for HIV/AIDS in Maine?	Maine electronic HIV/AIDS Reporting System (eHARS) database
	National Electronic Disease Surveillance System Base System (NBS)
	U.S. Census Bureau, Population Division, Population Estimates Program
	Behavioral Risk Factor Surveillance System (BRFSS), 2017 and 2019
	Maine Integrated Youth Health Survey (MIYHS), 2019
	Web Infrastructure for Treatment Systems (WITS)
	Evaluation Web (HIV testing)
	Maine electronic HIV/AIDS Reporting System (eHARS) database
SECTION 2: Additional Priority Populations in Maine	National Survey on Drug Use and Health (NSDUH), 2018-2019
	Maine Integrated Youth Health Survey (MIYHS), 2019
	CAREWare (data for the Maine AIDS Drug Assistance Program)
SECTION 3: HIV Care in Maine	Maine electronic HIV/AIDS Reporting System (eHARS) database

SECTION 1: CORE EPIDEMIOLOGICAL QUESTIONS

Question 1: Characteristics of Maine's population

Examining the general characteristics of Maine's population provides context for understanding HIV in the state. This section will consider geographic, demographic, and socioeconomic data that describe Maine's population.

Geographic Information

With a land area of 30,843 square miles and a population of approximately 1.3 million, Maine is a geographically large but sparsely populated state. Maine's overall population density is considerably lower than that of the United States as a whole. In 2019, Maine's statewide population density was 44 individuals per square mile, while the overall population density of the U.S. was about 87 individuals per square mile.[1]

According to data from the 2010 U.S. Census, approximately 39 percent of Maine's residents lived in urban communities (defined as those with populations more than 50,000), while 61 percent lived in rural communities. Maine's population reflects a very different distribution of rural to urban residents compared to the United States generally. According to the most recent decennial U.S. Census, in 2010, about 81 percent of Americans lived in urban areas.

Many Maine residents live in areas with small numbers of healthcare providers and facilities. According to HRSA, 94,537 Maine residents live in areas designated as primary care Health Professional Shortage Areas (HPSAs)[a], and 51 communities in Maine are designated as Medically Underserved Areas (MUAs) or Medical Underserved Populations (MUPs).[b] Large geographic areas of western, northern, and northeastern Maine are designated as MUAs.

As of 2019, Maine's population was estimated to be 1,344,212. The state experienced low population growth in recent years. The U.S. Census estimates that Maine's total population grew 1.2 percent from 2010 to 2019. The Census further estimates that during 2018 and 2019 Maine experienced 2,262 more deaths than births.[2]

Maine is made up of 16 counties which vary considerably in population. In 2019, approximately 37 percent of Maine residents lived in Maine's two southernmost counties, York and Cumberland. Piscataquis County in north central Maine was the least populated county with just 1.2 percent of the state's total population. Maine's counties and corresponding populations are listed in Table 2 and displayed geographically in Figure 1.

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[a] Health Professional Shortage Areas (HPSAs) are designated by HRSA. The primary factor used to determine a HPSA designation is the number of health professionals relative to the population with consideration of high need.

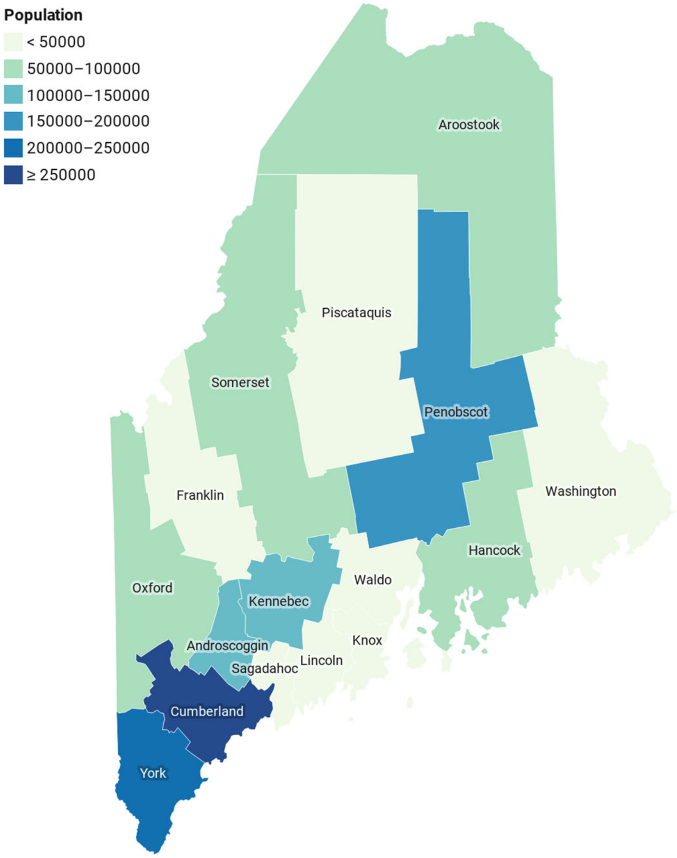
[b] Medically Underserved Areas (MUAs) and Medically Underserved Populations (MUPs) are designated by HRSA, and are areas or populations that have too few primary care providers, high infant mortality, high poverty, and/or high older adult population.

Table 2. Population count and distribution of Maine counties, 2019

County	Population Count	Percent (%) of population
Cumberland	295,003	21.90%
York	207,641	15.40%
Penobscot	152,148	11.30%
Kennebec	122,302	9.10%
Androscoggin	108,277	8.10%
Aroostook	67,055	5.00%
Oxford	57,975	4.30%
Hancock	54,987	4.10%
Somerset	50,484	3.80%
Knox	39,772	3.00%
Waldo	39,715	3.00%
Sagadahoc	35,856	2.70%
Lincoln	34,634	2.60%
Washington	31,379	2.30%
Franklin	30,199	2.20%
Piscataquis	16,785	1.20%
TOTAL	**1,344,212**	**100 %**

Source: U.S. Census Bureau, Population Division. County Population Totals: 2019

Figure 1. Population of Maine by county, 2019



Source: U.S. Census Bureau, Population Division. County Population Totals: 2019

Maine has eight Public Health Districts (PHDs). Some districts are composed of single counties and others include multiple counties. Maine also has a Tribal Health District which encompasses the state's five tribal communities located in Aroostook, Penobscot, and Washington counties. These districts were created by the Maine Department of Health and Human Services (DHHS) in 2007 as part of an effort to establish a coordinated, regionally-based public health system in the state. The eight districts and their corresponding populations are listed below in Table 3.

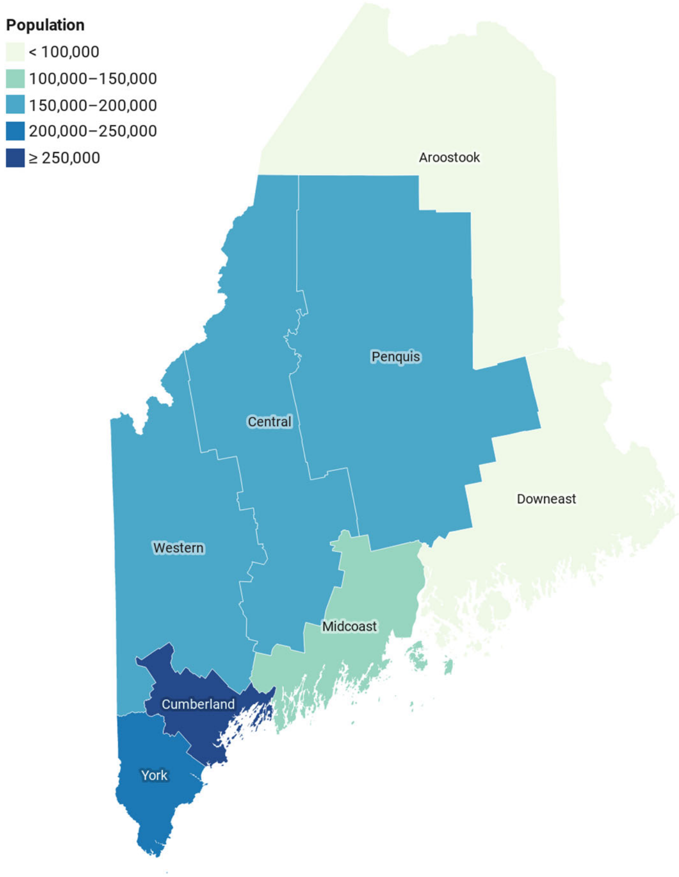
Table 3. Population of Maine public health districts, 2019

Public Health District	Population	Percent (%) of State's Population
York, District 1 (York County)	207,641	15.4%
Cumberland, District 2 (Cumberland County)	295,003	21.9%
Western, District 3 (Androscoggin, Franklin, and Oxford counties)	196,451	14.6%
Midcoast, District 4 (Knox, Lincoln, Sagadahoc, and Waldo counties)	149,997	11.2%
Central, District 5 (Kennebec and Somerset counties)	172,786	12.9%
Penquis, District 6 (Penobscot and Piscataquis counties)	168,933	12.6%
Downeast, District 7 (Hancock and Washington counties)	86,366	6.4%
Aroostook, District 8 (Aroostook County)	67,055	5.0%

Source: U.S. Census Bureau, Population Division. County Population Totals: 2019

Figure 2 presents a geographic display of Maine's PHD boundaries and their respective populations. Accounting for more than fifth of the state's population, the Cumberland PHD is the most populous, with 295,003 residents. The Aroostook PHD, with 67,055 residents, is the least populous district.

Figure 2. Population of Maine by Public Health District, 2019



Source: U.S. Census Bureau, Population Division. County Population Totals: 2019

Demographic Information

Age and Sex

Table 4 shows the distribution of Maine's 2019 population by age group and sex. In 2019, the median age of Maine residents was 45.1 years, several years older than that of the nation (38.5 years). Adults over 55 years old accounted for more than one-third of Maine's total population, while youth under 25 years accounted for approximately 15 percent. Fifty-one percent of Maine's population was female.

Table 4. Population of Maine by age group and sex, 2019

Age Group	Males	Females	Total (Age)	Percent (%) of State Population
<15	102,318	98,239	200,557	14.9%
15-19	40,293	37,916	78,209	5.8%
20-24	38,043	36,251	74,294	5.5%
25-29	41,202	40,966	82,168	6.1%
30-34	40,233	41,830	82,063	6.1%
35-39	39,417	38,177	77,594	5.8%
40-44	36,724	39,297	76,021	5.7%
45-49	41,320	42,729	84,049	6.3%
50-54	45,005	47,375	92,380	6.9%
55+	231,775	265,102	496,877	37.0%
Total	**656,330**	**687,882**	**1,344,212**	**100%**

Source: U.S. Census Bureau. Population Division, 2019 Annual Population Estimates

Race and Ethnicity

According to 2019 population estimates from the U.S. Census Bureau, Maine is among the least racially diverse states in the nation, despite experiencing a 29 percent increase in its racial and ethnic minority population since 2010. Table 5 shows the population distribution of both Maine and the U.S. by race and ethnicity according to U.S. Census Bureau's 2019 Annual Population Estimates. As Table 5 indicates, the majority of Maine's population identified as non-Hispanic White (93 percent). Maine residents of other races accounted for 5.3 percent of the state's population, and individuals of any race who identified their ethnicity as Hispanic/Latino made up 1.8 percent of Maine's population. In contrast, in 2019, non-Hispanic Whites made up approximately 60 percent of the United States' total population and 18.5 percent of U.S. residents identified their ethnicity as Hispanic/Latino.[3]

Table 5. Population of Maine and the United States by race and ethnicity, 2019

Race/Ethnicity	Maine		United States	
	Count	Percent (%)	Count	Percent (%)
White*	1,249,597	93.0%	197,309,822	60.1%
Black or African American*	21,554	1.6%	41,147,488	12.5%
American Indian/ Alaska Native*	8,990	0.7%	2,434,908	0.7%
Asian*	17,083	1.3%	18,905,879	5.8%
Native Hawaiian /Pacific Islander*	375	0.0%	595,908	0.2%
Two or More Races*	22,913	1.7%	7,273,281	2.2%
Hispanic/Latino (any race)	23,700	1.8%	60,572,237	18.5%

* Non-Hispanic/Latino

Source: U.S. Census Bureau. Population Division, 2019 Annual Population Estimates

While the population of Maine is racially and ethnically homogenous overall, some areas of the state are more racially and ethnically diverse. As indicated in Table 6, three Maine counties - Washington, Cumberland, and Androscoggin - have percentages of White, non-Hispanic populations that are below the statewide rate of 93 percent. Washington County is home to Maine's largest American Indian and Hispanic populations, Cumberland County contains the state's largest Asian population, and Androscoggin is home to the state's largest African American/Black population.[4]

Table 6. Maine counties by race and ethnicity (percent), 2019

County	White*	Black*	American Indian / Alaska Native*	Asian*	Native Hawaiian / Pacific Islander*	Two or more races*	Hispanic (any race)
Washington	89.3%	0.6%	5.2%	0.5%	<0.1%	1.9%	2.6%
Cumberland	90.1%	3.1%	0.3%	2.4%	<0.1%	1.9%	2.2%
Androscoggin	90.2%	4.3%	0.4%	0.9%	<0.1%	2.2%	1.9%
Maine	93.0%	1.6%	0.7%	1.3%	<0.1%	1.7%	1.8%
Penobscot	93.4%	0.9%	1.3%	1.2%	<0.1%	1.7%	1.5%
Aroostook	93.7%	1.1%	1.8%	0.5%	<0.1%	1.4%	1.4%
York	93.9%	1.0%	0.3%	1.3%	<0.1%	1.6%	1.8%
Kennebec	94.4%	0.7%	0.5%	1.0%	<0.1%	1.7%	1.7%
Sagadahoc	94.4%	0.8%	0.4%	0.8%	<0.1%	1.6%	1.9%
Hancock	94.5%	0.9%	0.4%	1.2%	<0.1%	1.3%	1.6%
Piscataquis	94.7%	0.5%	0.6%	1.0%	<0.1%	1.5%	1.5%
Knox	95.0%	0.8%	0.4%	0.6%	<0.1%	1.6%	1.6%
Oxford	95.0%	0.6%	0.4%	0.8%	<0.1%	1.6%	1.5%
Waldo	95.3%	0.6%	0.5%	0.6%	<0.1%	1.4%	1.6%
Somerset	95.4%	0.6%	0.5%	0.7%	<0.1%	1.5%	1.2%
Franklin	95.6%	0.5%	0.5%	0.5%	<0.1%	1.5%	1.3%
Lincoln	95.7%	0.6%	0.4%	0.8%	<0.1%	1.2%	1.3%

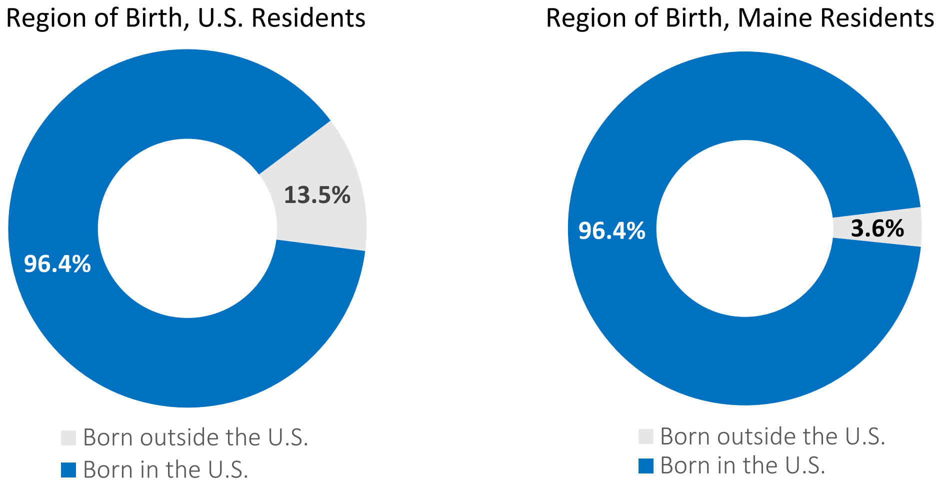
*Non-Hispanic/Latino

Source: U.S. Census Bureau. Population Division, 2019 Annual Population Estimates

Region of Birth

According to the 2018 U.S. Census American Community Survey, an estimated 3.6 percent of Maine residents were born in a country other than the United States (Figure 3). This represents an increase from 2.9 percent in 2000. Nationally in 2018, 13.5 percent of the overall U.S. population was born outside of the U.S., an increase from 11.1 percent in 2000.[5]

Figure 3. Percent of U.S. and Maine residents by region of birth, 2018


Region of Birth, U.S. Residents

Region of Birth, Maine Residents

Source: U.S. Census Bureau, 2018 American Community Survey 5-Year Estimates

In 2018, four Maine counties had a higher proportion of residents born outside of the U.S. than the state overall (Table 7). Cumberland County had the highest proportion of foreign-born residents (6.1 percent), while Franklin County had the lowest (1.3 percent).

Table 7. Maine counties by percent of foreign-born residents, 2018

Maine County	Percent foreign-born
Cumberland County	6.1%
Aroostook County	4.4%
Washington County	4.1%
Sagadahoc County	3.7%
Maine	3.6%
Androscoggin County	3.3%
York County	3.3%
Hancock County	3.1%
Lincoln County	3.0%
Knox County	2.8%
Penobscot County	2.7%
Kennebec County	2.4%
Waldo County	2.4%
Piscataquis County	1.9%
Somerset County	1.6%
Oxford County	1.5%
Franklin County	1.3%

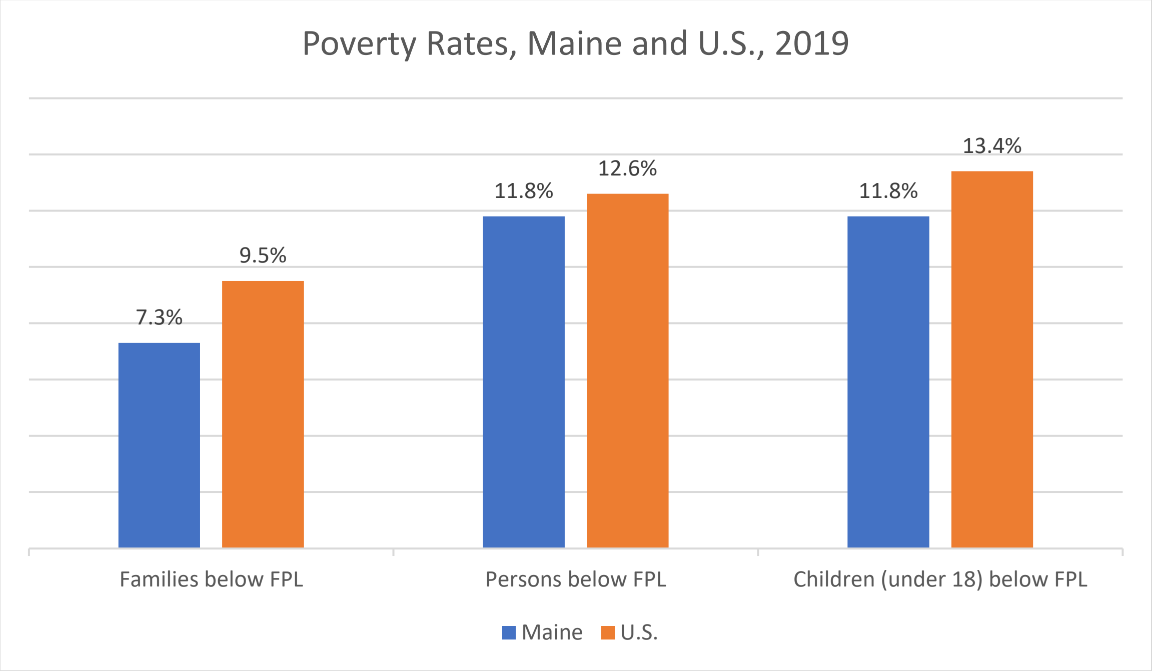
Source: U.S. Census Bureau, 2018 American Community Survey 5-Year Estimates

Socioeconomic Information

Poverty

In 2019, the federal poverty level (FPL) for the 48 contiguous U.S. states was $12,490 in annual income for an individual and $25,750 in annual income for a family of four.[6] As illustrated in Figure 4, in 2019, the estimated proportion of Maine residents living below the FPL was 11.8 percent—slightly below the national estimate of 12.6 percent. Maine's median annual household income during 2015-2019, was about $5,000 lower than that of the U.S. overall ($57,918 per year versus $62,843 per year, respectively).[7]

Figure 4. Poverty Rates, Maine and U.S., 2019



Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

During the five-year period from 2015-2019, nine Maine counties had a higher proportion of residents living below the FPL than the state overall (Table 8). Somerset County had the highest proportion of residents living below the poverty level (20.4 percent), while York County in southernmost Maine had the lowest (7.4 percent).[8]

Table 8. Maine counties by percent of residents living in poverty, 2019

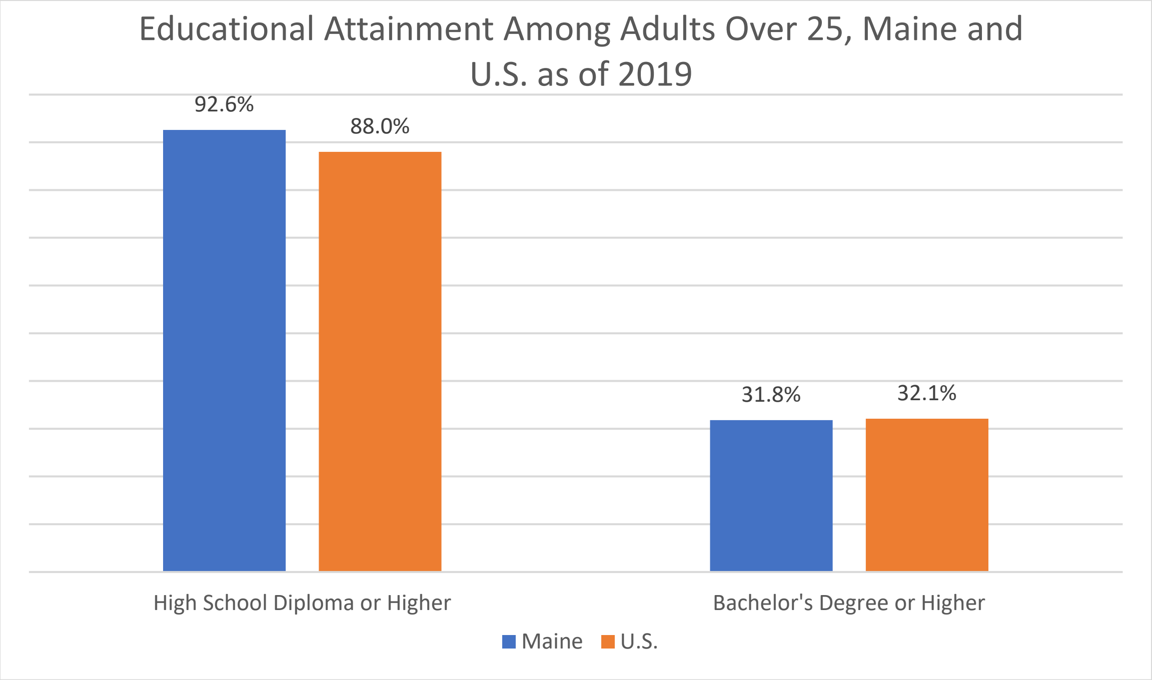
Maine County	Percent in Poverty (%)
Somerset County	20.4%
Washington County	18.9%
Piscataquis County	18.5%
Aroostook County	16.1%
Oxford County	15.1%
Penobscot County	14.8%
Waldo County	13.5%
Kennebec County	12.8%
Lincoln County	12.3%
Maine	11.8%
Androscoggin County	11.8%
Franklin County	11.5%
Hancock County	10.8%
Knox County	9.9%
Sagadahoc County	9.6%
Cumberland County	9.0%
York County	7.4%

Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

Educational Attainment

According to the U.S. Census Bureau's American Community Survey, in 2019, an estimated 92.6 percent of adults (25 years and older) living in Maine had completed high school. This was higher than the U.S. proportion of 88 percent during the same time period. Figure 5 compares the proportion of high school and college graduates in Maine and the U.S. in 2019.[9]

Figure 5. Educational Attainment Among Adults Over 25, Maine and the U.S., 2019



Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

Like poverty, educational attainment in Maine varied by county. Table 9 provides a breakdown by county of the average proportion of residents who completed high school and college during the five-year period from 2015-2019. Aroostook and Somerset counties had the lowest proportions of those with a high school diploma. Cumberland County had the highest proportion of both high school and college degrees attained.[10]

Table 9. Educational attainment among Maine adults over 25 by county as of 2019

Maine county	Percent (%) high school diploma* or higher	Percent (%) bachelor's degree or higher
Somerset County	88.4%	16.5%
Aroostook County	88.6%	19.2%
Washington County	89.3%	22.0%
Androscoggin County	90.2%	22.8%
Piscataquis County	90.3%	18.4%
Oxford County	91.9%	19.2%
Penobscot County	92.0%	27.7%
Waldo County	92.2%	31.4%
Kennebec County	92.5%	28.1%
Maine	92.6%	31.8%
Franklin County	92.6%	24.8%
Lincoln County	93.1%	33.5%
York County	93.2%	32.5%

Knox County	93.6%	33.5%
Sagadahoc County	94.0%	36.4%
Hancock County	94.1%	34.1%
Cumberland County	95.1%	47.6%

* Or equivalent

Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

Health Insurance Coverage

Health insurance coverage is an important indicator of access to preventive care and other health services. An estimated eight percent of Maine's population was uninsured in 2019, compared to 9.2 percent of the U.S. population. Table 10 provides a breakdown of Maine's uninsured population by age, gender, and race/ethnicity. Comparisons with Maine's overall population are also included.[11]

Table 10. Characteristics of Maine Uninsured Compared to Population, 2019

	Percent of Maine Population	Percent of Maine Uninsured
AGE		
Under 19 years	19.7%	13.8%
Adults (19 to 64 years)	59.4%	86.0%
Older Adults (65 years and older)	20.9%	0.3%
SEX		
Male	48.8%	55.1%
Female	51.3%	44.9%
RACE AND HISPANIC/LATINO ORIGIN		
White	94.0%	91.7%
Black or African American	1.6%	1.7%
American Indian and Alaska Native	0.7%	1.6%
Asian	1.1%	1.4%
Native Hawaiian and Other Pacific Islander	0.0%	0.0%
Some other race	0.4%	0.4%
Two or more races	2.1%	3.3%
Hispanic or Latino (of any race)	1.7%	2.0%

Source: U.S. Census Bureau, ACS 1-Year Estimates 2019

As Table 10 indicates, within Maine, the characteristics of the uninsured vary from the overall population characteristics. Adults aged 19 to 64 years make up a higher proportion of the uninsured than the general population, while older adults represent a very small proportion of the uninsured. Males make up a greater proportion of uninsured Mainers than females. The majority of the uninsured in Maine identified as white, which correlates with the general demographics of Maine, however some racial and ethnic minorities were overrepresented in the uninsured compared to the overall population.

Table 11 shows the proportion of uninsured Maine residents by county, with counties ranked by percent of uninsured. Hancock and Washington counties are shown to have the highest uninsured rates (12 percent), while Cumberland had the lowest rate (6 percent).[12]

Table 11. Maine counties by percent uninsured, 2018

Maine County	Percent uninsured
Hancock County	12%
Washington County	12%
Knox County	11%
Waldo County	11%
Lincoln County	10%
Oxford County	10%
Penobscot County	10%
Piscataquis County	10%
Somerset County	10%
Aroostook County	9%
Franklin County	9%
Maine	8%
Androscoggin County	8%
Kennebec County	7%
Sagadahoc County	7%
York County	7%
Cumberland County	6%

Source: U.S. Census Bureau, 2014-2018 American Community Survey 5-Year Estimates

Table 12 details the types of insurance coverage held by Maine residents in 2019. According to data from the U.S. Census Bureau's American Community Survey, the majority of Maine residents—more than two-thirds—were covered by private insurance plans, and 38 percent were covered by publicly-funded insurance. These insurance categories are not mutually exclusive; individuals may have multiple coverage types simultaneously.[13]

Table 12. Insurance coverage in Maine by type, 2019

Health Insurance Type*	Percent (%)
PRIVATE HEALTH INSURANCE	74.1%
Employment-based health insurance	55.2%
Direct-purchase health insurance	15.5%
TRICARE/military health coverage	3.4%
PUBLIC COVERAGE	44.8%
Medicare coverage	22.6%
Medicaid/means-tested public coverage	18.8%
VA Health Care	3.4%
UNINSURED	**8.0%**

* Note: Individuals may hold multiple types of coverage simultaneously. Categories are not mutually exclusive.

Source: U.S. Census Bureau, 2019 American Community Survey 5-Year Estimates

Key Points

Question 1 explored the geographic, demographic, and socioeconomic characteristics of Maine's population in order to provide a context for understanding HIV in the state.

Geography and population

- Maine is a geographically large and sparsely populated state, with the majority of its population (61 percent) residing in rural communities.
- Maine's most densely populated areas are in the central and southern areas of the state.
- As of 2019, Maine's population was estimated to be 1,344,212.
- Maine experienced low population growth in recent years. The U.S. Census Bureau estimates that Maine's total population grew slightly more than one percent from 2010 to 2019.
- Many Maine residents live in areas with small numbers of healthcare providers and facilities. Large geographic areas of western, northern, and northeastern Maine are considered by HRSA to be medically underserved.

Demographics

- In 2019, the median age of Maine residents was 45 years, several years older than that of the nation (39 years). Adults over 55 years old accounted for more than one-third of Maine's total population.
- Fifty-one percent of Maine's population was female.
- Maine's population was predominantly White and non-Hispanic/Latino. Seven percent of Maine residents identified as a race or ethnicity other than non-Hispanic White.
- Just under four percent of Maine's population was estimated to be born outside the U.S., compared to 14 percent of the U.S. population as a whole. Cumberland County had the highest proportion of foreign-born residents, at approximately six percent.

Socioeconomic factors

- In 2019, the estimated proportion of Maine residents living below the federal poverty level (FPL) was 11.8 percent, which is slightly below the national average of 12.6 percent.
- Nine of Maine's 16 counties had poverty rates above the state's overall rate. Somerset County, in rural western Maine, had the highest proportion of residents below the FPL, at 20.4 percent; York County in southern Maine had the lowest proportion, at 7.4 percent.
- In 2019, it was estimated that 92.6 percent of adults in Maine had completed high school, slightly higher than the national average of 88 percent. 31.8 percent of Maine adults have a college degree. County rates of high-school completion ranged from a low of 88 percent in Aroostook and Somerset counties to 95 percent in Cumberland County.
- Approximately 8 percent of Maine residents did not have health insurance, compared to an estimated 9.2 percent of the U.S. population.
- Among insured Maine residents, private health insurance was the most common insurance type.

Question 2: What is the scope of HIV in Maine?

Question 2 examines the extent and impact of HIV in Maine, including the number, distribution, and rate of HIV infection in the state. Data are also examined by demographic characteristics including sex, age, race/ethnicity, region of residence at HIV diagnosis, mode of HIV transmission, and region of birth.

HIV Data Sources and Limitations

HIV infection is a notifiable condition in Maine. Healthcare providers and clinical laboratories are required by law to report information about HIV to the MeCDC. Information provided by clinical entities includes patient demographics such as age, sex, race, HIV risks (if known), and region of residence, as well as information about disease status and progression. These data form the core of HIV surveillance data in Maine.

Although processes are in place to ensure that disease reports are completed in a timely and accurate manner, disease report data are imperfect. There are several limitations to Maine's HIV surveillance data which may impact its overall accuracy and completeness. Of note:

- Maine HIV data only include information about individuals who have been tested for HIV and been reported to the MeCDC. Individuals who are living with HIV in Maine but are not aware of their infection are not included in prevalence estimates and counts of new diagnoses.

- Positive HIV tests reported to the MeCDC do not always distinguish between individuals being diagnosed for the first time and those previously diagnosed with HIV outside of the United States. HIV diagnoses counted as new within a given year may therefore actually include both those truly being diagnosed for the first time and those who were previously diagnosed internationally but are receiving their first diagnosis of HIV within the United States.

- Data on mode of HIV transmission are based on a diagnosed individual's self-report of HIV risk factors. Individuals may not disclose, or may inaccurately disclose, information on HIV risk for a variety of reasons, including social stigma regarding certain HIV risk behaviors.

- Maine has recently undertaken efforts to improve the quality of data on deaths among HIV-positive individuals. As this process is ongoing, it may further impact estimates of HIV prevalence in the future.

Due to these limitations, the HIV data reported here represent *estimates*. Finally, readers are cautioned that all HIV data from 2019 should be considered preliminary, given the possibility of delays in case and clinical data reporting.

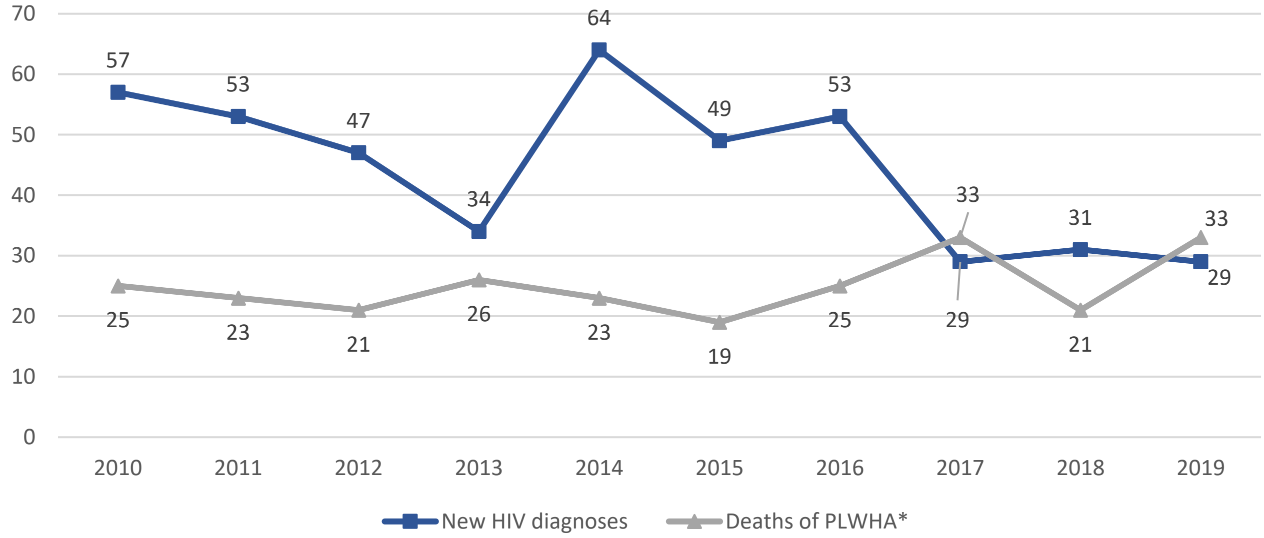
Overall HIV Prevalence and New Diagnoses in 2019

During 2019, there were 29 new diagnoses of HIV (all stages) reported to the MeCDC. Of those, 11 individuals (37.9 percent) were diagnosed with stage 3 or 4 HIV infection (AIDS). In 2019, the rate of newly diagnosed HIV infections was 2.2 (95 percent CI: 1.4 – 2.9) per 100,000 individuals. Maine's rate of diagnosis is substantially lower than the United States, which was 11.1 in 2019.[14]

From 2010 through 2019, the average number of HIV diagnoses per year was 44.6. The number of cases diagnosed annually over the past decade fluctuated from a high of 64 cases in 2014 to a low of 29 cases in both 2017 and 2019. New HIV diagnoses during the past three years (2017-2019) were lower than at any point in the past decade. However, because of the significant fluctuation in year-over-year totals, it remains to be seen if this decrease will be sustained in coming years.

Figure 6 illustrates trends in new HIV diagnoses and deaths among persons living with HIV in Maine from 2010 through 2019. Figure 7 shows the estimated number of people living with HIV in Maine.

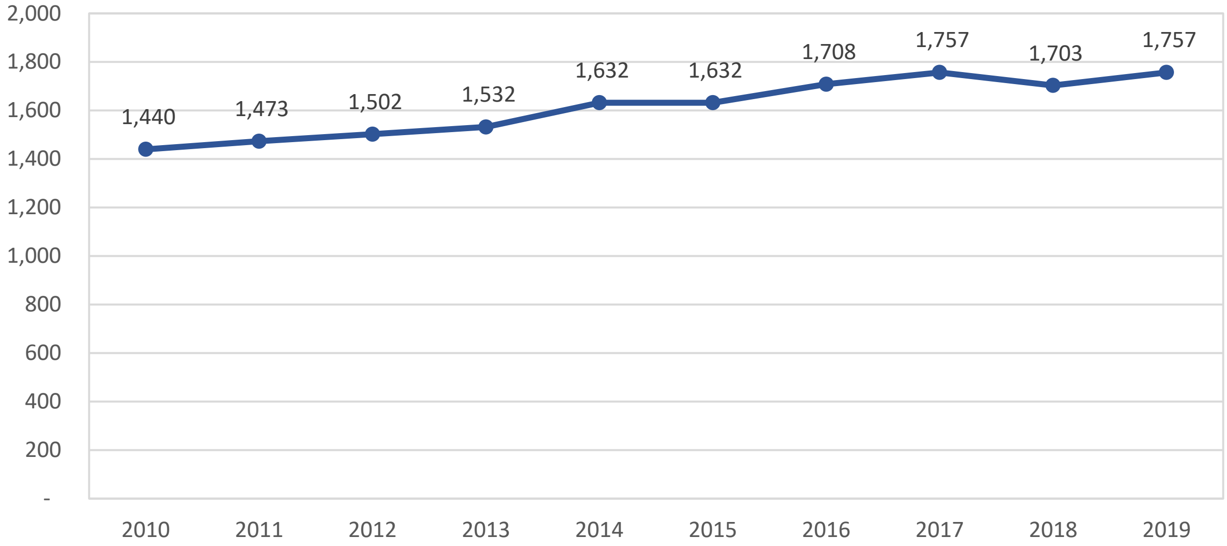
Figure 6. Number of new HIV diagnoses and deaths among PLWHA in Maine, 2010-2019



* Death counts are limited to individuals known to have died in Maine and exclude cases who died in other states or are missing data on location of death. The number of deaths for 2018 and 2019 should be considered preliminary and incomplete due to delays in reporting and availability of federally maintained death data.

Source: Maine electronic HIV and AIDS Reporting System (eHARS)

Figure 7. Estimated number of people living with diagnosed HIV in Maine



Source: Maine electronic HIV and AIDS Reporting System (eHARS)

As Figure 6 illustrates, during eight of the past 10 years the number of deaths among PLWHA living in Maine was lower than the number of new HIV diagnoses in the state, which contributed to Maine's gradually increasing HIV prevalence (Figure 7).

In 2019, 1,757 individuals with diagnosed and reported HIV disease (any stage) resided in Maine. Of these, 52 percent were infected with HIV (stages 1, 2 or unknown) and 48 percent were infected with AIDS (HIV stage 3). The estimated prevalence rate of HIV disease during 2019 was 130.7 (95 percent CI: 124.6 – 136.8) cases per 100,000 people. The 2019 rate represents an overall increase since 2010, when the estimated prevalence rate of HIV/AIDS in Maine was 108.2 (95 percent CI: 102.6 – 113.8) cases per 100,000.

The overall increase in the prevalence of PLWHA in Maine is likely the result of improvements in HIV/AIDS care. However, it is important to note that HIV prevalence estimates may also be artificially increased or decreased because of better reporting of HIV cases by health care providers or better ascertainment of deaths among persons living with HIV. If more testing occurs, particularly among high-risk populations, more cases of HIV will be diagnosed and identified.

Demographic Characteristics of People Living in Maine with Diagnosed HIV/AIDS

This section highlights key demographic characteristics of Maine PLWHA. This information is critically important for prevention and care planning, as some demographic groups may be at higher risk for HIV acquisition or in greater need of HIV care services. The demographic information included in this section is presented in as much detail as possible, while protecting individual privacy and adhering to the MeCDC rules regarding small cell size. Additionally, sex in this section refers to an individual's assigned sex at birth. At this time, Maine is unable to thoroughly and accurately report on current gender identity, which may be different than sex at birth.

Sex

Aligning with national and historic trends, the majority of new diagnoses in Maine in 2019 were among individuals whose sex at birth was male. Of the 29 individuals diagnosed with HIV in 2019, 21 were male (72.4 percent), and 8 were female (27.6 percent). Males also make up the majority (78.3 percent) of all Maine PLWHA. Table 13 provides a breakdown of Maine PLWHA by sex and stage of disease.

Table 13. PLWHA in Maine by sex, 2019

	HIV (stage 1, 2 or unknown)		**AIDS (HIV stage 3)**		**Total HIV (all stages)**	
	Count	Percent (%)	Count	Percent (%)	Count	Percent (%)
Female	209	22.8%	172	20.5%	381	21.7%
Male	708	77.2%	668	79.5%	1,376	78.3%
TOTAL	**917**	**100%**	**840**	**100%**	**1,757**	**100%**

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Age

In 2019, the majority of new HIV diagnoses in Maine were among individuals over the age of 30 (73 percent). There were no pediatric cases (under 13 years old) in 2019. At the end of 2019, almost all (96%) Maine PLWHA were over the age of 30, and 65% were over the age of 50. Table 14 provides a breakdown by age group of both new HIV diagnoses and existing HIV cases in 2019.

Table 14. New HIV diagnoses and PLWHA by age group, 2019

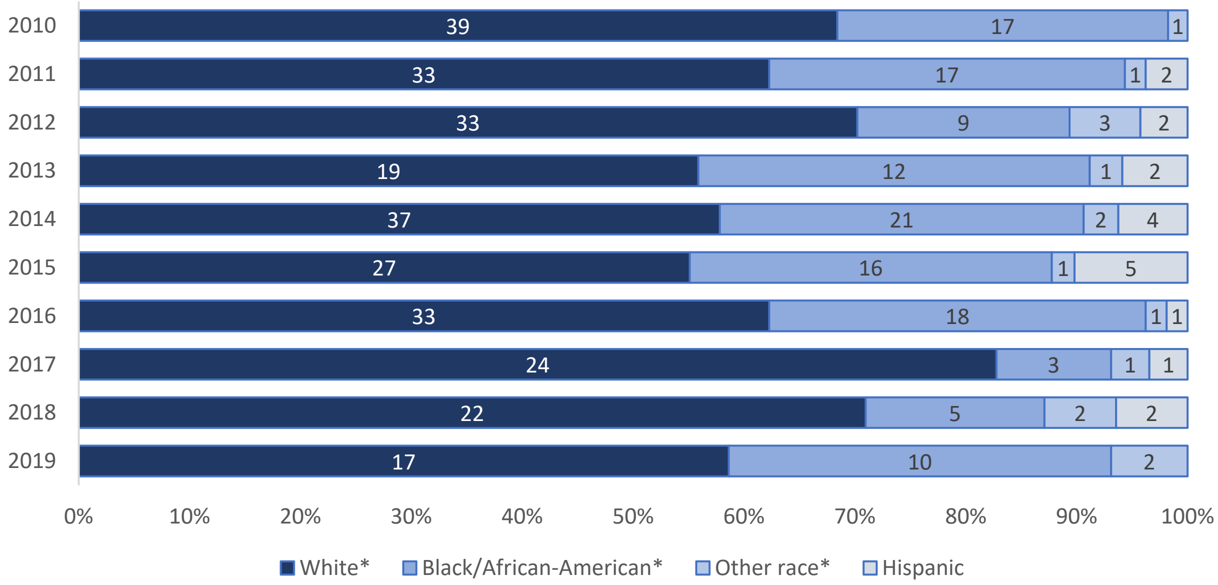
	New HIV diagnoses (all stages)		**Existing HIV cases (PLWHA)**	
Age group	Count	Percent (%) of new Diagnoses	Count	Percent (%) of PLWHA
under 15	0	0	14	0.8%
15-19	0	0	7	0.4%
20-29	7	24.1%	54	3.1%
30-39	9	31.0%	200	11.4%
40-49	6	20.7%	336	19.1%
50-59	3	10.3%	573	32.6%
over 60	4	13.8%	573	32.6%
TOTAL	**29**	**100%**	**1,757**	**100.0%**

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Race and Ethnicity

Of the 29 new adult HIV diagnoses in Maine in 2019, 17 (58.6 percent) were among non-Hispanic White individuals, 10 (34.5 percent) were among non-Hispanic Black/African American individuals, 1 (3.5 percent) was a non-Hispanic Asian individual, and 1 was a non-Hispanic multi-race individual (3.5 percent). Figure 8 shows the trends in the number and distribution of new HIV diagnoses from 2010 – 2019 among individuals over the age of 13 years old by race and ethnicity.

Figure 8. Number and distribution of new HIV diagnoses (among ≥ 13 years old) by year and race/ethnicity, 2010 – 2019



*non-Hispanic

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

In 2019, non-Hispanic White individuals made up the majority of both those living with diagnosed HIV (stages 1, 2, or unknown) and those living with AIDS (HIV stage 3). Table 15 provides a breakdown of PLWHA by race/ethnicity, disease status, and adult/pediatric designation.

Table 15. Number and distribution of Maine PLWHA by disease status and race/ethnicity, 2019

	HIV (Stage 1, 2 or unknown)			**AIDS (HIV stage 3)**			**Total (all stages)**	
	Adult	Pediatric	% of HIV (adult + pediatric)	Adult	Pediatric	% of AIDS (adult + pediatric)	Total	Percent (%) of total
American Indian/ Alaska Native*	3	0	0.3%	6	0	0.7%	9	0.5%
Asian*	6	0	0.7%	5	0	0.6%	11	0.6%
Black/ African-American*	197	14	23.0%	113	3	13.8%	327	18.6%
Hispanic/Latino	54	3	6.2%	59	1	7.1%	117	6.7%
Multi-race*	13	1	1.5%	10	1	1.3%	25	1.4%
White*	611	6	67.3%	638	4	76.4%	1,259	71.7%
Race unknown	9	0	1.0%	0	0	0.0%	9	0.5%
Total	**893**	**24**	**100%**	**831**	**9**	**100%**	**1,757**	**100%**

* Non-Hispanic

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

While 72 percent of PLWHA in Maine were non-Hispanic White, HIV/AIDS disproportionately affected Black/African American and Hispanic/Latino(a) residents. The prevalence rate of HIV among Black/African American residents was the highest in the state: 1,517.1 cases per 100,000. Additionally, 52 percent of known pediatric HIV/AIDS cases in Maine were Black/African American. Table 16 provides a breakdown of the distribution and rate of HIV infection in Maine by race and/or ethnicity.

Table 16. Estimated rate of diagnosed HIV infections (any stage) in Maine by race/ethnicity, 2019

Race/ethnicity	**Count**	**Percent (%)**	**Rate per 100,000**	**95% CI for rate**
White*	1,259	71.7%	100.8	95.2 – 106.3
Black /African American*	327	18.6%	1,517.1	1,352.7 - 1,681.6
Hispanic/Latino	117	6.7%	493.7	404.2 - 583.1
Other race or multi-race	54	3.0%	109.4	80.2 – 138.6

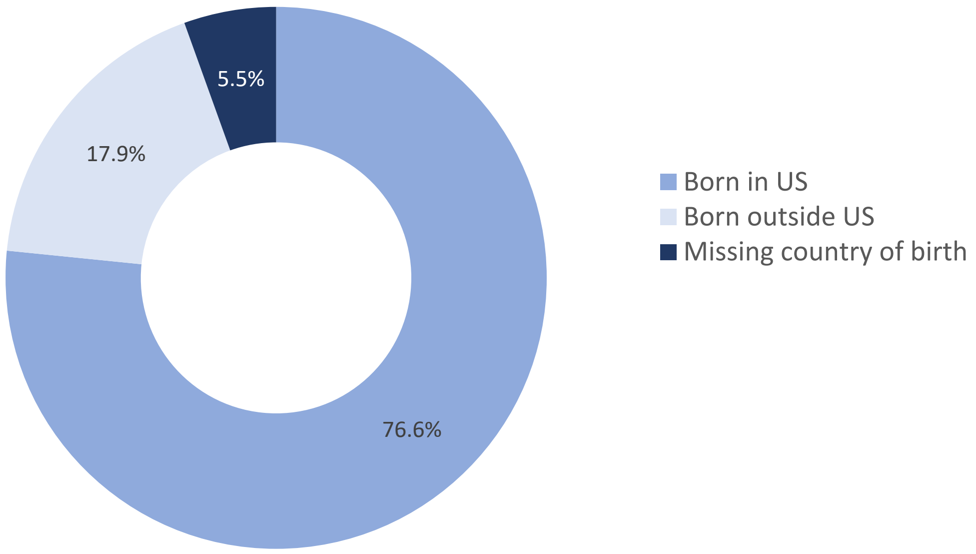
*Non-Hispanic

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Region of Birth

In 2019, 1,345 of the 1,757 PLWHA in Maine were born in the U.S. (76.6 percent), and 315 (17.9 percent) were born outside the U.S. (Figure 9). In addition, nine of the 29 people diagnosed with HIV in 2019, or 30 percent, were born outside the United States. According to the U.S. Census Bureau, in 2019 approximately 3.6 percent of Maine residents were born in a country other than the U.S. This suggests that Maine residents born outside the U.S. may be disproportionally impacted by HIV.

Figure 9. Region of birth among Maine PLWHA, 2019



Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Mode of HIV Transmission

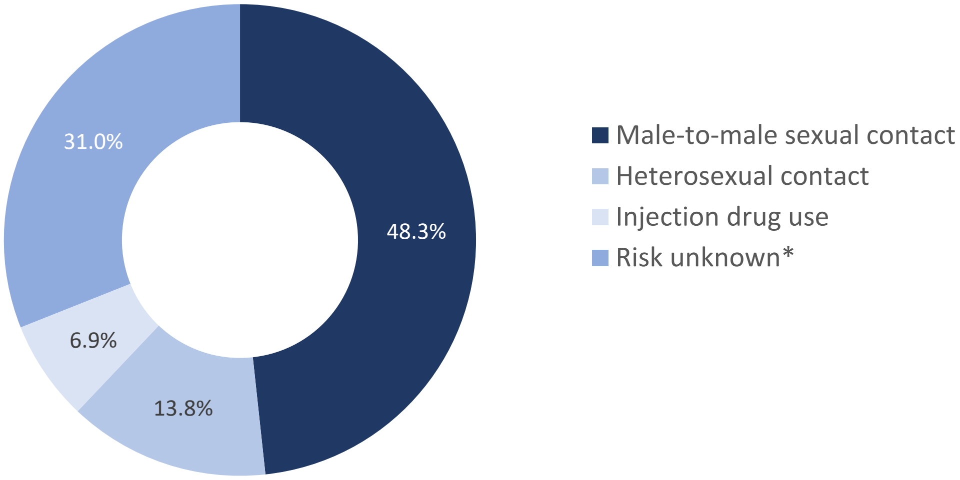
There are certain behaviors associated with an increased risk for the acquisition and/or transmission of HIV. Risk behaviors associated with HIV transmission include unsafe male-to-male sexual contact, sharing needles and other equipment in the course of injection drug use, and high-risk sexual contact. High-risk heterosexual contact includes sexual contact with partners who are infected with HIV, inject nonprescription drugs, or are men who have sex with men and women (MSMW).

Mode of Transmission: Special Considerations

When an individual receives a new diagnosis of HIV, it is public health practice to gather additional information from that individual to better understand what circumstances and/or behaviors were most likely associated with the HIV transmission. In Maine, Disease Intervention Specialists (DIS) or healthcare providers gather this information through voluntary interviews with newly diagnosed patients. Newly diagnosed individuals may refuse to participate in risk interviewing, and those who do agree to participate may refuse to disclose their true risk factor(s) or may report their risk factors inaccurately or incompletely. Among other reasons, individuals might decline to provide risk factor information due to fears about the consequences associated with disclosing illegal or culturally stigmatized behaviors. Readers are therefore cautioned that inaccurate or incomplete disclosure of risk behavior information may artificially inflate the “no risk reported” (NRR) and “no identified risk” (NIR) transmission category counts and deflate counts in the male-to-male sexual contact, injection drug use, and combined male-to-male sexual contact/injection drug use transmission categories. Transmission modes are categorized in accordance with U.S. CDC guidance based on the individual’s reported risk factors and reflect the most likely route of transmission.

Figure 10 displays the distribution of new HIV diagnoses in 2019 by mode of transmission. Male-to-male sexual contact was the most common mode of transmission (14 cases or 48.3 percent) and heterosexual contact was the second most common (four cases or 13.8 percent). Two of the 30 diagnoses (6.9 percent) were determined to have injection drug use as the mode of transmission. Risk was unknown for nine diagnoses, categorized as either “Adult, no risk factor reported” (five cases or 17.2 percent), or “Adult, no identified risk factor” (four cases or 13.7 percent). Of the nine cases with unknown transmission risk, eight had a country of origin outside of the U.S.

Figure 10. Distribution of new HIV (any stage) diagnoses by mode of transmission, 2019



* Includes adult case with no identified (NIR) or no reported risk (NRR).

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Table 17 provides a breakdown of Maine PLWHA by mode of HIV transmission and sex at birth. Among all PLWHA in Maine in 2019, the majority (53 percent) were likely to have been infected through unprotected male-to-male sexual contact. High-risk heterosexual contact accounted for 11 percent of all known infections but was the most frequent mode of identified transmission for female PLWHA (36 percent). Infection via injection drug use accounted for eight percent of infections overall, and 13 percent of HIV infections among women living with HIV/AIDS. Three percent of cases were attributed to the combined risk of male-to-male sex and injection drug use.

Table 17. Number and distribution of Maine PLWHA by transmission category and sex, 2019

TRANSMISSION CATEGORY	**FEMALE**		**MALE**		**TOTAL**	
	Count	% of Female	Count	% of Male	Count	% of Total
Male-to-male sexual contact	n/a	n/a	937	68.1%	937	53.3%
Injection drug use	49	12.9%	86	6.3%	135	7.7%
Male-to-male sexual contact & injection drug use	n/a	n/a	54	3.9%	54	3.1%
Heterosexual contact	136	35.7%	57	4.1%	193	11.0%
Perinatal transmission (diagnosed at any age)	11	2.9%	12	0.9%	23	1.3%
Other*	185	48.6%	230	16.7%	415	23.6%
Total	381	100.0%	1,376	100.0%	1,757	100.0%

*Includes transmission via clotting factor, transplant/transfusion, other confirmed risks, and those with no identified (NIR) or no reported risk (NRR).

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Perinatal transmission was a relatively rare mode of transmission in Maine. As of 2019, there were 23 individuals living in Maine known to have acquired HIV through perinatal transmission, accounting for approximately one percent of the total PLWHA.

People infected through contaminated blood products represent less than one percent of Maine PLWHA. Additionally, there have been no documented or reported instances of occupationally-acquired HIV infection in the state.

Region of Residence at HIV Diagnosis

This subsection describes the location of residence of Maine PLWHA at the time of their HIV diagnosis. Data in this subsection are presented by Public Health District (PHD) only due to the very low numbers (<5) of HIV cases diagnosed in some Maine counties (see Section 1 for PHD definitions).

Fifteen of the 29 individuals (51.7 percent) newly diagnosed with HIV in 2019 resided in the Cumberland PHD. The remaining diagnoses were spread across the remainder of the state.

More than one-third of Maine PLWHA were living in the Cumberland PHD at the time of their HIV diagnosis. Table 18 details the distribution of all Maine PLWHA by their PHD of residence at diagnosis.

Table 18. PHD of residence at HIV diagnosis among Maine PLWHA, 2019

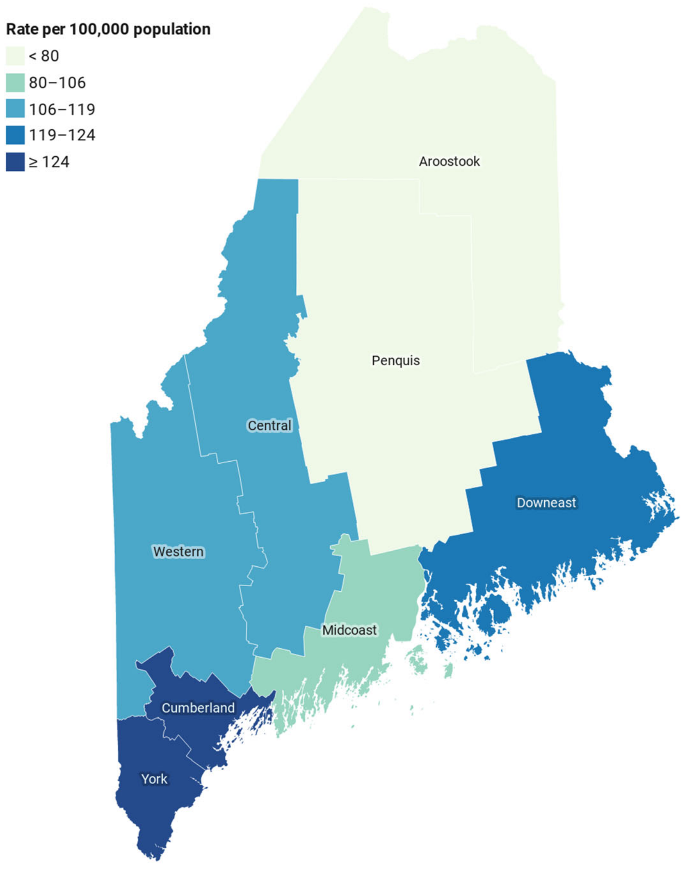
Public Health District*	PLWHA	% of Total	Rate per 100,000 persons	95% CI for rate (per 100,000 persons)
Aroostook	46	2.6%	69	48.8 - 88.4
Central	191	10.9%	111	94.9 - 126.2
Cumberland	650	37.0%	220	203.4 - 237.3
Downeast	104	5.9%	120	97.3 - 143.6
Midcoast	127	7.2%	85	70.0 - 99.4
Penquis	129	7.3%	76	63.2 - 89.5
Western	233	13.3%	119	103.4 - 133.8
York	261	14.9%	126	110.4 - 140.9

*Missing residence: n = 16

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Figure 11 provides a geographic display of the PHD of residence at HIV diagnosis among PLWHA in Maine in 2019.

Figure 11. PHD of residence at HIV diagnosis among PLWHA in Maine, 2019



Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

The population of individuals living in the Cumberland PHD at the time of diagnosis was the most racially diverse in the state. Approximately 65 percent of the state's Black/African American PLWHA lived in the Cumberland PHD at the time of their HIV diagnosis. Table 19 details the region of residence at HIV diagnosis among Maine PLWHA by racial group.

Table 19. PHD of residence at time of HIV diagnosis among Maine PLWHA by race/ethnicity, 2019

	Hispanic/ Latino		White**		Black/ African American**		Other race/ Multi-race**		Total*	
Public Health District	N	%	N	%	N	%	N	%	N	%
Aroostook	--	--	32	2.6%	--	--	--	--	46	2.6%
Central	--	--	170	13.6%	10	3.1%	--	--	191	11.0%
Cumberland	43	37.1%	363	29.1%	225	69.2%	19	35.2%	650	37.3%
Downeast	14	12.1%	83	6.7%	--	--	--	--	104	6.0%
Midcoast	--	--	106	8.5%	10	3.1%	--	--	127	7.3%
Penquis	--	--	108	8.7%	10	3.1%	--	--	129	7.4%
Western	16	13.8%	168	13.5%	42	12.9%	7	13.0%	233	13.4%
York	17	14.7%	216	17.3%	19	5.8%	9	16.7%	261	15.0%
Total*	116	100.0%	1,246	100.0%	325	100.0%	54	100.0%	1,741	100.0%

* Missing residence at diagnosis: n = 16

** Non-Hispanic

-- Suppressed due to small cell size

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

HIV/AIDS Deaths in Maine

Data on deaths among HIV-positive individuals in Maine are obtained by MeCDC's Office of Data, Research, and Vital Statistics from death certificates. HIV surveillance staff link death data to the State's eHARS database annually. For the purposes of this report, deaths among PLWHA in Maine were considered to be those deaths that occurred in Maine, regardless of where the individuals were diagnosed.

In 2019, 33 PLWHA were known to have died in Maine. As illustrated in Figure 6, the number of deaths among people known to have HIV/AIDS in Maine has remained relatively steady over the past ten years. During 2010 through 2019, the average number of deaths per year among PLWHA was 22, and 75.5 percent were aged 50 years or older.

Table 20 provides a demographic breakdown of the cumulative deaths among PLWHA who died in Maine between 2010 and 2019.

Table 20. Cumulative deaths among Maine PLWHA by select demographic characteristic, 2010-2019

Demographic characteristic	Count	Percent (%) of total deaths
SEX		
Male	183	83.2%
Female	37	16.8%
AGE		
Under 50	54	24.5%
Over 50	166	75.5%
RACE		
White*	186	84.5%
African American*	13	5.9%
Other race/ethnicity	21	9.5%
TOTAL DEATHS	220	100%

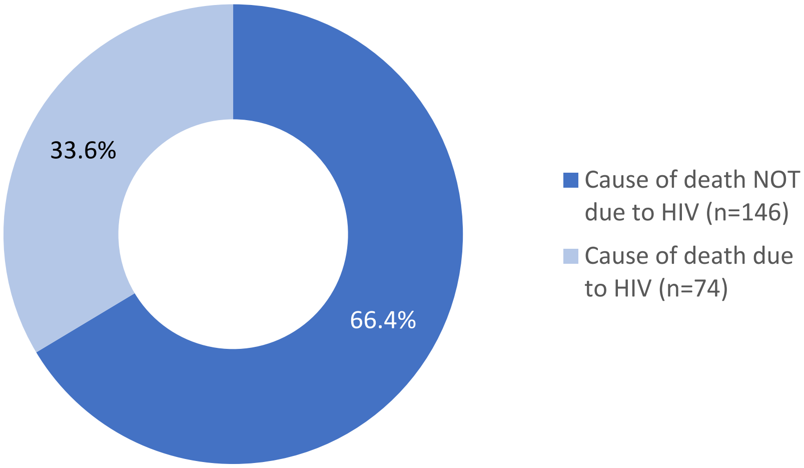
* Non-Hispanic/Latino

NOTE: Data excludes individuals who died in a state other than Maine or for whom location at death was unknown.

Source: Maine electronic HIV and AIDS Reporting System (eHARS)

In the 10-year period between 2010 and 2019, the majority of deaths that occurred in Maine among PLWHA were due to causes other than those directly related to HIV. Figure 12 displays the relative proportions of HIV and non-HIV causes of death among PLWHA who died in Maine between 2010 and 2019. Among those with an HIV-related cause of death during this time period, the average age at death was 55 years old, while the average age at death for those with a cause of death not directly related to HIV was 56 years old (data not shown).

Figure 12. Cumulative causes of death among PLWHA in Maine, 2010-2019



Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Key Points

Question 2 examined the extent and impact of HIV in Maine, including the number, distribution, and rate of HIV infection in the state. Demographics, transmission risk, and deaths among both PLWHA are also described.

HIV Prevalence and 2019 HIV diagnoses:

- During 2019, there were 29 new diagnoses of HIV reported to the MeCDC. The rate of newly diagnosed HIV infections was 2.2 per 100,000 individuals. Maine's rate of diagnosis is substantially lower than the United States, which was 11.1 in 2019.
- From 2010 through 2019, the average number of annual HIV diagnoses per year was 44.6. The number cases diagnosed annually over the past decade fluctuated from a high of 64 cases in 2014 to a low of 29 cases in both 2017 and 2019.
- A total of 1,757 people are estimated to be living with diagnosed HIV/AIDS in Maine. This figure does not include those who have not been tested and/or reported to the MeCDC.
- Estimated HIV prevalence in Maine has gradually increased over the past decade. This is likely due to improvements in medical care which have improved the health of the population of Mainers living with HIV and reduced the number of deaths.

Demographic characteristics of PLWHA:

- Approximately 28 percent of 2019 HIV diagnoses were among females, and approximately 22 percent of Maine's total population of PLWHA were female.
- Fifty-nine percent of 2019 HIV diagnoses were among non-Hispanic White individuals, and 35 percent were among non-Hispanic Black/African Americans. Likewise, the majority of PLWHA in Maine were non-Hispanic White (72 percent), followed by Black/African Americans (19 percent) and Hispanic/Latino individuals of any race (7 percent).
- HIV/AIDS disproportionately affected Black/African American and Hispanic/Latino(a) residents. The rate of diagnosed HIV among Black/African American residents was 1,517.1 cases per 100,000 population, followed by Hispanics at 494 per 100,000. The rate among White, non-Hispanic residents was 101 per 100,000.
- Thirty percent of those diagnosed with HIV in 2019 were born outside the U.S. Likewise, approximately 18 percent of Maine PLWHA were born outside the U.S.

Mode of HIV transmission

- For 2019 diagnoses, male-to-male sexual contact was the most common mode of transmission (48 percent), followed by heterosexual contact (14 percent), and injection drug use (7 percent).
- Approximately 53 percent of PLWHA were infected through male-to-male sex, 11 percent through heterosexual sex, eight percent through injection drug use, and three percent through a combination of male-to-male sex and injection drug use.

Deaths among persons with HIV

- Thirty-three people with HIV died in Maine in 2019. During the 10-year period between 2010 and 2019, a total of 220 deaths occurred among PLWHA, or an average of 22 deaths per year. Of these, 34 percent were attributed to HIV disease and the remainder were attributed to causes other than HIV.

Question 3: What are the indicators of risk for HIV infection in Maine's population?

Population-level estimates of certain behaviors or diseases known to be associated with HIV transmission can assist in understanding trends and changes in HIV risk. This section addresses HIV risk factors in Maine, including HIV testing, sexual risk behaviors, sexually transmitted diseases, viral hepatitis, and injection drug use.

High-risk behaviors

The risk of transmitting or acquiring HIV varies by behavior or exposure. Three behaviors are associated with the majority of HIV infections in the state. These include needle sharing during injection drug use, male-to-male sexual contact, and high-risk heterosexual contact.

Injection drug use

People who use injection drugs are at heightened risk for HIV infection due to their increased risk of sharing contaminated injection equipment.

As of the end of 2019, there were 135 individuals with HIV (any stage) living in Maine who likely acquired the disease via injection drug use, representing approximately eight percent of Maine PLWHA (see Table 17). An additional 54 individuals were likely to have acquired HIV (any stage) via a combination of male-to-male sexual contact and injection drug use. These counts are based on individual self-report through diagnostic interviewing and may underestimate the true number of PLWHA in Maine who acquired HIV via sharing contaminated injection equipment.

Table 21 provides a breakdown by age, race, and sex assigned at birth of Maine PLWHA for whom the HIV mode of transmission was determined to be injection drug use. Some racial categories and counts have been omitted or suppressed because of small cell size.

Table 21. Counts of Maine PLWHA with injection drug use mode of transmission by age group, race and sex, 2019

RACE	**20-29 years**	**30-39 years**	**40-49 years**	**50-59 years**	**60 + years**	**Total**
Hispanic/Latino	--	--	6	8	--	24
Black/ African American *	--	--	--	--	--	21
White*	0	18	19	57	48	142
SEX						
Female	1	10	5	18	15	49
Male	1	14	23	55	47	140
Total	**2**	**24**	**28**	**73**	**62**	**189**

* Non-Hispanic

-- Suppressed due to small cell size

SOURCE: Maine Electronic HIV and AIDS Reporting System (eHARS)

According to the University of Michigan's "Monitoring the Future" survey—an on-going national study of substance use among American youth and young adults—about 1.5 percent of survey respondents between age 21 and 30 report using injection drugs at least once. Additionally, about 0.5 percent of survey respondents report sharing needles in the course of injection drug use.[15]

Additionally, data from the 2018 NSDUH—an annual survey sponsored by the Substance Abuse and Mental Health Services Administration (SAMHSA)—indicated that approximately 0.3 percent of the U.S. population (12 years and older) used heroin at least once during the year preceding the survey.[16]

Data reported to Maine's Office of Behavioral Health shows that over the past five years, there were almost 80 thousand admissions to substance abuse treatment facilities in Maine. Of these, 21 percent reported using injection drugs within the past six months. Of those reporting injection drug use, approximately one-third (35.4 percent) reported sharing needles. Table 22 shows admission data by year from 2015 to 2019. During the five-year period, approximately 1 percent of treatment facility admissions reported injection drug use and HIV-positive serostatus (data not shown in table).

Table 22. Patients admitted to substance abuse treatment facilities in Maine reporting injection drug use and needle sharing, 2015-2019

Year	Total admissions	Admissions reporting IDU w/in the past 6 months		Admissions reporting needle sharing w/in the past 6 months	
		Count	Percent (%)	Count	Percent (%)
2015	18,723	4,170	22.3%	1,202	6.4%
2016	17,689	3,725	21.1%	1,268	7.2%
2017	15,270	3,008	19.7%	1,082	7.1%
2018	14,582	2,923	20.0%	1,238	8.5%
2019	13,566	2,940	21.7%	1,144	8.4%
Total	**79,830**	**16,766**	**21.0%**	**5,934**	**7.4%**

Source: Maine Office of Behavioral Health, Web Infrastructure for Treatment Systems (WITS)

Male-to-male sexual contact

Men who have sex with men (MSM) make up the majority of PLWHA in Maine (56.4 percent) and nationally.[17] In 2019, the majority of individuals in Maine who acquired HIV through male-to-male sexual contact were 50 years old or older (70.6 percent), reflecting an age distribution similar to Maine PLWHA overall. However, of those MSM cases diagnosed in 2019, more than half (57.1 percent) were between age 20 and 39, reflecting a younger cohort than Maine PLWHA overall.

Concerning race and ethnicity, the racial distribution of PLWHA who acquired HIV via male-to-male sexual contact differed from that of Maine PLWHA overall. While Black/African American individuals accounted for 18.6 percent of all Maine PLWHA in 2019, just 4.7 percent of PLWHA with a male-to-male sexual contact mode of transmission were Black/African-American. Table 23 provides the number and distribution of Maine PLWHA who acquired HIV via male-to-male sexual contact by age group and race/ethnicity.

Table 23. Number and distribution among Maine PLWHA with male-to-male sexual contact mode of transmission by select demographic characteristics, 2019

Select demographic characteristics	Count (n=991)	Percent (%)
AGE AT DIAGNOSIS		
under 19	0	0
20-29	25	2.5%
30-39	102	10.3%
40-49	164	16.5%
50-59	345	34.8%
over 60	355	35.8%
RACE/ETHNICITY		
Hispanic (any race)	65	6.6%
Other race or missing race (non-Hispanic)	29	2.9%
Black/ African-American (non-Hispanic)	47	4.7%
White (non-Hispanic)	850	85.8%

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

MSM also made up the largest proportion (46.1 percent) of cumulative new diagnoses of HIV in diagnosed in Maine during the years 2015 through 2019. Consistent with national trends, individuals aged 20-29 made up the largest proportion of five-year cumulative diagnoses with an MSM mode of transmission. Nationally, young men aged 25 to 34 accounted for the largest proportion of new HIV diagnoses among MSM from 2014-2018.[18] Table 24 provides a breakdown of cumulative new diagnoses among MSM in Maine by age group and race for the years 2015 through 2019.

Table 24. Cumulative new diagnoses of HIV (any stage) among MSM in Maine by select demographic characteristic, 2015-2019

Select demographic characteristics	Count (n=88)	Percent (%)
AGE AT DIAGNOSIS		
under 19	2	2.3%
20-29	23	26.1%
30-39	19	21.6%
40-49	21	23.9%
50-59	14	15.9%
over 60	9	10.2%
RACE/ETHNICITY		
Hispanic (any race)	6	6.8%
Other race or missing race (non-Hispanic)	4	4.5%
Black/ African American (non-Hispanic)	7	8.0%
White (non-Hispanic)	71	80.7%

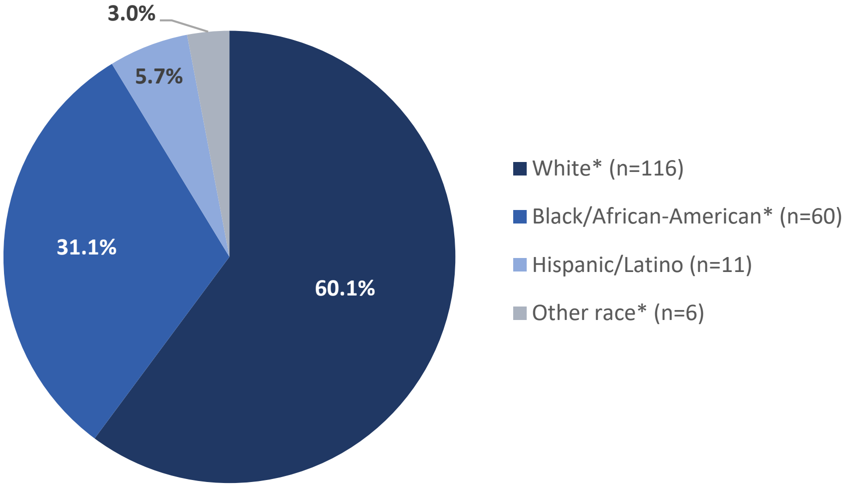
Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

High-risk heterosexual contact

Eleven percent of Maine PLWHA acquired HIV via high-risk heterosexual contact. This mode of transmission affected a higher proportion of females than males: 35.7 percent of female PLWHA were infected through high-risk heterosexual contact versus 4.1 percent of males. Eighty-three percent of those with a high-risk heterosexual contact mode of transmission identified sex with an HIV infected partner as their likely HIV risk factor.

Individuals who acquired HIV via high-risk heterosexual contact were more likely to be Black/African American than Maine PLWHA as a whole. In 2019, African Americans accounted for 31.0 percent of PLWHA with a high-risk sexual contact mode of transmission but made-up 18.6 percent of Maine's total PLWHA. Figure 13 provides a breakdown of Maine PLWHA who acquired via high-risk heterosexual contact by race/ethnicity.

Figure 13. Maine PLWHA with heterosexual mode of transmission by race/ethnicity, 2019



N=193
Note: American Indian/Alaska Native are excluded due to a case count of 0
* Non-Hispanic

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Behavioral Surveillance for HIV Risk Factors

Two surveys in Maine provide information about HIV risk factors in the general population. These include the Behavioral Risk Factor Surveillance Survey (BRFSS), which explores risk behaviors in adults, and the Maine Integrated Youth Health Survey (MIYHS), which provides information about HIV among high school-aged youth.

MIYHS, is a biannual self-report survey of Maine kindergarten through 12th grade students, which measures a variety or health-related factors, including condom use, among Maine middle and high school students. In the 2019 MIYHS, among high school students who had ever had sexual intercourse, 59.5 percent reported they used a condom at their last sexual intercourse. Table 26 provides a breakdown of high school students reporting condom use at their last sexual intercourse by gender, grade in school, race/ethnicity, and sexual orientation.[19]

Table 25. **Students reporting condom use at last sexual intercourse, MIYHS, 2019**

Characteristic	Percent (%) who reported using a condom at last sexual intercourse
Overall	**59.5% (CI: 57.8%-61.2%)**
GENDER	
Female	55.3% (CI: 53.3%-57.2%)
Male	63.8% (CI: 61.6-66.0%)
GRADE	
9th	65.9% (CI: 61.4%-70.4%)
10th	62.9% (CI: 59.7%-66.1%)
11th	57.7% (CI: 55.1%-60.3%)
12th	57.4% (CI: 54.9%-59.9%)
RACE/ETHNICITY	
American Indian or Alaska Native*	61.5% (CI: 54.1%-68.9%)
Asian*	63.8% (CI: 55.0%-72.5%)
Black or African American*	60.4% (CI: 51.4%-69.4%)
Hispanic/Latino(a)	56.2% (CI: 50.4%-61.9%)
Native Hawaiian or Other Pacific Islander*	37.0% (CI: 20.7%-53.3%)
White*	59.5% (CI: 57.8%-61.3%)
Multiple races*	60.1% (CI: 53.4%-66.7%)
SEXUAL ORIENTATION	
Heterosexual	61.7% (CI: 59.9%-63.5%)
Gay/Lesbian	33.8% (CI: 25.1%-42.4%)
Bisexual	51.2% (CI: 46.5%-55.8%)
Not Sure	49.7% (CI: 40.8%-58.6%)

*Non-Hispanic
CI = Confidence Interval.
Note: cells in the same category with overlapping CIs are not significantly different from one another.
Source: Maine Integrated Youth Health Survey, 2019

HIV Testing

HIV testing is a key component of reducing the spread of HIV. Testing allows individuals to know their HIV status, which in turn may positively impact an individual's decisions regarding healthcare treatment, sexual activity, and injection drug use. HIV-infected persons who have not been tested and do not know they are infected may not achieve viral suppression and/or avoid unsafe behaviors, thereby placing others at risk for acquiring HIV.

One source of information about HIV testing in the general adult population comes from the BRFSS survey. Table 27 details responses to the HIV testing question included in the 2019 BRFSS, which shows that about 36 percent of adults surveyed reported ever having an HIV test.

Table 26. Maine adults reporting ever received an HIV test, BRFSS, 2019

	Count	Percent (%)	95% CI
Yes	2,872	35.7%	34.1-37.3
No	7,258	64.3%	62.7-65.9

SOURCE: Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Division of Population Health. BRFSS Prevalence & Trends Data [online].

The Maine CDC funds agencies (sub-grantees) to provide testing to people at increased risk for HIV using the CTR (counseling, testing, and referral) model. The CTR model includes HIV testing, risk reduction counseling, safe-sex supply distribution, and referrals for services. The sub-grantees regularly provide data to the Maine CDC about their HIV testing trends. HIV testing sites include a STD clinic, family planning locations, and dozens of community-based testing sites. Data from HIV testing entities in Maine provide a closer look at HIV testing trends.

In 2019, 1,838 HIV tests were performed at CTR sites in Maine. Five of these tests were positive.
In the five-year period between 2015 and 2019, 32 individuals tested by Maine CTR sites tested positive for HIV, including 30 males and two females. Although the majority of the positive tests occurring at Maine CTR sites between 2015 and 2019 identified truly new HIV cases, seven of the 32 positive tests (22 percent) were among individuals who were previously diagnosed with HIV. Individuals who are already aware of their HIV status may seek additional HIV testing for a variety of reasons, including documentation for service eligibility purposes.

Sexually Transmitted Diseases

HIV and STDs share similar behavioral risk factors, therefore data on these diseases can provide some suggestion about the future direction of HIV in the state. Additionally, the presence of an STD can facilitate HIV transmission between sexual partners. Individuals infected with an STD are estimated to be two- to five-times more likely to acquire HIV compared to individuals who are not infected with an STD.[20]

Like HIV, gonorrhea, chlamydia, and syphilis are notifiable conditions in Maine. This section includes STD case reports received through December 31, 2019. Trend data for the previous five or 10-year period (as available) are included to present a more comprehensive picture. Trends in reported cases of STDs can be influenced by a number of factors, including changes in screening, diagnosis, and reporting practices, as well as a change in actual disease incidence.

Chlamydia and Gonorrhea

Chlamydia is the most frequently reported STD in the state. In 2019, there were 3,989 cases of chlamydia reported to the MeCDC, a case rate of 296.8 (95 percent CI: 287.5 – 306.0) per 100,000 individuals. Rates were highest among women, adolescents, and young adults in 2019. Table 28 provides a breakdown of chlamydia cases reported to the MeCDC in 2019 by sex, age group, and PHD. Due to the large numbers of gonorrhea and chlamydia cases reported without data on race and/or ethnicity, comparisons by race/ethnicity are not included.

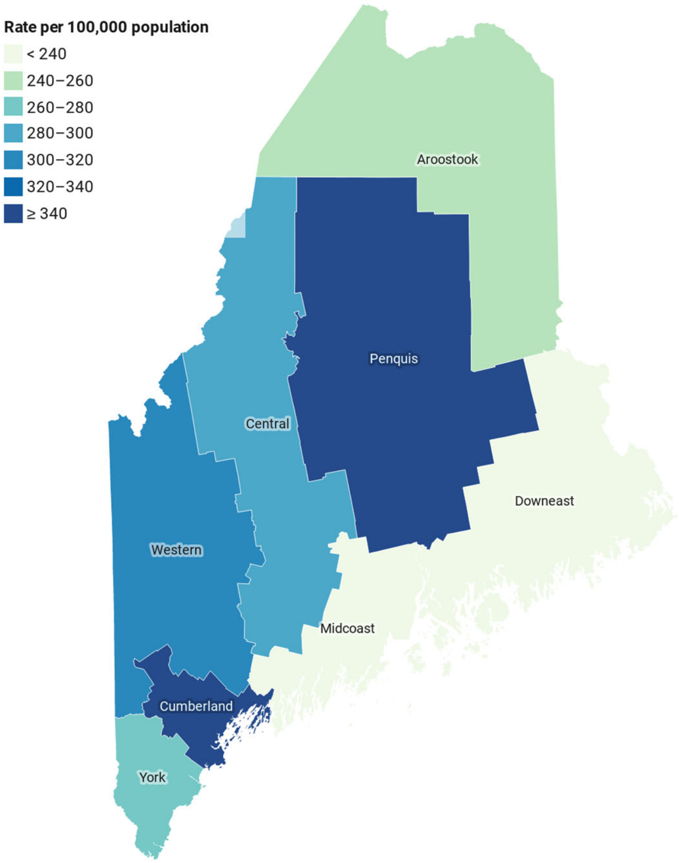
Table 27. Reported cases of chlamydia by sex, age, and PHD, Maine, 2019

Demographic Characteristic	Cases	Percent (%) of cases	Rate (per 100,000)	95% CIs for rate (per 100,000)
SEX				
Male	1,394	34.9%	212.4	201.2 – 223.5
Female	2,595	65.1%	377.2	362.7 – 391.8
AGE GROUP				
<15	8	<1%	4.0	1.2 – 6.8
15-24	2,511	62.9%	1,646.50	1,582.1 - 1,710.9
25-34	1,107	27.8%	674.10	634.3 - 713.8
35-44	266	6.7%	173.2	152.4 - 194.0
45-54	68	1.7%	38.5	29.4 - 47.7
55+	29	<1%	5.8	3.7 - 8.0
PHD				
Aroostook	171	4.3%	255.0	216.8 – 293.2
Central	485	12.2%	280.7	255.7 – 305.7
Cumberland	1,039	26.0%	352.2	330.8 – 373.6
Downeast	206	5.2%	238.5	205.9 – 271.1
Midcoast	333	8.3%	222.0	198.2 – 245.9
Penquis	590	14.8%	349.3	321.1 – 377.4
Western	626	15.7%	318.7	293.7 – 343.6
York	539	13.5%	259.6	237.7 – 281.5
TOTAL	**3,989**	**100%**	**296.8**	**287.5 – 306.0**

Source: Maine CDC, Infectious Disease Prevention Program, NBS

In 2019, the rates of reported chlamydia cases were highest in the Cumberland and Penquis PHDs and lowest in the Midcoast and Downeast PHDs. Figure 14 provides a geographic display of the case rate of chlamydia in Maine by PHD.

Figure 14. Rate (per 100,000) of reported cases of chlamydia by Maine PHD, 2019



Source: Maine CDC, Infectious Disease Prevention Program, NBS

In 2019, there were 547 cases of gonorrhea reported to the MeCDC, a case rate of 40.7 (95 percent CI: 37.3 - 44.1) per 100,000 individuals. The rate was highest among men and young adults. Approximately one in five cases (20.8 percent) occurred among those reporting male-to-male sexual contact and 5.9 percent were among persons coinfected with HIV. Table 29 provides a breakdown of gonorrhea cases reported to the MeCDC in 2019 by sex, age group, and PHD.

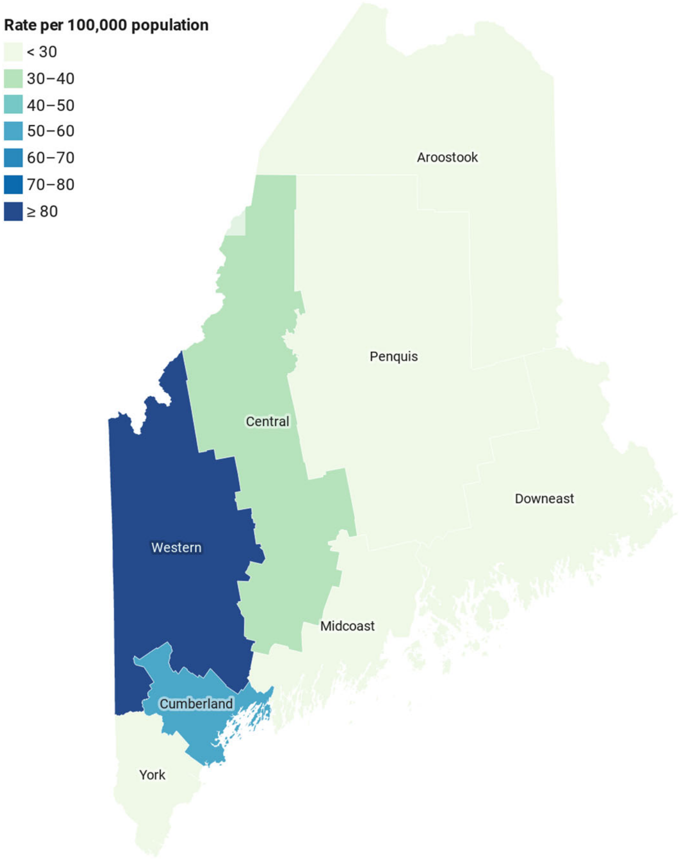
Table 28. Reported cases of gonorrhea by select demographic characteristics, Maine, 2019

Demographic Characteristic	Cases	Percent (%) of cases	Rate (per 100,000)	95% CIs for rate (per 100,000)
SEX				
Male	344	62.9%	52.4	46.9 - 58.0
Female	203	37.1%	29.5	25.5 - 33.6
AGE GROUP				
<15	2	<1%	1.0	0.4 - 2.4
15-24	189	34.6%	123.90	106.3 - 141.6
25-34	171	31.3%	104.10	88.5 - 119.7
35-44	113	20.7%	73.6	60.0 - 87.1
45-54	51	9.3%	28.9	21.0 - 36.8
55+	21	3.8%	4.2	2.4 - 6.0
PHD				
Aroostook	18	3.3%	26.8	14.4 – 39.2
Central	56	10.2%	32.4	23.9 – 40.9
Cumberland	174	31.8%	59.0	50.2 – 67.7
Downeast	18	3.3%	20.8	11.2 – 30.5
Midcoast	31	5.7%	20.7	13.4 – 27.9
Penquis	36	6.6%	21.3	14.3 – 28.3
Western	159	29.1%	80.9	68.4 – 93.5
York	55	10.1%	26.5	19.5 – 33.5
TOTAL	**547**	**100.0%**	**40.7**	**37.3 - 44.1**

Source: Maine CDC, Infectious Disease Prevention Program, NBS

In 2019, the rates of reported gonorrhea cases were highest in the Western and Cumberland PHDs, which had rates of 81 and 59 cases per 100,000 population, respectively. Rates were much lower in the remaining PHDs, at or below 40 cases per 100,000 population. Figure 15 provides a geographic display of the case rates of gonorrhea in Maine by PHD.

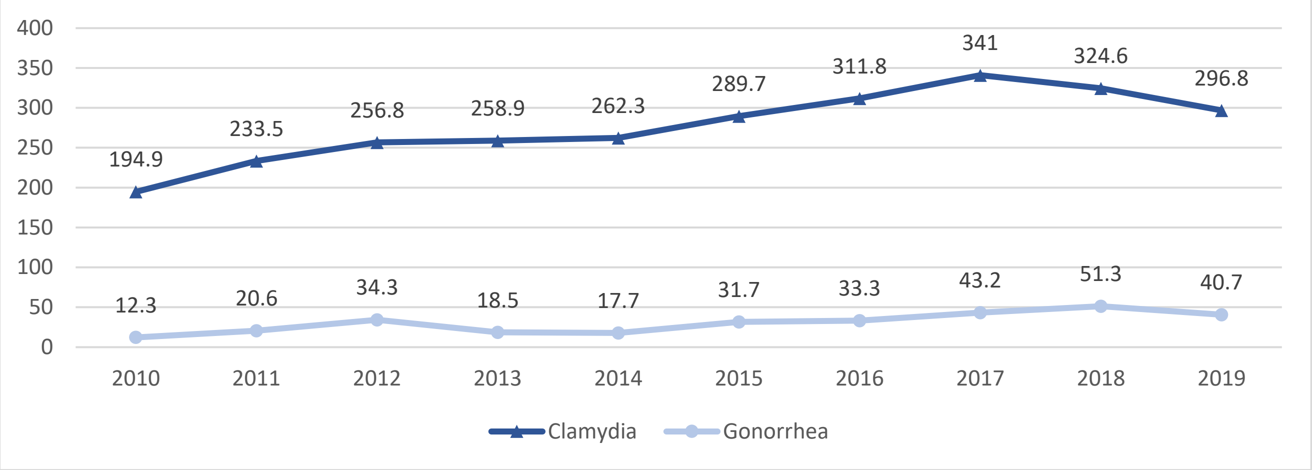
Figure 15. Rate (per 100,000) of reported cases of gonorrhea by Maine PHD, 2019



Source: Maine CDC, Infectious Disease Prevention Program, NBS

As Figure 16 illustrates, the annual rate of reported cases of both chlamydia and gonorrhea in Maine have grown consistently and over the past decade, with a slight reduction in chlamydia cases in 2018 and 2019 and a drop in gonorrhea cases in 2019.

Figure 16. Rate (per 100,000) of reported cases of chlamydia and gonorrhea in Maine by year, 2010 - 2019

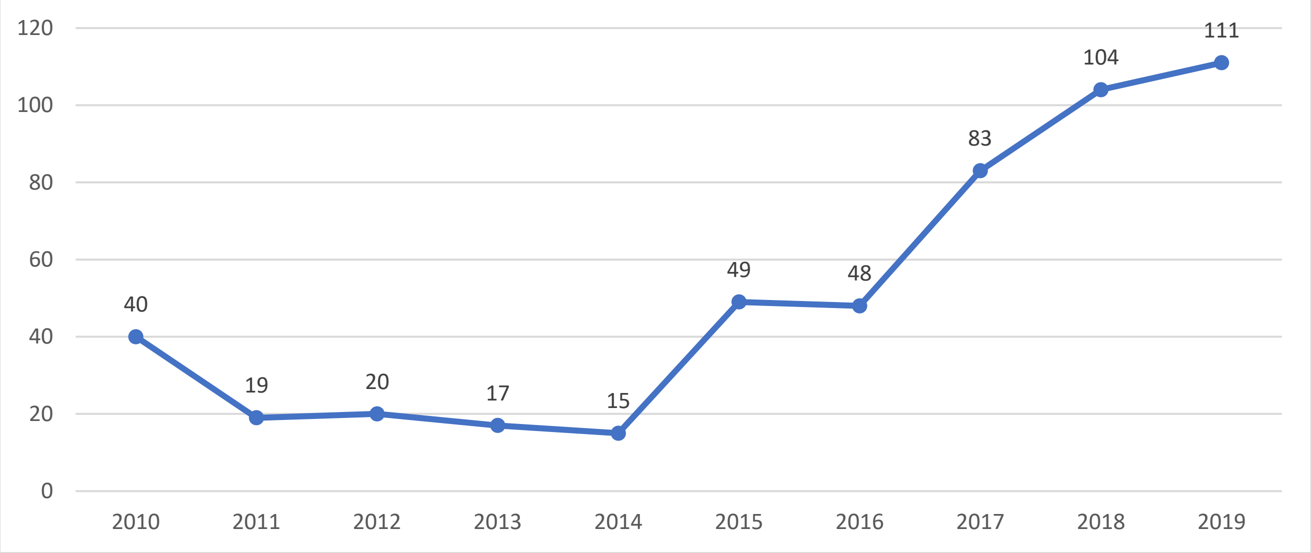


Source: Maine CDC, Infectious Disease Prevention Program, NBS

Syphilis

Syphilis can pose serious health risks if left untreated and can facilitate the transmission of HIV infection between partners. Since 2014, the number of syphilis cases (primary, secondary, and early latent) in Maine has rapidly increased (Figure 17). In 2019, 111 cases of syphilis were reported to the MeCDC.

Figure 17. **Number of reported cases of syphilis by year, Maine, 2010-2019**



SOURCE: Maine Infectious Disease Prevention Program, NBS

Ninety-eight of the 111 reported syphilis cases were among males (88 percent) and 96 cases (87 percent) were among non-Hispanic White individuals. Approximately half of 2019 syphilis cases (51.4 percent) occurred among those reporting male-to-male sexual contact, and a quarter (25.2 percent) were among persons coinfected with HIV. Table 30 provides a breakdown of syphilis cases reported to the MeCDC in 2019 by sex, age group and PHD.

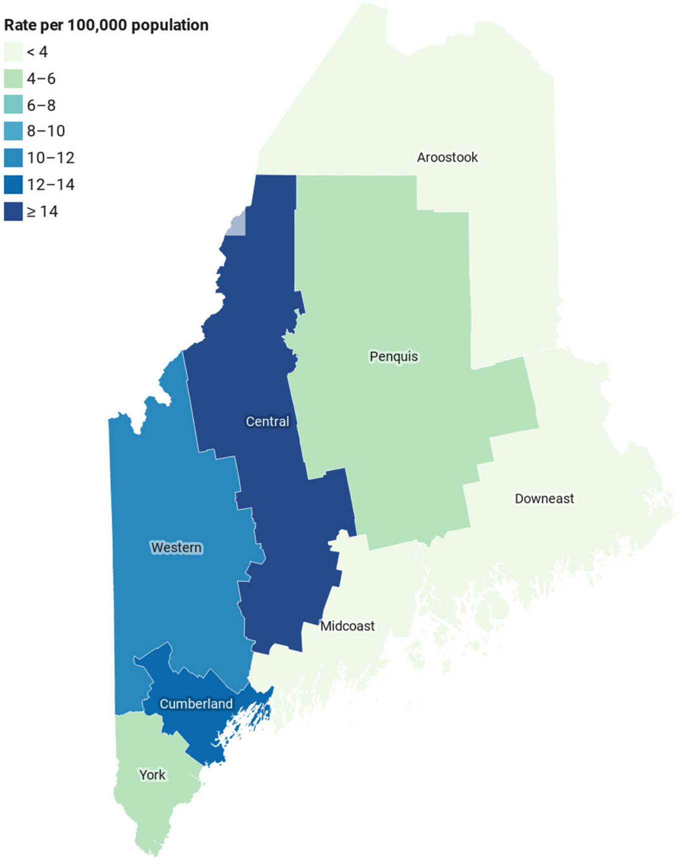
Table 29. Reported cases of syphilis by select demographic characteristics, Maine, 2019

Demographic Characteristic	Cases	Percent (%) of cases	Rate (per 100,000)	95% CIs for rate (per 100,000)
SEX				
Male	98	88.3%	14.9	12.0 - 17.9
Female	13	11.7%	1.9	0.9 - 2.9
AGE GROUP				
<15	0	0.0%		
15-24	24	21.6%	15.7	9.4 - 22.0
25-34	32	28.8%	19.5	12.7 - 26.2
35-44	18	16.2%	11.7	6.3 - 17.1
45-54	21	18.9%	11.9	6.8 - 17.0
55+	16	14.4%	3.2	1.6 - 4.8
PHD				
Aroostook	1	0.9%	1.5	0.0 - 3.0
Central	26	23.4%	15	20.8 - 9.3
Cumberland	38	34.2%	12.9	8.8 - 17.0
Downeast	2	1.8%	2.3	0.0 - 5.5
Midcoast	5	4.5%	3.3	0.4 - 6.3
Penquis	7	6.3%	4.1	1.1 - 7.2
Western	21	18.9%	10.7	6.1 - 15.3
York	11	9.9%	5.3	2.2 - 8.4
TOTAL	**111**	**100.0%**	**8.0**	**6.5 - 9.5**

Source: Maine CDC, Infectious Disease Prevention Program, NBS

In 2019, the rate of reported syphilis cases was highest in the Central PHD, with a rate of 15 cases per 100,000 population, and lowest in Aroostook, Downeast, and Midcoast Districts, which all had rates at below 4 cases per 100,000 population. Figure 18 provides a geographic display of the case rate of syphilis in Maine by PHD.

Figure 18. Rate (per 100,000) of reported cases of syphilis by Maine PHD, 2019



Source: Maine CDC, Infectious Disease Prevention Program, NBS

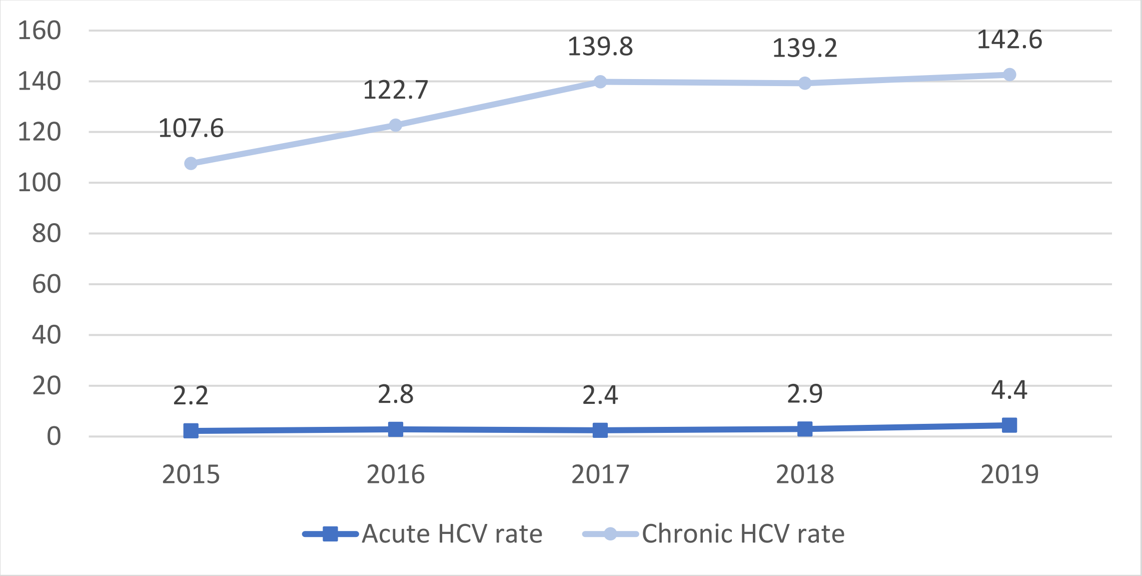
Viral hepatitis

According to the U.S. CDC, the most common causes of hepatitis in the U.S. are the hepatitis A virus (HAV), the hepatitis B virus (HBV), and the hepatitis C virus (HCV).[21] Viral hepatitis shares common modes of transmission with HIV. HAV, HBV, and HCV can be transmitted through the sharing of contaminated drug injection equipment. Sexual contact with an infected person is also a risk factor for contraction of HAV and HBV. HCV is bloodborne and not commonly transmitted via sexual activity.

HIV-positive individuals are particularly at risk for viral hepatitis infection. The CDC estimates that approximately 21 percent of people with HIV in the U.S. are co-infected with HCV[22], and between five and 10 percent are co-infected with HBV[23]. Hepatitis is a condition of particular concern for PLWHA, as the presence of HIV may hasten the progression of disease and increase the risk of developing cirrhosis and end-stage liver disease. Data on HIV and viral hepatitis co-infection rates in Maine were not available for this report.

HCV is the most common form of viral hepatitis in Maine. In 2019, there were 59 reported acute cases of HCV, representing an incidence rate of 4.4 (95 percent CI: 3.3 – 5.5) per 100,000 Maine residents. There were 1,917 reported cases of chronic hepatitis C, representing a prevalence rate of 142.6 (95 percent CI: 136.2 – 149.0) per 100,000. HCV chronicity is defined by a time period of lingering infection of more than six months post transmission.[24] Timely and appropriate treatment reduces the risk that an acute infection will become chronic.[25] Figure 19 illustrates trends in acute and chronic from 2015-2019. Case rates for both acute and chronic HCV increased over the past five years.

Figure 19. Acute and chronic Hepatitis C rates per 100,000 by year, Maine, 2015-2019



Source: Maine Center for Disease Control, Division of Infectious Disease, NBS

In Maine, acute HBV went from 9 cases in 2015 to 77 cases in 2017 and back down to 58 cases in 2019. Chronic HBV went from 107 cases in 2015 to 201 cases in 2018 and 165 cases in 2019. The incidence rates for acute and chronic HBV among Maine residents in 2019 were 4.3 for acute (95 percent CI: 3.2 - 5.4) and 12.3 for chronic (95 percent CI: 10.4 – 14.1) per 100,000. Males accounted for 69 percent of chronic HBV cases and 64 percent of acute HBV cases in 2019. Maine has had a concerning increase in acute and chronic HBV over the past few years and has relatively high rates compared to the U.S. average.

HAV is the least common form of hepatitis reported in Maine. The number of cases of HAV reported in Maine between 2015 and 2019 ranged from a low of eight cases in 2015 to a high of 45 cases in 2019. The sharp jump in cases during 2019 was due to a food service-related outbreak and an increase of cases among both homeless persons and those who inject drugs.

Key Points

Question 3 addressed factors associated with HIV risk in Maine, including HIV testing, sexual risk behaviors, sexually transmitted diseases, viral hepatitis, and injection drug use.

High-risk behaviors

- Three behaviors are associated with the majority of HIV infections in the state. These include needle sharing during injection drug use, male-to-male sexual contact, and high-risk heterosexual contact.
    - Injection drug use: Individuals who use injection represent approximately eight percent of Maine PLWHA. National studies show that 1.5 percent of people 21-30 years old report having ever used injection drugs, and about half a percent have shared needles. From 2015-2019, 21 percent of injection drug users admitted for substance abuse treatment also reported sharing needles.
    - Male-to-male sexual contact: Men who have sex with men (MSM) make up 56 percent of all PLWHA and comprised 46 percent of new HIV diagnoses in Maine over the past five years. Of diagnoses among MSM in 2019, 57 percent were between the ages of 20 and 39. In 2019, an estimated 85 percent of PLWHA with MSM risk in Maine were non-Hispanic White.
    - High-risk heterosexual contact: Eleven percent of Maine PLWHA acquired HIV via high-risk heterosexual contact. This mode of transmission affected a higher proportion of females than males: 36 percent of female PLWHA were infected through high-risk heterosexual contact versus four percent of males. In 2019, African Americans accounted for 31 percent of PLWHA with a high-risk sexual contact mode of transmission but made-up 19 percent of Maine's total PLWHA.

Behavioral surveillance for HIV risk factors

- The 2019 MIYHS showed that among high school students who had ever had sexual intercourse, 59.5 percent reported they used a condom at their last sexual intercourse.

HIV testing

- According to the 2019 BRFSS, one-third of adults surveyed reported ever having an HIV test.
- The Maine CDC funds agencies to provide testing to people at increased risk for HIV at Counseling, Testing, and Referral (CTR) sites throughout Maine. In the five-year period between 2015 and 2019, 32 individuals tested by Maine CTR sites tested positive for HIV.

Sexually transmitted diseases

- Chlamydia: In 2019, there were 3,989 cases of chlamydia reported to the MeCDC. Rates were highest among women and were also higher among adolescents and young adults than under 35 years old. The annual rate of reported cases of chlamydia in Maine grew consistently and over the past decade from a low of 195 cases per 100,000 population in 2010 to a high of 341 cases per 100,000 population in 2017. The rate decreased slightly in 2018-2019.
- Gonorrhea: In 2019, there were 547 cases of gonorrhea reported to the MeCDC. The rate was highest among men and were also higher among adolescents and young adults under age 35. Approximately one in five 2019 cases occurred among those reporting male-to-male sexual contact and 6 percent were among persons coinfected with HIV. The annual rate of reported cases of gonorrhea in Maine has grown consistently over the past decade.
- Syphilis cases in Maine rapidly increased from a low of 15 cases in 2014 to 111 cases in 2019, representing seven-fold increase. Ninety-six of the 108 reported syphilis cases were among

males (89 percent). Approximately half of 2019 syphilis cases occurred among those reporting male-to-male sexual contact and a quarter were among persons coinfected with HIV.

Viral hepatitis

- Hepatitis C is the most common form of viral hepatitis in Maine. In 2019, there were 59 reported acute cases of hepatitis C and 1,917 reported cases of chronic hepatitis C. Case rates for both acute and chronic hepatitis C increased over the past five years.
- Hepatitis B cases in Maine have increased in acute and chronic HBV over the past few years and Maine has relatively high rates compared to the US average. In 2019, there were 58 reported cases of acute hepatitis B and 165 reported cases of chronic hepatitis B, and males accounted for 69 percent of chronic and 64 percent of acute hepatitis B cases.
- Hepatitis A is the least common form of hepatitis reported in Maine. The number of cases of HAV reported in Maine between 2015 and 2019 ranged from a low of eight cases in 2015 to a high of 45 cases in 2019.

SECTION 2: ADDITIONAL PRIORITY POPULATIONS IN MAINE

The following section provides additional information related to priority populations of special concern. These populations have an impact on program planning and implementation.

Youth and Young Adults (13-24 years)

Youth represent a population of special concern for HIV planning and prevention, as they experience several significant risk factors related to HIV—such as higher-risk sexual behaviors, substance abuse, and lack of access to health care—at higher rates relative to other age groups. HIV-positive youth may require special attention to ensure they achieve and maintain viral suppression to maximize their life span and quality of life while also reducing their chances of transmitting HIV to others.

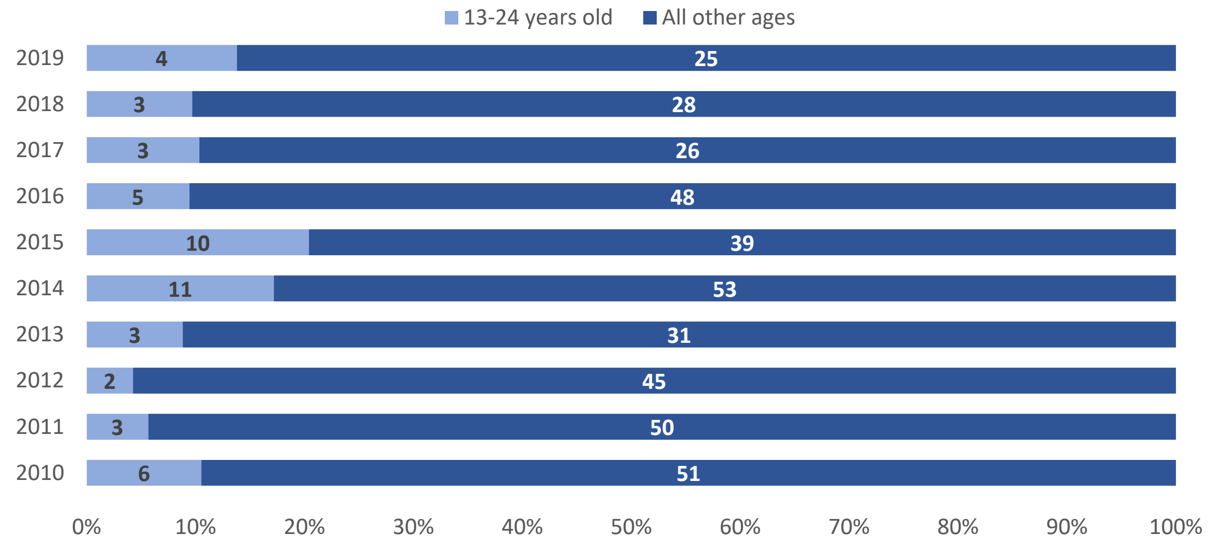
As indicated in Section 1, Question 3, adolescents and young adults have the highest rate of reported chlamydia and gonorrhea incidence in Maine, and nearly 41 percent of high school students surveyed in the 2019 MIYHS reported they did not use a condom at their last sexual intercourse. Additional data from the 2019 MIYHS indicate that seven percent of surveyed high school students reported they had four or more lifetime sexual partners, and only 10 percent had been tested in the past 12 months for a STD.[26]

According to the State of Maine's *2019 Substance Abuse State Epidemiological Profile*, Maine young adults age 18 to 25 had the highest rates of binge-dinking, marijuana use, cocaine use, and non-medical prescription drug abuse in the state.[27]

According to the U.S. Census Bureau, one in 10 young adults aged 18 to 25 in Maine were uninsured in 2018, which could impede access to routine care and testing for STD and HIV (see Section 1, Question 1, Table 10).

In 2019, four of the 29 new HIV diagnoses (any stage) in Maine in were among youth aged 13-24 (14 percent). Youth made up 11 percent of the cumulative new HIV diagnoses reported in Maine between 2010 and 2019. As illustrated in Figure 20, the number of youths diagnosed with HIV fluctuated during this time, although Maine saw diagnoses among youth in each of the past 10 years.

Figure 20. New HIV diagnoses among Maine youth (as number and percent of total), 2010-2019



Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

At the end of 2019, there were 32 people aged 13 to 24 living with HIV (any stage) in Maine, representing 1.8 percent of all PLWHA in the state. Of the 32 known HIV-positive youth in Maine, 16 (50 percent) were Black/African American and 10 (31.3 percent) were non-Hispanic White. Nineteen cases were male (59.4 percent).

People Who Inject Drugs (PWID)

People who inject drugs (PWID) are at heightened risk for HIV infection due to their increased risk of sharing contaminated injection equipment. Data from diverse sources indicate that injection drug use continues to impact Maine residents.

Approximately eight percent of Maine PLWHA are identified as having acquired HIV via injection drug use; however, given the illicit and socially stigmatized nature of injection drug use, this is likely an underestimate. See Section 1, Question 3 for more detailed information about HIV among PWID in Maine.

State-level estimates of current injection drug use among either Maine PLWHA or Maine residents generally are not available. However, federal data show that in 2017, Maine had the second-highest rate of HBV and is ranked tenth for its rate of HCV, both of which can be spread through injection drug use. Maine has the sixth-highest opioid overdose death rate in the U.S.[28]

In 2019, there were 5,594 individuals enrolled in needle exchange programs in Maine.[29] During 2019, Maine's seven needle exchange programs collected 879,853 contaminated needles and distributed 535,117 clean needles. The collection of contaminated needles increased 3.7 percent from the 2018 total.[30]

Data from Maine's Office of Behavioral Health indicated that there were 2,940 individuals admitted to substance abuse treatment in 2019 who reported using injection drugs, representing 22 percent of all substance treatment admissions that year. Of those, more than a third (39 percent) disclosed that they had shared needles in the past six months.

People Who Use Substances (other than injection drugs)

Apart from the inherent HIV risks associated with injection drugs and needle-sharing, use of drugs and alcohol can facilitate HIV transmission. Substance use may alter judgement and reduce inhibition, which can lead to risky sexual behaviors. For people living with HIV, substance use may affect overall health as it can impact self-care and adherence to antiretroviral therapies.[31]

According to the NSDUH, in 2018-2019, an estimated 56 percent of Maine residents over the age of 12, and 60 percent of those over the age of 18, used alcohol in the past month preceding the survey. In addition, 19 percent of Mainers over age 12 reported using a least one illicit drug in the past month, with marijuana use being most common (18 percent). Use of other drugs in the past month, including cocaine/crack cocaine, heroin, hallucinogens, inhalants, and methamphetamines was just under three percent. Among individuals surveyed, those age 18 to 25 years had the highest rate of reported illicit drug use in the past month, at 37 percent.[32]

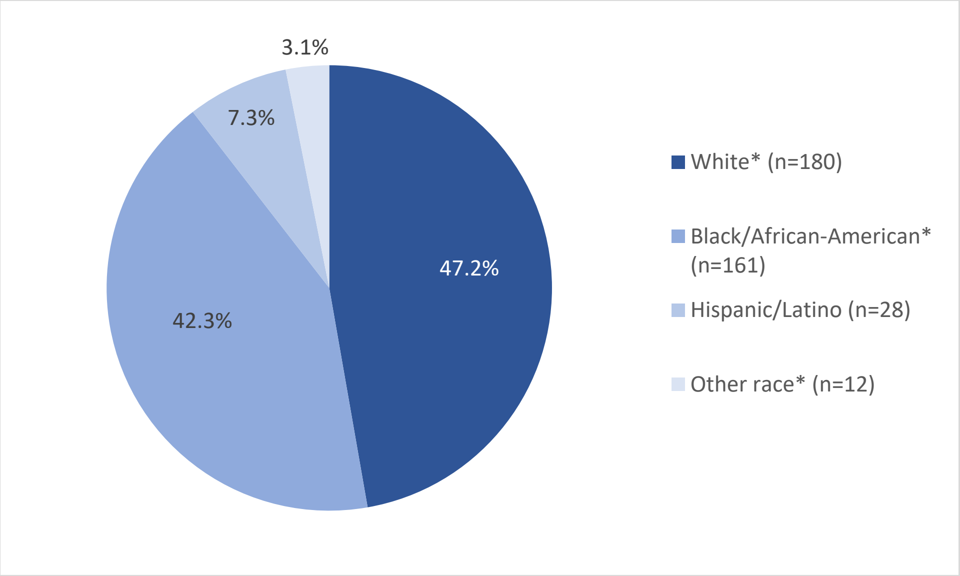
Limited data are available on the substance use patterns of PLWHA in Maine. While eight percent of PLWHA in Maine are likely to have acquired HIV via injection drug use, the number of HIV-positive individuals in Maine currently using injection drugs or other substances is unknown.

Women

As of the end of 2019, there were 381 individuals living in Maine with diagnosed HIV/AIDS whose sex at birth was female, accounting for 21.7 percent of Maine PLWHA. The characteristics of female PLWHA in Maine differed from male PLWHA, and Maine PLWHA overall, in several ways. Female PLWHA were more likely to have acquired HIV via high-risk heterosexual contact and injection drug use compared to male PLWHA (see Section 1, Question 2, Table 17).

Female PLWHA were also more racially diverse: non-Hispanic White individuals accounted approximately 47 percent of female PLWHA, while they accounted for approximately 78 percent of male PLWHA and 72 percent of Maine PLWHA overall. Forty-two percent of female PLWHA in Maine were Black/African American (Figure 21) compared to 19 percent of Maine PLWHA overall.

Figure 21. Female PLWHA in Maine by race, 2019



N = 381

***** Non-Hispanic

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

As discussed in Section 1. Question 3, adolescent and young adult women have the highest rates of chlamydia in Maine and are less likely than young men to report their most recent sexual intercourse was protected by use of a condom (see Table 26). According to the 2019 MIYHS, female high school students in Maine report lower rates of illicit drug use including heroin use than male high school students.

Key Points

Priority populations identified as: youth ages 13–24, injection drug users, substance users other than injection drug users and women as populations that are critical to program planning and implementation are listed below. This section provides key data points for each of these populations.

Youth

- Youth may experience significant risk factors related to HIV. HIV-positive youth may require special attention to ensure they achieve and maintain viral suppression.
- In 2019, 14 percent of new HIV diagnoses in Maine in were among youth aged 13-24, and youth made up 11 percent of the cumulative HIV diagnoses reported in Maine from 2010 to 2019.
- At the end of 2019, there were 32 people aged 13 to 24 living with HIV in Maine, representing 1.8 percent of all PLWHA in the state. Of these, 16 (50 percent) were African American/Black, and 10 (31.3 percent) were non-Hispanic White. Nineteen cases were male (59.4 percent).

People who inject drugs

- Approximately eight percent of Maine PLWHA are identified as having acquired HIV via injection drug use.
- In 2019, there were 5,594 individuals enrolled in needle exchange programs in Maine.
- Twenty-two percent of individuals admitted to substance abuse treatment in 2019 reported injection drug use. Of those, 39 percent disclosed sharing needles in the past six months.

People who use substances (other than injection drugs)

- Substance use may alter judgement and reduce inhibition, which can lead to risky sexual behaviors. For people with HIV, substance use might affect overall health as it can impact self-care and adherence to antiretroviral therapies.
- According to the 2016 National Survey on Drug Use and Health, 56 percent of Maine residents over the age of 12 used alcohol in the month preceding the survey and 19 percent used at least one illicit drug.

Women

- As of the end of 2019, there were 381 individuals living in Maine with diagnosed HIV/AIDS whose sex at birth was female, accounting for 21.7 percent of Maine PLWHA.
- Female PLWHA were more racially diverse than males: 42 percent of female PLWHA in Maine were Black/African American compared to 18 percent of Maine PLWHA overall. Nearly 18 percent of Maine PLWHA were female.
- Female PLWHA were more likely to have acquired HIV via high-risk heterosexual contact and injection drug use compared to male PLWHA.

SECTION 3: HIV CARE IN MAINE

Engagement in appropriate HIV medical care reduces morbidity and mortality among people living with HIV and can have important impacts for HIV prevention. This section provides data about care access, linkage, and health outcomes for PLWHA in Maine.

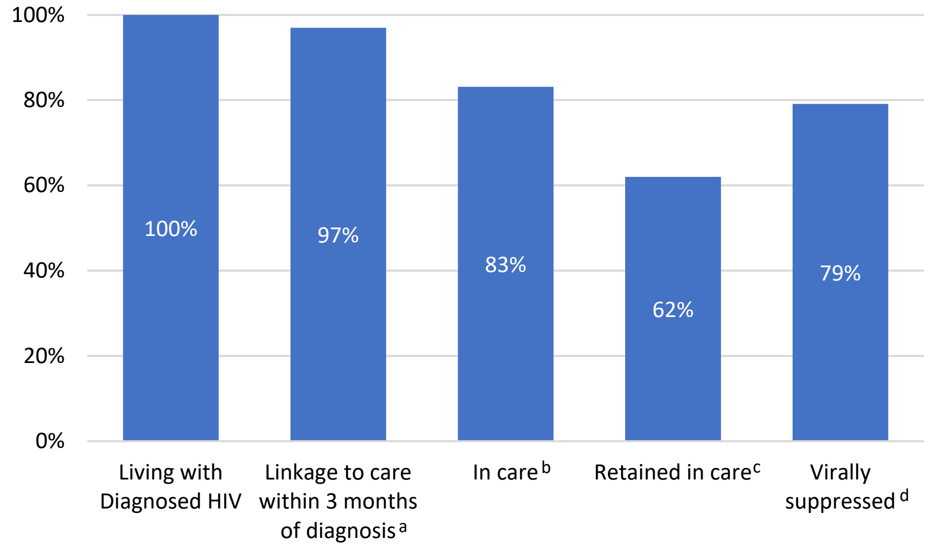
Continuum of HIV Care in Maine

The HIV care continuum describes a series of critical points for PLWHA in engagement in HIV care, with viral load suppression as a key goal to improve health outcomes and reduce HIV transmission.

In 2019, nearly 97 percent of individuals newly diagnosed with HIV were linked to HIV care within three months of their diagnosis. The CDC defines being "linked to care" as having received at least one CD4+, viral load, or HIV-1 genotype test during within 30 days after initial HIV diagnosis.

Among the 1,577 individuals (ages 13+) diagnosed with HIV in Maine and living in the state as of the end of 2019, approximately 83 percent were in HIV care, and 79 percent were considered virally suppressed, meaning that their most recent HIV viral load test during 2019 resulted in a value of $\leq$ 200 copies/mL. Figure 22 illustrates Maine's care continuum for 2019. Individuals are considered in care if they attended at least one health care visit in 2019.

Figure 22. Continuum of care among adult PLWHA in Maine, 2019



[a] For individuals newly diagnosed in 2019 only (n=29)

[b] Defined as the number of persons (ages 13+) who had either ≥1 CD4+ or viral load test result during 2019.

[c] Defined as the number of persons who had ≥ 2 CD4/VL at least 90 days apart in 2019.

[d] Defined as the number of persons who had suppressed VL (≤200 copies/mL) at most recent test during 2019.

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

The rate of viral suppression among PLWHA is higher in Maine than the U.S. as a whole. The U.S. CDC estimated that approximately 65 percent of the 1.2 million PLWHIV were virally suppressed in 2018.[33] Despite this encouraging statistic, some racial and ethnic minorities in Maine have lower rates of viral suppression. The rate among White PLWHA is 82 percent, whereas the rate among Black/African American individuals is 73 percent and the rate among Hispanics is 69 percent.

Access to Care

Due to the high costs associated with HIV medical and pharmacological care, one key factor in the engagement and retention of PLWHA in HIV care is access to health insurance coverage. According to data from the 2018 National Health Interview Survey, the cost of healthcare can be a major deterrent from seeking healthcare for American adults, especially among individuals in poor health.[34]

While data on health insurance coverage among all Maine PLWHA are not available, data from ADAP can provide some insight into health insurance coverage among HIV-positive Maine residents. In 2019, approximately 63 percent of the 1,757 individuals living with diagnosed HIV (any stage) in Maine were enrolled in ADAP at some point in the year. During 2019, 92 percent of ADAP enrollees had some type of health insurance coverage, and many had multiple forms of coverage. As detailed in Table 31, Medicare was the most common primary insurance type among Maine ADAP enrollees, followed by Medicaid.

Table 30. Primary health insurance types among Maine ADAP enrollees, 2019

Primary Insurance Type	Count	Percent (%)
Medicaid	371	33%
Medicare	400	36%
Private (employee)	131	12%
Private (individual)	123	11%
Veterans' Administration	3	<1%
No Insurance	85	8%
Total	**1113**	**100%**

Source: Maine CAREWare Database

Promising practices: Pre-exposure prophylaxis (PrEP) and treatment as prevention (TasP)

Pre-exposure prophylaxis (PrEP)

Pre-exposure prophylaxis (PrEP) is a course of HIV drugs used by people who are HIV-negative to protect against HIV transmission. PrEP has been proven highly effective in preventing infection when taken consistently and correctly by HIV-negative people. PrEP reduces the risk of getting HIV from sex by about 99 percent and reduces the risk of transmission through needle-sharing by at least 74 percent.[35]

As of 2017, it was estimated that up to 1.2 million people in the U.S. were eligible to receive PrEP because of HIV risk behavior. Of these, approximately 13 percent had been prescribed PrEP since its approval for use in 2012.[36]

Nationally, research shows an emerging association between PrEP use and declines in rates of new HIV infections, particularly in populations and jurisdictions where uptake of PrEP is high.[37] Other research points to climbing rates of STIs among PrEP users because of decreased inhibition, riskier sexual behaviors, and decreases in condom use.[38]

The number of individuals currently using PrEP in Maine is unknown, and it is not known if PrEP has impacted HIV or STD rates in the state. This is a topic for future exploration and study.

Treatment as prevention (TasP)

Over the past decade, research has shown that HIV antiretroviral therapy, along with providing obvious health benefits for PLWHA, can also play an important role in HIV prevention. The concept of HIV prevention through medical treatment is referred to as Treatment as Prevention (TasP). For TasP to be effective, persons with HIV must have regular access to care and treatment, adhere to treatment regimens, and have an undetectable HIV viral load. It is estimated that most people will attain viral suppression within six months of beginning treatment.[39]

Maine has a higher rate of viral suppression than the U.S., with 83 percent of Maine PLWHA in HIV care and an estimated 79 percent considered virally suppressed. Research shows that, among PLWHA with an undetectable viral load, the risk of transmitting HIV to sexual partners is virtually eliminated. The effectiveness of TasP to prevent HIV transmission during needle sharing has not been determined.[40]

Key Points

Engagement in appropriate HIV medical care reduces morbidity and mortality among people living with HIV. This section provides data about care access, linkage, and health outcomes for PLWHA in Maine.

Continuum of HIV care in Maine

- The HIV care continuum describes a series of critical points for PLWHA in engagement in HIV care, with viral load suppression as a key goal to improve health outcomes and reduce HIV transmission.
- In 2019, it was estimated that 97 percent of individuals newly diagnosed with HIV were linked to HIV care within three months of their diagnosis.
- Eighty-three percent of PLWHA with a known HIV diagnosis were engaged in care during 2019, and 62% had two or more care visits.
- Seventy-nine percent of all PLWHA in Maine with a known HIV diagnosis were estimated to be virally suppressed. That is substantially higher than the rate of viral suppression in the U.S., which was estimated to be 65 percent in 2018.
- Some racial and ethnic minorities in Maine have lower rates of viral suppression. The 2019 rate among White PLWHA was 82 percent, while the rate among Black/African American individuals was 73 percent, and the rate among Hispanics was 69 percent.

Access to care

- Due to the high costs associated with HIV medical care, one key factor in the engagement and retention of PLWHA in HIV care is access to health insurance coverage.
- Data on health insurance coverage among all Maine PLWHA are not available. However, these data are available for people enrolled in ADAP, which covers 63 percent of PLWHA in the state.
- In 2019, 92 percent of ADAP enrollees had some type of health insurance coverage, and many had multiple forms of coverage. Medicare was the most common primary insurance type among Maine ADAP clients (36 percent), followed by Medicaid (33 percent). Twenty-three percent of ADAP enrollees had private insurance.

Pre-exposure prophylaxis and treatment as prevention

- Pre-exposure prophylaxis (PrEP) has been proven to reduce the risk of getting HIV from sex by about 99 percent and reduces the risk of transmission through needle-sharing by at least 74 percent. National research shows an emerging association between PrEP use and declines in rates of new HIV infections. This is a topic for future exploration and study in Maine, as the number of individuals currently using PrEP is unknown, and its impact is in the state is yet to be determined.
- Treatment as prevention (TasP) is the concept of HIV prevention through medical treatment. For PLWHA with a suppressed viral load, the risk of transmitting HIV to sexual partners is virtually eliminated. Among PLWHA in Maine with diagnosed HIV in 2019, approximately 83 percent were in HIV care and 79 percent were considered virally suppressed, a higher rate than the national average.

CONCLUSION

This document was produced to serve as a tool to aid in HIV care and prevention planning efforts in Maine. Despite medical advances and focused HIV prevention and care programs, HIV continues to impact the health and well-being of Maine people. Because a significant number of new infections are occurring in Maine (even as HIV-related deaths decline) HIV prevalence is slowly but steadily increasing. For this reason, continued work in prevention and care services continues to be critically important in promoting the health of all Maine residents.

Sections of this Epidemiological Profile dealing with HIV and STD data will be updated annually. Other sections pertaining to Maine population data and needs assessment activities will be updated as new data become available, likely on a biannual basis.

APPENDIX A: DATA SOURCES

Behavioral Risk Factor Surveillance System (BRFSS)

Overview: A State-based random-digit-dialed telephone survey that monitors State-level prevalence of the major behavioral risks associated with premature morbidity and mortality among adults. Each month, a sample of households is contacted and one person in the household who is 18 years-old or older is randomly selected for an interview. Multiple attempts are made to contact the sampled household. A Spanish translation of the interview is available. Respondents are asked a variety of questions about their personal health behaviors and health experiences. Since 1994, the BRFSS questionnaire has included questions related to HIV/AIDS for respondents aged 18 to 65 years. These questions include perceived risk of getting an HIV infection, use of HIV testing, reasons for testing, if tested and the type of place where tested. As of 2001, respondents have been asked about HIV testing.

Population: All non-institutionalized adults, 18 years and older, who reside in a household with a telephone.

Strengths: Data are population based, thus estimates about testing attitudes and practices can be generalized to the adult population of a State. The sample is large. Information collected from the BRFSS survey may be useful for planning community-wide education programs.

Limitations: BRFSS data are self-reported, thus the information may be subject to recall bias. No attempt is made to corroborate information given in this survey. Respondents are contacted by telephone survey, thus the data are not representative of households without a telephone. In addition, BRFSS data are representative of the general non-institutionalized adult population in an area, not just persons at highest risk for HIV/AIDS. The extent of HIV behavioral risk information collected by the BRFSS questionnaire is limited and inferences can be made only at the State level.

CAREWare

Overview: CAREWare is a free software distributed by the Health Resources and Services Administration HIV/AIDS Bureau for Ryan White HIV/AIDS Programs. It collects client- and service-level data. In Maine, the Ryan White Part B Program hosts a centralized CAREWare network that includes two of the three Ryan White Part C recipients, four community-based HIV service organizations, and the Office of MaineCare Services.

Population: All PLWHA in Maine who are enrolled in Ryan White Part B services.

Strengths: Data are individualized and include certain demographics not routinely collected in disease surveillance activities.

Limitations: CAREWare data do not reflect all PLWHA in Maine, only those who are enrolled in Ryan White Part B services.

HIV/AIDS Surveillance

Overview: Reporting of HIV infections to local health authorities as an integral part of HIV/AIDS surveillance activities has been recommended by CDC and other professional organizations since HIV was identified and a test for HIV was licensed. As part of ongoing active HIV surveillance, State and local health departments educate providers on their reporting responsibilities, establish active surveillance sites, establish liaisons with laboratories conducting CD4+ T-lymphocyte cell analysis and enzyme immunoassay and Western blot testing and follow-up of HIV cases of epidemiologic importance. HIV case reporting is mandated in Maine by State law. Surveillance data included in this report come primarily from Maine's electronic HIV/AIDS Reporting System (eHARS).

Population: All persons who test positive for HIV and are reported to the MeCDC.

Strengths: Among U.S. states, HIV infection reporting is estimated to be 80-90 percent complete for persons who have tested positive for HIV. HIV surveillance provides a minimum estimate of the number of persons known to be HIV infected and reported to the health department, may identify emerging patterns of transmission, and can be used to detect trends in HIV infections among populations of particular interest. HIV surveillance provides a basis for establishing and evaluating linkages to the provision of prevention and early intervention services and can be used to anticipate unmet needs for HIV care.

Limitations: HIV surveillance data may underestimate the number of recently infected persons because some infected persons either do not know they are infected or have not sought testing. National HIV surveillance data represent infections in jurisdictions that have reporting laws for HIV. Reporting of behavioral risk information may not be complete.

HIV Testing System

Overview: EvaluationWeb is an online system created by Luther Consulting to collect and report data from HIV testing and prevention activities. The CDC uses this data to monitor agencies and health departments funded to perform HIV prevention activities. The EvaluationWeb system allows users to either directly enter or upload data and generate reports of data variables.

Population: Persons that accessed CDC-funded HIV testing services within the State of Maine.

Strengths: Data are captured on a paper form completed by HIV test counselors during HIV test session. Data are directly key-entered into the EvaluationWeb system from the paper form. Validation codes built into the system prevent common data entry errors. MeCDC staff ensures quality and completeness of data prior to entry. Real-time reports are available to users.

Limitations: Data that were entered prior to 2012 were not directly entered, and the quality and completeness of the data are lower. Some data may be missing due to failure to capture data at point of service or due to worker entry error. HIV tests may have been performed but not captured by a data entry form.

Maine Integrated Youth Health Survey (MIYHS)

Overview: MIYHS is a bi-annual survey of Maine students in kindergarten through grade 12. The MIYHS was first administered in 2009 and is overseen collaboratively by the Maine DHHS (MeCDC and the Office of Behavioral Health) and the Maine Department of Education. Its purpose is to quantify the health of kindergarten and grade three students through parent interviews and the health-related behaviors and attitudes of fifth through 12th graders by direct student survey. Each grade-based section of the survey contains four modules with some question variation among each module. Data reported in this profile are from the 2019 survey and limited to data from high school student respondents.

Population: Students of participating Maine public high schools present in school on day of survey.

Strengths: Data are population-based and the sample of students is large. Information collected from the MIYHS survey may be useful for planning community-wide youth and outreach education programs.

Limitations: The MIYHS is a survey of students in school, therefore some subpopulations of youth, including students who have dropped out or have high rates of absenteeism, home-schooled students, homeless youth and/or runaway youth will be missed or underrepresented. Some schools with very small enrollments may also be underrepresented due to enrollment-based sampling exclusions. Finally, the MIYHS is a "pencil and paper" survey, therefore students with very limited English language proficiency and/or students with reading abilities below that of the survey may be underrepresented as well.

National Survey on Drug Use and Health (NSDUH)

Overview: The National Survey on Drug Use and Health is a source of statistical information on the use of illicit drugs by the U.S. civilian population 12 years-old and older. The survey collects data by administering questionnaires to a representative sample of the population through face-to-face computer-assisted interviewing at the respondent’s residence. The information includes use of cocaine, receipt of treatment for illicit drugs and need for treatment for illicit drug use during the past year; use of alcohol, tobacco or marijuana during the past month; and perceived risk for binge drinking, marijuana use or smoking during the past month.

The NSDUH uses a 50-State sampling design; for the eight States with the largest populations, the sampling design provides a sample large enough to support direct State estimates. For the 42 remaining States and the District of Columbia, small-area estimation techniques are used to calculate State estimates. Youths and young adults are oversampled so that each State’s sample is approximately equally distributed among three age groups: 12–17 years, 18–25 years and ≥26 years.

Population: Non-institutionalized, civilian U.S. population aged ≥12 years.

Strengths: To increase the level of honest reporting, information since 1999 has been collected by using a combination of computer-assisted interviewing methods to provide respondents with highly private and confidential means of responding to questions about substance use and other sensitive behaviors.

Limitations: Smaller States, including Maine, must rely on statistical estimates. NSDUH estimates represent behaviors in the general population, thus the survey may underestimate the level of substance use in the population at highest risk for HIV. Data from the NSDUH are self-reported and thus subject to recall bias and underreporting of the level of a sensitive behavior.

Sexually Transmitted Disease Surveillance

Overview: MeCDC conducts surveillance to monitor the levels of syphilis, gonorrhea and chlamydia. Additionally, Maine (and all other States and U.S. territories) regularly submit case reports of STDs that have met the respective case definition for infection to CDC. Case report forms include information on patient demographics, type of infection and source of report (private or public sector). Maine conducts passive and active surveillance of STDs to monitor the STD epidemic in the State. The database used for STD surveillance is NBS.

Population: All persons with a diagnosis of an infection that meets the CDC surveillance case definition for the infection and who are reported to the local health department.

Strengths: STD data are widely available at the State and local level and because of shorter incubation periods between exposure and infection, STDs can serve as a marker of recent unsafe sexual behavior. Changes in trends of STDs may indicate changes in community sexual norms (e.g., unprotected sex).

Limitations: Reporting of STDs from private-sector providers may be incomplete. Although STD risk behaviors result from unsafe sexual behavior, they do not necessarily correlate with HIV risk. For example, trends in chlamydia infections may reflect changes in reporting and screening practices rather than actual trends in disease.

Substance Abuse Treatment Data

Overview: Web Infrastructure for Treatment Systems (WITS) is Maine’s Statewide Substance Abuse Treatment database that includes information about clients admitted to and discharged from treatment services. Analyses are based on entries made to the system by licensed substance abuse treatment providers on clients’ reported primary, secondary and tertiary drug(s) of choice as well as other demographic and background information that is collected at intake and discharge. It is important to note that the WITS system is not static and numbers run for a time period on one day may differ when run on another day as providers are constantly inputting and updating information in the system.

Population: Individuals admitted to Maine substance abuse treatment services.

Strengths: Participation is required of all licensed substance abuse treatment providers in the State.

Limitations: Data are limited to individuals who are admitted to substance abuse treatment and are dynamic as providers are constantly inputting data. Figures are accurate only as of the date they were obtained.

Viral Hepatitis Surveillance

Overview: Surveillance for hepatitis C includes reporting of acute hepatitis C and hepatitis C virus (HCV) infection (past or present) to CDC's National Notifiable Diseases Surveillance System. The purpose of hepatitis C surveillance is to identify new cases, determine risk factors for infection, identify infected persons who can be counseled and referred for medical follow-up and evaluate prevention efforts. The database used for viral hepatitis surveillance is NBS.

Population: All persons whose reported cases of acute hepatitis C or HCV infection meet the case definitions approved by the Council of State and Territorial Epidemiologists.

Strengths: Surveillance for acute hepatitis C provides information needed to determine incidence trends, transmission patterns and persons at highest risk for infection. Persons can be characterized by gender, race/ethnicity, age and risk behavior for HCV. Surveillance for HCV infection can be used to provide infected persons with information on how to reduce both their risk of transmitting HCV to others and their risk for further liver injury and to provide them with referral for medical evaluation. It also can be used to evaluate prevention efforts by providing estimates of the proportion and characteristics of persons with HCV infection.

Limitations: Hepatitis C surveillance data should be interpreted cautiously because many reporting areas do not have the resources required for case investigations to determine whether a laboratory report represents acute infection, chronic infection, resolved infection, repeated testing of a person previously reported or a false-positive result. In addition, hepatitis C is largely asymptomatic. As a result of this, many people living with chronic HCV are unaware of their disease status, resulting in under reporting of the disease and underestimation of true acute and chronic rates of disease.

APPENDIX B: DATA TABLES

Table 31. New diagnoses and people living with HIV (any stage) in Maine, 2010-2019

Year	Total PLWHA	New Diagnoses of HIV disease	Deaths of PLWHA*	Disease rate (per 100,000)	Disease rate 95% CI (per 100,000)	Diagnosis rate (per 100,000)	Diagnosis rate 95% CI (per 100,000)
2010	1,440	57	25	108.2	102.6 - 113.8	4.3	3.2 - 5.4
2011	1,473	53	23	110.7	105.1 - 116.4	4	2.9 - 5.1
2012	1,502	47	21	112.9	107.2 - 118.6	3.5	2.5 - 4.5
2013	1,532	34	26	115.2	109.4 - 120.9	2.6	1.7 - 3.4
2014	1,632	64	23	122.7	116.7 - 128.6	4.8	3.6 - 6.0
2015	1,632	49	19	121.04	115.5 - 127.3	3.6	2.6 - 4.7
2016	1,708	53	25	127.1	121.0 - 133.1	3.9	2.9 - 5.0
2017	1,757	29	33	130.7	124.6 - 136.8	2.2	1.4 - 2.9
2018	1,703	31	21	126.7	120.7 - 132.7	2.3	1.5 - 3.1
2019	1,757	29	33	130.7	124.6 - 136.8	2.2	1.4 - 2.9

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Table 32. New diagnoses and PLWHA in Maine by diagnosis status and select demographic characteristics, 2019

	New HIV/AIDS Diagnoses		**People living with diagnosed HIV/AIDS**			
	Diagnosis count	**% of new diagnoses**	**HIV count ****	**AIDS Count *****	**Total PLWHA**	**% of PLWHA**
SEX						
Male	21	72.4%	708	668	1,376	78.3%
Female	8	27.6%	209	172	381	21.7%
TOTAL	**29**	**100.0%**	**917**	**840**	**1,757**	**100.0%**
RACE/ETHNICITY						
Hispanic/Latino	0	0.0%	57	60	117	6.7%
American Indian/Alaska Native	0	0.0%	3	6	9	0.5%
Asian	1	3.4%	6	5	11	0.6%
Black/ African-American	10	34.5%	211	116	327	18.6%
White	17	58.6%	617	642	1,259	71.7%
Multi-race	1	3.4%	14	11	25	1.4%
Missing	0	0.0%	9	0	9	0.5%
TOTAL	**29**	**100.0%**	**917**	**840**	**1,757**	**100.0%**
AGE GROUP (age at diagnosis for new diagnoses, current age for PLWHA)						
Under 15	0	0.0%	14	0	14	0.8%
15-19	0	0.0%	5	2	7	0.4%
20-29	7	24.1%	46	8	54	3.1%
30-39	9	31.0%	153	47	200	11.4%
40-49	6	20.7%	191	145	336	19.1%
50-59	3	10.3%	271	302	573	32.6%
60+	4	13.8%	237	336	573	32.6%
TOTAL	**29**	**100.0%**	**917**	**840**	**1,757**	**100.0%**
RESIDENCE AT DIAGNOSIS (PHD)						
Aroostook	1	3.4%	20	26	46	2.6%
Central	1	3.4%	98	93	191	10.9%
Cumberland	15	51.7%	354	296	650	37.0%
Downeast	1	3.4%	53	51	104	5.9%
Midcoast	1	3.4%	57	70	127	7.2%
Penquis	3	10.3%	61	68	129	7.3%
Western	5	17.2%	132	101	233	13.3%
York	2	6.9%	138	123	261	14.9%
Unknown/missing	0	0.0%	16	0	16	0.9%
TOTAL	**29**	**100.0%**	**929**	**828**	**1,757**	**100.0%**
REGION OF BIRTH						
Born in US	20	0.0%	640	705	1,345	76.6%
Born outside US	9	31.0%	209	106	315	17.9%

Birth country unknown	0	69.0%	68	29	97	5.5%
TOTAL	**29**	**100.0%**	**917**	**840**	**1,757**	**100.0%**
MODE OF HIV TRANSMISSION						
Male-to-male sexual contact	14	48.3%	491	446	937	53.3%
Injection drug use	2	6.9%	51	84	135	7.7%
Male-to-male sexual contact & injection drug use	0	0.0%	26	28	54	3.1%
Perinatal transmission (diagnosed at any age)	0	0.0%	17	6	23	1.3%
Other[†]	9	31.0%	244	171	415	23.6%
Heterosexual contact	4	13.8%	88	105	193	11.0%
TOTAL	**29**	**100.0%**	**917**	**840**	**1,757**	**100.0%**

**Non-Hispanic*

***HIV stages 1, 2 or unknown*

**** HIV stage 3*

[†] *Includes transmission via clotting factor, transplant/transfusion, other confirmed risks, and those with no identified (NIR) or no reported risk (NRR).*

-- *Suppressed due to small cell size*

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

Table 33. PLWHA in Maine by sex and select demographic characteristics, 2019

	Male		Female		Total	
	Count	**% of Total**	**Count**	**% of Total**	**Count**	**% of Total**
AGE						
14 and under	5	0.4%	9	2.4%	14	0.8%
15-19	4	0.3%	3	0.8%	7	0.4%
20-29	35	2.5%	19	5.0%	54	3.1%
30-39	146	10.6%	54	14.2%	200	11.4%
40-49	227	16.5%	109	28.6%	336	19.1%
50-59	467	33.9%	106	27.8%	573	32.6%
>= 60	492	35.8%	81	21.3%	573	32.6%
Total	**1,376**	**100.0%**	**381**	**100.0%**	**1,757**	**100.0%**
RACE/ETHNICITY						
Hispanic/ Latino	89	6.5%	28	7.3%	117	6.7%
American Indian/ Alaska Native*	5	0.4%	4	1.0%	9	0.5%
Asian*	9	0.7%	2	0.5%	11	0.6%
Black/ African-American*	166	12.1%	161	42.3%	327	18.6%
White*	1,079	78.4%	180	47.2%	1,259	71.7%
Multi-race*	20	1.5%	5	1.3%	25	1.4%
Unknown/ Missing	8	0.6%	1	0.3%	9	0.5%
Total	**1,376**	**100.0%**	**381**	**100.0%**	**1,757**	**100.0%**
MODE OF TRANSMISSION						
Male-to-male sexual contact	937	68.1%	N/A	N/A	937	53.3%
Injection drug use	86	6.3%	49	12.9%	135	7.7%
Male-to-male sexual contact & injection drug use	54	3.9%	N/A	N/A	54	3.1%
Heterosexual contact	57	4.1%	136	35.7%	193	11.0%
Perinatal transmission (diagnosed at any age)	12	0.9%	11	2.9%	23	1.3%
Other **	230	16.7%	185	48.6%	415	23.6%
Total	**1,376**	**100.0%**	**381**	**100.0%**	**1,757**	**100.0%**

**Non-Hispanic*

*** Includes transmission via clotting factor, transplant/transfusion, other confirmed risks, and those with no identified (NIR) or no reported risk (NRR).*

-- *Suppressed due to small cell size*

Source: Maine Electronic HIV and AIDS Reporting System (eHARS)

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Appendix C: Detailed Resource Inventory

Activity	MaineCare	Maine CDC	City of Portland	FPC	MAP	HEAL	RMCL	GPH	Horizon	AETC	Family Planning	Activity Total
AIDS pharmaceutical assistance	$15,797,041	$575,000										$16,372,041
Early intervention services								$52,639	$28,000			$80,639
Health insurance premium and cost-sharing assistance		$2,100,000					$400		$13,000			$2,113,400
Home and community-based health services	$419,455						$800					$420,255
Hospice	$6,947											$6,947
Case management (targeted, medical, non-medical)	$648,679	$228,145		$146,311		$275,000	$70,230		$32,000			$1,400,365
Medical nutrition therapy							$1,050		$10,000			$11,050
Mental health services	$53,675			$49,000			$81,107	$34,410				$218,192
Oral health care	$14,244	$245,000		$6,000		$29,000	$12,000	$31,373				$337,617
Outpatient/ambulatory health services	$626,222						$139,768	$157,911	$85,000			$1,008,901
Substance abuse outpatient care	$34,720											$34,720
Emergency financial assistance				$10,000		$6,000			$7,000			$23,000
Food assistance		$150,000		$15,000		$14,000						$179,000
Health education/risk reduction			$125,000		$60,000				$9,000			$194,000
Housing		$150,000		$838,613		$1,000			$10,000			$999,613
Medical transportation		$3,500		$11,000		$4,000	$1,200		$7,000			$26,700
Other professional services									$6,000			$6,000
Outreach and social marketing/communications		$5,000				$10,000		$15,807	$6,000			$36,807
Psychosocial support services									$15,000			$15,000
Rehabilitation services	$16,340											$16,340
HIV counseling, testing, referral services		$329,523	$120,434								$6,276	$456,233
STD counseling, testing, referral services		$184,662	$136,068								$29,588	$350,318
Hepatitis counseling, testing, referral services		$310,610	$10,278								$925	$321,813
PrEP			$1,200									$1,200
Syringe Service Programming		$1,065,400	$150,000			$37,500						$1,252,900
Naloxone distribution			$900,000		$484,063							$1,384,063
Substance use/overdose prevention, outreach, education, and navigation		$400,000	$183,000		$367,332				$11,000			$961,332
Tuberculosis Control and Assistance		$38,000										$38,000
Other: Advocacy activities compliant with 501(c)3				$3,750								$3,750
Other: Provider education and training		$3,000								$62,432		$65,432
Other: Behavioral health clinician	$385,046											$385,046
Other: Optometrist and vision center	$7,410											$7,410
Other: Nursing home & PNMI	$230,660											$230,660
Other: Hospital and ambulance	$1,502,487											$1,502,487
Other: Community provider	$173,765											$173,765
Other: Durable medical equipment supplier	$40,707											$40,707
Other: Fiscal employer agent	$213,251											$213,251
Other: COVID STD Workforce Supplemental		$100,000										$100,000
Other: COVID and adult vaccination community education and linkage to care					$85,234							$85,234
Total	**$20,170,649**	**$5,887,840**	**$1,625,980**	**$1,079,674**	**$996,629**	**$376,500**	**$306,555**	**$292,140**	**$239,000**	**$62,432**	**$36,789**	**$31,074,188**

STATE OF MAINE

Maine Shared Community Health Needs Assessment Report

2022

Rev 7.12.2022

COVID-19 AND OUR HEALTH

While our quantitative data pre-dates the COVID-19 pandemic, the 2021 community health needs assessment outreach took place during the pandemic, and participants noted its impacts in deep and meaningful ways. It was impossible not to recognize the pandemic’s impacts on healthcare, health outcomes, behavioral health, and social support systems, especially for those who experience systemic disadvantages.

Challenges in accessing care have impacted chronic disease management and caused delays in non-emergency procedures. Rates of those seeking medical care for even acute health events such as heart attack, stroke, and uncontrolled high blood sugar were low during the early phase of the pandemic due to COVID-19 concerns. This occurred even while the use of telemedicine increased (Kendzerska, et al., 2021). Later in the pandemic, health care usage data from July 2020 through July 2021 show that increases in ICU bed occupancy were followed weeks later by a higher number of deaths not caused by COVID than typically seen before the pandemic. ICU bed occupancy had exceeded 75% of capacity nationwide for at least 12 weeks as of October 25, 2021 (French G., et al., 2021).

Previous disasters have shown that the secondary impacts on population health are long-lasting. For instance, 10 years after Hurricane Katrina, Tulane University Health Sciences Center saw a significant increase in heart disease and related risk factors such as increases in A1C levels, blood pressure, and LDL cholesterol (Fonseca, et al., 2009). The after-effects of disasters such as the Iraqi occupation of Kuwait in 1990, the London bombings in 2005, and the tidal waves and the nuclear meltdown in Fukushima, Japan in 2011 have revealed the need for immediate as well as long-term mental health care (McFarlane & Williams, 2012).

Emerging concerns on the lasting impacts of this pandemic also include the long-term effects of COVID infection as our newest chronic disease. A recent systematic review estimates that more than half of COVID-19 survivors worldwide continue to have COVID-related health problems six months after recovery from acute COVID-19 infection (Groff, et al., 2021). New evidence shows increases in adult diagnoses of diabetes, the risk for diabetes among children, and worsening diabetes among those who already had diabetes after COVID-19 infection (Barrett, et al, 2022).

There are some concerns that the pandemic has had negative impacts on health behaviors. However, the evidence is not yet clear. In Maine, newly available 2020 Maine Behavioral Risk Factors Surveillance System (BRFSS) data on a few key measures give us an early snapshot of the health of Maine adults in the first year of the pandemic. These data do not show any evidence of adverse impacts on trends in smoking, alcohol use, overweight, obesity, or physical activity. Self-reported alcohol use, binge drinking, and current smoking in 2020 were at the lowest levels since 2011 (Maine CDC, unpublished analysis). Drug overdose deaths increased by 33% in 2020 and by another estimated 23% in 2021 according to preliminary findings (Maine Attorney General’s Office); it is not clear whether this is a continuation of previous trends, other factors, or due to the pandemic.

The pandemic is affecting different segments of the population more than others. The August 2021/COVID Resilience Survey showed that younger people, people of color, and those with lower incomes all had elevated stress (American Psychological Association). In Maine, Black or African Americans experience a disproportionate share of the COVID-19 burden as they are only 1.4% of Maine’s total population yet, as of January 19, 2022, make up 3.1% of cases and hospitalizations (Maine DHHS).

Thus, the findings in the 2022 Maine Shared CHNA Reports which show the most often identified priorities such as mental health, substance and alcohol use, access to care, and social determinants of health take on new meaning and an increased sense of urgency.

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INTRODUCTION

The Maine Shared Community Health Needs Assessment (Maine Shared CHNA) is a collaboration between Central Maine Healthcare (CMHC), Maine Center for Disease Control and Prevention (Maine CDC), MaineGeneral Health (MGH), MaineHealth (MH), and Northern Light Health (NLH).

The vision of the Maine Shared CHNA is to turn health data into action so that Maine will become the healthiest state in the U.S.

The mission of the Maine Shared CHNA is to:

- Create Shared CHNA Reports,
- Engage and activate communities, and
- Support data-driven health improvements for Maine people.

This is the fourth Maine Shared CHNA and the third conducted on a triennial basis. The Collaboration began with the One Maine initiative published in 2010. The project was renamed the Shared Health Needs Assessment and Planning Process in 2015 which informed the 2016 final reports, and renamed to the Maine Shared CHNA in 2018, which informed the 2019 final reports. The 2021 community engagement cycle has informed the 2022 final reports.

New this cycle is an expanded effort to reach those who may experience systemic disadvantages and therefore experience a greater rate of health disparities. Two types of outreach were piloted in this effort. One effort included nine community-sponsored events hosted by organizations representing the following communities: Black or African Americans; people who are Deaf and Hard of Hearing; people with a mental health diagnosis; people with a disability; people who define themselves or identify as lesbian, gay, bisexual, transgender, queer and/or questioning (LGBTQ+); people with low income; older adults; people experiencing homelessness; and youth. In addition to these events, 1,000 oral surveys were conducted in collaboration with 10 ethnic-based community organizations' community health workers to better reach Maine's immigrant population. A complete description of how these efforts were deployed and a listing of those who provided input are provided in the Methodology section on page 69.

All of the County, District, and State reports and additional information and data can be found on our web page: www.mainechna.org

EXECUTIVE SUMMARY

LEADING CAUSES OF DEATH

Noting Maine's leading causes of death helps to put community-identified health priorities, related health data, and public health initiatives into perspective. In only two years, COVID-19 deaths have overtaken unintentional injury, chronic lower respiratory disease, and stroke to become the 3rd leading cause of death in Maine .

Table 1. Leading Causes of Death: 2021

RANK	MAINE
1	Cancer
2	Heart Disease
3	COVID-19
4	Unintentional Injury
5	Chronic Lower Respiratory Disease

DEMOGRAPHICS

Maine is the most rural state in the nation and the least populated state east of the Mississippi. In 2019, Maine had the largest proportion of adults over 65 (21.2%), a lower median household income, and a higher percentage of individuals who have a disability, yet fewer children and adults who live in poverty. Maine's birth rate has been among the lowest in the nation and has been decreasing.[1]

Table 2. Race/Ethnicity in Maine.

	PERCENT	NUMBER
American Indian/Alaskan Native	0.7%	9,419
Asian	1.1%	15,323
Black/African American	1.6%	21,983
Native Hawaiian or other Pacific Islander	<0.1%	222
White	94.0%	1,263,287
Some other race	0.4%	5,442
Two or more races	2.1%	28,536
Hispanic	1.7%	23,067
Non-Hispanic	98.3%	1,321,145

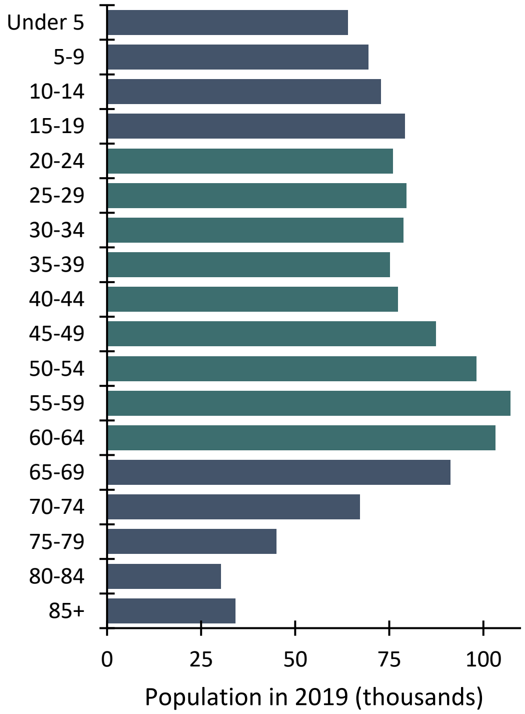
1,372,247

Maine Population, 2021

Table 3. Selected Demographics.

	MAINE	U.S.
Median household income	$57,918	$65,712
Unemployment rate	5.4%	8.1%
Persons with a disability	16.0%	12.7%
Individuals living in poverty	10.9%	12.3%
Children living in poverty	13.8%	16.8%
MaineCare enrollment	29.1%	24.1%
65+ living alone	29.9%	26.6%
Associate's degree or higher (age 25+)	43.2%	41.7%
Gay, lesbian, and bisexual (adults)	4.4%	-
Persons with a disability	16.2%	12.7%
Veterans	8.9%	6.9%

Figure 1. Age Distribution in Maine, 2019.



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TOP HEALTH PRIORITIES

Common concerns identified by participants in 2021 include an ongoing mental health crisis; challenges in accessing health care - especially mental health providers - and increasing rates of substance use. Participants also noted social risk factors such as poverty and lack of transportation as barriers to getting and staying healthy. A list of all the health priorities identified by various communities is included on the next page in Table 4. This is then followed by a series of bar graphs depicting priorities for the statewide county forums and the 9 community events that can be traced to each participant's vote. Note the Youth event chose priorities by consensus, not by each participant's vote.

ABOUT THIS REPORT

There are two major sections to this report. The first section provides an overview of each of the four statewide priorities including their related health indicators and participant's key takeaways identified through the community engagement process. There is also a description of community-identified resources available to address those concerns and any related gaps or needs, and a table of related health indicators.

The second section provides a full description of the results from focused outreach among 10 diverse communities. These communities included:

- Black or African Americans
- People who are Deaf and Hard of Hearing
- People who live with a disability
- People with low income
- People Experiencing Homelessness
- Immigrants
- LGBTQ+ community
- People with a mental health diagnosis
- Older adults
- Youth

For a more quantitative look at how these populations experience different health outcomes, see the Health Equity Data Sheets, also found on the Maine Shared CHNA website: www.mainechna.org.

NEXT STEPS

This assessment report will be used to fulfill the Internal Revenue Service (IRS) requirements for non-profit hospitals as well as the Public Health Accreditation Board (PHAB) requirements for state and local public health departments. The next steps include:

- For hospitals, create an informed implementation strategy designed to address the identified needs.
- For District Coordinating Councils, create District Health Improvement Plans.
- For the Maine CDC, create an informed State Health Improvement Plan.

This report will also be used by policymakers, non-profits, businesses, academics, and countless community partners to support strategic planning, coalition building, and grant writing.

This report can also be used as a catalyst for deeper collaboration to improve the health outcomes of those currently experiencing health disparities within our state.

Taken together, these steps can lead to Maine becoming the healthiest state in the nation.

The following table provides a summary of the top health priorities selected by participants during the community engagement process. The total number of participants in each set of events (or oral survey in the case of the immigrant population) is provided in the column labeled ‘N’. The percentages reflect the percentage of participants who selected the issue as a top health priority. The darker the cells are shaded, the higher percentage of participants who selected it as a top health priority. The exception is for the youth event where no formal voting took place. Instead, checkmarks are used to indicate recurring themes in those discussions.

Table 4. State of Maine Health Priorities.

Population	N	Mental Health	Social Determinants of Health	Access to Care	Substance and Alcohol Use	Older Adult Health	Diabetes	Oral Health	Cancer	Communi-cation
County Forums	1,029	54%	41%	40%	39%	17%	6%	6%	8%	-
Black or African American	8	50%	50%	75%	25%	-	-	13%	38%	-
People who are Deaf and Hard of Hearing	20	20%	20%	30%	15%	30%	15%	5%	-	55%
People who live with a disability	35	40%	37%	17%	7%	6%	-	31%	3%	-
People Experiencing Homelessness	31	52%	16%	35%	42%	3%	10%	10%	3%	-
Immigrant	1,000	69%	-	19%	-	28%	65%	61%	20%	-
LGBTQ+ community	13	69%	69%	62%	38%	15%	-	-	-	-
People with low income	21	38%	48%	19%	29%	19%	10%	19%	5%	-
People with a mental health diagnosis	15	53%	40%	44%	20%	20%	-	13%	-	-
Older adults	75	32%	37%	43%	4%	32%	1%	9%	1%	-
Youth	30	✓	✓	✓	-	-	-	✓	-	-

Figure 2-1. Priority areas by population.

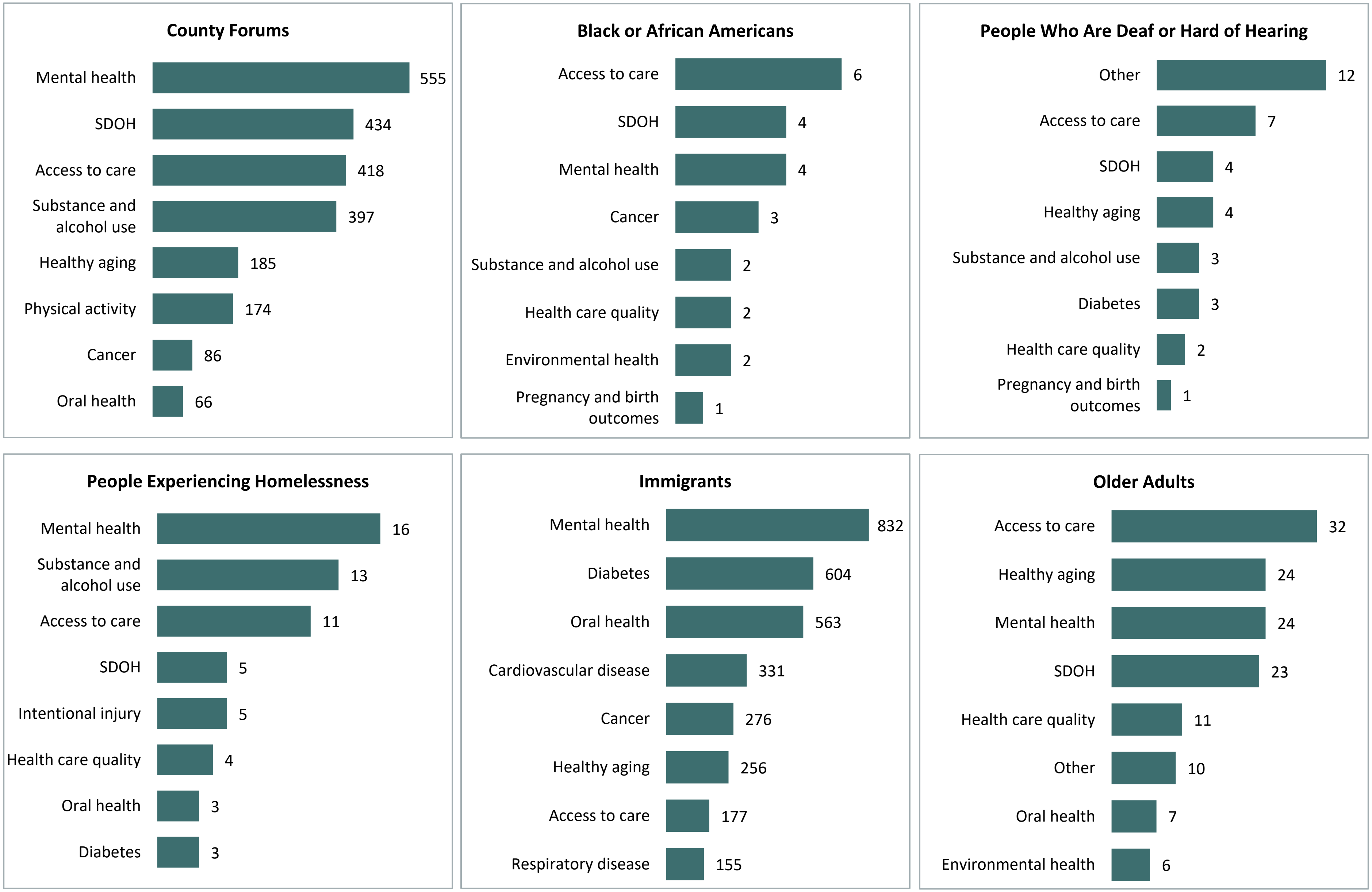
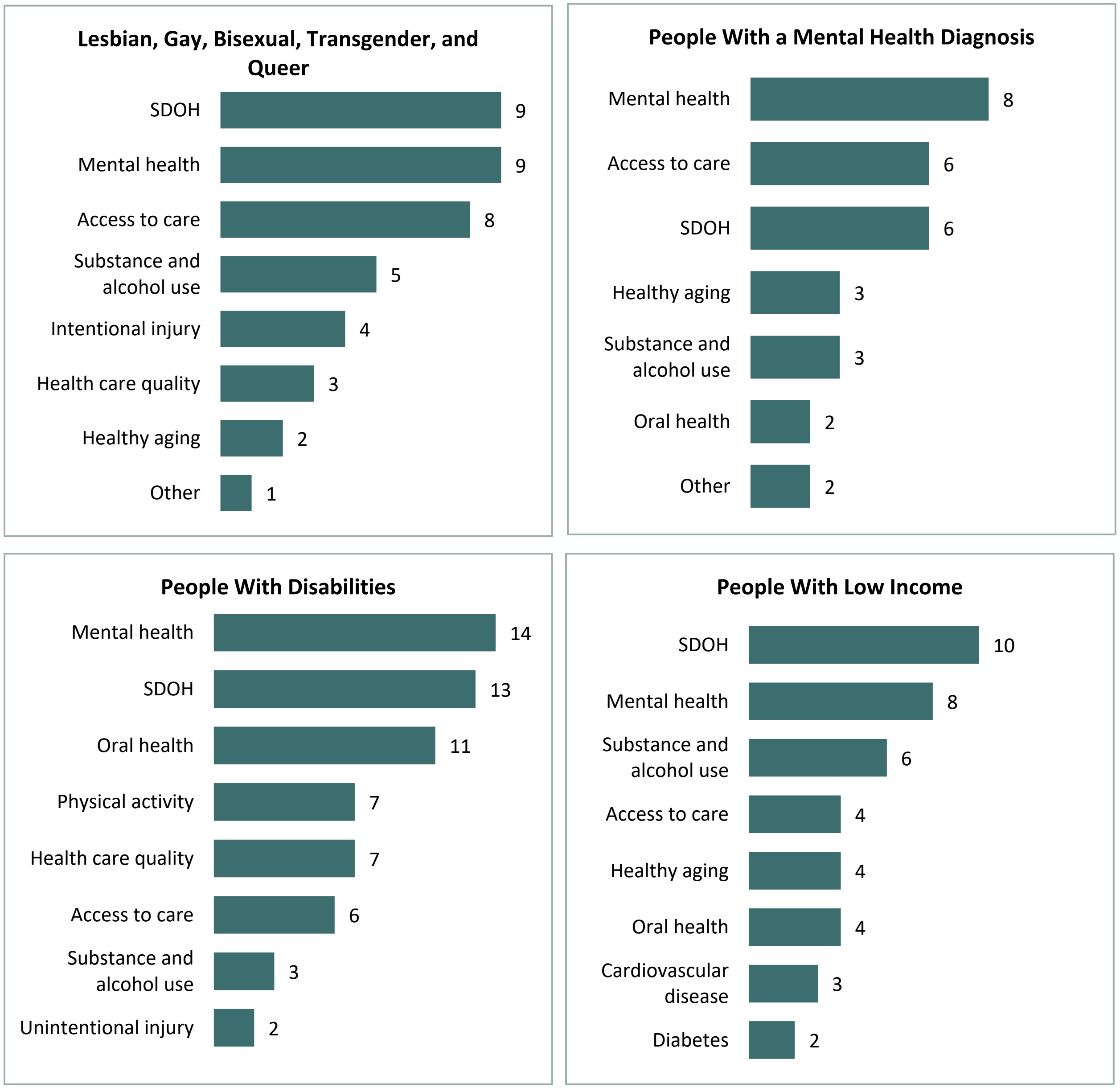


Figure 2-2. Priority areas by population (continued).



STATEWIDE PRIORITY: MENTAL HEALTH

KEY TAKEAWAYS FOR MENTAL HEALTH

Figure 3. Ratio of population to psychiatrists, 2019.

Mental Health was a top priority identified across all counties and community-sponsored events. Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also determines how we handle stress, relate to others, and make healthy choices.[2]

> *There is a lack of African American mental health workers. Someone who can relate to their lived experiences and feel safe to open up to."*
> *-Black/AA Event Participant*

The availability of providers was the most frequently mentioned indicator related to mental health. There is concern that the current health care workforce cannot meet mental health needs. This shortage of providers increases mental health emergencies and the use of the emergency department for care.

A second key theme is a concern for youth mental health - depression, suicide ideation, stress/anxiety, and mental health impacts of adverse childhood experiences. In 2019, 32.1% of high school students and 24.8% of middle school students reported feeling sad or hopeless for two or more weeks in a row, while 16.4% of high school students and 19.8% of county middle school students seriously considered suicide.

Community members were concerned that the pandemic exacerbated mental health issues across the state, leading to increased isolation, trauma, and stress.

> *"There is a stigma around mental health, it plays a factor with people trying to reach out to get help and seek resources. People struggling financially would be less likely to seek help due to reimbursement with these programs. Everything ties together." - Lincoln County Forum Participant*

Those with a mental health diagnosis noted extremely long waitlists for services, highlighting a need for more high-quality mental health services.

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[2] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm.

STATEWIDE DATA: MENTAL HEALTH

	MAINE			BENCHMARKS	
INDICATOR	**POINT 1**	**POINT 2**	**CHANGE**	**U.S.**	**+/-**
MENTAL HEALTH					
Mental health emergency department rate per 10,000 population	2016 **186.7**	2018 **170.6**	★	—	N/A
Depression, current symptoms (adults)	2013 **9.9%**	2017 **9.6%**	○	—	N/A
Depression, lifetime	2013 **23.4%**	2017 **26.0%**	○	2017 **19.1%**	!
Anxiety, lifetime	2013 **18.8%**	2017 **21.8%**	!	—	N/A
Sad/hopeless for two weeks in a row (high school students)	2015 **25.9%**	2019 **32.1%**	!	—	N/A
Sad/hopeless for two weeks in a row (middle school students)	2015 **21.2%**	2019 **24.8%**	!	—	N/A
Seriously considered suicide (high school students)	2015 **14.8%**	2019 **16.4%**	○	—	N/A
Seriously considered suicide (middle school students)	2015 **15.7%**	2019 **19.8%**	!	—	N/A
Chronic disease among persons with depression	2013 **27.8%**	2017 **34.0%**	○	—	N/A
Ratio of population to psychiatrists	—	2019 **12,985.0**	N/A	—	N/A
Currently receiving outpatient mental health treatment (adults)	2013 **17.4%**	2017 **18.6%**	○	—	N/A

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COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times a type of resource or gap/need was mentioned in one of the mainstream forums or community-sponsored events.

Resources that Maine has to address mental health include various treatment options, community-based collaboration and cohesion, school-based services focusing on youth, and a shift away from punitive approaches toward community efforts that raise awareness, reduce stigma, and build resilience. Common gaps related to mental health care in the state include barriers to getting treatment or medication, a lack of mental health providers, the need for more community collaboration, a lack of additional youth mental health services, and a need to improve services relative to the needs of this population.

Table 5. Gaps/Needs and Available Resources (Mental Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Treatment Options Treatment, including community-based and trauma, informed treatment (24)	**Barriers to Treatment** Barriers to treatment, including medications (24)
Collaboration and Community Cohesion Collaboration & Community cohesion (14)	**Providers** Lack of mental health treatment providers (21) Collaboration, coordination & community cohesion (10) Schools, youth, and families (15)
Youth Services Supports provided for youth through school-based services and programs (11)	**Culturally Competent Care** Inadequate services, including lack of culturally competent care, care integration across co-occurring or continuum of care, & poor quality (8)
Prevention Prevention, awareness, stigma reduction, and resilience-building efforts (9) Other Services (9)	**Adverse Childhood Events** Need to address underlying causes, including adverse childhood experiences (ACEs), trauma stress, isolation, & equity (9)
Law Enforcement Public safety policy shifts away from incarceration towards providing community-based interventions (law enforcement, first responders) (4) Training in mental health first aid or best practices for those on the front lines (3)	**Lack of Prevention** Need more prevention, awareness, & advocacy (5) Need to decrease poor health consequences such as intentional injury (1)
	Law Enforcement Need more law enforcement training in de-escalation and community-based intervention (6) Lack of data on the impact of COVID-19 on mental health (1)

STATEWIDE PRIORITY: SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS FOR SOCIAL DETERMINANTS OF HEALTH

Figure 4. Individuals living in poverty, 2015-2019.

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access, environment, and social connectedness. Examples include access to healthy food, housing, water, and relationships[3]. These social determinants can create disparities that impact vulnerable populations.

Social determinants of health were a top priority identified across 15 counties and seven community-sponsored events. Poverty was the most mentioned health indicator of social determinants of health. Recent data shows that 10.9% of individuals and 13.8% of children in Maine live in poverty.

> *“So much relates to trauma and poverty – lack of education, food, and housing. Without a good set of baseline assets, it’s hard to navigate.”*
> *-Cumberland (Lakes Region) Forum Participant*

Community members identified Adverse Childhood Experiences (ACEs) as the second most frequently mentioned concern. ACEs are a list of potentially traumatic events that occur during childhood and increase the likelihood of negative health and behavioral outcomes later in life. In 2019, 21.3% of Maine high school students reported experiencing four or more ACEs.

Housing insecurity was the third most frequently mentioned indicator. Recent data show that 3.3% of Maine high school students have insecure housing. In many cases, housing insecurity is linked to housing costs. In 2019, 12.0% of residents spent more than half of their income on housing. The cost of housing was the fourth most identified health indicator.

> *Health care may be low on the list of [people’s] priorities – [they are] busy dealing with their immediate needs.”*
> *-Somerset Forum Participant*

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[3] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

STATEWIDE DATA: SOCIAL DETERMINANTS OF HEALTH

	MAINE			BENCHMARKS	
INDICATOR	**POINT 1**	**POINT 2**	**CHANGE**	**U.S.**	**+/-**
SOCIAL DETERMINANTS OF HEALTH					
Individuals living in poverty	2015 **13.4%**	2019 **10.9%**	★	2019 **12.3%**	N/A
Children living in poverty	2016 **16.7%**	2019 **13.8%**	★	2019 **16.8%**	★
Children eligible for free or reduced lunch	2017 **47.3%**	2021 **38.2%**	N/A	2017 **15.6%**	N/A
Median household income	2015 **$51,494**	2019 **$58,924**	★	2019 **$65,712**	!
Unemployment	2016 **3.8%**	2020 **5.4%**	N/A	2020 **8.1%**	N/A
High school student graduation	2018 **86.7%**	2020 **87.4%**	N/A	2019 **87.1%**	N/A
People living in rural areas	—	2019 **66.2%**	N/A	—	N/A
Access to broadband	—	2017 **88.6%**	N/A	2017 **90.4%**	N/A
No vehicle for the household	2015 **2.5%**	2019 **1.8%**	○	2019 **4.3%**	★
Persons 65 years and older living alone	2015 **29.5%**	2019 **29.9%**	N/A	2019 **26.6%**	N/A
Households that spend more than 50% of income on housing	2013-2017 **13.0%**	2015-2019 **12.0%**	★	—	N/A
Housing insecure (high school students)	2017 **3.6%**	2019 **3.3%**	○	—	N/A
Adverse childhood experiences (high school students)	2017 **23.4%**	2019 **21.3%**	○	—	N/A
Associate's degree or higher among those age 25 and older	2015 **39.8%**	2019 **43.2%**	N/A	2019 **41.7%**	N/A
Commute of greater than 30 minutes driving alone	2015 **31.0%**	2019 **33.6%**	N/A	2019 **37.9%**	N/A

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COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times a type of resource or gap/need was mentioned in one of the mainstream forums or community-sponsored events.

Resources that Maine has to address social determinants of health include various treatment options, community-based collaboration and cohesion, school-based services focusing on youth, and a shift away from punitive approaches toward community efforts that raise awareness, reduce stigma, and build resilience. Common gaps related to mental health care in the state include barriers to getting treatment or medication, a lack of mental health providers, the need for more community collaboration, a lack of additional youth mental health services, and a need to improve services relative to the needs of this population.

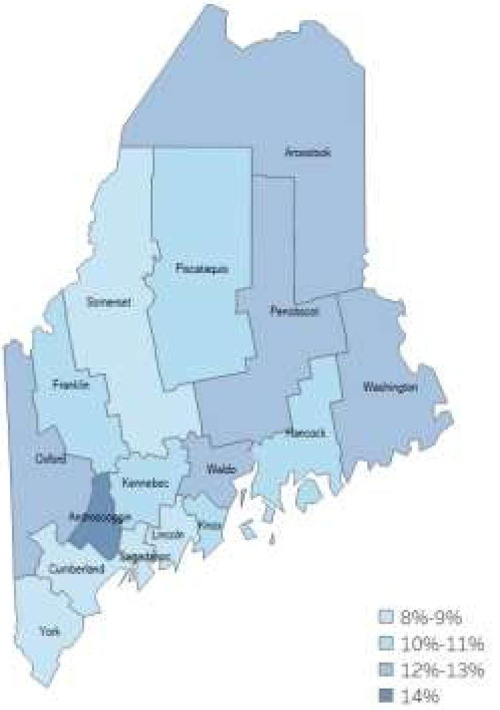
Table 6. Gaps/Needs and Available Resources (Social Determinants of Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Community cohesion (19) Technology (1) **Food** Food safety net programs (17) **Child and Family Services** Child development, youth, family supports & schools (13) **Housing and Transportation** Housing supports (9) Transportation (6) **Adverse Childhood Events** ACEs/Trauma/Resiliency (6) **Funding** Funding (4) **Employment Opportunities** Jobs (4) **Law Enforcement** Public safety's support for alternative policing models (2) **Prevention** Health services & screening (13) Physical activity (7) Prevention services (1) **Awareness and Options for Services** Awareness (1) Substance Use Disorder Recovery options (2) Older adult supports (2)	**Barriers to Treatment** Barriers to Treatment, including medications (24) **Lack of Providers** Lack of mental health treatment providers (21) **Collaboration, Coordination & Community Cohesion** Collaboration, Coordination & Community cohesion (10) Lack of data on the impact of COVID-19 on mental health (1) **Child and Family Services** Schools, youth, and families (15) **Culturally Competent Care** Inadequate services, including lack of culturally competent care, care integration across co-occurring or continuum of care, & poor quality (8) **Prevention** Need to address underlying causes, including adverse childhood experiences (ACEs), trauma stress, isolation, & equity (9) Need to decrease poor health consequences such as intentional injury (1) Need more prevention, awareness, & advocacy (5) **Law Enforcement** Need more law enforcement training in de-escalation and community-based intervention (6)

STATEWIDE PRIORITY: ACCESS TO CARE

KEY TAKEAWAYS FOR ACCESS TO CARE

Figure 5. Cost barriers to health care, 2015-2017.



Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: insurance coverage, availability of services, timeliness of access, and the provider workforce.[4]

Access to care was a top priority identified across all counties in Maine. Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of coverage, services, timeliness, and workforce.[5]

Cost barriers to care and a lack of health insurance were identified as concerns by the majority of participants. Between 2015 and 2017, 10.6% of adults reported there was a time in the last 12 months when they needed to see a doctor but could not due to the cost. In 2019, 8.0% of Mainers were uninsured. Members highlighted the challenges in getting health insurance, notably among those with disabilities.

> *There's a lack of health insurance for people with disabilities. For many the only option is MaineCare. Many offices don't accept MaineCare. There are co-pays and what you have to pay out of pocket is the difference between buying food, medicine, or health care." - Deaf/HOH Event Participant*

Another key theme emerged regarding access to care and workforce issues. Almost half (48%) of community members identified the number of primary care providers throughout the state as a key indicator of concern. In 2019, 20.0% of primary care visits across the state were more than 30 miles from the patient's home. In some counties, particularly in the more rural parts of the state, participants shared that it is difficult to recruit and retain providers. Members also mentioned the need for culturally competent and educated providers.

> *"It's a challenge to get PCPs to come to the area. Some PCPs stay for a few years, others come and leave. It's all over the place."*
>
> *-Piscataquis County Forum Participant*

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[4] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

[5] Chartbook on Access to Health Care. Agency for Healthcare Research. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html.

STATEWIDE DATA: ACCESS TO CARE

	MAINE			BENCHMARKS	
INDICATOR	**POINT 1**	**POINT 2**	**CHANGE**	**U.S.**	**+/-**
ACCESS TO CARE					
Uninsured	2015 **8.4%**	2019 **8.0%**	○	2019 **9.2%**	★
MaineCare enrollment (all ages)	2016 **25.0%**	2020 **29.1%**	N/A	2020 **24.1%**	N/A
MaineCare enrollment (ages 0-19)	2016 **40.0%**	2020 **43.8%**	N/A	—	N/A
Ratio of population to primary care physicians	—	2019 **1332.0**	N/A	—	N/A
Usual primary care provider (adults)	2013 **87.4%**	2017 **87.2%**	○	2017 **76.8%**	N/A
Primary care visit to any primary care provider in the past year	2013 **72.1%**	2017 **72.8%**	○	2017 **70.4%**	N/A
Cost barriers to health care	2013 **10.1%**	2017 **11.7%**	○	2017 **13.5%**	★
Primary care visits that were more than 30 miles from the patient's home	—	2019 **20.0%**	N/A	—	N/A

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COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Resources that Maine has to address access to care include community organizations and programs, workforce development programs, and housing options. Common gaps related to access to care in the state include a lack of sufficient numbers of providers, culturally competent care, and offerings for specific services including oral health, medications, long-term care, and home care.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times a type of resource or gap/need was mentioned in one of the mainstream forums or community-sponsored events.

Table 7. Gaps/Needs and Available Resources (Access to Care).

AVAILABLE RESOURCES	GAPS/NEEDS
Alternative Services Access with alternatives (22) Other services (3)	**Barriers to Care** Barriers to care & access (21) Cost of care (9) Measuring access to care (1)
Coordination and Community Cohesion Community organizations & programs (20) Community cohesion (18)	**Lack of Providers and Services** Providers and workforce issue (17) Specific services, including oral health, medications, long-term care, home care, and others (14)
Technology Technology (12)	**Housing and Transportation** Transportation (14) Stable, affordable, and safe housing (3)
Education Education (8)	**Culturally Competent Care** Culturally competent care, that is inclusive of diverse populations, ages, languages, and literacy levels (9)
Employment Opportunities Workforce development (7)	**Coordination and Community Cohesion** Coordination collaboration, & community organizations (9)
Housing Housing options (1)	**Youth Services** Youth, schools, health education (6)
Health Care Equity Equity (1)	**Education** Education (5)
Funding Funding (1)	**Funding** Need for stable and reliable funding and resources (3)

STATEWIDE PRIORITY: SUBSTANCE AND ALCOHOL USE

KEY TAKEAWAYS FOR SUBSTANCE AND ALCOHOL USE

Figure 6. Overdose deaths per 100,000, 2020.

Substance and alcohol use was identified as a top priority among all counties across the state. Recurring use of alcohol and/or drugs can cause clinically significant impairment, including health problems, disability, and failure to meet major responsibilities at work, school, or home. Substance and alcohol use has also been linked to co-occurring mental health issues such as anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD), among others.[6]

Drug overdose deaths were identified by the majority of participants (79%) as a top health indicator of concern. Indeed in 2020, the rate of overdose deaths in Maine per 100,000 residents was 37.3, which is much higher than the 2019 rate of 21.5 in the U.S. overall.

Furthermore, there was a recognition that these deaths do not occur in isolation, and that substance use disorder has rippling effects across families and communities across the state.

> *"Substance abuse is hurting communities and families and needs to be treated as a condition." - Aroostook County Forum Participant*

Participants also perceived an overall lack of preventive services and treatment options across the state, such as psychiatrists, counselors/social workers, and harm reduction and prevention outreach. Due in part to this lack of preventive services, the majority of participants (52%) indicated that hospital utilization for overdoses was a top health indicator of concern.

However, there was an acknowledgment from participants that recent efforts to support individuals with substance use issues have been working and have had a real impact on their communities.

> *"The decrease in the amount of use in this county has shown that the work that has been done has had an impact" - Washington County Forum Participant*

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[6] Mental Health and Substance Use Disorders. Substance Abuse and Mental Health Services Administration (SAMHSA). Available from: https://www.samhsa.gov/find-help/disorders.

STATEWIDE DATA: SUBSTANCE AND ALCOHOL USE

	MAINE			BENCHMARKS	
INDICATOR	**POINT 1**	**POINT 2**	**CHANGE**	**U.S.**	**+/-**
SUBSTANCE AND ALCOHOL USE					
Overdose deaths per 100,000 population	2016 **28.2**	2020 **37.3**	!	2019 **21.5**	!
Drug-induced deaths per 100,000 population	2015 **21.8**	2019 **31.3**	!	2019 **22.8**	!
Alcohol-induced deaths per 100,000 population	2015 **11.6**	2019 **11.3**	○	2019 **10.4**	○
Alcohol-impaired driving deaths per 100,000 population	2015 **3.8**	2019 **3.8**	○	2019 **3.1**	○
Drug-affected infant reports per 1,000 births	2015 **80.5**	2019 **72.9**	○	—	N/A
Chronic heavy drinking (adults)	2013 **7.2%**	2017 **8.9%**	!	2017 **6.2%**	!
Binge drinking (adults)	2013 **17.2%**	2017 **17.9%**	○	2017 **17.4%**	○
Past-30-day marijuana use (adults)	2013 **7.8%**	2017 **16.3%**	!	—	N/A
Past-30-day misuse of prescription drugs (adult)	2013 **1.0%**	2017 **1.3%**	○	—	N/A
Past-30-day alcohol use (high school students)	2015 **23.8%**	2019 **22.9%**	○	—	N/A
Past-30-day alcohol use (middle school students)	2015 **3.9%**	2019 **4.0%**	○	—	N/A
Binge drinking (high school students)	2015 **12.2%**	2019 **8.2%**	★	—	N/A
Binge drinking (middle school students)	2015 **1.5%**	2019 **1.3%**	○	—	N/A
Past-30-day marijuana use (high school students)	2015 **19.6%**	2019 **22.1%**	!	—	N/A
Past-30-day marijuana use (middle school students)	2015 **3.8%**	2019 **4.1%**	○	—	N/A
Past-30-day misuse of prescription drugs (high school students)	2015 **4.8%**	2019 **5.0%**	○	—	N/A
Past-30-day misuse of prescription drugs (middle school students)	2015 **2.2%**	2019 **3.0%**	!	—	N/A
Narcotic doses dispensed per capita by retail pharmacies	2018 **13.1**	2020 **12.1**	★	—	N/A
Overdose emergency medical service responses per 10,000 population	2018 **65.9**	2020 **76.7**	○	—	N/A
Opiate poisoning emergency department rate per 10,000 population	2016 **9.6**	2018 **8.6**	★	—	N/A
Opiate poisoning hospitalizations per 10,000 population	2016 **1.4**	2018 **1.2**	○	—	N/A

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COMMUNITY RESOURCES TO ADDRESS SUBSTANCE AND ALCOHOL USE

Resources that Maine has to address substance and alcohol use include community organizations, treatment programs, and recovery communities. Common gaps related to substance and alcohol use in the state include feelings of stigma among community members asking for help, a lack of harm reduction initiatives, and a need for more prevention, awareness, and education regarding substance use.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times a type of resource or gap/need was mentioned in one of the mainstream forums or community-sponsored events.

Table 8. Gaps/Needs and Available Resources (Substance and Alcohol Use).

AVAILABLE RESOURCES	GAPS/NEEDS
Coordination and Community Cohesion Collaboration & Organizations (22) **Treatment Options** Treatment options (17) Pre/post-natal care (2) Recovery community & other supports (17) **Prevention and Awareness** Prevention and awareness (13) Harm reduction programs (13) Improved focus on stimulant misuse (1) **Funding** Federal and state grant funding (10) **Youth Services** Youth camps, groups, and supports (7) **Law Enforcement** Alternative approaches in law enforcement (4)	**Lack of Treatment Options** Need more treatment options (18) Harm reduction initiatives - needle exchanges, access to Naloxone, and disposal options (10) Other services, including transportation, or treatment for specific substances (6) Workforce (4) **Stigma** Fear of stigma when asking for help (14) **Coordination and Community Cohesion** Community support for people in recovery - Recovery homes and hiring practices (13) Ease of access and community norms (9) Collaboration, coordination & community engagement (7) **Youth Services** Need more screening, brief intervention, and referrals to treatment options geared toward youth and their families (11) **Prevention** Prevention, awareness, & education (8) **Funding** Funding and other community resources (5) **Health Care Equity** Equity (4) Poverty, housing supports (3) **Culturally Competent Care** Other barriers such as lack of linguistically appropriate resources (1)

HEALTH EQUITY IN MAINE

Healthy People 2030 defines **health equity** as, “the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.” Healthy People 2030 defines a **health disparity** as, “a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater obstacles to health based on their racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or other characteristics historically linked to discrimination or exclusion.”[7]

THE PEOPLE OF MAINE

There are approximately 81,000 people of color in Maine. This includes Latino/a/x communities, Asian American/Pacific Islanders, Native Americans, and Black or African Americans. Many are from families who have been in Maine or other areas of the U.S. for generations, while others have more recently immigrated from outside the U.S. Many Mainers also identify as more than one race. When added together, there are more people of color in Maine than the populations of Piscataquis, Franklin, and Washington Counties combined.

There are five Native American Tribes whose ancestors have lived on the land we call Maine for centuries. The relationship between these sovereign Nations and the State of Maine reflects a problematic history that continues today. The ongoing justified lack of trust in historical White institutions limits the inclusion of their perspective in this assessment.

Maine’s diversity is also enriched by individuals who identify as lesbian, gay, bisexual, transgender, and/or those who may have gender diverse or gender-expansive identities or sexual identities. Maine is also home to those who possess a wide range of intellectual, physical, and psychological abilities. While group labels can be a convenient way to quantify those who share certain characteristics, it is important to note one individual can identify as a member of several groups. As just one example, Maine has the highest percentage of individuals who identify as White and the highest percentage of people aged 65 and over in the nation. Statistically then a portion of these individuals must also identify either as someone with low income, live in a rural setting, or identify as lesbian, gay, bisexual, transgender, or among those who possess a range of intellectual, physical, and psychological characteristics.

While Maine’s diversity is a source of strength and pride, for some, their identities also predict a disproportionate share of health disparities. These disparities have complex causes but are often driven by inequitable access to good jobs, quality education, safe housing, ample healthy food, and other basic needs. Achieving health equity requires close collaboration with those who experience disparities to identify the best strategies, policies, or programs that work for them.

COMMUNITY ENGAGEMENT

The Maine Shared CHNA 2021 community engagement effort, launched in 2020, sought to gain a better understanding of these disparities. To do so, the MSCHNA partnered with just a few of the many non-profit organizations that provide support to Maine’s under-resourced communities. These partnerships resulted in outreach guided by, hosted for, and facilitated with community members. For nine of these communities, this consisted of a single two-hour event attended by a small portion of their communities. For Maine’s immigrant

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[7] Health Equity in Health People 2030, last accessed 4/19/2022: Health Equity in Healthy People 2030 - Healthy People 2030 | health.gov

population, this consisted of 1,000 seven-question oral surveys.

There were three goals in this effort. The first goal was to establish and strengthen relationships across Maine to foster collaboration in removing health disparities. The second goal was to provide a space and empower those who experience health disparities to own and tell their stories. The third goal was to build the skills, experience, and capacity of those who have limited opportunities to conduct this type of assessment so that they may lead their public health initiatives.

The relationships that have been built, the stories that have been collected, and the knowledge that has been gained are only the beginning. While there is significant agreement between the top health priorities chosen during county forums and those identified with Maine's diverse communities, the underlying root causes differ depending on local resources and unique characteristics and cultural norms across the state. We intend that public health, healthcare, advocacy groups, and policymakers use these reports as conversation starters to explore these differences and form collaborations to address these findings.

Since the Maine Shared CHNA equity outreach effort began, Maine has established an Office of Population Health Equity. In the coming months and years, this office is charged with advancing health equity in Maine. One of their initiatives will be community-led health needs assessments. The Maine Shared CHNA looks forward to supporting these efforts.

ABOUT THE QUANTITATIVE DATA

For a quantitative look at how these differences affect health outcomes, see the Health Equity Data Sheets, found on the Maine Shared CHNA website, www.mainechna.org. The MSCHNA collects and analyzes data on health outcomes, health behaviors, social determinants of health, and demographics wherever those data are available.

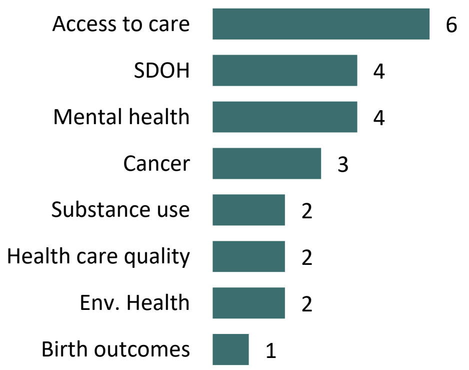
Not all data sources collect a full set of social or demographic data. In addition, some sub-populations experiencing health disparities are small, resulting in data that is less reliable due to low numbers or unavailable due to privacy concerns. These limitations have reduced the number of data points available for publication of county state-level data. This is another area where the Maine Shared CHNA looks forward to supporting the efforts of Maine's Office of Population Health Equity to enhance data collection practices.

BLACK OR AFRICAN AMERICANS

Black or African American is a term often used to describe residents who can trace their ancestry in Maine from pre-colonial times up to, and including, today's immigrants from predominately Black nations. Regardless of genealogy or country of origin, Black or African Americans face similar racial barriers and discrimination while at the same time, the differences in their history create unique cultural identities. In 2019, 21,983 people identified as Black or African American in Maine, 1.6% of the population.

The first record of a Black or African American in Maine dates back to 1608 when Mathieu da Costa served as a translator between Native Americans and the French and Dutch. In the seminal work *Maine's Visible Black History*[8], Maine has a mixed history of both participating in the slave trade during the colonial era through its connections to the shipbuilding industry and opposing slavery, supporting abolitionism, and embracing vibrant Black communities. Despite facing systematic disadvantages, Maine has a long history of Black or African American journalists, scientists, US patent holders, doctors, lawyers, professors, and artists.

Figure 7. Priority Areas – Black or African Americans.



Yet still, Black and African Americans in Maine, and across the U.S., face segregation, racism, and injustices creating social, economic, and environmental disadvantages. Many of these injustices are systemic, created and sustained by institutional systems that were created by those seeking advantage over others based on race, and not yet transformed to eliminate these systemic biases. These disadvantages have created avoidable health disparities due to a lack of timely and quality care, undue stress, and a general lack of similar opportunities to those who identify as White.

The Maine Shared CHNA partnered with the Green Memorial A.M.E. Zion Church to host a community event to gain a deeper understanding of the unique health priorities, gaps, and assets of Black or African Americans. Built in 1914, the Green Memorial A.M.E. Zion Church houses one of Maine's oldest African American congregations. The church is named for Moses Green, an escaped slave. The event was held on November 4, 2021, and attended by nine community members. The four priorities identified during this event were:

- Access to Care (66%)
- Social Determinants of Health (44%)
- Mental Health (44%)
- Cancer (33%)

Due to limited time during this one 2-hour event, participants were unable to explore the topic of Mental Health and Cancer more deeply. Concerns raised about these priorities are mentioned in the Access to Care section. Many of the identified health needs during this event are linked to access to healthcare, in particular, the impact this has on health outcomes and quality of care.

It should be noted that not all data sources collect a full set of social or demographic data. In addition, some sub-populations experiencing health disparities are small, resulting in data that is less reliable due to low numbers or unavailable due to privacy concerns. These limitations have reduced the number of data points available for publication of county or state-level data.

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[8] Price, H.H., Talbot, G.E. (2006). Maine's Visible Black History, Tilbury House Publishers, Gardiner, ME. ISBN: 0884482758.

ACCESS TO CARE

KEY TAKEAWAYS

Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.

MaineCare enrollment was the most frequently mentioned health indicator among event participants. Of those who identify as Black or African American in Maine, 57.3% are enrolled in MaineCare. This is more than twice the rate of those who identify as White (21.7%) in 2020. As mentioned by other communities who experience health disparities, it can be difficult to find a provider who accepts MaineCare, making it challenging to access preventative screenings and ongoing medical monitoring of chronic conditions.

Participants also mentioned the difficulty in understanding the MaineCare application forms. It was noted that the reading level is too high, especially for those who do not speak English as their primary language. They also noted a lack of sustained effort to get those who qualify for MaineCare to enroll in the program.

Cost barriers to care were the second most frequently identified health indicator related to access to care. Between the years 2011-2017, 24.7% of the Black or African American residents reported that there was a time during the last 12 months when they needed to see a doctor but could not because of the cost. This is a significantly higher rate than White residents (10.4%). This rate was also higher than residents of more than one race (18.3%), and Asians (15.5%), but not significantly.

The third health indicator mentioned by participants as a concern was the rate of uninsured. In Maine, 12.8% of Black or African Americans do not have any form of health insurance. This is higher than Whites (8.8%) and lower than those who identified as some other race (15.5%). The uninsured rate includes those who do not have any form of health insurance, whether purchased individually, through an employer, or provided through the government. These data are from 2017.

Of particular concern was the link between a lack of access to care and Cancer. Collectively, those who identify as Black or African American have the highest death rates and shortest survival rates of any racial/ethnic group in the US for most cancers.[9] Cancer is the second leading cause of death for Black or African American Mainers. Participants noted the challenges in accessing healthcare to obtain regular, early, preventative screenings to avoid detecting late-stage cancers.

> *"[There is a] lack of African American mental health workers. Someone who can relate."*

Additional barriers to accessing care included limited paid time off to go see a doctor. Participants also mentioned a desire for being able to choose from a diverse pool of providers as well as the need for multicultural training. This was a particular concern for those who identified **Mental Health** as a priority concerning the quality of care.

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[9] American Cancer Society. Cancer Facts and Figures for African American/Black People, 2022-2024. Atlanta; American Cancer Society, 2022.

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Participants identified MaineCare enrollment, cost barriers, rates of the uninsured, location of primary care providers, and the number of providers and specialists as ongoing challenges or needs that impact individuals who are Black or African American.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 9. Gaps/Needs and Available Resources (Access to Care).

AVAILABLE RESOURCES	GAPS/NEEDS
Access Alternatives Expansion of MaineCare to include more adults New Marketplace available **Community Organizations** Maine Immigrant and Refugee Services (MEIRS)	**Culturally Competent Care** Lack of diversity among providers (3) **Need multicultural training for providers** Barriers to Care Underinsurance High deductible insurance plans **Lack of available vacation/sick time to see a doctor** Forms are not accessible/easily understood (3) Youth Lack of school-based health centers/services (2) **Mental Health** African American providers who can relate **Cancer** Access to regular screenings

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships. Differences in social determinants can create economic and health disparities.

Economic stability was the top concern among participants, in particular, the rate of Black or African Americans who live in poverty. During the 2015-2019 time period, the rate of Black or African Americans living in poverty (34.8%) was more than three times the rate of Whites (11.1%). During the same period, Black or African American median household income ($42,901) also lagged behind those of Whites ($58,459).

According to the U.S. Bureau of Labor Statistics, the Black unemployment rate has been and continues to be higher than the national average. There is also a lower rate of high school students who graduate with a regular diploma four years after starting ninth grade for Black or African Americans (82%) than Whites (94.8%). According to the 2016-2020 five-year estimates, the percentage of adults age 25 and older with a bachelor’s degree or higher in Maine was 32.5%. Ninety-four percent of those were white compared to 1.7% who identify as Black or African American. The persistently lower socioeconomic stability was mentioned by participants as a leading cause of challenges in breaking the cycle of poverty.

Youth well-being was also raised as a concern. Participants noted that Black or African American high school students are significantly more likely to report experiencing housing insecurity (9.1%) compared to Whites (2.6%). High school housing insecurity is defined as those who report they usually do not sleep in their parent’s or guardian’s home. These data are from 2019. Participants particularly noted the lack of transitional housing for young people who experience homelessness.

Adverse Childhood Experiences (ACEs) were also discussed as a concern by participants. ACEs are a list of potentially traumatic events that occur during childhood and increase the likelihood of negative health and behavioral outcomes later in life. In 2019, roughly 1 in 5 Maine high school students report having experienced 4 or more ACEs in their lifetimes. These rates are similar for Black and African American high school students (20.1%), Whites (21%), and Maine overall (21.3%). It should be noted that students who identify as White, Black or African American, or Asian have significantly lower rates than students who identify as from more than one race (29.4%), or Native Hawaiian or other Pacific Islander (32%).

Participants also mentioned intentional injury as a concern. These rates are lowest among Black or African American high school students (17.3%) in comparison to all other race categories and the state overall (18.7%) in 2019.

Housing was also mentioned as a concern. In Maine, 12% of households spend more than 50% of their income on housing costs between 2015-2019. Beyond affordability were the health and safety levels of Maine’s homes. During the 2012-2016 timeframe, 3.8% of Portland and Lewiston - Auburn and 1.8% of Bangor children who were screened had confirmed elevated lead blood levels. The state rate was 2.2% during this same period.

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Participants identified poverty, unemployment, limited transportation, and education as ongoing challenges or needs that impact individuals who are Black or African American.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 10. Gaps/Needs and Available Resources (Social Determinants of Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Religious institutions Community-based organizations School facilities **Substance Use Recovery** R.E.S.T. Center (Recovery, Employment, Support, Training)	**Poverty** Underemployment (2) **Transportation** Lack of transportation (2) **Housing** Lack of transitional housing for young people who are homeless Lack of safe housing **Education** Lack of health education/community outreach (2) Lack of education - general (2) Families Lack of childcare

PEOPLE WHO ARE DEAF AND HARD OF HEARING

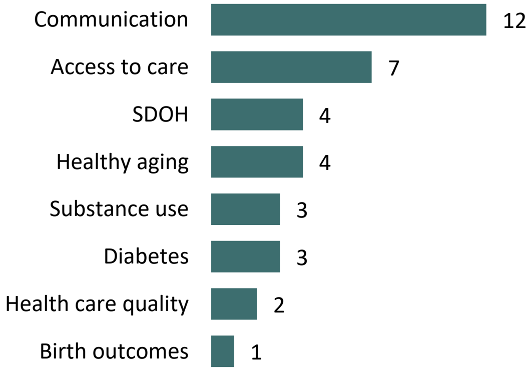
The Deaf and Hard of Hearing population is richly diverse. Individuals who were born deaf and use sign language typically do not see themselves as having lost their hearing, but rather as members of a Deaf cultural and linguistic minority. This centers their identity in a way that may be different from someone who became deaf later in life or who uses spoken languages. People who are Hard of Hearing may fall into several cultural groups depending on their desired affiliation with the Deaf community.

During 2015-2019, 5.1% of Mainers of all ages had hearing difficulty. Nationally, according to the U.S. CDC, about 2-3 out of every 1,000 children in the U.S. are born with a detectable level of hearing loss in one or both ears.[10]

Many people who are Deaf and Hard of Hearing experience health disparities. Examples include higher rates of fair to poor health, psychological distress, diabetes, and high blood pressure. In addition, smoking rates, binge drinking, not engaging in leisure-time physical activity, getting less than 6 hours of sleep, and being obese were also found to be more prevalent among people who are Deaf and Hard of Hearing.[11] There are also socioeconomic disparities. This includes lower educational attainment rates and higher rates of poverty and unemployment compared with hearing adults.[12]

The Maine Shared CHNA collaborated with Disability Rights Maine to host a health needs assessment event for people who are Deaf and Hard of Hearing. Disability Rights Maine advocates for the legal rights of people with disabilities. The most common theme was the desire to be able to get the same quality of healthcare, services, information, and resources as hearing people get. Put another way: people who are Deaf and Hard of Hearing want equity.

Figure 8. Priority Areas – People who are Deaf or Hard of Hearing.



The event was held at Baxter School for the Deaf on Mackworth Island, on September 9, 2021. There were 19 community members in attendance. The four priorities identified during this event were:

- Communication Access (57%)
- Access to Care (37%)
- Older Adult Health/Healthy Aging (32%)
- Physical Activity, Nutrition, and Weight (32%)

It should be noted that not all data sources collect a full set of social or demographic data. In addition, some sub-populations experiencing health disparities are small, resulting in data that is less reliable due to low numbers or unavailable due to privacy concerns. These limitations have reduced the number of data points available for publication of county or state-level data.

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[10] https://www.cdc.gov/mmwr/preview/mmwrhtml/mm5908a2.htm.

[11] Schoenborn, C., Heyman, K. (2008). Health Disparities Among Adults with Hearing Loss: United States, 2000-2006. U.S. CDC national Center for Health Statistics. Last accessed 4/27/2022: https://www.cdc.gov/nchs/data/hestat/hearing00-06/hearing00-06.htm.

[12] Emmet, S., Francis, H., (2015). The Socioeconomic Impact of hearing Loss in US Adults. Otol Neurotol. 2015 March; 36(3): 545–550. doi:10.1097/MAO.0000000000000562

COMMUNICATION ACCESS

KEY TAKEAWAYS

Communication access is a top issue for the Deaf and Hard of Hearing community. Participants' overarching concern was that providers generally lack awareness of the unique communication needs of Deaf and Hard of Hearing patients. In the healthcare setting, participants noted that a lack of successful patient-provider communication limits their ability to understand their diagnosis and make informed decisions regarding options. Lack of understanding also impacts a patient's ability to understand or follow provider instructions.

In particular, participants noted the challenges of accessing care through provider networks or healthcare systems that are not well-trained or equipped to meet the needs of a patient who is Deaf and Hard of Hearing. The provision and effective use of American Sign Language interpreters was a top concern. There is a need for professional training on communication aids and services, as well as how to communicate with a patient through an interpreter.

> *"Some interpreters are not a good fit for me. They don't understand me; I don't understand them. But they don't get that. To them, an interpreter is an interpreter."*

Some common experiences included providers who question the need for sign language interpreters or ask patients to pay for their interpreters, as well as providers who address the interpreter or a family member instead of the patient when speaking. In addition, there is a preference for local interpreters, as American Sign Language (ASL), like any other language, has many different dialects that are not always understood across states or regions.

Some communication technologies and tools can also come with challenges if misused or not used under the right conditions. For instance, the use of Video Remote Interpreters (VRI), when used appropriately, can help facilitate communication quickly. However, when a patient is in distress or pain, it can be difficult to keep an eye on the screen or to hold a tablet and sign at the same time. Other participants expressed frustration with common VRI problems, like freezing screens.

It is a common assumption that those who are Deaf and Hard of Hearing can read and write in English or lip-read. In reality, Deaf and Hard of Hearing adults are at high risk for low literacy and reading comprehension skills. In addition, lip reading is not a universal or common skill, and is an unreliable tool for accurate understanding.[13]

Participants also expressed a desire for access to health education. Deaf American Sign Language users are at high risk of inadequate health literacy. Communication and language barriers isolate them from mass media, healthcare messages, and healthcare communication.[14] To fill this gap, there is a desire for health education via videos with captioning and sign language or live workshops held in collaboration with Deaf community organizations and clubs.

> *"For five weeks, a hard of hearing man sat in the hospital before he got communication access. He had no accessible phone. He couldn't contact a loved one."*

In-patient hospital stays pose unique challenges. One participant noted they were told to bring their hard of hearing family member's hearing aids home from the hospital so they would not get lost. This left the patient unable to hear or understand

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[13] Altieri, N., Pino, D., Townsend, J. (2011). Some Normative data on lip-reading skills. Journal of the Acoustical Society of America; July; 130(1) doi: 10.1121/1.3593376

[14] McKee, M., Paasche-Orlow, M., Winters, P. et al. (2015). Assessing Health Literacy in Deaf American Sign Language Users. Journal of Health Communication. doi: 10.1080/10810730.2015.1066468

conversations during their stay. This meant the patient could not understand what the doctors, nurses, or other care providers were saying and therefore unable to understand their treatment options or participate in decision making.

Participants did express their appreciation for providers who are aware of the need to bridge the communication gap. This included longer appointment times to accommodate the extra time needed to work with interpreters or captioning. Telehealth and video remote care were also mentioned as options. Other strengths or assets mentioned were interpretation and accommodation coordinators who can help providers and patients bridge the communication gap.

COMMUNITY RESOURCES TO ADDRESS COMMUNICATION

Participants identified interpretation/miscommunication, provider competency and Deaf awareness, mistrust/disrespect, and patient education and support as ongoing challenges or needs that impact the Deaf and Hard of Hearing community.

The following information was gathered from participants during a group activity. Participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 11. Gaps/Needs and Available Resources (Communication).

AVAILABLE RESOURCES	GAPS/NEEDS
Interpretation Local American Sign Language (ASL) interpreters and agencies (2) Interpretation/accommodation coordinators Hospitals with staff interpreters or contracts with interpreters MaineCare reimbursement for interpreters	**Interpretation/Miscommunication** Being asked to provide/pay for own interpreter (2) MaineCare reimbursement for interpreters is widely misunderstood Communication access in hospitals (2) Miscommunications/misunderstanding of body language (3) Looking at the interpreter instead of the patient Masks impede communication Video Remote Interpreters (VRI) introduce information errors and detract from interpersonal communication -- there is a lot of misinformation while using this service-- and therefore could be dangerous if misinformation is relayed (2)
Providers Providers who try and are sincere Providers who schedule longer appointment times	**Provider Competency** Lack of provider training and awareness on how to work with Deaf and Hard of Hearing individuals (8) Overall lack of understanding on how to communicate with Deaf patients Limited appointment times (interpretation is time-consuming)
Telehealth Virtual appointments/telehealth (2)	**Mistrust/Respect** Need for bias training Lack of respect for individual needs Avoidance of physician care due to mistrust or a history of bad experiences
Training/Advocacy Maine Medical Center's Deaf & Hard of Hearing Patient Advisory Board Deaf awareness training (2)	**Patient Education and Support** Need workshops on health topics in American Sign Language (ASL) for the Deaf community to increase health literacy via on-site or in-person; can also include education delivered via video Lack of funding/resources geared at Deaf and Hard of Hearing people Language deprivation among Deaf children with hearing parents People unaware/unable to advocate for themselves

ACCESS TO CARE

KEY TAKEAWAYS

Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.[15]

One of the top concerns in accessing care for People who are Deaf and Hard of Hearing was insurance coverage. MaineCare is often the only insurance option due to the large percentage of People who are Deaf and Hard of Hearing who live in poverty. MaineCare recipients can experience challenges in finding providers who accept MaineCare. This can compound the challenges in finding a provider, especially in rural areas where there are a limited number of providers.

> *“I had that [lack of health care services] experience when I lived up north. I did not have all the services I needed. Everything was harder.”*

MaineCare only covers one hearing aid every five years and participants with private insurance noted their experiences with insurers denying claims for hearing aids despite the recent changes in coverage laws. Medicare does not provide coverage for hearing aids. Hearing aids are expensive, and without insurance, the personal cost for hearing aids can conservatively range from $1,500-$6,000 per aid. Even with insurance, the out-of-pocket cost can vary widely and remain a barrier, depending on an individual’s insurance deductible or cost-share obligations.

Participants also noted when healthcare requires co-pays or when certain services are not covered at all, they often need to choose between buying food, fuel, or medicine.

> *"There's a lack of health insurance for people with disabilities. For many the only option is MaineCare. You have to go to suboptimal care if you have MaineCare. It's sad. It's not right."*

Another challenge in access to care is the advances in, and reliance on, technology.

Participants also noted the lack of patient education materials delivered in a way that is accessible for individuals who use sign language or have limited English literacy. Without this type of support, it can compound the challenges of navigating an already complex health care system. As noted in the Communication priority section, traditional appointment time slots often do not have enough time to use interpretation services.

> *"Many people don't know how to download apps or use technology that's supposed to help with hearing loss."*

Participants also noted their challenges in not having a usual primary care provider. Having at least one person that a patient considers as their healthcare provider is the gateway to preventative care, screenings, and ongoing monitoring for chronic conditions. Without access to these services, community members are at risk of not detecting preventable or treatable health conditions or keeping chronic diseases from worsening.

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[15] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Participants identified culturally competent care, cost of care, and lack of screening as ongoing challenges or needs that impact the Deaf and Hard of Hearing community. Available resources include community organizations, access alternatives, and culturally competent workforce development.

The following information was gathered from participants during a group activity. Participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 12. Gaps/Needs and Available Resources (Access to Care).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Organizations Disability Rights Maine	**Culturally Competent Care** Confusion on how to navigate the health care system Need longer appointment times Oppression of the Deaf and Hard of Hearing community
Access Alternatives Some culturally competent (strong) providers/audiologists (2) Some providers allow for longer appointments	**Cost of Care** Insurers skirting Hearing Aid Mandate (3) Lack of health insurance/insurance issues/high copays (3) Hearing aids are expensive (1) Cost of preventative care
Workforce Development Deaf and Hard of Hearing awareness training for providers (2)	**Screening** Lack of screening from birth onward

OLDER ADULT HEALTH

KEY TAKEAWAYS

Older adult health was mentioned as a top concern for Deaf and Hard of Hearing community members. Age-related hearing loss (presbycusis) is the loss of hearing that gradually occurs in most of us as we grow older. It is one of the most common conditions affecting older adults. Approximately one in three people in the United States between the ages of 65 and 74 has hearing loss, and nearly half of those older than 75 have difficulty hearing. Having trouble hearing can make it hard to understand and follow a doctor's advice, respond to warnings, and hear phones, doorbells, and smoke alarms. Hearing loss can also make it hard to enjoy talking with family and friends, leading to feelings of isolation.

Age-related hearing loss most often occurs in both ears, affecting them equally. Because the loss is gradual, many do not notice the loss in the ability to hear. There are many causes of age-related hearing loss. It commonly arises from changes in the inner ear as we age, but it can also result from changes in the middle ear or complex changes along the nerve pathways from the ear to the brain. Certain medical conditions and medications may also play a role.[16]

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[16] National Institute on Deafness and Other Hearing Disorders. Last accessed on 4/727/2022: https://www.nidcd.nih.gov/health/age-related-hearing-loss

Participants noted the added complexity of meeting the needs of older adults who are also Deaf and Hard of Hearing.

One example is the connection between hearing loss and cognitive decline.[17] In 2016, 10.3% of adults in Maine ages 45 and over had cognitive decline, defined as experiencing confusion or memory loss that happened more often or got worse within the past 12 months. Participants expressed concern for the number of Older Adults who may be exhibiting cognitive decline due to undetected and untreated hearing loss. With Maine's aging population, participants noted screening for hearing loss should be considered a routine procedure.

> *"Their doctor kept talking about therapy, but we helped them get a hearing evaluation and hearing aids. It made such a difference."*

Communication was also mentioned in the context of meeting the unique health needs of older adults. Specific examples included a lack of long-term care or nursing homes with staff or residents who can sign. Community members indicated that the nearest facility that offers this is located in Massachusetts and there are excessively long wait times. It was also noted that the lack of advanced directives or do not resuscitate orders among the Deaf and Hard of Hearing older adult population makes it impossible to meet a patient's end-of-life expectations.

Participants also noted the additional challenges for Deaf and Hard of Hearing older adults to age in place. This included a lack of support or services for hearing family members who are often the primary caregivers. For those living in rural areas, difficulty accessing transportation services and social opportunities can compound feelings of isolation and loneliness. Rurality can also mean a lack of access to broadband, which is necessary to access technology such as telehealth visits and support apps.

COMMUNITY RESOURCES TO ADDRESS OLDER ADULT HEALTH

Participants identified health care access, a lack of providers/staff/workforce, long-term care, awareness around navigating resources, and a lack of community support as ongoing challenges or needs that impact the Deaf and Hard of Hearing community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 13. Gaps/Needs and Available Resources (Older Adult Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Programs New England Home for the Deaf (Danvers, MA) Maine Deaf Senior Citizens Group (Senior citizen social group through Maine Association for the Deaf, Inc.) Hearing loss support groups Adult hearing screenings Local interpreting agencies	**Health Care Access** Cost of care Untreated hearing loss can lead to mental health and cognitive decline Deaf people don't have Advance directives/DNRs **Workforce** Not enough providers/staff/workforce for our older adult population

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[17] Yuan, J., Sun, Y., Sang, S. et al. The risk of cognitive impairment associated with hearing function in older adults: a pooled analysis of data from eleven studies. Sci Rep 8, 2137 (2018). https://doi.org/10.1038/s41598-018-20496-w

Table 13. Gaps/Needs and Available Resources (Older Adult Health) (Continued).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Community involvement The Deaf community supports one another Senior citizen social group through Maine Association for the Deaf, Inc. Disability Rights Maine **Alternative Care Options** Relay services for phone access **Training** Deaf culture training for long-term care	**Long-Term Care** No nursing homes or rehabilitation providers with professional interpretation services (3) No Deaf-friendly places **Navigating Resources** Providers unaware of hearing loss resources **Lack of Support** Viewing older people as "less" Isolation among Deaf seniors Memory loss/cognitive decline Support for hearing family members who help Deaf family members Lack of services to support aging in place

PHYSICAL ACTIVITY, NUTRITION, AND WEIGHT

KEY TAKEAWAYS

Physical activity, nutrition, and weight are top health concerns for Deaf and Hard of Hearing community members. Participants expressed a desire for health education on physical activity, nutrition, and weight formatted to be more accessible to them. Communication and language barriers isolate them from mass media, healthcare messages, and healthcare communication.[18] Participants also mentioned their experience with obesity and their lack of leisure-time physical activity to help address this. In addition, higher poverty levels among this population may also result in less access to nutritious foods like fruits and vegetables which are more expensive than processed foods.

Many participants expressed a desire for outdoor adventure. While there are a few resources to assist in this, such as the Maine Deaf Senior Citizens Group and the Maine Association for the Deaf, participants noted the need for more outdoor instructors who can sign.

The list of gaps also includes a lack of workshops and educational opportunities provided with American Sign Language (ASL) interpretation services or with closed captioning. Examples include dieticians and health education classes. There was a recognition of the need to understand communication access and the unique needs and challenges of the community for these opportunities to be accessible and engaging.

Participants noted they were not even sure where to go to get referrals for health education or more information. Not unlike the hearing community, there was also the recognition of a lack of encouragement and willpower necessary to make healthy food choices.

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[18] McKee, M., Paasche-Orlow, M., Winters, P. et al. (2015). Assessing Health Literacy in Deaf American Sign Language Users. Journal of Health Communication. doi: 10.1080/10810730.2015.1066468

COMMUNITY RESOURCES TO ADDRESS PHYSICAL ACTIVITY, NUTRITION, AND WEIGHT

Participants identified health care gaps, health education, and a lack of resources/support as ongoing challenges or needs that impact the Deaf and Hard of Hearing community. Resources include community organizations and outdoor programs for people who are Deaf and Hard of Hearing.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 14. Gaps/Needs and Available Resources (Physical Activity and Weight).

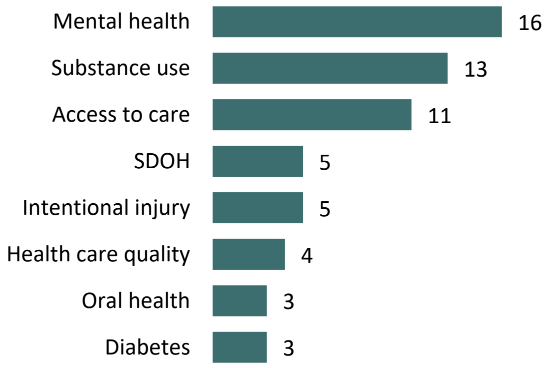
AVAILABLE RESOURCES	GAPS/NEEDS
Programs Outdoor education for people who are Deaf and Hard of Hearing **Organizations** Maine Deaf Senior Citizen Group Maine Association for the Deaf	**Health Care Gaps** Lack of Deaf-friendly, culturally competent dieticians **Health Care Gaps - Continued** Bifurcated approach to physical/mental health **Health Education** Expensive healthy foods Lack of health education for Deaf people (3) Unsure of where to get referrals for health education/info **Resources/Support** Lack of encouragement/willpower (2) Lack of funding/resources No instructors who are Deaf and Hard of Hearing or can sign

PEOPLE WHO EXPERIENCE HOMELESSNESS

Homeless is defined by the U.S. Department of Housing and Urban Development (HUD) as individuals and families who lack a fixed, regular, and adequate nighttime residence; including those who will imminently lose their nighttime residence; homeless under other federal statutes, or those fleeing domestic violence, assault, stalking, or other violence against an individual or family member.[19]

Maine's 2020 Point in Time (PiT) count identified 2,097 individuals experiencing homelessness, as reported by the Maine Continuum of Care (MCoC) to the U.S. Department of Housing and Urban Development (HUD).

Figure 9. Priority Areas – People experiencing homelessness.



The Continuum of Care (CoC) Program is a federal program designed to promote communitywide commitment to the goal of ending homelessness. Maine's CoC covers the entire state. Local agencies wishing to submit applications to the U.S. Department of Housing and Urban Development's McKinney-Vento homeless assistance funding opportunities must do so through the Maine CoC (MCoC). The MCoC's mission is to plan and coordinate an inclusive system that helps Maine people avoid or exit quickly from homelessness, and to address the underlying causes of homelessness.[20]

HUD expects all CoCs across the country to conduct the PiT count annually to quantify homelessness on one night in January. Of the total counted in 2020, 260 were family households, 103 were Veterans, 139 were unaccompanied young adults (aged 18-24), and 248 were individuals experiencing chronic homelessness.

Maine public school data reported to the U.S. Department of Education during the 2018-2019 school year shows that an estimated 2,552 public school students experienced homelessness over the year. Of that total, 105 students were unsheltered, 535 were in shelters, 284 were in hotels/motels, and 1,628 were doubled up, meaning households that cannot afford the cost of housing share housing with others.[21]

> *"Data isn't accurate and [true] numbers aren't portrayed; there are subpopulations of individuals who are housing insecure (not necessarily homeless) that likely aren't included in the data."*

Participants recognized the challenges of a lack of robust data on homelessness and that for many of the reported health indicators, there was likely a higher incidence for those in this population.

Participants also noted that those utilizing emergency housing are often not included in any of the data sets. Because housing status is often not collected in health surveys and questionnaires, the Maine Shared CHNA is unable to obtain health outcome data based on housing status. Participants also noted a lack of data regarding the time spent

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[19] HUD Exchange, Homeless Emergency Assistance and Rapid Transition to Housing (HEARTH): Defining Homeless Final Rule. Last accessed 4/15/2022: https://www.hudexchange.info/resource/1928/hearth-defining-homeless-final-rule/ United States Interagency Council on Homelessness, Maine Homeless Statistics. Last accessed 4/15/2022: https://www.usich.gov/homelessness-statistics/me/

[20] Maine Continuum of Care. Last accessed 4/15/2022: https://www.mainehomelessplanning.org/maine-coc/

[21] United States Interagency Council on Homelessness, Maine Homeless Statistics. Last accessed 4/15/2022: https://www.usich.gov/homelessness-statistics/me/

on waitlists for family housing, which they report can be very long.

The lack of permanent shelter can lead to a complex set of challenges, many of which can impact an individual's ability to secure a fixed residence. This cycle can be difficult to break given a lack of a fixed address to receive mail, store and prepare food, or securely store belongings and medications. The inability to meet even these primary needs makes meeting daily social, emotional, and physical needs challenging.

The Maine Continuum of Care hosted a community event on December 14, 2021, to share insights on the health priorities, as well as the gaps and resources experienced by this population. The event was attended by 31 individuals who either have experienced homelessness and housing insecurity or provide support and services to those who do. The top three health priorities identified by participants included:

- Mental health (52%)
- Substance and alcohol use (42%)
- Access to care (35%)

There was a tie for fourth place**: Intentional Injury** and **Social Determinants of Health**. There was not enough time during this event to explore these topics more deeply. However, what limited data was gathered via discussion notes, and any identified indicators of concern are discussed in their abbreviated sections.

MENTAL HEALTH

KEY TAKEAWAYS

Mental health was the number one concern among those who experience housing insecurity. This was also a top concern for every group across the state. Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[22]

The majority (58%) of participants identified the availability of mental health care providers as a top health indicator. Over half (52%) identified the use of the emergency department for mental health issues. Statewide, the mental health emergency department rate per 10,000 had decreased from 186.7 in 2016 to 170.6 in 2018. As of 2017 in Maine, 18.6% of adults in Maine were receiving outpatient mental health treatment. These numbers do not reflect the impact of the pandemic.

Participants noted the need for an increase in Assertive Community Treatment (ACT) models for those with a mental health diagnosis to retain stable housing. ACT teams provide wrap-around services from multiple disciplines to coordinate the complex needs of this population. Participants mentioned Portland's Shalom House as a valued community resource and an example of how delivering these services could work. Shalom House supports those with severe mental illness through various programs, housing, and housing supports.

Youth mental health was identified as a concern among participants. In 2019, approximately one-third (32.1%) of Maine's high school students and one-quarter (24.8%) of Maine's middle school students **felt sad or hopeless** for two weeks in a row. Across Maine, 16.4% of high school students and 19.8% of middle school students **seriously considered suicide** during the same year (2019).

> *"Mental health is health care."*

Depression and anxiety were also identified as top health indicators. In Maine, 26% of adults reported having depression and 21.8% reported having anxiety within their lifetimes.

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[22] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Participants identified the Shalom House, community organizations, and outreach services, particularly Project for Assistance in Transition from Homelessness (PATH), as resources available to those experiencing homelessness. The community also identified a lack of access to care and health care quality issues as ongoing challenges the state will need to overcome.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 15. Gaps/Needs and Available Resources (Mental Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Collaboration Community-based organizations (3)	**Barrier to Treatment** Lack of access to MH care (4) Not enough rehab (inpatient) beds (4) Need for more rehab facilities (3) Limited education for dealing with mental health personally or in the family (6)
Treatment Shalom House (6) Learning Collaborative and Greater Portland Health in Portland-targeted at providing mental health Community-based organizations (3)	**Providers** Not enough mental health providers (3) Not enough ACT teams in Maine for people unable to retain stable housing due to behavioral health issues (3)
Other Services Projects for Assistance in Transition from Homelessness (PATH) for those with mental health conditions	

SUBSTANCE AND ALCOHOL USE

KEY TAKEAWAYS

Substance and alcohol use was identified as a health priority among the homeless or formerly homeless event participants.

Drug overdose deaths are a top priority health indicator of concern by 61% of participants. In 2020, the rate of overdose deaths per 100,000 population in Maine was 37.3, a significant increase from 28.2 in 2016. These numbers are not available by housing status.

The rate of **drug-induced deaths** in Maine per 1000,000 population was 29.5 from 2015 to 2019. This is higher than the rate in the U.S. in 2019 of 22.8 drug-induced deaths per 100,000 population. This rate in the homeless and formerly homeless population is unknown, but of concern according to community members.

Table 16. Overdose Deaths by Year, Maine.

YEAR	NUMBER
2016	378
2017	417
2018	354
2019	380
2020	502
2021	633*

*Preliminary number from the Office of the Chief Medical Examiner

The second indicator of concern identified by 45% of participants was the rate of alcohol-induced deaths in Maine. Between 2015 to 2019, the rate of alcohol-induced deaths per 100,000 population was 11.6. This is again higher than the rate in the U.S. rate of 10.4 in 2019. The rate of alcohol-induced deaths specifically in the homeless and the formerly homeless population is also unknown but was identified as a top health indicator.

Approximately one-third of participants also identified misuse of prescription drugs (36%), drug-affected infants (36%), and alcohol-impaired driving (32%) as top health indicators.

Participants expressed their perception that a lack of housing options was hindering individuals struggling with opioid use from recovering.

> *"Opioid users need housing, substance, and mental health. If we had housing, we could support and give people recovery."*

Participants noted a series of barriers to recovery that were especially acute for those experiencing homelessness. These barriers were all related to the instability of being homeless while in recovery. This included a lack of stable housing, Medication-Assisted Treatment, housing support programs, and supported living environments that offer opportunities for skill-building before independent living. There was a recognition of the limited amount of education and skill-building available to those from multi-generational substance use settings.

COMMUNITY RESOURCES TO ADDRESS SUBSTANCE & ALCOHOL USE

Participants identified a lack of treatment options, housing support systems, and educational opportunities as ongoing challenges or needs that impact the homeless and formerly homeless community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 17. Gaps/Needs and Available Resources (Substance and Alcohol Use).

AVAILABLE RESOURCES	GAPS/NEEDS
Prevention Great local community health coalitions working on prevention (2) **Recovery/Maintenance** Increased access to vouchers (3) The Farm (3) Limestone Maine (3) **Treatment** Medication-Assisted Treatment (MAT) (3) **Harm Reduction** Harm reduction (2) Milestone Recovery Shelter allows people using substances to have a place to stay (4)	**Treatment** Not enough inpatient treatment (7) Need for more detox centers (3) Lack of Medication Assisted Treatment and housing support programs (3) **Harm Reduction** Lack of fentanyl testing (3) **Housing Supports** Lack of housing for the recovery community (3) Lack of supported living environments that offer opportunities for skill-building before independent living (4) **Awareness/Education** Limited education for dealing with substance use disorders personally or in the family (6)

ACCESS TO CARE

KEY TAKEAWAYS

Access to care was identified as a health priority by 35% of participants. Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.[23]

Almost half (45%) of participants identified cost as a barrier to accessing care. Between 2015 and 2017, 10.6% of adults across Maine reported that there was a time in the last 12 months when they needed to see a doctor but could not because of the cost.

Cost of care is related to one's health insurance status. In Maine, 8% of adults report they were uninsured in 2019. This percentage can vary from county to county. For instance, 12.1% of Washington County residents reported they do not currently have any form of health insurance, compared to 5.8% of Cumberland County residents. In addition, while the statewide percentage is lower than the percentage of uninsured across the U.S. in 2019 (9.2%), this was still noted as a concern within the homeless and formerly homeless community where the percentage of those uninsured is likely to be much higher than the general population.

There are other unique challenges in accessing care for those who are homeless. As one participant noted, visiting a doctor puts them at risk of losing everything they may own.

"Homeless people risk losing belongings to go to appointments and therefore only go when they are very sick."

The association between homelessness and lack of other resources such as transportation was also discussed. While transportation is often considered a social determinant of health, lack of transportation can be a barrier to accessing care. Approximately one-quarter (26%) of participants identified long commutes to see primary care providers as a top health indicator. In Maine, 20% of adults report they needed to travel over 30 miles for a primary care visit. Further investigation is warranted to document the link between this indicator and the percentage of people living in rural areas and those who report there is no vehicle for the household.

"There may be providers, but people are scattered all over the county."

About a quarter (23%) of participants indicated the number of primary care providers as a top health indicator. Participants noted long waitlists to see providers.

The ability to see a primary care provider is vital to disease prevention and management such as cancer screenings and diabetes management. If left unmanaged, Type I diabetes can be fatal. The lack of a secure place to store the insulin necessary to manage this disease is a risk factor for this population. This was also noted as a chief concern for deaf clients and those who have language barriers that complicate access to care, insulin, and diabetes management.

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[23] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Participants identified housing, transportation, and the limited number of providers as ongoing challenges or needs that impact the homeless and formerly homeless community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 18. Gaps/Needs and Available Resources (Access to Care).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Caring and determined people are doing their best in all levels of care (2) **Community Organizations** Federally Qualified Healthcare Center in Portland - Greater Portland Healthcare (3) Office of Child and Family Services (Maine DHHS) CFS does have a program for youth transitioning from foster care (3) Portland-area partners have teams that outreach to homelessness (2) Mercy Hospital in Portland (2) Caseworkers from Frannie Peabody Center and outreach from Spurwink can navigate health care for members of this community (2) City of Portland providing harm reduction supplies to community members (2) **Access Alternatives** More express/urgent care facilities (2) South Portland Community Paramedics team provides great support to people experiencing homelessness who are sheltered at hotels in South Portland (3) **Housing Options** Emergency housing in hotels (4) Hotels willing to partner during COVID (4) Financial rental assistance like the Bridging Rental Assistance Program (BRAP) (2) Maine State Housing Authority (MSHA)/ MaineHousing Emergency Rental Assistance Program (2)	**Housing** Emergency hotel housing programs ending soon (4) Long waitlists (3) Lack of affordable/subsidized housing (5) Background checks limit access to housing (3) Lack of housing for formerly incarcerated (3) Lack of day housing spaces, especially during winter months (2) Lack of safe places for people fleeing Domestic Violence situations (2) Lack of transitional housing support services (2) Only one homeless center in Aroostook (2) Lack of isolation areas when there are infectious disease outbreaks (2) **Workforce** Health care staff shortage (5) **Youth** Lack of Transition programs for youth (2) Inconsistency around the availability of child welfare services for older minors who are not in DHHS custody (1) **Barriers to Care** Lack of medical services to those unhoused (4) Long waitlists (3) Homeless people risk losing belongings to go appointments-only when very sick (2) Lack of education regarding accessing care (4) Need for more Mobile Clinics (3) Poor medication management (2) **Transportation** Limited transportation resources (6)

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health (SDOH) were tied for the fourth health priority during the event hosted for those who experience homelessness. There was not an opportunity to explore this topic more deeply due to lack of time. However, given the close relationship between housing and the other social determinants of health, what limited data was gathered via discussion notes and indicators of concern are discussed in this section.

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[24] Differences in social determinants can create disparities that impact vulnerable populations. These disparities in SDOH are often referred to as social risks.

Participants from the state's homeless and formerly homeless population identified several social risk factors that affect their health. The top four SDOH health indicators of concern were all related to income or housing. More than half (52%) of participants identified **poverty** as a top health indicator. Between 2015 and 2019, 11.8% of Maine residents reported living in poverty. While this is lower than the number of people reporting living in poverty across the U.S. (12.3% in 2019), the proportion among the homeless and formerly homeless population is likely much higher given their lack of participation and representation in most data sources. Another indicator that almost half (48%) of all participants mentioned related to economic security was **Unemployment**. A similar number of participants also identified **median household income** (45%).

Housing costs as a percentage of income were also mentioned by almost half of all participants (45%). During the 2015-2019 time period, 12% of Maine's households spent 50% or more of their household income on housing. This exceeds the recommended 30% of income for housing expenditures to allow for other living expenses such as food, clothing, and transportation.

The reasons for homelessness are complex and impact people from a wide variety of backgrounds and life experiences. Of note are those who lack housing opportunities due to their status as **formerly incarcerated**. Limited options for safe places for those **fleeing domestic violence** were also mentioned. Comments were also made about the rise in homelessness for **people with disabilities**. People with disabilities are often in poverty and heavily reliant on scarce resources for affordable housing. A lack of accessible housing further shrinks their housing options. For all these groups, there is also the challenge of overcoming discrimination or stigma.

"[Securing] housing is especially hard for the Deaf and Hard of Hearing community."

Participants also **identified housing insecure youth** as a concern. According to the Maine Youth Integrated Health Survey, 3% or 1,256 high school students, reported they usually do not sleep in their parent's or guardian's home in 2019.

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[24] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

INTENTIONAL INJURY

KEY TAKEAWAYS

Intentional injury was also identified as a health priority and was tied for fourth place during the event. There was limited time to explore this topic more deeply. However, there were three top indicators of concern related to intentional injury identified by participants.

In addition to noting the high rates of youth suicide ideation, **suicide** was mentioned by 58% of participants. There were 19.4 suicides per 100,000 population in Maine in 2019. This is higher than the national rate of 13.9.

Using combined data over 5 years, the percentage of **rape/non-consensual sex** among females over their lifetime was 14.9%. Using combined data over 4 years, the percentage of reported **violence by current or former intimate partners** in the past 12 months was 1.5% in Maine. Given the lack of data on homeless or formerly homeless populations and the fact that 45% of participants also identified these last two indicators as concerning, further exploration is warranted to determine the extent of the abuse and its relation to housing security.

IMMIGRANTS

As of 2019, 52,421 people in Maine were born outside of the U.S., including 31,039 immigrants who have become U.S. citizens.[25] Forty-one percent (41%) of foreign-born Mainers came to the U.S. before 1990, while 29% came after 2010.[26] These numbers do not reflect the children of immigrants who are born in the U.S. and grow up in households where the dominant culture is that of their parent's country of origin. Native-born U.S. children under age 18, with at least one immigrant parent, make up a total of 7.5% of Maine's under-age 18 population.[27]

These numbers include naturalized U.S. citizens, refugees, asylees, permanent resident immigrants, those here on student, work, or other temporary visas, and undocumented immigrants, including those who have stayed beyond a temporary visa time frame. These designations can dictate the level of access to services and employment opportunities.

A **refugee** is any person who is outside his or her country of nationality or habitual residence and is unable or unwilling to return to or seek the protection of that country due to a well-founded fear of persecution based on race, religion, nationality, membership in a particular social group, or political opinion. They are deemed refugees and granted refugee status overseas by the U.S. Department of Homeland Security, and then come to the United States for resettlement by the U.S. Department of State.[28] Refugees in Maine include primary refugees and secondary migrants who originally resettled in another state and then moved to Maine. There were 2,181 primary refugees and 287 secondary migrants served by Catholic Charities Maine Refugee and Immigration Services from 2013 to 2018.[29]

An **asylee** is also any person who is outside his or her country of nationality or habitual residence and is unable or unwilling to return to or seek the protection of that country due to a well-founded fear of persecution based on race, religion, nationality, membership in a particular social group, or political opinion individuals.[30] However, an asylee enters the United States differently than a refugee. They may enter as students, tourists, businessmen, or even in an undocumented status. Once in the U.S., or at a land border or port of entry, they apply to the Department of Homeland Security (DHS) for asylum.[31] Catholic Charities Maine Refugee and Immigration Services served 396 asylees between 2013-2018.[32]

Permanent resident immigrants are issued immigrant visas by the Department of State overseas or adjusted to permanent resident status by Homeland Security in the U.S.[33] Refugees and resident aliens are eligible for public assistance and may work, while asylum seekers with pending asylum applications are not.

Undocumented residents are the most difficult to count. The Migration Policy center assigns legal status based on U.S. Census data and estimates that Maine is home to less than 5,000 undocumented immigrants.[34] Fifty are Deferred Action for Childhood Arrivals (DACA) recipients.[35]

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[25] Migration Policy Institute tabulations of the U.S. Census Bureau American Community Survey (ACS) 2019 one-year estimate State Demographics Data | migrationpolicy.org

[26] Migration Policy Institute

[27] Migration Policy Institute

[28] U.S. Department of Homeland Security, Definition of Terms, https://www.dhs.gov/immigration-statistics/data-standards-and-definitions/definition-terms

[29] Catholic Charities Maine Refugee Immigration Services FAQs | Catholic Charities of Maine (ccmaine.org)

[30] U.S. Department of Homeland Security, Definition of Terms

[31] U.S. Department of Health and Human Services, Office of Refugee Resettlement, https://www.acf.hhs.gov/orr/policy-guidance/who-we-serve-refugees

[32] Catholic Charities

[33] U.S. Department of Homeland Security, Definition of Terms

[34] Migration Policy Institute Program: Unauthorized Immigrant Population Profiles | migrationpolicy.org

[35] U.S. Citizenship and Immigration Services Approximate Active DACA Recipients (uscis.gov)

Immigrants are a diverse group. In Maine, immigrants have come from more than 122 countries,[36] with the greatest proportion coming from Asia followed by Europe, North America, and Africa. The top countries of origin are Canada, the United Kingdom, China, Germany, the Philippines, India, Somalia, Korea, and Vietnam.[37] Between 2014-2019, the majority of intakes served by Catholic Charities' Refugee and Immigrant Services (RIS) include Iraq, Congo, Somalia, Sudan, Burundi, Rwanda, and others. The number of intakes served by RIS in 2018 has been greatest in Portland (107), followed by Lewiston (26), and Augusta (4).

Three out of four foreign-born Mainers (76%) report speaking only English or speaking English "very well."[38] There are 77,312 people ages 5 and over in Maine who speak a language other than English, 62,592 of whom also speak English very well. Of those with limited English proficiency, the most common languages spoken at home are[39]:

- French, including Cajun
- Spanish
- Chinese
- Amharic, Somali, or other Afro-Asiatic languages
- Arabic
- Portuguese
- Swahili or other languages of Central, Eastern, or Southern Africa
- Russian, Polish, or other Slavic languages
- Khmer
- Vietnamese
- Portuguese
- German
- Tagalog or Filipino
- Thai

Most immigrants in Maine have pursued an education at the college level or above, with only 15% of those ages 25 and older with less than a high school diploma, and 41% with a bachelor's degree or higher.[40] Despite this, they are often under-employed outside of their training area leading to disparities in income and other social determinants of health. While Portland and Cumberland County have the greatest number of immigrants, there are also significant numbers of immigrants in Androscoggin, Aroostook, Kennebec, Penobscot, and York Counties.[41] Some migrant workers reside seasonally or year-round in more rural counties such as Aroostook, Washington, and Hancock Counties.

An oral survey was the primary assessment method used to engage with Maine's immigrant community for the 2021 Maine Shared CHNA effort. There were several reasons for this. First was the recognition that Maine's linguistically and culturally diverse immigrant community would make holding forums a complex effort. Another reason is the lack of representative data on which to base feedback and conversation. Traditional data sources are not nuanced enough to reflect the diversity within the immigrant community and are typically restricted to the five race and two ethnicity categories from the Office of Management and Budget. Those race categories are White; Black or African American; American Indian or Alaska Native; Asian; Native Hawaiian or Other Pacific Islander. Ethnicity is captured only as i) Hispanic or Latino/a/x or ii) non-Hispanic or Latino/a/x. Many immigrants do not identify with these narrowly defined options. Finally, the City of Portland's Minority Health Program had success in meeting the challenges of assessing the health needs of their immigrant population using an oral survey. It was this survey instrument that was adapted and used.

Despite the lack of nuanced data, such as by country of origin, the report does include health data collected by race and ethnicity if there is relevant health data available. Please note

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[36] American Immigration Council https://www.americanimmigrationcouncil.org/research/immigrants-in-maine#:~:text=Four%20percent%20of%20Maine%20residents, 5%2C399%20children%20who%20were%20immigrants

[37] U.S. Census American Community Survey, five-year estimates 2016-2020

[38] Migration Policy Institute tabulations of the U.S. Census Bureau American Community Survey (ACS) 2019 one-year estimate U.S. Immigrant Population by State and County | migrationpolicy.org.

[39] Migration Policy Institute

[40] Migration Policy Institute

[41] Migration Policy Institute

American Indian and Alaska Native data are not included here because they are not immigrants. Data for his racial group can be found on the Interactive Portal.

Oral surveys were conducted in collaboration with seven ethnic-based community organizations' (ECBOs) and one municipality's (City of Portland) community health worker (CHWs). The CHWs used their networks to recruit respondents. This method was designed to assist in respondent recruitment, culturally competent interviewing techniques, and to increase respondents' comfort level. The demographic information on respondents is as follows:

Table 21. Top languages in which the survey was conducted (1000 responses).

	PERCENT (number)
English	31% (312)
Somali	24% (244)
Arabic	23% (232)
French	9% (85)
Spanish	5% (54)
Lingala	3% (33)
Other	3% (24)
Swahili	2% (15)

Other languages in which the survey was conducted include Portuguese (5), Maay Maay (2), Amharic (2), Amara (1), Creole/Haitian (1), Oromo (1), Pashto (1), Tigrinya (1), and Kirundi (1).

Of the total surveys that were conducted in English, the majority of respondents were between the ages of 18-29, (63% or 197 responses); and 28% were born outside the U.S. For those surveys conducted in Somali, the majority of respondents were between the ages of 30-44 (31% or 76 responses); and 81% were born outside the U.S. Of the total surveys conducted in Arabic, the majority of respondents were also between the ages of 30-44 (52% or 121 responses), and 100% were born outside the U.S. Not all respondents provided their age range.

Table 22. Top countries of origin (890 responses).

	PERCENT
United States	24%
Iraq	24%
Somalia	17%
Democratic Republic of Congo	7%
Djibouti	8%
Kenya	3%
Mexico	3%

Other countries of origin mentioned included Afghanistan, Angola, Brazil, Burundi, Canada, El Salvador, Eritrea, Ethiopia, France, Gabon, Guatemala, Honduras, Jamaica, Mali, Morocco, Nicaragua, Nigeria, Palestine, Peru, Republic of the Congo, Rwanda, South Africa, Sudan, Syria, and Uganda.

Of note, the distribution of languages, countries of origin, and age groups may not mirror the makeup of Maine's total immigrant population, and the survey data was not weighted to make it representative.

Respondents were asked to identify their top 4 priorities. Due to a tie for 4th, the top five health priorities identified by the 926 respondents who answered this question were:

- Mental health (69%)
- Diabetes (65%)
- Oral Health (61%)
- Heart Disease (30%)
- Cancer (30%)

The following table depicts how the priority votes are broken down by global region of origin. The darker the cell, the higher the priority.

Table 23. Priority Votes by Region.

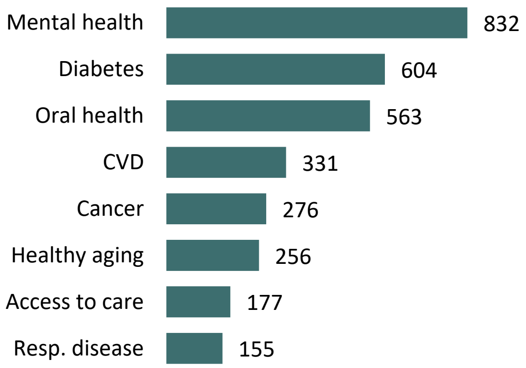
Global Region	Number of Votes	Health Priority				
		Mental Health	Diabetes	Oral Health	Cancer	Heart Disease
Central Africa	83	61%	65%	54%	40%	33%
East Africa	290	68%	66%	66%	18%	28%
Mexico, Central America, & the Caribbean	47	43%	30%	51%	13%	13%
The Middle East and West/Central Asia	230	74%	76%	65%	18%	36%
The U.S.	213	73%	60%	53%	59%	30%

Table 24. All Priority Health Topic Areas (926 responses).

PRIORITIES	# OF VOTES	% OF PARTICIPANTS
Mental Health	832	90%
Diabetes	604	65%
Oral Health	563	61%
Heart Disease	276	30%
Cancer	276	30%
Older Adult Health	256	28%
Access to healthcare	177	19%
Lung disease/respiratory health	155	17%
Other	127	14%
Domestic Violence	112	12%
Motor vehicle crash	55	6%
Blood pressure	43	5%
COVID-19	34	4%
Stroke	12	1%

Respondents were also asked to describe any gaps or barriers or assets and resources related to their chosen priorities. What follows is a summary of what was shared. In many instances, a number of those responses apply not only to specific health priorities but describe more universal community conditions as well.

Figure 10. Priority Areas – Immigrants.



Responses that can be attributed to specific health priorities are included in the following sections on **Mental Health**, **Diabetes**, **Oral Health**, **Cancer**, and **Heart Disease**. Responses which are more generally related to universal community conditions are described in the **Overall Wellbeing** section.

Like all communities, the underlying root causes for those who may experience systemic disadvantages differ depending on local resources, unique community characteristics, and cultural norms. These differences are best identified through further collaboration at the community level. For some of the ECBOs who participated in this project, the health survey results have helped them become aware of the concerns of their communities and will assist them in planning the types of support they can provide. For other public health, healthcare, and policy stakeholders, these results can be used as a starting point for future collaboration.

OVERALL WELLBEING

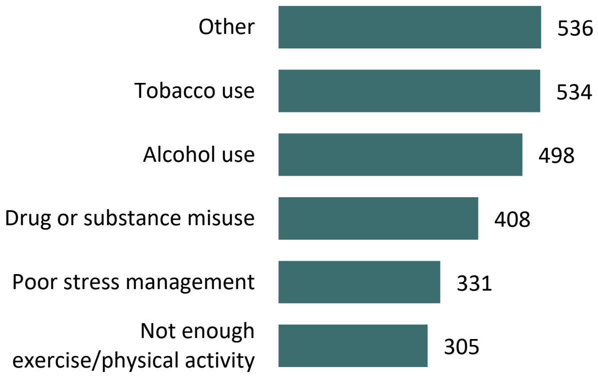
KEY TAKEAWAYS

Respondents were asked to rate the overall health of their community, 30% chose neither unhealthy nor healthy, 31% chose unhealthy or very unhealthy, and 35% chose healthy or very healthy.

According to Maine CDC Vital Records, the overall death rate per 100,000 population during the 2010-2019 time period, adjusted for age, is significantly lower for those who identify as Black or African American (494.4) and Asian (329.4) than for those who identify as White (757.6). There are significantly lower rates for Hispanic or Latino/a/x (289.3) compared to non-Hispanic or Latino/a/x (754.5) during the same period.

When asked for the four most common barriers or challenges that contribute to their chosen health priority, several responses related to more than one health priority and generally focused on health behaviors. The top responses included the following:

Figure 11. Barriers Contributing to Health Priorities.



Barriers related to language accessibility and cultural sensitivity, including cultural awareness, community norms, isolation, and stigma, also make up 58% of the responses when combined (see 'Other' category).

When asked what trusted services were missing or what they might like to have available, 86 responses mentioned affordable healthcare, affordable insurance, or free care; 75 responses mentioned the need for more affordable and accessible dental care; 47 responses mentioned case management, and 24 responses included interpreters and language support.

> *"When I was new, I did not know where to go for healthcare, and then I found someone to help me out and understood what I needed even if my English was little."*

Other types of health services that were mentioned as missing were providers, including mental health providers, drug use prevention, and counseling.

When asked what were the strengths or resources that help to keep members of the respondents' community healthy, the number one response (51%) was a strong sense of community and sense of belonging. Another 39% of responses mentioned a safe and welcoming environment. Other strengths listed included churches (25), a friendly environment (13), a safe place to live (12), a sense of community (11), and mosques (9).

When asked about trusted services available in the community, there were 63 responses related to local clinics, free clinics, pop-ups, and mobile clinics, an additional 50 responses for doctors or doctor's offices, and 26 mentioned healthcare. There were 51 responses related to not being able to find trusted services.

Trusted sources for healthcare included doctor's office (68%), emergency department (42%), urgent care (34%), mental health counseling (25%), and free clinics (24%).

> *"[We need] access to proper health care and it should be affordable. It makes them feel like you won't survive in America if you don't have money to pay for healthcare."*

When asked if someone in the family received assistance from someone that speaks their language or understands their culture, or is from their community to access healthcare, 98% of responses were, “Yes.”

The types of assistance and number of responses included interpreters (106), Community Health Outreach Workers (CHWs) or cultural brokers (32), and translated materials (31).

Examples of the types of assistance varied widely and included meeting several daily living requirements. One top example was the challenge in accessing healthcare such as trying to find a doctor, scheduling appointments, and providing translation during the appointment. Respondents also mentioned the need for extra time during appointments to ensure patients understood care instructions, such as the need for follow-up appointments, diagnosis, and treatment regimens.

> *“[We need] well-educated translators that would explain the exact words that the doctor said.”*

Other examples of assistance included finding healthy, culturally appropriate, and affordable food or food pantries; translating letters from employers or the Department of Health and Human Services; assistance in finding employment, transportation, and applying for MaineCare. An important theme was being able to fully communicate with someone in a preferred language and who was familiar with the culture to avoid mistakes.

COMMUNITY RESOURCES FOR OVERALL WELLBEING

Respondents identified transportation, access to community health workers/interpreters, and culturally and linguistically appropriate services as ongoing challenges or needs that impact the immigrant community.

The following information was gathered from survey participants who were asked to share their knowledge of the gaps and needs or resources and assets in their communities about their identified health priorities.

Table 25. Gaps/Needs and Available Resources (Overall Wellbeing).

TRUSTED RESOURCES	GAPS/NEEDS
B Street Health Clinic at St. Mary's Career Centers Catholic Charities Church Community Home Health Care ConvenientMD Cultivating Community Down East Community Hospital Downeast Clinic Downeast Coastal Conservancy Eastern Maine Medical Center Eastport Machias Clinic Free clinics Gateway Community Services Machias Bank Maine Immigrant and Refugee Services (MEIRS) Maine Medical Center Maine Mobile Health Program Mano en Mano Mosques MYAN New England Arab American Organization Passamaquoddy Health Center Tree Street Youth Tribal Fitness Center Wabanaki Public Health Walgreen's Pharmacy	Transportation (6) Timely access to CHWs, interpreters (3) Local, immigrant-owned businesses (3) Culturally and linguistically appropriate assistance (speaks client's dialect, understands their culture) (2) Interpreters who understand the American medical system (1)

MENTAL HEALTH

KEY TAKEAWAYS

Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[42]

The majority (653 or 71%) of survey participants identified mental health issues as their number one health priority.

In addition to votes for mental health as a priority, the 6th health priority mentioned by respondents was trauma-related health concerns (179 or 19%). Those who report an East African nation as their global region of origin were more likely to identify trauma-related health concerns as a top priority. While this was identified as a distinct health priority among participants, it is important to note trauma's impact on mental health and other long-term impacts on overall health and wellbeing.

The availability of mental health providers was one of the top concerns, in particular, the need for trauma health counselors. One common response to those who live in the Downeast region of the state was that providers or specialists were too far away.

During the period between 2011-2017, about one-fifth of all adults reported experiencing anxiety (21.4%) sometime throughout their lifetime. This rate is significantly higher for those who identify as from more than one race (33.8%) and similar to those who identify as White (19.9%), Hispanic or Latino/a/x (21.8%), and non-Hispanic or Latino/a/x (20.2%). These data are not available by Asian, Black or African American, Native Hawaiian or other Pacific Islander, or another identity.

Data show significantly different rates for mental health emergency department rate per 10,000 population by race and ethnicity, with those who identify as Asian (105.6) and Hispanic or Latino/a/x (105.9) significantly lowest. Significantly higher rates were among those who identify as Native Hawaiian or Other Pacific Islander (325.6), and Black or African American (262.2).

When asked about what types of services or healthcare were missing that could be used to get or stay healthy that could relate to Mental Health, responses included access to health care, stress management, and acceptance of mental health as a part of overall health.

“The only problem is that there are limited providers, you have to drive long distances to get what you want and the help you need.”

Another challenge was the length of time it can take to see a mental health provider.

“Seeing the specialist for the first time is scheduled too far, by that time the problem is already too bad physically and mentally.”

The idea of poor stress management being a significant barrier to overcome was mentioned by more than one-third (36%) of participants. A common cause of stress mentioned included references to economic and job security.

“There is a career center in the area that helps people find a job. When you have a job, you have less stress and you focus on building yourself.”

Respondents also mentioned a preference for culturally and linguistically appropriate care. Responses included the desire for therapists who shared the same ethnicity and language. Others mentioned resources for spiritual needs. One example was the desire for local leaders of mosques to express support for mental health conditions and include the topic in their discussions.

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[42] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm.

When asked what were the strengths or resources that help to keep members of your community healthy, the number one response (51%) was a strong sense of community and sense of belonging. Another 39% of responses mentioned a welcoming environment. Examples provided included churches (25), friendly environment (13), safe (12), sense of community (11), mosques (9), and socializing (3).

"We support each other as co-workers and friends."

Other responses regarding assets or resources to help with mental health included opportunities for exercise and opportunities for socialization. One participant shared that community activities help you to feel better.

When asked about the types of trusted services available that could be related to mental health, top responses included doctor's offices (68%). Other responses specifically mentioned therapist, family doctors, case management, and their local ECBOs.

Further collaboration with each community is necessary to determine how these topics relate to Mental Health since local resources and cultural preferences can vary.

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Respondents identified a lack of providers with whom they could feel comfortable as ongoing challenges or needs that impact the immigrant community.

The following information was gathered from survey participants who were asked to share their knowledge of the gaps and needs or resources and assets in their communities about their identified health priorities.

Table 26. Gaps/Needs and Available Resources (Mental Health).

AVAILABLE RESOURCES	GAPS/NEEDS
ARISE drug treatment and rehabilitation Atlantic Mental Health Center B Street Health Clinic at St. Mary's Churches Cultivating Community DLTC Healthcare Downeast Coastal Conservancy Eastport Healthcare Gateway Community Services Machias Bank (3) Maine Seacoast Mission Mano en Mano (9) MAS Community Health Mental health counseling Mosques Maine Youth Action Network (MYAN) New Mainers Public Health Initiative Passamaquoddy Health Center Pleasant Point Health Center Wabanaki Public Health	Culturally and linguistically appropriate mental health providers Lack of trauma counselors Somali or Arabic psychiatrists and therapists Online counseling Limited providers in the area Long distances to travel to see a provider Walk through mental health clinics

DIABETES

KEY TAKEAWAYS

Diabetes was the second most mentioned health priority, identified by 604 or 65% of respondents.

Diabetes can be a chronic (long-lasting) health condition that affects how your body turns food into energy. Diabetics are unable to efficiently process the sugars in the food they eat. This can lead to long-term health problems such as heart disease, vision loss, and kidney disease. If left untreated, diabetes can be fatal and is the 7th leading cause of death in the United States.[43]

There are three types of diabetes. Type 1 diabetes is usually diagnosed in children and requires lifelong treatment with insulin. Type 2 diabetes can be prevented or delayed with healthy lifestyle changes, such as losing weight, eating healthy food, and being active. Gestational diabetes develops in pregnant women who have never had diabetes. It usually goes away after childbirth.[44]

Addressing diabetes requires prevention programs that emphasize healthy lifestyles, including exercise and eating habits and disease management strategies that involve good primary health care. When asked about what types of services or healthcare were missing that could be used to get or stay healthy that could relate to Diabetes, responses included topics such as access to health care and healthy lifestyle choices.

Access to healthcare was mentioned in 22% of the responses. Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of coverage, services, timeliness, and workforce.[45] Regular doctor's visits can help to identify and monitor diabetes with regular blood glucose testing and lifestyle coaching from a trusted doctor.

A lack of exercise or physical activity was also mentioned as one of the top five challenges or barriers that contribute to their identified health priority by 33% of those surveyed. Between 2011 and 2017, between 1/4 to 1/5 (from 24.7% to 20.9%) of adults reported a lack of leisure-time physical activity in Maine. This includes all adults from all races or ethnicities. There are also similarities in obesity rates among adults by race between 2011 and 2017, with 29% of Whites reporting a BMI greater than 30 compared to 28.6% of those from more than one race, and 25.6% of Black or African Americans. While only 13.2% of those who identify as Asian report a BMI greater than 30, the difference is not statistically significant. The overall rate for the state of Maine during the same period was 28.9%.

When asked what kind of trusted services the community might like to have, responses included free personal trainers, more exercise programs, and affordable facilities. Several responses included the desire for women-only facilities. Other barriers related to physical activity included lack of time and the expense of gym memberships, especially during the cold winter months. Several responses noted the difficulty in getting outdoors during cold weather. Respondents also commented on the need for women-only gyms.

Other exercise resources respondents mentioned included parks and other options for walking.

> *"[Need] nutrition center for all ages and cultures, … nutrition specialists that can help people to make better eating choices and what is better for the body to stay healthy."*

Access to healthy foods was another common response when asked what types of services are

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[43] U.S. CDC Diabetes. Last accessed 5/3/2022: https://www.cdc.gov/diabetes/basics/diabetes.html

[44] Ibid

[45] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html.

used to get and stay healthy or resources that help to keep community members healthy. Examples included the ability to afford nutritional, organic food and the value of food pantries and food clubs sponsored by ethnic-based community organizations and churches. Respondents expressed a desire for more food stamps (called SNAP), and more nutritional and lifestyle education.

> *"[We need] more training about processed food, and advice on what's healthy and what's not."*

Further collaboration with each community is necessary to determine how these topics relate to Diabetes since local resources and cultural preferences can vary.

COMMUNITY RESOURCES TO ADDRESS DIABETES

Respondents identified affordability of healthy options, culturally appropriate services, and education/information as a few of the ongoing challenges or needs that impact the immigrant community.

The following information was gathered from survey participants who were asked to share their knowledge of the gaps and needs or resources and assets in their communities about their identified health priorities.

Table 27. Gaps/Needs and Available Resources (Diabetes).

AVAILABLE RESOURCES	GAPS/NEEDS
B-Street Nutrition Center Catholic Charities Cultivating Community Farmers markets First Assembly of God food donations Food pantries with fresh food General Assistance Good Shepherd Food Bank Hannaford Lewiston Nutrition Center Maine Mobile Health Program Mano en Mano MEIRS food pantry New Mainers Public Health Initiative New Roots Farm Passamaquoddy Health Center Portland Farmers Market on Saturday Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) Temporary Assistance for Needy Families (TANF) Tribal Government Services Trinity Jubilee Center Wabanaki Public Health Washington County Food and Fuel Alliance	Affordable gyms Women-only gyms Culturally appropriate, affordable healthy food Easier access to healthy food Affordable gym memberships during cold weather months Nutrition and lifestyle education/information

ORAL HEALTH

KEY TAKEAWAYS

Oral health was the third most important priority health issue identified by 563 or 61% of respondents.

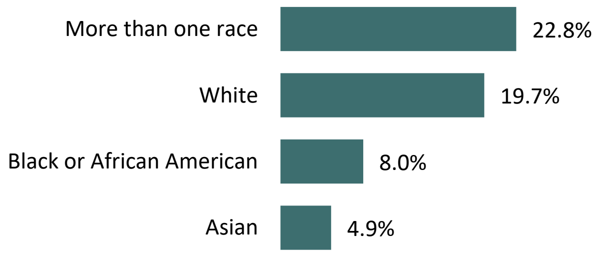
Oral health refers to the health of the teeth, gums, and the entire oral-facial system that allows us to smile, speak and chew. Oral conditions are frequently considered separate from other chronic conditions, but these are interrelated. Poor oral health is associated with other chronic diseases such as diabetes and heart disease. Oral diseases are also associated with risk behaviors such as using tobacco and consuming sugary foods and beverages. Due to several social risk factors, some groups experience a greater rate of oral disease than others. These social risk factors include the inability to pay for co-pays or other out-of-pocket expenses, lack of dental insurance whether public or private, and the inability to take time off from work to see a dentist. Environmental inequities include lack of fluoridated water, school sealant programs, healthy non-sugary foods, or public transportation to get to the dentists.

When asked about what types of services or healthcare were missing that could be used to get or stay healthy that could relate to Oral Health, responses included topics such as cost of care and lack of insurance.

The quantitative data does show differences in oral health. For instance, during the years 2012, 2014, and 2016 combined, there were 64.8% of White adults who reported having had a dental visit in the last year compared to 49.1% of those from more than one race. There were no differences in the percentage of adults who reported having a dental visit in the last year between those who identify as Hispanic or Latino/a/x (62.7%) and non-Hispanic or Latino/a/x (64.3%).

For adults without access to preventative dental care, this can mean an increase in rates for dental emergency care. Unfortunately, options for dental care in the emergency departments are often limited to pain management or extraction. During the years 2012, 2014, and 2016 combined, almost 1 in 5 Maine adults (19.8%) have lost 6 or more teeth due to decay or gum disease. The percentage of adults who report having lost 6 or more teeth varies by race.

Figure 12. Percentage of Adults Experiencing Tooth Loss by Race.



In 2019, 80.3% of children were covered by dental insurance. There were 62.6% of insured children with at least one preventative dental visit that same year. During the 2016-2018 time period, the rate per 10,000 Black or African American children who visited the emergency department for dental-related reasons (42.8) was significantly higher compared to those who identify as White (16.7) or Asian (11). During the same period, the rate among Hispanic or Latino/a/x children was not significantly different than the rate among non-Hispanic or Latino/a/x children (13 vs 17 per 10,000, respectively).

When asked about some of the trusted services most often used to keep the community healthy, responses related to oral health included several dental clinics around the state including those sponsored by Mano en Mano, Maine Mobile Health, CCS Dental, and Community Dental. A common theme for barriers or challenges included obtaining dental insurance, and distance to clinics.

Further collaboration with each community is necessary to better understand the relationship between these topics and Oral Health since local resources and cultural preferences can vary.

COMMUNITY RESOURCES TO ADDRESS ORAL HEALTH

Respondents identified a lack of treatment options and the cost of dental insurance as ongoing challenges or needs that impact the immigrant community.

The following information was gathered from survey participants who were asked to share their knowledge of the gaps and needs or resources and assets in their communities about their identified health priorities.

Table 28. Gaps/Needs and Available Resources (Oral Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Mano en Mano dental clinics Maine Mobile dental clinics CCS Dental Clinic of St. Mary's Community Dental in Portland	**Lack of Treatment Options** Lack of dental clinics in general Dental clinics that were located nearby **Cost** Difficulty in finding and affording dental insurance

CANCER

KEY TAKEAWAYS

Cancer was tied for 4th place, along with Heart Disease, as a priority health concern with 276 or 30% of responses. It should be noted that Cancer and Heart Disease are the top two causes of death in Maine.

The leading risk factors for known preventable cancers are smoking, getting too much UV radiation from the sun or tanning beds, being overweight or obese, and drinking too much alcohol. Some kinds of cancers (like breast, cervical, and colorectal) can be caught early through screening. Other kinds of cancers can be prevented. Examples of cancer prevention include vaccination to protect from cervical cancer or the removal of abnormal growths in the colon.[46]

Between 2010 and 2019, the data show there were significantly greater rates of cancer deaths for those who identify as White or non-Hispanic or Latino/a/x than for all other races and ethnicities. Cancer deaths for those who identify as Black or African American were, in turn, greater than for all other races other than White. These rates are age-adjusted meaning that age is not a factor in these numbers.

Table 29. All cancer deaths per 100,000 population by race and ethnicity, 2010-2019.

	PERCENT
White	174.1
Black/African American	134.2
Asian	77.6
Two or more races	59.4
Native Hawaiian or other Pacific Islander	40.8
Some other race	—
Non-Hispanic or Latino/a/x	173.6
Hispanic or Latino/a/x	59.8

When asked about what types of services or healthcare were missing that could be used to get or stay healthy that could relate to Cancer, responses included topics such as tobacco use, access to healthcare, alcohol use, and obesity.

Tobacco use was identified by 58% of respondents as a common barrier or challenge that contributes to poor health. During the 2013-2017 time period, adult self-reported tobacco use among

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[46] U.S. CDC Cancer Fast Facts. Last accessed 5/4/2022: https://www.cdc.gov/chronicdisease/resources/publications/factsheets/cancer.htm

those who identified with more than one race was 30% compared to Black or African Americans (22.6%), Whites (18.8%), and Asians (13.4%). Among those who identified as Hispanic or Latino/a/x, 25.2% reported smoking every day or some days compared with 19.1% of those who identified as non-Hispanic or Latino/a/x. These differences are not statistically significant.

Many noted that tobacco use in public places was often observed, despite policies that ban this. Respondents also noted the addictive nature of tobacco as a challenge.

Alcohol use was also mentioned by 54% of respondents. Data show no significant differences in chronic heavy drinking, as defined as more than two drinks a day for men and one a day for women, by race. The rate in Maine overall is 8.5% during the 2015-2017 time period.

When asked what type of health care services were missing, responses included a lack of AA meetings, drug rehabilitation, and counseling.

A lack of exercise or physical activity was also mentioned as one of the top five challenges or barriers that contribute to their identified health priority by 33% of those surveyed. The resources and challenges regarding physical activity and nutrition are discussed in the Diabetes section above.

Cancer screenings play a key role in cancer prevention. The MSCHNA data set does not include Cancer screening rates by race or ethnicity. During the years 2012, 2014, and 2016 combined, Maine's overall screening rates were 82.5% for breast cancer, 74.1% for colorectal cancer, and 84.9% for cervical cancer.

Primary care visits are often another indication of how often a population is monitored for several health outcomes, including cancers. During the 2011-2017 time period, 71.9% of Whites report having visited a primary care provider in the past year compared to 67.4% of Asians, 66.4% of Black or African Americans, and 65% of those who identify as being from more than one race. This rate is 66% for those who identify as Hispanic or Latino/a/x and 72% for those who identify as non-Hispanic or Latino/a/x during the same period.

"There are not a lot of health resources and accessing them is hard. They are either too far away or don't have hours after work."

Barriers and challenges related to seeing a doctor included a limited number of providers, long commutes to get to the doctor's office, not following up on checkups, and missing appointments. When asked what type of trusted services the community might like to have, responses included trusted providers, translation services, and case management.

Vaccinations also play a key role in cancer prevention. In Maine, 36% of 13-year-olds were up-to-date on HPV Immunization. This data is not available by race or ethnicity. The rate of HPV-associated new cancer cases per 100,000 is significantly higher among Whites (13.1) than those who identified as from some other race (7.6), or Hispanic or Latino/a/x (5.8), and higher than for Black or African Americans (7) during the 2009-2018 time period.

Further collaboration with each community is necessary to better understand the relationship between these topics and Cancer since local resources and cultural preferences can vary.

COMMUNITY RESOURCES TO ADDRESS CANCER

Respondents identified the lack of affordable healthcare, and culturally and linguistically appropriate health education materials as ongoing challenges or needs that impact the immigrant community.

The following information was gathered from survey participants who were asked to share their knowledge of the gaps and needs or resources and assets in their communities about their identified health priorities.

Table 30. Gaps/Needs and Available Resources (Cancer).

AVAILABLE RESOURCES	GAPS/NEEDS
Mano en Mano Maine Mobile Health Alcohol and tobacco trainings to get healthy Pleasant Point Health Center Indian Health Services Tribal Government services Passamaquoddy Health Center Wabanaki Public Health Avoiding smoking; breathing fresh air Campus gyms Down East Community Hospital Maine Medical Center Portland Health & Human Services Tribal Fitness Center Down East Machias Hospital Eastport Machias Hospital MaineCare Access to free clinics and free care Case managers Med-management	Affordable healthcare Having a man as an interpreter when I am a woman Drug and alcohol addiction treatment Lack of enforcement for tobacco-free zones Smoking Transportation Playgrounds and sports centers with lots of activities Affordable gyms Laboratory and diagnostic care

HEART DISEASE

KEY TAKEAWAYS

Heart Disease was tied for 4th as a priority health concern along with Cancer by 276 or 30% of responses. It should be noted that Cancer and Heart Disease are the top two causes of death in Maine overall.

Table 31. Heart Disease % of votes by global regions of origin.

	PERCENT
Middle East and West/Central Asia	35.7%
Central Africa	32.5%
U.S.	30.0%
East Africa	28.3%
Mexico, Central America, & the Caribbean	12.8%

> *"[There are] too many requirements to access health resources."*

Heart disease, also called cardiovascular disease, refers to a group of diseases that affect the heart and blood flow throughout your body. These diseases include high blood pressure, high cholesterol, heart attacks, coronary artery disease, and stroke. Risk factors for developing heart disease are similar to diabetes and cancer, including tobacco use, obesity, excessive alcohol use, unhealthy diet, and lack of exercise.

The quantitative data does show some key disparities in heart disease by race and ethnicity. The hospitalization rate per 10,000 for heart attacks is higher for those who identify as Native Hawaiian or Other Pacific Islander (78.9) compared to Black or African American (18.9) and is significantly higher than those who identify as White (22.5) or Asian (7.8). High blood pressure hospitalizations were significantly higher for Black or African Americans (30.6) compared to Whites (13.6). The rate was also higher for Native Hawaiian or other Pacific Islanders (21.5), but not significantly so. Hospitalizations for stroke were also significantly higher for Native Hawaiian or other Pacific Islanders (137) than any other group including Black or African Americans (25.2), White (20.8), and Asian (14.1).

When asked about what types of services or healthcare were missing that could be used to get or stay healthy that could relate to heart disease, responses included the same risk factors and resources as those for Diabetes and Cancer. See those sections for more discussion on tobacco and alcohol use, access to healthcare, and healthy lifestyle needs.

Further collaboration with each community is necessary to better understand the relationship between these topics and Cancer since local resources and cultural preferences can vary.

COMMUNITY RESOURCES TO ADDRESS HEART DISEASE

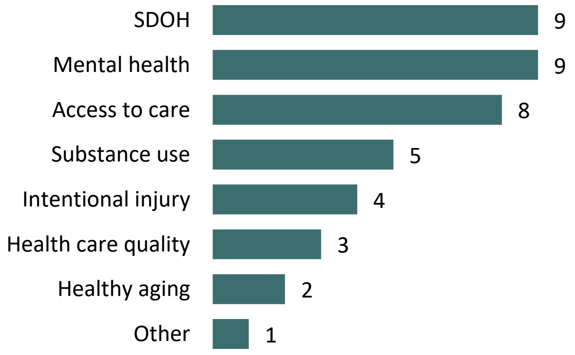
See Gaps/Needs and Available Resource Tables for Diabetes and Cancer

LESBIAN, GAY, BISEXUAL, TRANSGENDER, AND QUEER

Individuals who identify as lesbian, gay, bisexual, transgender, and/or queer, and those who may have gender diverse, gender expansive, or diverse sexual identities (often referred to as LGBTQ+), experience significant health disparities compared to individuals who are cisgender and/ or heterosexual.

However, a single label does not do justice to the diverse backgrounds and identities this grouping of five letters may suggest. Sexual orientation, gender identity, and expression (SOGIE) is diverse, exists on a spectrum, and spans cultures across the world. Those who identify as LGBTQ+ can include anyone of any age, income level, race, ethnicity, or educational attainment, and can be from a rural small town, or a large metropolitan area, and may have intersectional identities that can present more challenges and barriers.[47] It's important to note that while the term "queer" has historically had harmful impacts on the community, and may still be offensive to some, it is increasingly a reclaimed term used to include various gender and sexual identities and embraced by many in this community.

Figure 13. Priority Areas – Lesbian, Gay, Bisexual, Transgender, and Queer.



Historically LGBTQ+ people have had to fight against their identities being both pathologized and criminalized. While in much of the world different sexual orientations are no longer considered an illness, this acceptance is more recent for those with different gender identities and expressions. At the same time, the stigma associated with LGBTQ+ identities has often made data collection for this population difficult and sparse. While great strides have been made towards equity, much work is yet unfinished to dispel the systematic discrimination and health disparities that still exist today.

Globally, those who identify as LGBTQ+ are more likely to experience stigma and discrimination due to structural and interpersonal experiences and barriers that make it more difficult for LGBTQ+ individuals to access and advocate for care. In some instances, stigma can cause a person to not advocate for their needs. In other instances, healthcare providers are not well prepared to provide the needed care.

> *"We are not necessarily one (LGBTQ+) community in how we experience health. Different genders have different experiences, comparing lesbian women to gay men is not an accurate picture."*

Health Equity Alliance (HEAL) is a non-profit which provides medical case management services to people with HIV, harm reduction programs, and sexual health and wellness services. HEAL's work with the LGBTQ+ community is deeply rooted. Formally as Down East AIDS Network, HEAL was founded in response to the HIV epidemic in 1987, and began work with the LGBTQ+ community due to the disproportionate impacts of HIV among gay men or men who have sex with men. HEAL continues to support and advocate for LGBTQ+ communities to combat stigma and help individuals access health equity. On December 9, 2021, HEAL hosted an event to support data collection on the

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[47] World Health Organization, Improving the health and well-being of LGBTQI+ people. Last accessed 4/19/2022: https://www.who.int/activities/improving-the-health-and-well-being-of-lgbtqi-people

impacts of health disparities among the LGBTQ+ community in Maine. HEAL hosted an event on December 9, 2021, which was attended by 13 people. The top four health priorities identified by participants during this event included:

- Mental Health (69%)
- Social Determinants of Health (69%)
- Access to Care (62%)
- Substance and Alcohol Use (38%)

There is limited health data collected on LGBTQ+ Mainers, especially so for those who are transgender or who are gender diverse. Sexual orientation data is slightly more available, and therefore the quantitative data presented here is presented by lesbian, gay, or bisexual (LGB) identity. While there may be gender-based differences, data is generally not reliable when disaggregated by gender. However, it is possible to separate lesbian and gay responses from those of bisexual individuals.

MENTAL HEALTH

KEY TAKEAWAYS

Event participants were divided in naming their top health priority between mental health and Social Determinants of Health (SDOH). Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[48]

Participants reported the **availability of mental health providers** is of particular concern. They further emphasized the need for not only enough providers, but enough providers that are capable of creating and facilitating safe and affirming spaces and experiences for LGBTQ+ patients.

> *"We need to have providers who are ‘affirming’ and have ‘competency’ in recognizing issues that are unique to the LGBTQ+ community.”*

The second reported indicator of concern was **depression**. There is a significant difference in the percentage of those with current depression who identify as gay or lesbian (13.9%), or bisexual (22.3%), than those who identify as straight or heterosexual (9.4%). The same is true for those who have ever been told by a healthcare provider that they have a depression disorder for those who identify as gay or lesbian (37.3%), or bisexual (58.1%), compared to those who identify as straight or heterosexual (23.3%). This is also a significant difference between those who identify as gay or lesbian compared to those who identify as bisexual. These same significant disparities also exist for the percentage of adults who have ever been told by their healthcare provider that they have an **anxiety** disorder.

Suicide ideation among high school students was the third indicator identified as a concern. In 2019, 16.4% of all high school students reported they had seriously considered suicide. The rate for those who identify as gay or lesbian was 35.1%, or bisexual (43.3%), which is significantly higher compared to those who identify as straight or heterosexual (12.3%).

What’s more, 2 out of every 3 (66.6%) students who identify as bisexual and over half (57.6%) of students who identify as gay or lesbian report feeling so sad or hopeless for two weeks in a row that they stopped doing usual activities. There is not only a significant difference between these two groups but between these two groups and students who identify as straight or heterosexual (26.8%).

Participants noted the data was collected before COVID-19 pandemic policies decreased access to social networks and support. Participants expressed concern for the impact on mental health from the isolation, social distancing, and working and learning from home on those who were already feeling marginalized and excluded.

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[48] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Participants identified a lack of providers trained on or specializing in LGBTQ+ issues, stigma, and isolation as ongoing challenges or needs that impact the LGBTQ+ community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 32. Gaps/Needs and Available Resources (Mental Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Treatment Use of more evidence-based practices (5) Creation of online safe spaces to prevent self-harm (5)	**Providers** Lack of awareness, affirming, competent providers for LGBTQ (7)
Youth Teachers who are out or affirming	**Barriers to Treatment** Stigma (4)
	Community Cohesion Isolation during COVID Fear outing, lack of community connections, and lack of support in rural communities

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Event participants were divided in naming their top health priority between Mental Health and Social Determinants of Health (SDOH). Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[49]. Differences in social determinants can create disparities that impact vulnerable populations.

The top health indicator identified as a concern was for those **living in poverty**. While the Maine CHNA data set does not include data on poverty by SOGIE, research has shown that those who identify as LGBT have higher rates of poverty compared to those who identify as straight or heterosexual[50].

Participants noted concern for those living in rural areas. In Maine, the percentage of adults who identify as LGB live in greater concentrations in metropolitan areas (4.5%), compared to isolated rural (3%). Participants noted the lack of social support and networks, mentors for youth and families, and difficulty in finding affirming churches that provide safe community spaces. The link between rurality and these concerns can widely depend on local resources, unique characteristics, and cultural norms across the state and are best explored through further collaboration at the community level. The Maine Shared CHNA data set does not include health outcome data on **rurality** by SOGIE.

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[49] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

[50] University of Wisconsin, Madison. (2021). The Complexity of LGBT Poverty in the United States, Fast Focus Policy Brief, No. 53-2021. Last accessed 4/25/2022: https://www.irp.wisc.edu/resource/the-complexity-of-lgbt-poverty-in-the-united-states/

The concern for youth's social risks was also mentioned by participants. In 2019, the percentage of high school students reporting they usually do not sleep in their parent's or guardian's homes was significantly higher for those who identify as bisexual (5.2%), than gay or lesbian (8.4%), and both were significantly higher than those who identify as straight or heterosexual (2.4%).

The impact of adverse childhood experiences (ACEs) on the LBGTQ+ community was identified as a concern. ACEs increase the likelihood of negative health and behavioral outcomes later in life. The most commonly used list contains 10 events. Individuals who experience 4 or more of these events by age 17 double their risk of heart disease and cancer, increase the likelihood of becoming an alcoholic by 700 percent, and the risk of attempting suicide by 1200 percent. Events can include experiencing violence, abuse, or neglect. Participants expressed concern for youth may not have a nurturing supportive environment as they explore their sexual orientation, gender identity, and gender expression. In particular, participants reported concern with the lack of policies in place to protect children who express their gender outside of the traditional, binary gender they were assigned at birth.

Here the data show a similar pattern with the percentage of high school students who report experiencing 4 or more ACEs. In 2019, those who report experiencing 4 or more ACEs were greater for those who identify as bisexual (46%) and for those who identify as gay or lesbian (37.8%). This difference is not significant between these two groups, but both of these percentages are significantly higher than those who identify as straight or heterosexual (17.7%).

There was also a concern for older adults who are LGBTQ+. As such, participants mentioned the need to provide care to the diverse LGBTQ+ population that recognizes those who may live alone without strong networks or connections due to stigma or marginalization.

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Participants identified a lack of mentorship for LGBTQ+ youths, policies to protect children questioning their gender or orientation, and social support as ongoing challenges or needs that impact the LGBTQ+ community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 33. Gaps/Needs and Available Resources (Social Determinants of Health).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Increased support and recognition of LGBTQ+ inclusion and identities from within "mainstream" organizations (4) Committed community partners (3) **Support for Youth** OUT Maine Youth Art groups support (2) Teachers who are out or affirming	**Barriers to Services** Need a nuanced understanding of barriers for LGBT populations (7) **Youth/Families** Lack of LGBT mentors for youth and family (3) Lack of policies to protect children from affirming gender and orientation Schools that do not allow GSTA or other organizations (2) **Safety and Support** Lack of social support and networks for Q+(2) Difficulty finding affirming churches that provide safe places Safe community spaces

ACCESS TO CARE

KEY TAKEAWAYS

Access to care was the third most identified health priority. Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.[51]

Participants identified the rate of those without insurance as a top concern in accessing care. The percentage of those reporting there was a time in the last year when they needed to see a doctor but could not due to cost was twice as high for those who identify as bisexual (23.1%) than for those who identify as straight or heterosexual (9.8%) and significantly higher than for those who identify as gay or lesbian (11.3%). The Maine Shared CHNA data set does not include data on **insurance status** by SOGIE.

There is also a disparity in the percentage of adults who report having seen a primary care provider in the past year. Of those who identify as bisexual, gay, or lesbian, 64.8% and 66% percent respectively have seen a primary care provider in the past year. These percentages are significantly lower compared to those who identify as straight or heterosexual (71.2%). There is not a disparity by identity in the percentage of adults who report they have a usual primary care provider.

When discussing the types of care they would like to receive, community members frequently emphasized the need for health care providers trained specifically in how to work with and care for individuals identifying as LGBTQ+. Participants reported that not all providers have had cultural competency training around LGBTQ+ topics to promote access to gender-affirming care or specific needs they may have that relate to their gender identity and/or sexual orientation. Some of the specific concerns range from being misgendered to not having processes to collect legal or administrative names as well as name in use, in addition to gender identity, sexual orientation, and pronouns. If this information is not collected, or if providers are not trained, many times clients are stigmatized, face micro-aggressions, or are left educating their providers on their identity as well as their needs. This ultimately decreases confidence in the provider's ability to support their needs and can be a deterrent from wanting to access care. It's important to note that many providers may have never learned this information and may not choose to seek this information out

> *"We need to have providers who are 'affirming' and have 'competency' in recognizing issues that are unique to the LGBTQ+ community."*

Health care services for older adults were also mentioned as a concern. In particular, participants noted the need to understand the support system older LGBTQ+ individuals may have in place. Older LGBTQ+ individuals may have made great sacrifices to live their lives authentically – and this may have caused families to disown them. This is a particular concern for those living in assisted living, nursing homes, or in other care settings where there is often a need to have next of kin or emergency contact on record, or in aftercare planning.

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[51] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Participants identified a lack of access to providers specializing in LGBTQ+ issues, transportation, and housing in rural areas as ongoing challenges or needs that impact the LGBTQ+ community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 34. Gaps/Needs and Available Resources (Access to Care).

AVAILABLE RESOURCES	GAPS/NEEDS
Community Organizations Maine Family Planning Open Door for transgender health (2) **Access Alternatives** COVID funding opportunities for organizations to embrace and extend access related to DEI	**Culturally Competent Care** Lack of access to affirming and competent providers (3) Lack of clear methodology to assess and judge a care provider's level of competency (3) Lack of provider training re: LGBT/inclusion (5) Lack of trauma-informed care provision (2) **Barriers to Care** Lack of access to Wi-Fi for telehealth (3) Discrepancies between the name used and the name on legal documents Youth on parents' insurance being worried about being 'outed' Lack of providers and surgeons providing gender-affirming care **Transportation** Gaps in transportation in rural areas (2) Access to transportation in general (2) Far distance of providers for LGBT folks to travel to appointments **Housing** Gender requirements and recommendations specific to single-sex facilities. Need to promote inclusion in signage, intake forms, and policies that reflect inclusivity (2)

SUBSTANCE AND ALCOHOL USE

KEY TAKEAWAYS

Substance and alcohol use was identified as a top health priority. Recurring use of alcohol and/or drugs can cause clinically significant impairment, including health problems, disability, and failure to meet major responsibilities at work, school, or home. Substance and alcohol use has also been linked to co-occurring mental health issues such as anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD), among others.[52]

For the LGBTQ+ community, social marketing and history with gay spaces only being in bars have contributed to disparities in substance use rates. Another common cause for these disparities is to find relief from social or personal rejection and stigma.

The majority of forum participants noted **drug overdose deaths** as a top priority health indicator of concern in regards to substance and alcohol use. In 2020, the rate of overdose deaths per 100,000 population in Maine was 37.3, a significant increase from 28.2 in 2016. This data is unavailable by sexual orientation, gender identity, or expression.

Table 35. Overdose Deaths by Year.

YEAR	NUMBER
2016	378
2017	417
2018	354
2019	380
2020	502
2021	633*

*Preliminary number from the Office of the Chief Medical Examiner.

More than half of the participants (54%) also identified alcohol-induced deaths and binge drinking among youth as top health priority indicators of concern across the state.

While alcohol-induced deaths were identified as an indicator of concern, the MSCHNA data set does not contain this data by SOGIE. The data on adult binge drinking in Maine shows a health disparity by gender expression. Twenty-five percent (25.1%) of adults who identify as bisexual report binge drinking, compared to those who identify as straight or heterosexual (17%). Eighteen percent (17.7%) of those who identify as gay or lesbian report binge drinking during the years 2011-2015 & 2017.

In 2019 in Maine, the rate of self-reported binge drinking was higher among gay or lesbian high school students (9.1%) than straight or heterosexual students (8.2%), but it was not significantly so. There were disparities reported for past-30-day alcohol use among bisexual high school students (27%) in comparison to straight or heterosexual students (22.6%). The rate was 26% for gay or lesbian high school students, which was not a significant difference between either of these two other groups.

The percentage of adults who report past-30-day use of marijuana is 22.2% and 21.3% for those who identify as bisexual or gay or lesbian respectively, compared to 9.7% of those who identify as straight or heterosexual. These differences are significant.

> *"There is a need for promotion of LGBTQ+ care and services so [the] community knows this is available and can feel safe connecting to care."*

Participants mentioned concern for the need to provide harm reduction services in spaces that were safe for the LGBTQ+ community. This can include space for families as well as prevent self-harm. Complex barriers exist to overcoming the stigma of both sexual orientation, identity, and expressions that differ from the cultural norms and addiction.

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[52] Mental Health and Substance Use Disorders. Substance Abuse and Mental Health Services Administration (SAMHSA). Available from: https://www.samhsa.gov/find-help/disorders.

COMMUNITY RESOURCES TO ADDRESS SUBSTANCE & ALCOHOL USE

Participants identified a lack of LGBTQ+ affirming care, LGBTQ+ harm reduction programming, and stigma as ongoing challenges or needs that impact the LGBTQ+ community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

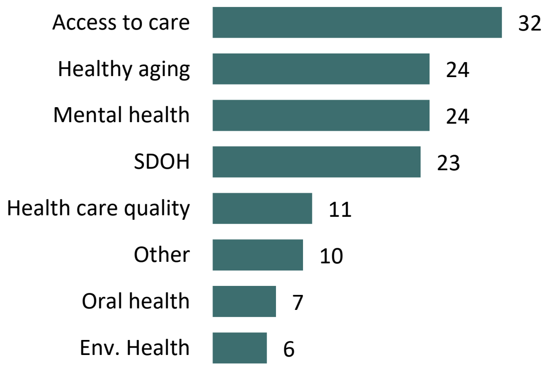
Table 36. Gaps/Needs and Available Resources (Substance and Alcohol Use).

AVAILABLE RESOURCES	GAPS/NEEDS
Prevention Specific safe places for youth and families of LGBT to prevent self-harm and addiction and promote wellness (2)	**Treatment** Lack of LGBTQ+ affirming care **Harm Reduction** Lack of LGBTQ+ harm reduction programming **Cultural Norms** Stigma (4)

OLDER ADULTS

Adults aged 65 and older make up a growing percentage of the population in Maine. Maine also has the largest percentage of those 65 and older of all U.S. states at 21% or 1 in 5 Mainers, compared to 16% in the U.S. overall. This is expected to increase to 1 in 4 by the year 2030. Maine's rural counties are home to a greater proportion of older adults.

Figure 14. Priority Areas – Older adults.



Of those 75 and older, 48.3% report having any one of the six disability types: hearing difficulty, vision difficulty, cognitive difficulty, ambulatory difficulty, self-care difficulty, and independent living difficulty.

The three leading causes of death among Maine adults 65 and over are heart disease, cancer, and chronic lower respiratory disease. The risk of having these conditions increases with age. Many of these conditions are preceded by high blood pressure, cholesterol, Type II Diabetes, and being overweight or obese and can be mitigated with behavioral health support and resources.

As with other populations that experience health disparities, participants noted that other than having age in common, this is a diverse group.

The MSCHNA partnered with the Maine Council on Aging to host an event on October 4, 2021, that was attended by 75 individuals. The top four health priorities identified during this event were:

- Access to Care (43%)
- Older Adult Health (32%)
- Mental Health (32%)
- Social Determinants of Health (31%)

ACCESS TO CARE

KEY TAKEAWAYS

Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.[53]

Participants in the event held with older adults identified access to care as their number one priority health area of concern. Given the prevalence of chronic conditions among older adults, ensuring timely access to preventative services such as screenings and chronic disease monitoring, accessing care can have a profound impact on the quality of life and longevity.

There was a concern about the lack of insurance among the older population. While Maine overall has a lower percentage of **uninsured** individuals (8.0%) compared to the nation (9.2%) in 2019, this is still almost 1 in 10 people at risk of financial strain should they require urgent or chronic healthcare.

While people 65 and older have access to Medicare, there are limits to that coverage that

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[53] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

amount to out-of-pocket costs for those without supplemental insurance. For those that are retired, these costs can have a significant impact on household budgets. There was also recognition of the overall complexity of the healthcare/health insurance system and its level of difficulty for some to navigate alone.

Participants also expressed concern over the need to travel over 30 miles to see a doctor. In Maine, one-fifth (20%) of all **primary care visits were 30 miles or more** from the patient's residence in 2019. While access to transportation is often considered a social determinant of health, participants noted the effects of not being able to understand or access the transportation resources available to them was a risk factor in being able to see a doctor.

Access to telehealth services was mentioned as a promising innovation. Challenges in access to broadband and the need for technical savvy to utilize these new resources were also discussed. On average, 88.6% of Mainers have **broadband access**. However, this can vary widely across the state, with only 41.8% having access in Franklin County and 99.9% having access in Cumberland in 2017.

Participants noted workforce shortages of all types and levels. This included specialists in neurology, hearing, ophthalmology, mental health, geriatrics, and home health care providers. They also pointed out a lack of incentives and resources to build a workforce that is well-trained to treat older adults, specifically in neuro diseases and home health care.

> *"The lack of home care workers is the biggest threat to the health of my patients."*

Other types of care that were mentioned as a gap were resources or services for individuals with disabilities such as loss of hearing or visual impairment.

While having a usual primary care provider was mentioned as a concern, 95.9% of adults aged 65-74 and 96.8% of adults 75 and older report they have at least one person they think of as their doctor or healthcare provider. This puts roughly 4% of older adults without a primary care provider at risk for lack of preventative healthcare screening and ongoing support for chronic disease management.

In 2017, 2.6% of adults 65-74 and 1.9% of adults 75 and over reported that there was a time during the last 12 months when they needed to see a doctor but could not because of the **cost**. This is significantly lower than the state overall (11.7%).

Participants also expressed concern over the length of time it took to access the care they needed. There was also recognition of the overall complexity of the health care and health insurance system which made it difficult to get timely care or any care at all.

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Community members identified a lack of health care services and providers, long waitlists, and transportation issues as ongoing challenges that impact Maine's older adults.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 37. Gaps/Needs and Available Resources (Access to Care)

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Neighbors Driving Neighbors Age-Friendly Communities efforts Volunteer transportation **Community Organizations** Small community-based orgs **Technology** Telehealth/technology (7) Online support groups Online social groups **Access Alternatives** Non-traditional models of care Mobile med practices In-home OT, PT, speech services **Workforce Development** Free CNA training at tech schools	**Barriers to Care** Access/understanding of technology Health insurance/cost of care Long waitlists (4) Some specialists do not accept Medicare Timely access to care Complexity of system Better communication about medications **Providers/Workforce** Workforce shortages **Age-Friendly Services** Providers not trained to work with older adults (2) More funding for age-friendly communities (2) **Transportation** Walkable communities Transportation problems (4) Rurality **Missing Services** Lack of home care (2) Lack of dentists Lack of specialists (neuro, hearing, visual, geriatrics) (4) Caregiver support MH access Respite access

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[54]. Differences in social determinants can create disparities that impact vulnerable populations and rural residents alike.

Maine is the most rural state in the nation and the least populated state east of the Mississippi. These distinctions are a source of local pride as well as a source of challenge in meeting the needs of daily living.

> *"[There is a lack of] understanding for what transportation resources are available and how to access them."*

Isolation can lead to a lack of social connections and feelings of loneliness. And for those with limited or no access to transportation or internet access, these risk factors can become exacerbated. In 2019, 29.9%, or 1 in 3, adults 65 and older were **living alone**, higher than the national rate of 26.6%. There are only two counties in Maine that are below the national average for adults 65 and older living alone during the four years between 2015-2019: Waldo and Oxford Counties.

Participants also expressed concerns about the challenges of living on retirement savings with limited alternatives for additional income. One example is the cost of housing. While there are "affordable" housing options, participants noted those options are not always in good condition. There was also a concern for limited housing options for caregivers, an important component for those wishing to remain living independently and in need of affordable care.

During four years between 2015-2019, 12.0% of Maine households spent **more than 50% of their income on housing**. There is no available data on this by age. However, 21% of households over 60 are renters, and in 2019, 45% of renters 60+ (or 15,917 people), were "rent-burdened," spending 30% or more of household income on rent.[55]

Access to affordable **healthy food** was also mentioned as a challenge. While some indicated that they had been able to identify and use local food programs, those options did not always offer healthy foods.

As with many other events held with those who experience health disparities, there was a desire for more data specific to their experiences, as well as a desire for more local data that could be used to take local action.

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[54] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

[55] Census ACS B25007 ACS 2020 5-year estimates and Census ACS B25072 ACS 2020 5-year estimates

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Community members identified a lack of social connections, food insecurity, and a lack of affordable housing as ongoing challenges that impact Maine’s older adults.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 38. Gaps/Needs and Available Resources (Social Determinants of Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Health Services Pathfinder in Aroostook County Mobile medical practices COVID clinics in senior centers **Food** Local food banks/gleaning programs SNAP benefits **Older Adult Supports** Age-Friendly Communities (2) Saco Aging program **Technology** National Digital Equity Center Telehealth **Housing** Home repair services **Awareness** More recent interest in SDOH More people understand the impacts of isolation/loneliness	**Poverty** Poverty **Transportation** Transportation (2) Lack of transportation **Housing** Lack of affordable housing (2) **Food** Food insecurity (2) Lack of healthy options at food pantries Healthy food is too expensive **Barriers to Services** Cumbersome systems Don't know about resources/programs Wrap-around care Lack of funding for programs Broadband access/equipment/support **Isolation** Lack of social connections and isolation (3) Coordination Better communication/coordination across providers **Workforce/Systems** Lack of workforce

OLDER ADULT HEALTH

KEY TAKEAWAYS

Forum participants noted the difference between this health priority area and the others. While many health priorities were concrete health conditions, Older Adult Health is based solely on a single inevitable factor: growing older. Participants also noted that as a health priority, older adult health was as complex and diverse as the population itself.

While data does show that with age comes a greater risk for poor health outcomes, with the right support, anyone can lead a full and engaging life. Research shows that people with a positive view towards aging live 7.5 years longer with fewer chronic conditions and less anxiety than those living with a negative view.[56]

Supports mentioned include caregivers, transportation, home health supports, and social opportunities. Also identified was a need for more education and resources around improving cognitive health, including programs that specifically addressed Alzheimer's disease and dementia. In Maine, 10.8% of adults age 45 and over report having experienced **confusion or memory loss** that happened more often or got worse within the past 12 months. This is the same as the national average.

Caregiving to support aging adults, including but not limited to those with cognitive decline, was also highlighted as a challenge.

In Maine, 4.8% of the population provides regular care or assistance to a friend or family member who has a health problem or disability for at least 20 hours a week during the past 30 days. Participants noted this data point may not reflect all those caring for an older adult family member, perhaps because the number of hours spent is under 20 per week or is underestimated. Recent data by AARP estimates nearly 1 in 5 Americans provide caregiving to a family member.[57]

> *"[There are] many age-friendly groups but need to bring younger people along."*

Arthritis is one health issue that is also affected by age. According to the data, the percentage of adults who have been told by a healthcare provider that they have arthritis shows a steady increase with 5.5% among 18-24-year-olds to 55.5% for those 75 and older reporting they have been told they have arthritis.

Ageism was also mentioned as a barrier to older adult health. According to the World Health Organization, ageism is defined as the stereotypes (how we think), prejudice (how we feel), and discrimination (how we act) towards others or oneself based on age.[58] Ageism can affect anyone at any age and can erode the connectedness across generations.

Participants expressed a desire for policies and municipal planning that would support age-positive cultures and age-friendly communities. Age-friendly communities require community-wide coordination of existing resources to meet the challenges that can come with decreased mobility and increasingly complex health needs. As with any group, those needs and resources can vary widely based on local conditions. These differences are best identified through further collaboration at the community level.

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[56] Levy, B. R., Slade, M. D., Kunkel, S. R., & Kasl, S. V. (2002). Longevity is increased by positive self-perceptions of aging. Journal of personality and social psychology, 83(2), 261–270. https://doi.org/10.1037//0022-3514.83.2.261

[57] AARP, Caregiving in the U.S. Last accessed 5/17/2022, https://www.caregiving.org/caregiving-in-the-us-2020/

[58] https://www.who.int/news-room/questions-and-answers/item/ageing-ageism#:~:text=Ageism%20refers%20to%20the%20stereotypes,of%20their%20culture's%20age%20stereotypes.

COMMUNITY RESOURCES TO ADDRESS OLDER ADULT HEALTH

Community members identified access to food, transportation, and appropriate home care as ongoing challenges that impact Maine's older adults.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 39. Gaps/Needs and Available Resources (Older Adult Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Neighbors/ community cohesion/ volunteers (3) Age-friendly communities Outdoor environment **Alternative Care Options** Mobile medical practices Telehealth Home health support Programs to get people into housing **Training** Increased understanding/education of impacts of falls (2)	**Workforce** Lack of workforce **Basic Needs** Food Transportation Medication Fuel assistance Poverty/lack of financial resources **Long-Term Care** Lack of home care **Navigating Resources** Technology barriers **Lack of Support** Social isolation (3) Ageism

MENTAL HEALTH

KEY TAKEAWAYS

Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[59]

The top health indicator identified as a concern among participants was chronic disease among adults with depression. This is defined as the percentage of adults who have reported current symptoms of depression and have three or more chronic conditions. Chronic conditions include skin cancer, other types of cancer, cardiovascular disease [such as stroke], coronary heart disease [such as heart attack], arthritis, COPD and asthma, obesity, and chronic kidney disease. As with other health indicators, the rates increase with age. For those aged 18-24, the rate is 6.5% compared to 50.9% of those aged 75 and older.

Participants also noted the rate at which the emergency department is used to address those with a mental health condition. In Maine, the highest rate of those discharged from the emergency room with a mental health diagnosis is those aged 15-24,

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[59] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm

at 281.9 per 10,000. This rate declines with age with 75.2 per 10,000 for those aged 65-74 except those 85 and older (141.8).

Many participants expressed concern over feeling isolated, anxious, depressed, sad, or hopeless. According to recent data, nearly one-quarter (23.7%) of adults across Maine reported having experienced depression. Isolation has a significant impact on the health of older adults. This is even more pronounced for those in rural areas, those without caregivers, and those who live alone.

> *“I’m concerned about suicide, isolation, and mental health in older adults."*

In 2019, the suicide rate per 100,000 people was 19.4 in Maine. This is significantly higher than the national rate of 13.9 during the same period. In Maine, these rates were the highest among those aged 45-54 (33.8) and 85 or older (26.6), and 75-85 (24.3) and 65-74 (21.9).

Participants expressed a need for more mental health specialists trained to treat older adult mental health issues. Participants expressed a desire for more health care providers that understood these additional needs of older adults that go beyond physical needs. They acknowledged the promise of emerging telehealth capabilities along with the challenge of mastering and accessing these new technologies.

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Community members identified a general lack of providers, resources, and community support as ongoing challenges that impact Maine's older adults.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

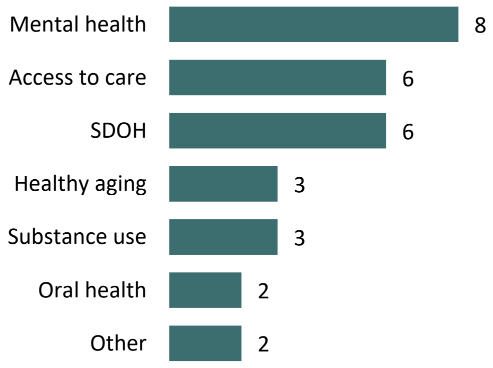
Table 40. Gaps/Needs and Available Resources (Mental Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Collaboration Good neighbors Volunteer programs Ability to make connections **Treatment** Licensed Clinical Social Workers Peer support programs and support groups **Law Enforcement** Local law enforcement check-ins **Resilience** Resilience	**Barriers to Treatment** Long wait times Research not translated into practice Not covered by Medicare Diagnosis of underlying conditions Isolation Interconnection with SDOH issues Rural state COVID Not enough support in the community Stigma **Providers** Lack of providers, generally (2) Lack of providers with training in older adult mental health (2) Not enough resources for older adult medication needs Medication misuse **Coordination** Fragmented system **Law Enforcement** Law enforcement needs training for mental health crisis

PEOPLE WITH A MENTAL HEALTH DIAGNOSIS

Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[60] Mental illness can affect anyone regardless of racial or ethnic identity; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location; or any other characteristic. Mental illnesses include many different conditions that vary in degree of severity. Severe Mental Illness is a subset of mental illness that affects fewer people but may be disabling and general requires more intensive professional care and case management.[61]

Figure 15. Priority Areas – People with a mental health diagnosis.



Depression and anxiety have been used as proxies for the general prevalence of mental health disorders, even though they are only a subset of these disorders. According to the results from the Maine Behavioral Risk Factor Surveillance Survey, in 2017, almost 1 in 10 adults in Maine (9.6%) reported having current symptoms of depression and 1 in 5 (21.8%) experienced anxiety in their lifetimes. Nationally, nearly 1 in 5 adults live with a mental illness.[62] Globally, depression is one of the leading causes of disability.

Mental illness is associated with increased premature death, including by suicide, which is the second leading cause of death among 15-29-year-olds. People with severe mental health conditions die prematurely – as much as two decades early – due to preventable physical conditions.

Due to the diverse nature of conditions and those who are affected, the diagnoses and treatment of mental illness require a nuanced, skilled, and individually tailored approach. Many mental health conditions can be effectively treated at a relatively low cost, yet the gap between people needing care and those with access to care remains substantial. People with mental health conditions often experience human rights violations, discrimination, and stigma, which can further impede treatment.[63]

The Consumer Council System of Maine (CCSM) is responsible for bringing an independent and effective consumer voice into mental health public policy, services, and funding decisions. CCSM consists entirely of past/present recipients of mental health services. To assist in engaging with those who have lived experience, MSCHNA partnered with the CCSM to host an event on October 14, 2021. The event was attended by 16 participants.

The three priorities that were identified and discussed at this event included:

- Mental Health (53%)
- Access to Care (40%)
- Social Determinants of Health (40%)

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[60] Centers for Disease Control and Prevention, last accessed 4/19/2022: https://www.cdc.gov/mentalhealth/index.htm

[61] National Institute of Mental Health, last accessed 4/21/2022: https://www.nimh.nih.gov/health/statistics/mental-illness#:~:text=Mental%20illnesses%20are%20common%20in,(52.9%20million%20in%202020).

[62] Ibid (NIH)

[63] World Health Organization, Mental Health, last accessed 4/19/2022: https://www.who.int/health-topics/mental-health#tab=tab_1

Three other priorities tied for fourth place. These included **Older Adult Health**, **Health Care Quality**, and **Substance and Alcohol Use**. Due to the limited amount of time during this one 2-hour event, participants were unable to explore these priorities more deeply.

Participants also noted the lack of data specific to those with a mental health diagnosis. The lack of integration of mental and physical health data, and incomplete social or demographic data in some data sets limits the ability to cross-reference health outcomes by subpopulations or health conditions. Additional steps are needed to enhance the data available for this population.

MENTAL HEALTH

KEY TAKEAWAYS

Mental health was identified as a top priority in every outreach effort and is one of the four top statewide priorities. Participants expressed concern that COVID-19 has created a new mental health crisis even as it has been an area of high concern for many years, and a priority in previous MSCHNA cycles. We await updated data that reflects new trends during the pandemic.

Individuals with a mental health diagnosis identified barriers that have prevented them from receiving the care they needed to address their mental health. Almost half (47%) of all participants indicated the usage of the **emergency room for mental health issues** as an indicator of concern. In 2018, the rate of visits to the emergency room related to mental health issues was 170.6 per 10,000 population in Maine.

Participants also noted concern for **youth mental health**. For instance, the rate of visits to the emergency room related to mental health issues was 281.9 for 15-24-year-olds in 2018. This is a significantly higher rate – almost twice as high – than the overall population. In 2017, 26.9% of high school students and 21.6% of middle school students reported feeling sad or hopeless for more than two weeks in a row. Additionally, 14.7% of high school and 16.1% of middle school students reported they had seriously considered attempting suicide during that same period.

Approximately one-fifth (18.0%) of Maine residents received outpatient mental health treatment between 2015 and 2017, while about a quarter (23.7%) reported having depression at some point throughout their lifetime. Participants commonly mentioned that wait times for mental health care providers were excessively long.

Participants conveyed the perception that traditional methods of addressing those with a mental health diagnosis in the community were not working. For example, one participant noted police involvement as a gap or barrier, and that people do not always know their rights. Others noted a general lack of options to address acute situations within both the community and clinical settings.

> *“A lot of traditional mental health services are not working, so let’s look at alternatives. Let’s look at social factors instead of pumping money into pharmaceuticals.”*

Compounding these issues was a feeling that not only is there a scarcity of available, highly skilled mental health care providers, but that it was difficult to find the right care and that the cost of the care is too high.

> *“[Increased services like case management and supportive/wrap-around services are] so important to people’s health care.”*

Other challenges included lack of transportation and the prevalence of the chronic disease among people with depression. In Maine, 34% percent of adults who have reported current symptoms of depression also have three or more chronic conditions. This has shown an increase from 29% in 2011, although not significantly.

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Community members identified accessing treatment, quality of treatment, and a lack of peer support as ongoing challenges or needs that impact individuals with a mental health diagnosis.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 41. Gaps/Needs and Available Resources (Mental Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Community-based Treatment Peer recovery community (vastly underutilized) Alternatives to crisis services/hospitalizations	**Barriers to Care** Treatment for children (2) Long wait times for services (2) Cost of care Lack of options Mental health facilities are cold/sterile Daily Living Supports no longer exists - barrier to becoming more independent Lack of peer support/peer centers (2) Transportation **Providers** Losing counselors to the private sector Highly trained/qualified psychiatrists **Awareness/Advocacy** Knowing how to find programs People not aware of rights/Knowing your rights Lack of advocacy opportunities **Law Enforcement** Police involvement

ACCESS TO CARE

KEY TAKEAWAYS

Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.[64]

One of the top concerns noted by participants was the lack of people covered by insurance. The rate of uninsured in Maine was 8% in 2019, which

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[64] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

was lower than the national rate of 9.2% that same year. MaineCare enrollment for all ages was 29.1% of adults and 43.8% of children ages 0-19 in 2020. Nationally, Medicaid (MaineCare's federal name) enrollment rate is 24.1% in 2020.

The rate of insured, as well as the type of insurance (MaineCare, Medicare, private, or other), can greatly impact the types of services that are covered by insurance and a patient's out-of-pocket expenses.

Cost of care was identified by 40% of participants as a priority health indicator and a major barrier to accessing care. Across the state, 11.7% of individuals reported that there was a time in the last 12 months when they needed to see a doctor, but could not due to cost in 2017.

The connection between physical health and mental health was highlighted during discussions. Indicators that concerned participants included adults with a usual primary care provider (87.2%) and adults who saw a primary care provider within the last year (71.3%) in 2017.

Another concern was the distance needed to travel for care. In Maine, 1 in 5 people (20%) needed to travel over 30 miles from home for a primary care visit. These long distances were mentioned as particularly challenging for those with limited options for transportation.

Participants commented on the wait times associated with receiving mental health care in the state. Participants stated that these waitlists are often very long and prevent them from receiving the care they need promptly. Participants also noted the need for highly skilled, trained, and qualified psychiatrists. Overall in Maine, there is one psychiatrist for every 12,985 people. In some rural counties like Aroostook, this number climbs to 64,856, reflecting even less availability, and more people a single provider could potentially need to serve. Higher ratios potentially impact wait times and timeliness of care.

> *"Let's look at alternatives. Let's look at social factors instead of pumping money into pharmaceuticals."*

Community members with a mental health diagnosis also perceived that traditional means of addressing health care needs may not be sufficient and encouraged the use of alternatives such as increased case management, supportive services, and wrap-around services.

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Community members identified affordability of care, lack of access to technology, and a lack of offered services as ongoing challenges or needs that impact individuals with a mental health diagnosis.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 42. Gaps/Needs and Available Resources (Access to Care)

AVAILABLE RESOURCES	GAPS/NEEDS
Access Alternatives Self-referrals for services Peer support groups	**Barriers to Care** Lack of universal healthcare Transportation barriers (2) Lack of broadband/smartphone for telehealth Location **Missing Services** Lack of vision care Lack of dental Lack of nutrition services

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[65]. Differences in social determinants can create disparities that impact vulnerable populations and rural residents alike.

Forum participants identified a variety of factors in their day-to-day lives that are affecting both their health and their ability to access the care they need. This includes a multitude of issues such as poverty, unemployment, housing insecurity, and access to broadband internet and a vehicle.

> *"[Social determinants of health are] so important to people's health care."*

In Maine, 10.9% of adults and 13.8% of children live in poverty in 2019. In some of Maine's more rural counties, the rate of adults living in poverty can be higher. For instance, 20.4% of adults in 2015-2019 and 64% of children in 2021 in Somerset County lived in poverty.

Participants identified both access to broadband internet and a vehicle as priority health indicators (40% of votes, each). In Maine, 88.6% of residents have access to broadband internet in 2017. This is lower than the national rate of 90.4% and can vary widely across the state, such as 99.9% of Androscoggin County residents compared to 41.8% of Piscataquis County residents who have broadband access.

According to recent data, Maine also has a lower proportion of households where no one owns a vehicle compared to the U.S. (2.1% vs 4.3%, respectively). However, several participants still noted transportation as a need. This could indicate several other barriers including reliability, affordability for repairs, insurance, and fuel, as well as the possibility of a limited number of vehicles to meet household needs. Maine also lacks a coordinated and well-connected public transportation system.

Other social risks noted by participants included people 65 and over living alone, housing insecure youth, and adverse childhood experiences (ACEs).

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[65] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Community members identified housing affordability, access to education, and food security as ongoing challenges or needs that impact individuals with a mental health diagnosis.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 43. Gaps/Needs and Available Resources (Social Determinants of Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Dedicated providers working with little resources Organizations trying to provide grants, education **Community Cohesion - Continued** Organizations teaching against discrimination Peer supporters **Substance Use Recovery** Recovery/reintegration coaches	**Housing** Lack of affordable/stable housing (2) **Education** Access to affordable colleges **Food** Lack of healthy food/food security **Equity** Sexism Discrimination Racism Homophobia **Environment** Pollution **Poverty** Lack of level wage **Public Safety** The prison model is based on punishment, not rehabilitation Violence

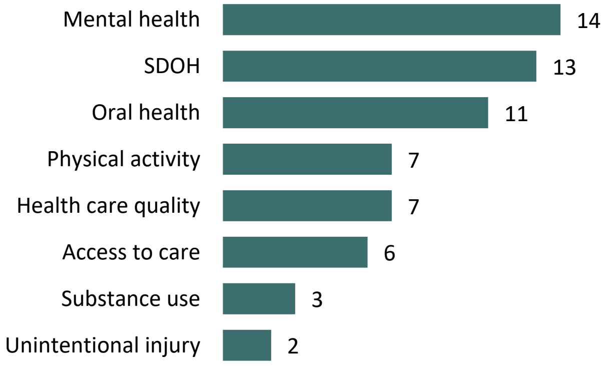
PEOPLE WITH DISABILITIES

People are not defined by their disability. Like gender and ethnicity, disability is merely a human characteristic; a natural part of the human experience. A disability does not imply a lack of ability or contribution.

> *"Disability is not a brave struggle or 'courage in the face of adversity.' Disability is an art. It's an ingenious way to live." - Neil Marcus*

One of the world's leading physicists published the record-breaking bestseller, *A Brief History of Time*, while paralyzed from ALS. Stephen Hawking offers just one example of the rich contributions made by members of our community who also happen to live with a disability.

Figure 16. Priority Areas – People with disabilities.



In Maine, it is estimated that 340,215 adults, or 1 in 3 adults, have some form of disability. As defined by the U.S. CDC, there are six disability types. **Mobility** is defined as having serious difficulty walking or climbing stairs. It is estimated that 13% of adults have mobility difficulties. **Cognition** disability is defined as having serious difficulty concentrating, remembering, or making decisions. It is estimated that 14% of adults in Maine have cognition difficulties. **Independent living** disability is defined as having serious difficulty doing errands alone, such as visiting a doctor's office. It is estimated that 9% of adults experience independent living difficulties. **Hearing** disability includes deafness or serious difficulty hearing. Eight percent (8%) of adults experience hearing difficulty. **Vision** disability includes blindness or serious difficulty seeing, even when wearing glasses. An estimated 5% of the adult population has vision difficulty. **Self-Care** disability type is defined as having difficulty dressing or bathing. It is estimated that 4% of adults in Maine have a self-care disability type.[66]

One of the challenges for anyone living with any one of these types of disabilities is that our society is often not designed in a way to accommodate their unique needs. This includes the need for inclusionary policies that take into account transportation and mobility, language accessibility, physical and programmatic access, and living supports.

It can be harder for disabled populations to maintain good health due to facing additional barriers that the general population does not. According to the U.S. CDC, 38% of adults in Maine with a disability are obese, compared to 28% of adults without a disability. Similarly, 31% of Maine adults with a disability smoke, compared to 14% of those without a disability. Rates of diabetes and heart disease are also higher among those with a disability (14% and 11%, respectively).[67]

The Maine Shared CHNA worked with Disability Rights Maine to engage with members of the disability community to help us better understand the health priorities and the related gaps and barriers which drive these disparities. Disability Rights Maine advocates for people with disabilities. The event was held on September 16, 2021, and was attended by 20 people. The five priorities identified during this event were:

- Mental Health (70%)
- Social Determinants of Health (65%)
- Oral Health (55%)

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[66] https://www.cdc.gov/ncbddd/disabilityandhealth/impacts/maine.html.
[67] Ibid.

- Health Care Quality (35%)
- Physical Activity, Nutrition, and Weight (35%)

Due to limited time during this one 2-hour event, participants were unable to explore the topic of Physical Activity, Nutrition, and Weight more deeply. Any comments on this topic are included in the Social Determinants of Health section.

It should be noted that not all data sources collect a full set of social or demographic data. In addition, some sub-populations experiencing health disparities are small, resulting in data that is less reliable due to low numbers or unavailable due to privacy concerns. These limitations have reduced the number of data points available for publication of county or state-level data.

MENTAL HEALTH

KEY TAKEAWAYS

Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[68]

Participants noted several barriers to accessing mental health care. The first was the number of providers who do not accept MaineCare. MaineCare is a means-tested program that provides safety-net services for vulnerable populations. MaineCare also has additional options for coverage for people with disabilities and certain health conditions. Due to these provisions, MaineCare is often a primary source of insurance coverage for community members. MaineCare does cover behavioral health services, however, with a lack of providers and an increasing demand for service, many providers can choose between clients with private or employer-sponsored insurance that have higher reimbursement rates for services than clients with MaineCare.

Another barrier noted by participants is the irony of having to prove their disability to receive services, while their disability itself created challenges in being able to follow the process to do so. Participants expressed concern about provider bias, discrimination, and overall lack of training in providing care for those with a disability.

> *"People need to be more comfortable talking to people with different disabilities - with different ways of feeling and communicating."*

Suicidality was also mentioned by participants as a concern. While there is no specific data by disability status, we do know that in Maine overall there were 19.4 **suicides** per 100,000 population in 2019. This is higher than the national rate of 13.9. The other intentional injury discussed was **domestic violence**. Again, referencing data from Maine overall using combined data over 4 years, the percentage of violence by current or former intimate partners was 1.5% per year in Maine.

Telehealth was identified as a potential solution by participants. It was also noted that to access services using telehealth, individuals need broadband access, and a certain level of technical savvy to understand how to use the equipment. For some people with disabilities this may also require special adaptive devices.

Participants noted positive experiences with the Behavioral Health Home (BHH) model. Health homes help patients manage their physical and behavioral health needs such as securing housing and helping clients reach their goals.

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[68] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Community members identified a lack of providers and specialists, waitlists, and discrimination as ongoing challenges or needs that impact individuals with disabilities.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 44. Gaps/Needs and Available Resources (Mental Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Treatment Telehealth Behavioral health home model Case management for adults	**Providers** Providers don't accept MaineCare Lack of providers & specialists (4) Undertrained case managers **Barriers to Treatment** Waitlists (4) Lack of care coordination (2) Social isolation **Poor Quality Care** Individuals with disabilities are dismissed/not well cared for Shaming people/Victim blaming Having to prove disabilities/difficulties Discrimination A one-size-fits-all approach to care Some specialists do not accept Medicare

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[69]. Differences in social determinants can create health disparities that impact vulnerable populations and rural residents alike. The challenges in finding safe, affordable, and accessible housing, employment, and living in poverty were among the social determinants of health mentioned by participants.

Adverse Childhood Experiences (ACEs) were one of the top concerns among participants. ACEs are a list of potentially traumatic events that occur during childhood and increase the likelihood of negative health and behavioral outcomes later in life. Participants noted the association between children with disabilities and a heightened risk of experiencing ACEs. This association could be related to the social isolation and stigma

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[69] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

experienced by children with special healthcare needs.

Maine is a rural state which lacks a robust public **transportation** system. Participants also noted that for many, their disability prevents them from driving a car. This immobility prevents physical access to the community to meet the demands of everyday living. This included employment, access to healthy food, making appointments, and socialization.

Housing and **homelessness** were also concerns expressed by participants As of January 2020, Maine had an estimated 2,097 experiencing homelessness on any given day.[70] Almost one-third of participants (28.6% or 6 out of 21) identified **housing costs** as the second priority health indicator. Between 2015-2019, 12.0% of Mainers paid more than 50% of their income toward housing. In addition to housing stability and affordability, participants also mentioned a statewide lack of safe, affordable, and accessible housing.

> *"Concerned with care moving to telehealth. It can be challenging with broadband access and use of the technology."*

Among the gaps or needs of SDOH, participants noted concerns related to care moving towards a **telehealth delivery model**. In particular, participants noted challenges in using the technology and a lack of broadband access.

Another health priority area mentioned was **Physical Activity, Nutrition, and Weight**. There was a lack of time to explore this topic more deeply. As mentioned earlier, according to the U.S. CDC, 38% of adults in Maine with a disability are obese, compared to 28% of adults without a disability. Similarly, rates of diabetes and heart disease are also higher among those with a disability (14% and 11%, respectively).[71]

Participants did express frustration with the lack of data for those living with a disability and the rate at which they experience food insecurity. **Food insecurity** is associated with being overweight or obese. This aligns with participants' concerns about housing, employment, and living in poverty. Eating on a budget often means purchasing pasta and highly processed foods which are cheaper than fresh fruits, vegetables, and fresh, lean protein. Participants also noted the connection offered by local churches and community organizations. These community assets often provide or distribute resources such as food and clothing.

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[70] United States Interagency Council on Homelessness, Maine Homeless Statistics. Last accessed 4/15/2022: https://www.usich.gov/homelessness-statistics/me/

[71] Ibid.

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Community members identified poverty, discrimination, and language barriers as ongoing challenges or needs that impact individuals with disabilities.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 45. Gaps/Needs and Available Resources (Social Determinants of Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Community Cohesion Local community orgs/churches distribute resources Informal help	**Poverty** Poverty Unemployment **Transportation** Transportation for people with disabilities (11) **Housing** Affordable/accessible housing & rising costs Homelessness **Equity** Discrimination Racism Language barriers Physical access within the community **Barriers to Services** Access to legal intervention and the judicial system to address violence and domestic violence Telehealth access (broadband issues, rurality, poverty) **Violence** Violence/domestic violence prevention and intervention

ORAL HEALTH

KEY TAKEAWAYS

Oral health was identified as a top health priority by event participants.

Oral health refers to the health of the teeth, gums, and the entire oral-facial system that allows us to smile, speak and chew. Some of the most common diseases that impact our oral health include cavities (tooth decay), gum (periodontal) disease, and oral cancer. Oral conditions are frequently considered separate from other chronic conditions, despite being connected. For instance, poor oral health is associated with other chronic diseases such as diabetes and heart disease.

Tooth decay is one of the most common and preventable chronic diseases.[72]

Participants noted the overuse or misuse of the emergency department for oral health care. Unfortunately, options for dental care in the emergency departments are often limited to pain management or extraction. In 2016, almost 1 in 5 Maine adults (19.5%) have lost 6 or more teeth due to decay or gum disease. In 2019, 80.3% of children were covered by dental insurance. There were 62.6% of insured children with at least one preventative dental visit that same year. These data are unavailable by ability status.

> *"There's a long history of people with disabilities having poor oral health. ... Sensory issues can make receiving oral health care more difficult. It can be done, but it takes more effort."*

Participants acknowledged the obstacles facing those with disabilities when it comes to oral health care. This includes mobility and transportation barriers to getting to appointments and into dental chairs. It also includes finding a provider who is willing to treat them or is trained and experienced in treating them.

COMMUNITY RESOURCES TO ADDRESS ORAL HEALTH

Community members identified oral healthcare quality and access as ongoing challenges or needs that impact individuals with disabilities.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 46. Gaps/Needs and Available Resources (Oral Health)

AVAILABLE RESOURCES	GAPS/NEEDS
	Healthcare Quality Better training for providers **Access** Dental care is too expensive (2) MaineCare does not cover adults (2) Lack of providers even for people with insurance Discrimination Educating providers regarding: communication and care for individuals with disabilities

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[72] U.S. CDC Oral Health. Last accessed 4/26/2022: https://www.cdc.gov/oralhealth/conditions/index.html

HEALTH CARE QUALITY

KEY TAKEAWAYS

The Institute of Medicine defines health care quality as "the degree to which health care services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge." Quality measurements include effectiveness, efficiency, equity, patient-centeredness, safety, and timeliness.[73]

The top concerns regarding healthcare quality expressed by participants related to patient-centeredness. Participants noted a need for training and discussion on best practices in communicating with individuals that may have intellectual or developmental disabilities, communication, or sensory barriers. This includes not only facility accessibility, but the use of other equipment necessary to provide equitable care like the ability to weigh a patient who uses a wheelchair. There is also a need for longer appointment times to meet the physical and intellectual needs of this population.

Participants noted the use of the emergency department to treat conditions that are usually addressed in a primary care physician's office. In Maine, the rate of those seeking treatment in the emergency department for ambulatory care sensitive conditions between 2016-2018 was 282.5 per 10,000 people. There are significant differences between counties. For instance, in Washington County, the rate is 592.8, while in Cumberland County the rate is 191.0 during the same period. These data are unavailable by ability status.

This rate can be affected by many factors including lack of insurance, access to preventative care, or putting off seeing a doctor due to cost. For those who live with a disability, this could also indicate the limited number of providers providing the type of patient-centered care they need. In addition, while more of an Access to Care measurement, participants also noted the challenges in accessing specialty care such as pediatrics and mental health providers.

> *"One barrier is not accepting the family as part of the individual's care team. The family is a resource - they certainly have information that can be useful."*

Participants shared their experiences of being dismissed by the provider when trying to communicate their needs or the provider speaking to the guardian or family member present, instead of to them.

Assets or resources that were working or could work included medical providers accepting supported decision-making agreements, shared decision-making models, medical home models, and reimbursements for transportation through MaineCare.

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[73] Agency for Healthcare Research and Quality. Last accessed 4/26/2022: https://www.ahrq.gov/patient-safety/quality-resources/tools/chtoolbx/understand/index.html

COMMUNITY RESOURCES TO ADDRESS HEALTH CARE QUALITY

Community members identified a lack of trusting relationships with providers, overuse of the emergency room, and lack of quality time with providers as to ongoing challenges or needs that impact individuals with disabilities.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

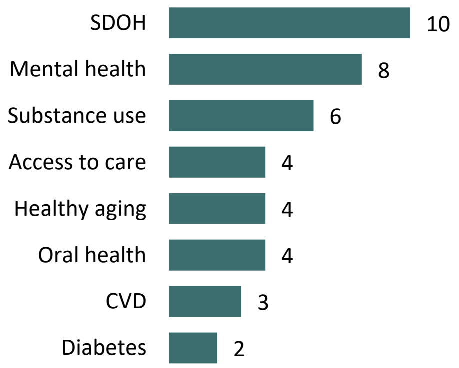
Table 47. Gaps/Needs and Available Resources (Health Care Quality).

AVAILABLE RESOURCES	GAPS/NEEDS
Providers Good relationships/ dialogue with providers Shared decision making (program by Pat Deegan) Supported Decision-Making agreements **Access Issues** Reimbursement for transportation through MaineCare	**Providers** Lack of trusting relationships w/ providers Lack of education for providers to understand disabilities (5) No team/family approach No medical home Providers that rush **Access Issues** Inaccessible medical equipment Emergency department overuse

PEOPLE WITH LOW-INCOME

Individuals with low income, including those who live in poverty, exist in every community. Low income and living in poverty are social risk factors that affects the ability for people to eat healthy foods, access healthcare, and live in safe, stable housing. More generally it is associated with poor health and are two of several social risk factors.

Figure 17. Priority Areas – People with low income.



There are a number of ways to measure poverty and economic security. One way people are characterized as living in poverty is when the total income of the householder's family is below the established federal poverty level. For a family of four, that would be $25,926 a year or $498 a week.[74] Income data is also available that describes the percentage of individuals living in poverty (11.8%) as well as the percentage of children ages 0-17 living in poverty (13.8%) in Maine. These data are from between 2015-2019.

Another way to view economic capacity is to consider the median household income. This is defined as the dollar amount that splits all households into two equal groups, using the median, or middle number when all income is listed in order, as the dividing line. In 2019, that number was $57,918 in Maine compared to $65,712 across the U.S.

Both poverty rates and median household income can vary widely from county to county and town to town, and even neighborhood to neighborhood. These differences in income are associated with an increase in health disparities. Those with low income experience higher rates of poor health outcomes such as diabetes, obesity, and poor mental health.

To better understand the health priorities for those with low income, the Maine Shared CHNA partnered with the Maine Primary Care Association (MPCA) to host a community event. MPCA is the statewide champion for Maine's Federally Qualified Healthcare Centers (FQHC's). FQHC's primary mission is to provide care to medically underserved in high need communities, regardless of ability to pay. Governing Boards are made up of no less than 51% of their consumers. Of the 206,211 patients served by 19 MPCA health centers in 2018, 68% were low income, 9% identify as an ethnic or racial minority, 5% were veterans, and 3% were homeless. Learn more about MPCA's impacts here. MPCA recruited leaders and staff from their member healthcare centers to discuss the health priorities, gaps and barriers experienced by their clients. The event was held on September 23, 2021. The event was attended by 22 participants. There were three clear top priorities chosen during this event:

- Social Determinants of Health (45%)
- Mental Health (36%)
- Substance and Alcohol Use (27%)

There were three priorities that tied for fourth place: Access to Care, Older Adult Health, and Oral Health with 18% of participants voting for each. Given their relevance to those served by Maine's FQHCs, these priorities are discussed together as, "Other Identified Priorities."

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[74] U.S. Census Poverty Thresholds, last accessed 4/19/22: https://www.census.gov/data/tables/time-series/demo/income-poverty/historical-poverty-thresholds.html

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[75]. Differences in social determinants, or social risk factors, can create disparities that impact vulnerable populations and rural residents alike.

Participants from the state's low-income population identified several social risk factors in their daily lives that affect both their health and ability to meet the needs of daily living.

> *"There is a lack of transportation in rural areas and a lack of access to healthy food resources."*

Nearly one-third (28.6%) of participants identified poverty as a concerning health indicator.

The same number of participants (28.6% or 6 out of 21) identified **housing costs** as the second priority health indicator. Between 2015-2019, 12.0% of Mainers paid more than 50% of their income toward housing. Housing costs can vary widely from county to county. For instance, in 2015-2019, the Somerset County median household income was $44,256 and 13.3% of households spent more than 50% of their income on housing. In Cumberland County, the median household income was $73,072 and 12.8% of households spent more than 50% of their income on housing. In this example, while there is a similar percentage of those who spend more than 50% or more of their household income on housing, there is a large difference in the amount of funds left over for daily living expenses.

Another third (28.6%) of participants identified adverse childhood events (ACEs) as a concern. While typically considered a risk factor for mental health, participants noted ACE's impacts on other factors. ACEs are a list of potentially traumatic events that occur during childhood and increase the likelihood of negative health and behavioral outcomes later in life. In 2019, 21.3%, or 1 in 5, high school students reported having experienced four or more ACEs.

Other indicators of concern included the percentage people living in rural areas (66% in 2019) and adults 65 and living alone (29.9% in 2019%).

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[75] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Community members identified access to food, poverty, and transportation as ongoing challenges or needs that impact the low-income community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 48. Gaps/Needs and Available Resources (Social Determinants of Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Food Food shelf at FQHCs for patients to have healthy foods Good Shepherd Food Bank **Screening** PREPARE screening tool	**Poverty** Poverty (3) **Transportation** Lack of public transportation, especially in rural areas. (7) **Food** Lack of reimbursement to increase access to food Food insecurity (3) **Economic Security** Lack of staff/unemployment

MENTAL HEALTH

KEY TAKEAWAYS

Mental health was the second priority identified among the low-income group. It was also identified as a top health concern in every county in the state and among other underserved community groups. Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[76]

The availability of mental health providers was the most frequently mentioned indicator related to mental health. Nearly one-third (28.6%) of community members noted the low availability of mental health providers across the state both for inpatient and outpatient care. They also shared their experiences with long waitlists to access mental health care services.

The stigma associated with receiving mental health services was mentioned as a barrier to accessing these services. Participants also noted the need for mechanisms for improving communication between primary care and behavioral health providers.

Emergency Department usage to address mental health needs was identified by 28.6% of community event participants as a concern. The rate of those seeking **mental health care in the emergency department** in Maine overall is 170.6 per 10,000 population in 2018.

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[76] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm.

Participants also noted concern for **youth mental health**. For instance, the rate of visits to the emergency room related to mental health issues was 281.9 for 15-24 year olds in 2018. This is a significantly higher rate – almost twice as high – than the overall population. In 2017, 26.9% of high school students and 21.6% of middle school students reported feeling sad or hopeless for more than two weeks in a row. Additionally, 14.7% of high school and 16.1% of middle school students reported they had seriously considered attempting suicide during that same time period. These data are not available by income level.

> *"Teen hopelessness travels into adulthood and tools are lacking for parents and kids."*

Participants also expressed concern about the impact of the COVID-19 pandemic on youth, including potential increases in adverse childhood experiences (ACEs) resulting from the pandemic which resulted in homeschooling in potentially unsafe situations while decreasing access to school-based supports.

The data show a health disparity for those reporting 14 or more days lost due to poor mental health by income. For those earning under $15,000, the percentage was 34.8% in 2017. These percentages decrease with each increasing income bracket. For those earning $75,000 or more, the percentage is 6.1% in 2017. This pattern is similar for the percentage of adults with current symptoms of depression, having ever had an anxiety diagnosis, and currently receiving outpatient mental health treatment. As with any population experiencing a health disparity, the underlying root causes for those who may experience systemic disadvantages differ depending on local resources and unique characteristics and cultural norms for each sub-population. These differences are best identified through further collaboration at the community level.

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Community members identified a lack of providers, stigma surrounding mental health, and lack of communication between providers as to ongoing challenges that impact the low-income community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 49. Gaps/Needs and Available Resources (Mental Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Telehealth	**Providers** Lack of providers (4) **Barriers to Treatment** Stigma to access services Lack of education Recordkeeping barriers b/w primary care/behavioral health

SUBSTANCE AND ALCOHOL USE

KEY TAKEAWAYS

Substance and alcohol use was selected as a top priority in the low-income community. It was also identified as one of the top health concerns in all the counties in the state and among other underserved communities. Recurring use of alcohol and/or drugs can cause clinically significant impairment, including health problems, disability, and failure to meet major responsibilities at work, school, or home. Substance and alcohol use has also been linked to co-occurring mental health issues such as anxiety, depression, and attention-deficit/hyperactivity disorder (ADHD), among others.[77]

> *"The number of overdoses that weren't fatal is going up. The problem is increasing but there is value in the tool (Narcan) that is being utilized."*

Community event participants expressed concerns about multiple drug and alcohol use health indicators. Overdose deaths were mentioned by 33.3% of event participants as a health indicator of concern. In 2020, the rate of overdose deaths per 100,000 population in Maine was 37.3, a significant increase from 28.2 in 2016. These numbers are not available by income.

Table 50: Overdose Deaths by Year.

YEAR	NUMBER
2016	378
2017	417
2018	354
2019	380
2020	502
2021	633*

*Preliminary number from the Office of the Chief Medical Examiner

Participants noted changing societal norms around drug use and increased access, especially for marijuana and alcohol, coupled with a lack of early intervention and education. The data show a significant difference in past-30-day marijuana use between lower and higher income brackets. In 2017, 27% of those earning less than $15,000 reported using marijuana in the past 30 days, compared to 11.1% of those earning $75,000 or more. The differences in use correspond with each subsequent increase in income brackets. In short, those who earn less report higher rates of marijuana use.

Alcohol consumption follows a different pattern by income. In 2017, 21.3% of those earning $75,000 or more reported binge drinking, a significant difference from the 11.3% of those earning less than $15,000 who reported binge drinking. These differences in use correspond with each subsequent decrease in income brackets. In short, those who earn more report higher rates of binge drinking. The percentage of adults who report chronic heavy drinking also show differences by income bracket, with higher wage earners reporting more chronic heavy drinking, but the pattern is not as clear.

There is no data on alcohol-induced deaths, alcohol-impaired driving deaths, nor drug-affected infants by income. The data shows no significant difference in past-30-day misuse of prescription drugs by income, with 1.3% of adults who misused prescription drugs in 2017.

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[77] Mental Health and Substance Use Disorders. Substance Abuse and Mental Health Services Administration (SAMHSA). Available from: https://www.samhsa.gov/find-help/disorders.

COMMUNITY RESOURCES TO ADDRESS SUBSTANCE & ALCOHOL USE

Community members identified lack of treatment options and long waitlists for services as ongoing challenges or needs that impact the low-income community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 51. Gaps/Needs and Available Resources (Substance and Alcohol Use)

AVAILABLE RESOURCES	GAPS/NEEDS
Low barrier services Sacopee has a strong focus on Medication-Assisted Treatment	**Treatment** Lack of providers (2) Long wait lists for case managers

OTHER IDENTIFIED PRIORITIES

KEY TAKEAWAYS

Participants noted with equal concern Access to Care, Oral Health, and Older Adult Health as their fourth priority. Given that many low income Mainer's are impacted by all three of these areas, below is a snapshot of these health priority areas.

Access to Care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of coverage, services, timeliness, and workforce.[78] It should be noted many FQHC's in Maine provide dental care, hence access to Oral Health is also considered as an Access to Care issue for these participants.

Adults aged 65 and older make up a growing percentage of the population in Maine. In 2019, 21% or 1 in 5 Mainers were 65 or older. This is expected to increase to 1 in 4 by the year 2030. Maine's rural counties are home to a greater proportion of older adults.

Cost barriers to care were the most frequently identified health indicator related to access to care, mentioned by 28.6% of community participants. In 2015-2017, 10.6% of adults reported that there was a time during the last 12 months when they needed to see a doctor but could not because of the cost.

Unsurprisingly, there is a significant difference among those who report **cost barriers to care by income level**. In 2017, 18.1% of those earning less than $15,000 compared to 4.7% of those earning $75,000 or more reported this barrier.

A **lack of health insurance** was the third most frequently identified health indicator mentioned by low-income community members. The percentage of those reporting they currently have **no insurance** was 8% in Maine and 9.2% nationally in 2019.

There are four primary means of obtaining health insurance: Medicaid (known and MaineCare in Maine), Medicare, employer sponsored private insurance, or non-group coverage, typically

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[78] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html.

obtained through the Affordable Care Act's Marketplace.

One in three (29.1%) Maine adults were enrolled in **MaineCare** in 2020 compared to 24.1% nationally. MaineCare is a means tested safety net program, meaning to be eligible, you must show proof of limited income and resources. As a federal and state funded program, enrollment eligibility and services can differ between states.

While people 65 and older have access to **Medicare**, there are limits to that coverage. Those coverage limits can create out-of-pocket costs. For those that are retired these costs can have a significant impact on household budgets. There was also recognition of the overall complexity of the healthcare/health insurance system and it is difficult for some to navigate alone.

> *"There's a lack of providers across the board. People are utilizing the emergency room for primary care needs."*

Participants also noted concern over access to primary care. In Maine, there is a significant difference between the percentage of adults who had a regular physical exam in the past year based on insurance status. This ranges from 85.5% of those who report 'Other' type of insurance, 83.5% covered by Medicare, 71.7% with private insurance, 70% with MaineCare, to only 35.7% for those who are uninsured.

For adults without access to preventative dental care, this can mean higher rates for dental emergency care. Unfortunately, options for dental care in the emergency departments is often limited to pain management or extraction. In 2016, almost 1 in 5 Maine adults (19.5%) have lost 6 or more teeth due to decay or gum disease.

In 2019, 80.3% of children were covered by dental insurance. There were 62.6% of insured children with at least one preventative dental visit that same year.

> *"People's healthcare is focused on emergency services, rather than preventative care."*

There is also disparity between adults who report they have a usual primary care provider based on income. In 2017, 84.7% of those who earn $35,000-$49,000 compared to 92.4% of those who earn over $75,000 report they have a usual primary care provider. There is a similar disparity for primary care visits in the past year. In 2017, 67.5% of those who earn $35,000-$49,000 compared to 76.7% of those who earn over $75,000 report they have had a primary care visit in the last year.

Participants noted barriers that are difficult to address, including attracting and keeping health care providers, staff shortages and burnout, a lack of providers for youth services, long travel distances, and a lack of broadband access that makes telehealth and other online services more difficult to implement. Participants also noted the overuse or misuse of the emergency department for preventative or routine care.

Long-distance travel to see a provider was identified as a top priority among the low-income community. While transportation is typically discussed as a social determinant of health, lack of transportation is a real barrier to all modes of care.

In 2019, 20.0% (1 in 5) Maine residents had to travel more than 30 miles to be seen by a primary care provider. According to recent data, Maine also has a lower proportion of households where no one owns a vehicle compared to the U.S. (2.1% vs 4.3%, respectively). However, a number of participants still noted transportation as a need. This could indicate a number of other barriers including reliability, affordability for repairs, insurance, and fuel, as well as the possibility of a limited number of vehicles to meet household needs. Maine also lacks coordinated and well connected public transportation system. For older adults who rely on family or caretakers for transportation, this is also particularly challenging to coordinate transportation and appointments. These data are not available by income.

COMMUNITY RESOURCES TO OTHER IDENTIFIED PRIORITIES

Community members identified a lack of providers as an ongoing challenge or need that impacts the low-income community.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 52. Gaps/Needs and Available Resources (Other Identified Priorities)

AVAILABLE RESOURCES	GAPS/NEEDS
Access to Care None listed	**Access to Care** Lack of providers (3) Lack of social workers
Oral Health Dental program at UNE	**Oral Health** Lack of providers Not enough people covered by dental insurance
Older Adult Health Area Agencies on Aging	**Older Adult Health** Lack of staff/unemployment Lack of long term care Lack of home care Stigma around cognitive impairment/aging Lack of community support No Program for All-inclusive Care for the Elderly (PACE) programs

YOUTH

There are approximately 146,519 young people aged 10-24 in Maine, which is 10.9% of the total population during the 2015-2019 time period. This is approximately the same number of people who live in all of Franklin, Lincoln, Piscataquis, Sagadahoc, and Washington Counties combined. One of the overarching themes from participant's input was that despite making up 10.8% of Maine's population, young people are under-represented in leadership roles and in decision-making processes that affect them.

The other piece participants wanted people to understand is that 'youth' is not a homogenous group just due to age. "Youth" or young people reflect the full spectrum of diversity present in Maine's overall population. The one commonality is that for young people, this is a time of rapid developmental transition to adulthood that includes changes in the brain and body, and is a time for healthy exploration of identity and learning independence.[79] It can also be a stressful or challenging time for teens because of these rapid changes. Young people also seek supportive environments and people who understand their journey towards growing independence and gaining power over their agency.

To gain insight into young people's views on health and healthcare, the Maine Youth Action Network (MYAN) hosted an event on November 18, 2021. MYAN's vision is for communities throughout Maine to foster the healthy development of youth and create a thriving network of engaged leaders. This out-of-school event had 30 participants. The top four health priorities identified during this event included:

- Access to Care
- Mental Health
- Social Determinants of Health
- Oral Health
- Health Education

ACCESS TO CARE

KEY TAKEAWAYS

Access to care means having the timely use of health services to achieve the best possible health outcomes. It consists of four main components: availability of insurance coverage, availability of services, timeliness of access, and the health care workforce.[80]

Participating youth indicated that access was a key barrier they had to overcome to receive the care they required. They often indicated that they didn't know where to find care or even where/who to ask for additional information on available resources.

In Maine, 57.2% of children ages 0-17 had **access to a medical home** during the 2018-2019 time period. This is significantly higher than the national rate of 47.7% during the same period. The medical home model helps to coordinate a patient's care across specialties, services, and supports.

Furthermore, youths indicated that health care was generally unaffordable and too time-consuming as most doctor offices were not geographically close enough to them.

An idea that found broad support was offering health services in school settings. This appears especially salient given that participating youth

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[79] Youth.Gov, last accessed 4/20/2022: https://youth.gov/youth-topics/adolescent-health/adolescent-development

[80] Chartbook on Access to Health Care, Agency for Healthcare Research and Quality. Available from: https://www.ahrq.gov/research/findings/nhqrdr/chartbooks/access/elements.html

indicated they often have busy schedules, and that time was a frequent barrier to receiving the care they required.

There were 43.8% of Maine **children aged 0-19 enrolled in MaineCare** in 2020. Overall, 1 in 5 or 20% of all **primary care visits were more than 30 miles from a patient's home**, regardless of age.

When asked what they needed to be healthy, participants noted they needed trusted community members with whom to share their thoughts and opinions without fear of being judged. This appears to extend into the health care setting where they indicated a desire for providers that would actively listen and not be dismissive. This includes providing care that is tailored to the unique needs of young people in a trusted, confidential manner.

> *"People in the positions of power need to become aware of the power they have so they can make students feel more comfortable."*

Participants also noted a desire to access healthcare without the need for parental consent.

COMMUNITY RESOURCES TO ADDRESS ACCESS TO CARE

Community members identified health care costs, long commutes to providers, social stigma, and a lack of education concerning mental health issues as ongoing challenges or needs that impact youth.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities. The numbers in parentheses indicate the number of times community members mentioned or concurred with what was listed.

Table 53. Gaps/Needs and Available Resources (Access to Care)

AVAILABLE RESOURCES	GAPS/NEEDS
School-based health clinics	**Cost Barriers** More affordable health care (2) Resources being too expensive Resources that are available to everyone, regardless of income Orthodontics not affordable **Transportation/Distance** Distance/transportation: Hospitals/ health services are far away Geographically closer doctor offices **Barriers to Care** Stigma and shame (2) Not knowing about services Time; busy schedules **Providers** Caring doctors who listen and are not dismissive **Medications** Need affordable and accessible medications

MENTAL HEALTH

KEY TAKEAWAYS

Mental health includes emotional, psychological, and social well-being. It affects how we think, feel, and act. It also helps determine how we handle stress, relate to others, and make healthy choices.[81]

Concern for youth's mental health was expressed during every one of Maine Shared CHNA's outreach events. This was in response to data that shows 16.4% of high school and 19.8% of middle school students reported they had **seriously considered suicide** in 2019. Data also show that 32.1% of high school and 24.8% of middle school students reported feeling so **sad or hopeless for two weeks or more** in a row during the past 12 months that they stopped doing some usual activities.

When participating youth were asked to identify what they need to be healthy, many mentioned aspects related to mental health. This included a supportive community of people where they could share their thoughts, feelings, and emotions without judgment. Youth highlighted the connection between mental and physical health and the need to support both, especially through time spent outdoors.

When asked what was holding them back from achieving health, many indicated a lack of mental health services. In particular, the need for additional therapy options was broadly supported by participating youth. Many expressed the understanding that needing to work through trauma and daily life experiences through therapy and other mental health care services were or should be considered normal, and accessible to everyone regardless of cost. Given the busy lives of youths across Maine, many indicated that offering mental health services through school would be a good way to reach youth in most need of these services.

> *"A lot of people can't handle all their emotions and need someone to talk to, especially anyone who has had trauma in their past."*

Participants in the event hosted for and by the LGTBQ+ community expressed concern for youth who wish to explore their sexual orientation or gender identity in environments that are not supportive.

Stigma was also perceived as a significant barrier that they needed to overcome to receive the mental health care they required. They expressed feeling that asking for help is seen as shameful and a weakness.

> *"[We experience] stigma against the things we are feeling and being told we are too young to feel that way."*

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[81] Centers for Disease Control and Prevention. Available from: https://www.cdc.gov/mentalhealth/index.htm

COMMUNITY RESOURCES TO ADDRESS MENTAL HEALTH

Community members identified the cost of therapy, access to medications and treatment options, and a lack of awareness of ongoing challenges or needs impacting youth.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities.

Table 54. Gaps/Needs and Available Resources (Mental Health)

AVAILABLE RESOURCES	GAPS/NEEDS
Spending time outdoors Letting things out, not holding things in	**Barriers to Treatment** Prioritize mental health. Free therapy! Lack of mental health resources A good, affordable therapist Eating disorder recovery/treatment Access to antidepressants, antipsychotics **Trauma** People have past trauma that needs to be addressed **Awareness** Speaking more about mental health Need to feel connected to people you are excited to be with

SOCIAL DETERMINANTS OF HEALTH

KEY TAKEAWAYS

Social determinants of health are the conditions in which people live, learn, work, play, worship, and age. Domains include education, economic stability, health care access and quality, the environment, and social connectedness. Examples include access to healthy food, housing, water, air, and relationships[82]. Differences in social determinants can create disparities that impact vulnerable populations and rural residents alike.

Participants expressed their perception that healthy living is multifaceted and extends beyond simply eating well and working out. They placed a particularly strong emphasis on the physical and mental connection of health and a high priority on one's ability to live within a community where they can openly discuss their issues.

As an example, the Search Institute has identified 40 positive supports and strengths that young people need to succeed. Half of the assets focus on the relationships and opportunities they need in their families, schools, and communities (external assets). The remaining assets focus on the social-emotional strengths, values, and commitments that are nurtured within young people (internal assets).[83]

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[82] Healthy People 2030, Office of Disease Prevention and Health Promotion, U.S. Department of Health and Human Services. Available from: https://health.gov/healthypeople/objectives-and-data/social-determinants-health

[83] Search Institute, last accessed 4/20/2022: https://www.search-institute.org/our-research/development-assets/developmental-assets-framework/

For those who work with young people, this is complimentary to preventing children and adolescents' exposure to adverse childhood experiences (ACEs). In Maine, 21.3%, or one in five, high school students report having experienced at least four out of nine **adverse childhood experiences** (ACEs). ACEs are a list of potentially traumatic events that occur during childhood and increase the likelihood of negative health and behavioral outcomes later in life. The most commonly used list contains 10 events. Individuals who experience 4 or more of these events by age 17 double their risk of heart disease and cancer, increase the likelihood of becoming an alcoholic by 700 percent, and the risk of attempting suicide by 1200 percent. Events can include experiencing violence, abuse, or neglect.

Building on Developmental Assets provides opportunities for youth to engage in positive experiences, feel they are cared for and supported. As one example, for those who are encouraged to participate in decision making are more likely to thrive later in life.[84]

When asked what resources are currently lacking, the participating youth indicated that healthy foods should be made more available, especially to homeless individuals. They also recognized the stigma and shame to get 'handouts' and that it was embarrassing to ask for help. Yet, in 2021, more than 1 in 3 students (38.2%) enrolled in all grades were **eligible for free and reduced lunch**. Over 1 in 10 (13.2%) children ages 0-17 were **living in poverty** in 2019.

In Maine, 3.3% of high school students reported being **housing insecure**, meaning they usually do not sleep in their parent's or guardian's home in 2019.

School culture and learning opportunities were discussed. Participants recognized that different students may have different needs to have equitable access to resources and learning opportunities. For instance, allowing students with ADHD to use headphones to stay focused.

As for educational attainment, **Maine's high school graduation rate** is 87.4% in 2020, similar to the national average of 87.1% in 2019. Those who go on to attain an **associate's degree or higher** by age 25 or older were 41.9% in Maine during the 2015-2019 time period. This is similar to the national average of 41.7% in 2019.

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[84] Search Institute (2020). The Intersection of Developmental Relationships, Equitable Environments, and SEL [Insights & Evidence Series]. Minneapolis, MN: https://www.search-institute.org/wp-content/uploads/2020/10/Insights-Evidence-DRs-DEI.SEL-FINAL.pdf

COMMUNITY RESOURCES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH

Community members identified the availability of food, education about minority populations, and accommodations for individuals with unique health needs as ongoing challenges or needs that impact youth.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities.

Table 55. Gaps/Needs and Available Resources (Social Determinants of Health)

AVAILABLE RESOURCES	GAPS/NEEDS
	Food Food should be more available Homeless people can't get the food they need **Poverty/Income** Resources that are available to everyone, regardless of income **Equity** Accommodations in schools that acknowledge and account for individual health needs Hearing voices of those who are non-binary, gender-fluid

ORAL HEALTH

KEY TAKEAWAYS

Participants noted a lack of access to timely and affordable dental care. It was noted that when health services are promoted through school, like the dental clinics at Deering and Portland High School, youth are more likely to gain access. It was also noted that once students leave school, not everyone can get what they need elsewhere.

According to the Children's Oral Health Network of Maine, oral health is closely connected to overall health and well-being. Lack of oral health care in childhood contributes to serious and costly complications for health and economic stability later in life.[85]

In Maine, 80.3% of children and young people under the age of 21 are **covered by dental insurance**. Regardless of insurance status, whether MaineCare or commercial insurance, only 65.7% of children and young people had at least **one preventative dental visit in the past year** in 2019. The percentage of children and young people who had **at least one dental claim** in 2019 was 70.9%.

> *"Orthodontic [services] are not affordable. I need braces, but it costs too much money."*

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[85] https://www.mainecohn.org/

Much attention is paid to general physical and mental wellbeing, with the recognition that dental health is an integral part of overall health.

COMMUNITY RESOURCES TO ADDRESS ORAL HEALTH

Community members identified the cost of oral health care as an ongoing challenge or need that impacts youth.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities.

Table 56. Gaps/Needs and Available Resources (Oral Health)

AVAILABLE RESOURCES	GAPS/NEEDS
	Orthodontics not affordable

HEALTH EDUCATION

KEY TAKEAWAYS

Participants noted the need for more information on a much broader set of health topics than what is currently being taught in schools. Participants felt the health class curriculum was not providing deep enough information on topics that affect them such as overall wellness, mental health, diversity, and sexuality.

"Being healthy means more than just eating well and exercising, and we should talk about that."

Participants expressed frustration in being made to take quizzes from the state about how many vegetables they eat or what their weight is in an acknowledgment that health encompasses so much more. There was also discussion on the desire to know more about how to get and stay healthy.

"[I] don't' know where to go to find resources without having to talk to strangers or adults."

They also expressed a desire for comprehensive mental health education that included perspectives from commonly marginalized populations.

"It's important we have all voices and bodies represented so everyone can feel included in these conversations."

Another health education topic was the need for sex education that was destigmatized and taught more broadly. Participants felt the health curriculum as it is, is very restrictive and heteronormative and focused on cis white males. Hearing the voices of those who are non-binary, or gender-fluid, was important to participants.

"There was a lack of health class education that covers reproductive health and anatomy. Instead, we learned how to meditate."

COMMUNITY RESOURCES TO ADDRESS HEALTH EDUCATION

Community members identified the need for education on diverse health topics as an ongoing challenge or need that impacts youth.

The following information was gathered from participants during a group activity, where participants were asked to share their knowledge of the gaps and needs or resources and assets in their communities about the identified health priorities.

Table 57. Gaps/Needs and Available Resources (Health Education)

AVAILABLE RESOURCES	GAPS/NEEDS
Things promoted through school are more accessible	**Awareness** Speaking more about mental health Not knowing about services **Equity** LGBTQ education Traditional ideas of health taught in today's curriculums are exclusive and don't account for diverse experiences The health curriculum as it is very restrictive and heteronormative. We must have all voices and bodies represented so everyone can feel included in these conversations. **Health Education/Schools** Health classes that go deep into the issues that affect young people (i.e., mental health and sexual education) (2) Healthy relationships

APPENDIX: METHODOLOGY

The Maine Shared CHNA is a collaboration governed by a Steering Committee, which is made up of representatives of each member organization (CMHC, MGH, MH, NLH, and Maine CDC). The Steering Committee sets fiscal and operational goals that are then implemented by the Maine Shared CHNA Program Manager. Input is provided by key stakeholder groups including the Metrics Committee and the Health Equity/Community Engagement Committee.

The Metrics Committee is charged with creating and reviewing a common set of population/community health indicators and measures every three years. Before the 2018-2019 Maine Shared CHNA, the Metrics Committee conducted an extensive review of the data using the following criteria as a guide: 1.] describes an emerging health issue; 2.] describes one or more social determinants of health; 3.] measures an actionable issue; 4.] the issue is known to have high health and social costs; 5.] rounds out our description of population health; 6.] aligns with national health assessments (i.e.: County Health Rankings, American Health Rankings, Healthy People); 7.] data is less than 2 years old; 8.] data was included in the previous data set, or 9.] the Maine CDC analyzes the indicator in a current program. This review process was carried into the 2021-2022 Maine Shared CHNA, where the Metrics Committee also reviewed the previous data set to check for changes in data sources, potential new sources of data to round out certain topics, and to deepen Social Determinants of Health data which many of our partners have included in their work.

The Health Equity/Community Engagement Committee is charged with updating outreach methodology to ensure a collection of broad, diverse, and representative qualitative data from those who experience systematic disadvantages. To ensure these methods reflect the needs and cultural expectations this committee included representatives from a variety of Maine's ethnic-based and community-based organizations, along with representatives from public health and health care, and a variety of additional partners.

The 2021-2022 Maine Shared CHNA process involved three phases.

Data Analysis

The first phase of the project involved the analysis of more than 220 health indicators for the state, counties, public health districts, selected cities, and by specific demographics when available.

Data analysis was conducted by the Maine CDC and its epidemiology contractor, the University of Southern Maine, with additional support from the contracted vendor, Market Decisions Research.

Community Outreach and Engagement

Community outreach and engagement for the Maine Shared CHNA included the following efforts:

- 17 County Forums (Maine)
- 9 Community Sponsored Events
- 1,000 Oral Surveys

County Forums were held in each of Maine's 16 counties, with one county, Cumberland, hosting one event in western Cumberland and one in eastern Cumberland in recognition of the differences between Greater Portland (Maine's most densely populated area) and the Lakes Region, a more rural area. Local planning teams led by local health care and public health district liaisons organized and promoted these events. Participants were shown a PowerPoint presentation with relevant county data and were led through guided discussions to identify indicators of concern. Participants then voted to identify their top four health priorities. They were then asked to share their knowledge on gaps and assets available in their communities to address each of the top priorities identified.

New this cycle is an expanded effort to reach those who experience systematic disadvantages and therefore experience a greater rate of health disparities. Two types of outreach were piloted. One effort included nine community-sponsored events.

The hosts and communities were chosen for their statewide reach. The communities included:

- Black or African American
- People who are Deaf and Hard of Hearing
- People who live with a disability
- People with a mental health diagnosis
- People Experiencing Homelessness
- LGBTQ+ community
- People with low income
- Older adults
- Youth

These events followed the same methodology as county forums.

Oral surveys were conducted in collaboration with 10 ethnic-based community organizations' (ECBOs) community health workers to better reach Maine's immigrant population. There were 1,000 surveys were conducted in either English (32%), Somali, (24%), Arabic (23%), French (8%), Spanish (5%), Lingala (3%), and other languages including Swahili, Maay Maay Portuguese, Oromo, Eretria, Kirundi, and Amara. When asked for their countries of origin, respondents most commonly cited the United States (212), Iraq (205), Somalia (157), The Democratic Republic of Congo (81), Djibouti (70), Kenya (30), and Mexico (29).

Other countries of origin mentioned included Rwanda, Ethiopia, Angola, Syria, Guatemala, South Africa, Palestine, Puerto Rico, Morocco, Afghanistan, El Salvador, Nigeria, Canada, Burundi, Eritrea, France, Honduras, Uganda, Jamaica, Mali, Gabon, Sudan, Nicaragua, Peru, and Brazil.

The survey was an adaptation of the City of Portland's Minority Health Program Survey conducted in 2009, 2011, 2014, and 2018. In 2021, a small group of stakeholders convened to adapt this survey to meet the needs of the Maine Shared CHNA. This group included those who deployed the survey as well as other interested parties.

Groups that piloted these new outreach methods were offered stipends for their time.

Due to concerns related to COVID-19, community engagement efforts were conducted virtually except for the event for the Deaf and Hard of Hearing, which was held in a gymnasium at the Governor Baxter School for the Deaf on Mackworth Island. Oral surveys were conducted telephonically or by following current U.S. CDC COVID-19 protocols.

Community engagement was supported by John Snow, Inc. (JSI), which also conducted the initial qualitative analysis. All support materials including Data Profiles and PowerPoints produced by Market Decisions Research.

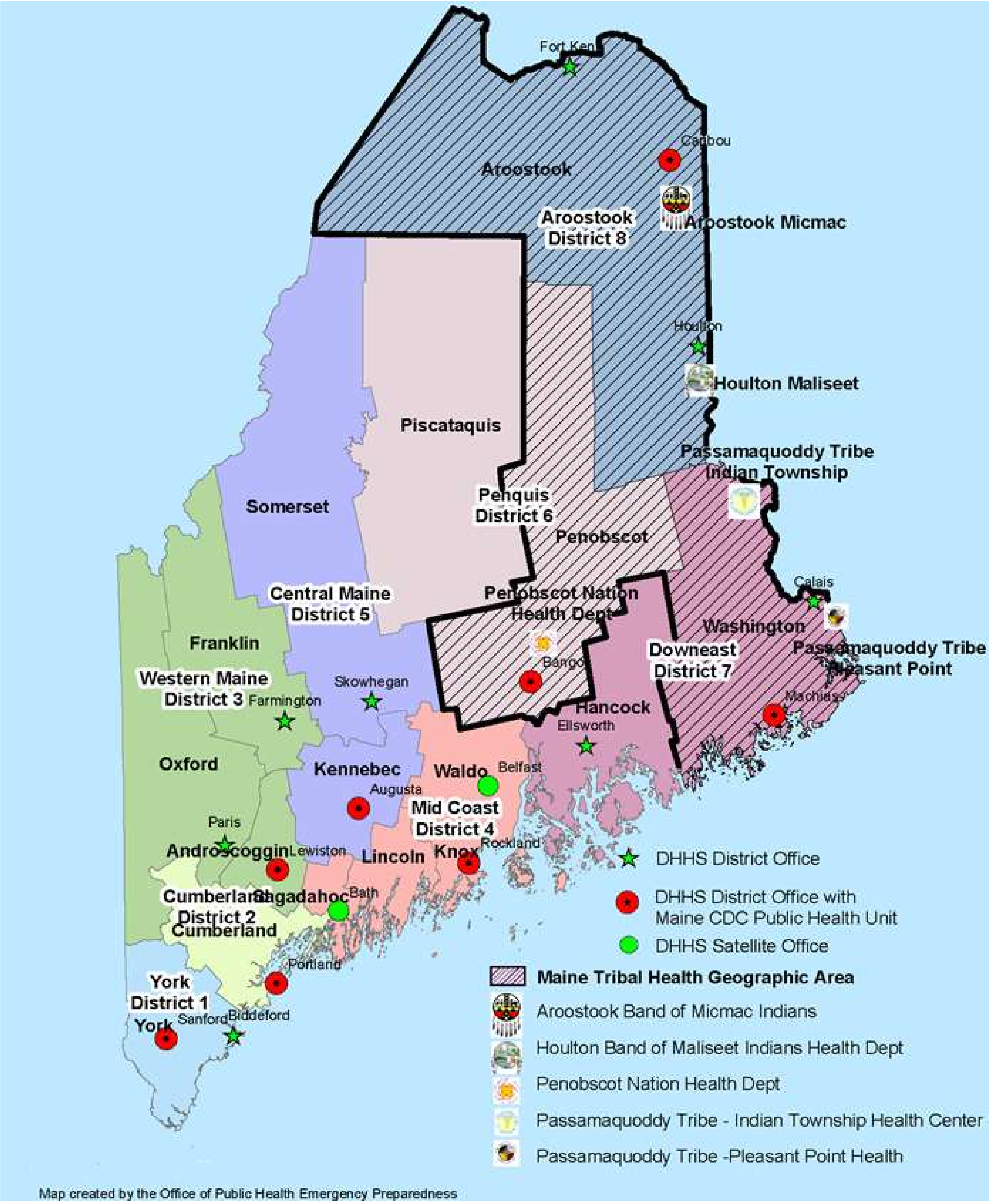
Reporting

Initial analysis for each event and the oral surveys were reviewed by local hosts for accuracy and to ensure the information the community may find sensitive was flagged. Final CHNA reports for the state, each county, and districts were developed in the spring of 2022. Final Reports were written and produced by Market Decisions Research.

In addition to Urban, County, and Health District reports, the data is also available on an Interactive Data Portal. The data in the portal is arranged by health topic and provides county and state-level data, as well as demographic comparisons, trends over time, definitions, and information on the data sources. Visit www.mainechna.org and click on Interactive Data in the menu to the left. The Maine Shared CHNA website is hosted by the Maine DHHS. (www.mainechna.org).

For a complete listing of organizations consulted please see the Acknowledgements found on the Maine Shared CHNA website, www.mainechna.org.

APPENDIX: PUBLIC HEALTH DISTRICTS*



Map created by the Office of Public Health Emergency Preparedness

*Map courtesy of Maine Department of Health and Human Services. Last accessed 7/5/2022: https://www.maine.gov/dhhs/mecdc/public-health-systems/scc/images/dhhs-districts_020618.jpg

Table 58. Public Health Districts and Hospitals (*Critical Access Hospitals, **Behavioral Health Hospitals)

PUBLIC HEALTH DISTRICTS	HOSPITALS
District 1, York	
York County	• Southern Maine Health Care, MaineHealth, Biddeford & Sanford • York Hospital, York
District 2: Cumberland	
Cumberland County	• Barbara Bush Children's Hospital, MaineHealth, Portland • Bridgton Hospital, Central Maine Healthcare, Bridgton* • Maine Medical Center, MaineHealth, Portland • Northern Light Mercy Hospital, Portland • New England Rehabilitation, MaineHealth, Portland • Spring Harbor Hospital, MaineHealth, Westbrook**
District 3, Western	
Androscoggin County	• Central Maine Medical Center, Central Maine Healthcare, Lewiston • St. Mary's Regional Medical Center, Lewiston
Oxford County	• Rumford Hospital, Central Maine Healthcare, Rumford* • Stephens Memorial Hospital, MaineHealth, Norway*
Franklin County	• Franklin Memorial Hospital, MaineHealth, Farmington
District 4, Midcoast	
Sagadahoc County	• Mid Coast Hospital, MaineHealth, Brunswick
Lincoln County	• LincolnHealth, MaineHealth, Damariscotta*
Waldo County	• Waldo County General Hospital, MaineHealth, Belfast*
Knox County	• Pen Bay Medical Center, MaineHealth, Rockport
District 5, Central	
Kennebec County	• MaineGeneral Health, Augusta • Northern Light Inland Hospital, Waterville • Riverview Psychiatric Center, Augusta**
Somerset County	• Redington-Fairview General Hospital, Skowhegan* • Northern Light Sebasticook Valley Hospital, Pittsfield*
District 6, Penquis	
Penobscot County	• Millinocket Regional Hospital, Millinocket* • Northern Light Eastern Maine Medical Center, Bangor • Northern Light Acadia Hospital, Bangor** • Dorothea Dix Psychiatric Center, Bangor** • Penobscot Valley Hospital, Lincoln* • St. Joseph Hospital, Bangor
Piscataquis County	• Northern Light Mayo Hospital, Dover-Foxcroft* • Northern Light CA Dean Hospital, Greenville*
District 7, Down East	
Washington	• Calais Community Hospital, Calais* • Down East Community Hospital, Machias*
Hancock County	• Mount Desert Island Hospital, Bar Harbor* • Northern Light Blue Hill Hospital, Blue Hill* • Northern Light Maine Coast Hospital, Ellsworth
Aroostook County	• Cary Medical Center, Caribou • Houlton Regional Hospital, Houlton* • Northern Light AR Gould Hospital, Presque Isle • Northern Maine Medical Center, Fort Kent
District 9, Tribal	
Aroostook, Penobscot, and Washington Counties	• This is a population-based district. There are five tribal health facilities located in Aroostook, Penobscot, and Washington Counties.

ACKNOWLEDGMENTS

Funding for the Maine Shared CHNA is provided by the partnering health care systems with generous support from the Maine CDC and countless community partners and stakeholder groups. Additional funding was provided by the Maine Health Access Foundation and the Maine CDC to pilot the additional outreach methods to reach those whose voices would not be distinctly heard otherwise. The Maine Shared CHNA is also supported in part by the U.S. Centers for Disease Control and Prevention (U.S. CDC) of the U.S. Department of Health and Human Services (U.S. DHHS) as part of the Preventive Health and Health Services Block Grant (awards NB01OT009343-01 & NB01OT009413-01). The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by the U.S. CDC/HHS, or the U.S. Government.

The infrastructure for community-led efforts is gaining strength. We are grateful to those who put their trust in the Maine Shared Community Health Needs Assessment process. Together, the MSCHNA and each of our community hosts have strived to ensure their voices are reflected herein:

Oral Survey Sponsors

Capital Area New Mainers Project
City of Portland's Minority Health Program
Gateway Community Services
Maine Access Immigrant Network
Maine Community Integration
Maine Department of Health and Human Services*
Maine Immigrant and Refugee Services
Mano en Mano
New England Arab American Organization
New Mainers Public Health Initiative

Community Event Sponsors

Consumer Council System of Maine
Disability Rights Maine
Green A.M.E. Zion Church
Health Equity Alliance
Maine Continuum of Care
Maine Council on Aging
Maine Primary Care Association
Maine Youth Action Network

*Includes the Manager of Diversity, Equity, and Inclusion and the Maine CDC.

Months of planning were conducted by stakeholder groups including the Metrics Committee, Data Analysis Team, Community Engagement Committee, Health Equity Committee, and Local Planning teams. For a complete listing please visit the Maine Shared CHNA website About Us page. Significant analysis was conducted by epidemiologists at the Maine CDC and the University of Southern Maine's Muskie School of Public Service. Market Decisions Research provided quantitative and qualitative analysis, as well as design and production support. John Snow, Inc. (JSI) provided methodology, community engagement, and qualitative analysis expertise and support. The oral survey was adapted from the City of Portland's Minority Health

Funding for the Maine Shared CHNA is provided by the partnering health care systems with generous in-kind support from the Maine CDC and countless community partners and stakeholder groups. These stakeholder groups include the Metrics Committee, Data Analysis Team, Community Engagement Committee, and of coursethe Steering Committee. Special thanks to the Maine Health Data Organization. Market Decisions Research (MDR) of Portland, Maine, and JSI served as the contractors for this project. For a complete listing please visit www.mainechna.org.

Significant analysis was conducted by epidemiologists at the Maine CDC and the University of Southern Maine's Muskie School of Public Service. Market Decisions Research provided analysis, methodology, and design support.

Department of Health and Human Services

State of Maine
Infectious Disease Prevention Program
2022 Workforce Survey Report

Tara B. Thomas, MFA
Data & Quality Specialist
Ryan White Part B Program

Introduction

The 2022 Workforce Survey consisted of electronic surveys conducted via anonymous Microsoft Forms for HIV Case Managers and HIV Prevention Partners as well as a brief paper survey mailed to primary care practices throughout Maine.

Survey instruments were based on prior surveys that had been developed by the Program to glean information about competencies and common practices.

The HIV Case Manager Training Survey was developed based on prior surveys distributed in September 2017, September 2018, and September 2019. The survey link was sent by email to all HIV Case Managers in February 2022. A total of 11 responses were received. Data from this survey were presented during the Spring 2022 Case Manager Training hosted by the Ryan White Part B Program on March 25, 2022.

The HIV Prevention Partner Survey link was sent by email to HIV/STD prevention and harm reduction partners in June 2022. A total of 16 responses were received.

The Health Care Provider Survey was sent by U.S. mail to primary care practices in April 2022. A total of 11 responses were received, primarily from practices in more rural counties:

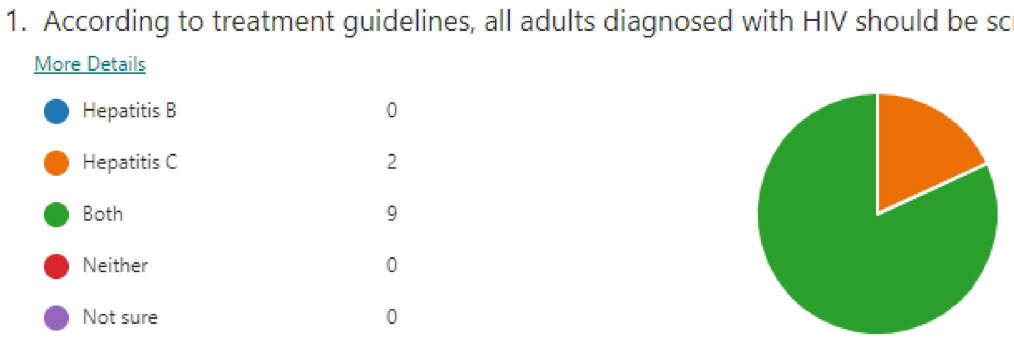
- Androscoggin
- Aroostook
- Hancock
- Lincoln
- Oxford
- Sagadahoc
- Somerset
- Washington (2)
- York (2)

These data may be a useful adjunct to the *Office of MaineCare Services HIV/AIDS Waiver 2020 Provider Survey Analysis*.

HIV Case Manager Training Survey

HIV Treatment Guidelines

Most respondents (82%) knew that the HIV Treatment Guidelines recommend all adults diagnosed with HIV be screened for both Hepatitis B and Hepatitis C. In 2017, 75% of respondents were aware of this.

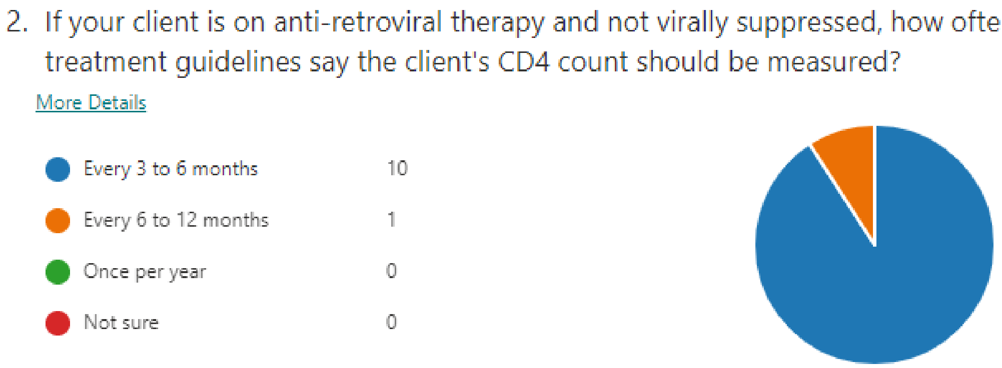


1. According to treatment guidelines, all adults diagnosed with HIV should be screened for:

More Details

● Hepatitis B	0
● Hepatitis C	2
● Both	9
● Neither	0
● Not sure	0

Nearly all respondents (91%) knew that clients who are on antiretroviral therapy and not virally suppressed should have their CD4 count measured every 3 to 6 months, compared to 67% of respondents in 2017.

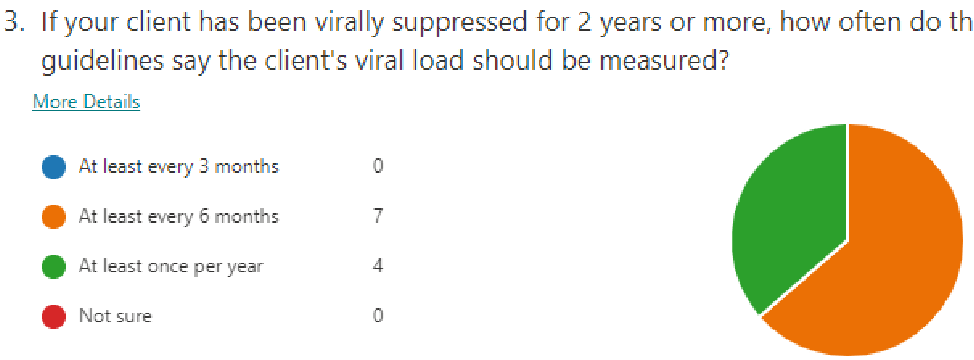


2. If your client is on anti-retroviral therapy and not virally suppressed, how often do the adult treatment guidelines say the client's CD4 count should be measured?

More Details

● Every 3 to 6 months	10
● Every 6 to 12 months	1
● Once per year	0
● Not sure	0

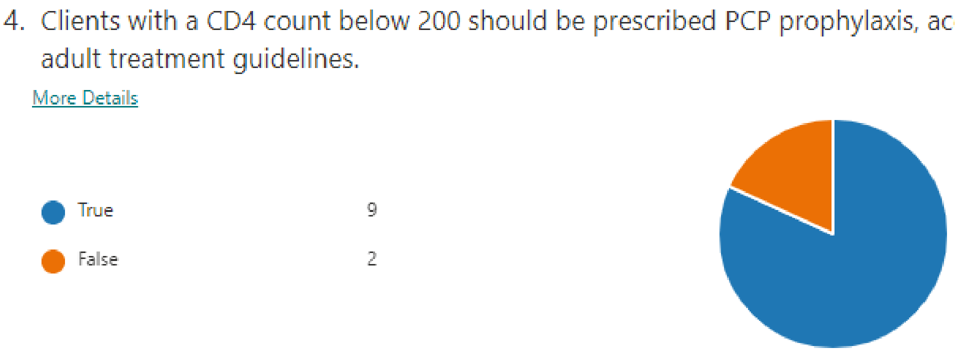
A majority of respondents (64%) knew that clients who have been virally suppressed for 2 years or more should have their viral load measured at least every 6 months, according to the treatment guidelines. Only 17% of respondents answered this question correctly in 2017.



3. If your client has been virally suppressed for 2 years or more, how often do the adult treatment guidelines say the client's viral load should be measured?

● At least every 3 months	0
● At least every 6 months	7
● At least once per year	4
● Not sure	0

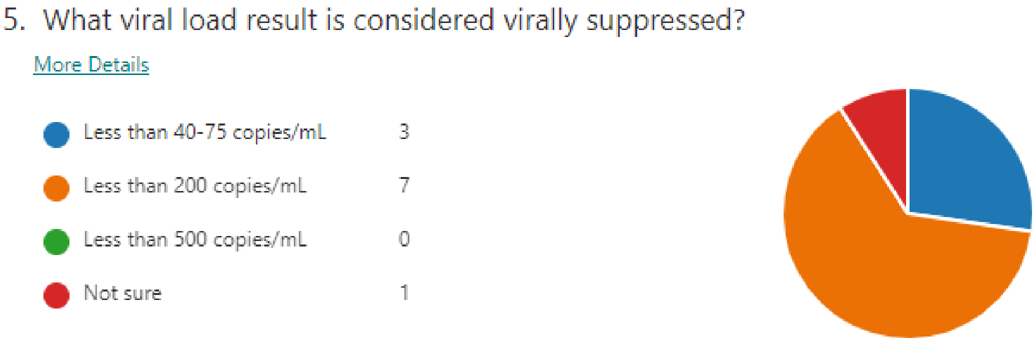
Most respondents (82%) knew that PCP prophylaxis is recommended for all clients with a CD4 count below 200, compared to 58% in 2017.



4. Clients with a CD4 count below 200 should be prescribed PCP prophylaxis, according to the adult treatment guidelines.

● True	9
● False	2

A majority of respondents (64%) knew that a viral load <200 copies/mL is considered virally suppressed, compared to 50% of respondents in 2017.

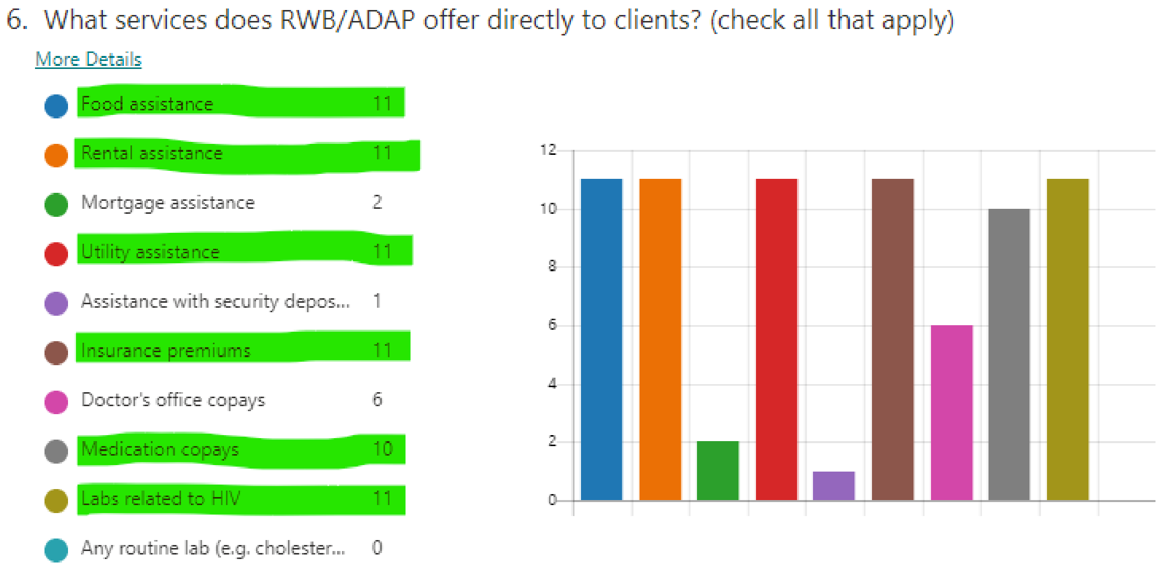


5. What viral load result is considered virally suppressed?

● Less than 40-75 copies/mL	3
● Less than 200 copies/mL	7
● Less than 500 copies/mL	0
● Not sure	1

Ryan White Part B and ADAP

Nearly all respondents answered correctly when asked to identify services that RWB/ADAP offers directly to clients. (Correct answers highlighted in green below.)

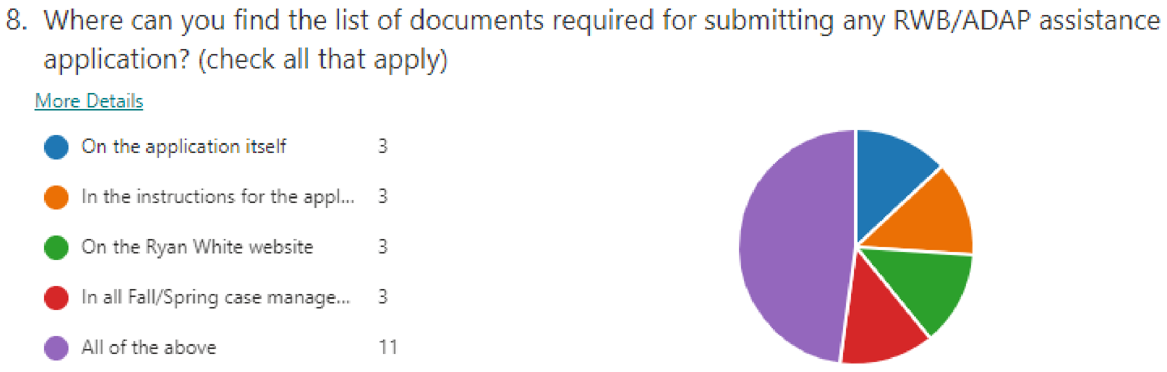


6. What services does RWB/ADAP offer directly to clients? (check all that apply)

More Details

●	Food assistance	11
●	Rental assistance	11
●	Mortgage assistance	2
●	Utility assistance	11
●	Assistance with security depos...	1
●	Insurance premiums	11
●	Doctor's office copays	6
●	Medication copays	10
●	Labs related to HIV	11
●	Any routine lab (e.g. cholester...	0

All respondents knew where to find the list of required documents for applications:

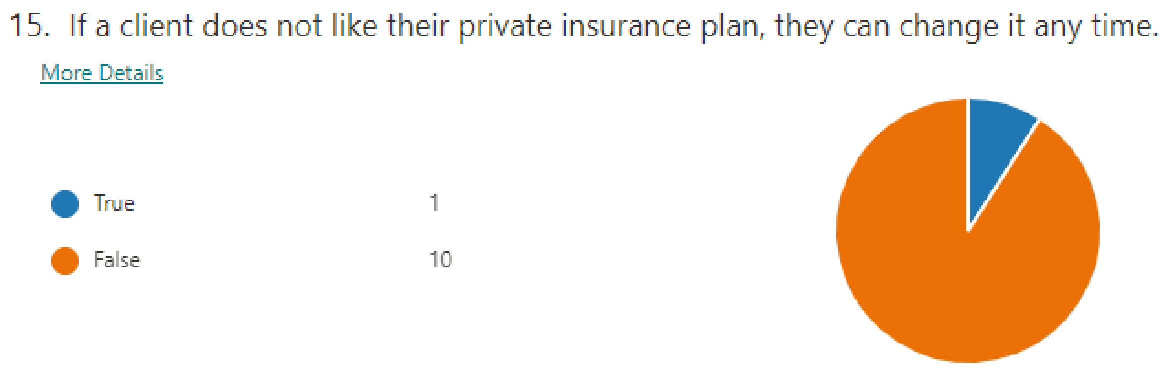


8. Where can you find the list of documents required for submitting any RWB/ADAP assistance application? (check all that apply)

More Details

●	On the application itself	3
●	In the instructions for the appl...	3
●	On the Ryan White website	3
●	In all Fall/Spring case manage...	3
●	All of the above	11

Nearly all respondents knew that if a client does not like their private insurance plan, they cannot change it outside of open/special enrollment periods:

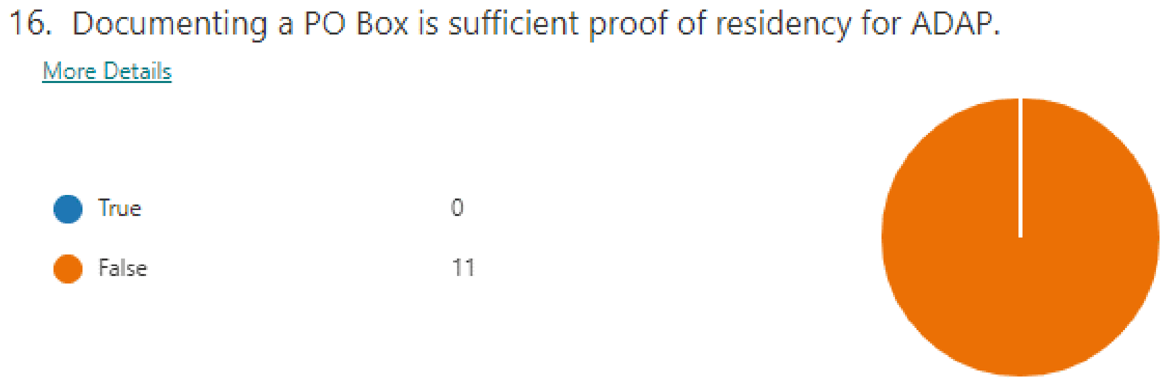


15. If a client does not like their private insurance plan, they can change it any time.

More Details

● True	1
● False	10

All respondents knew that post office boxes are not sufficient proof of residency for the Ryan White Part B Program:

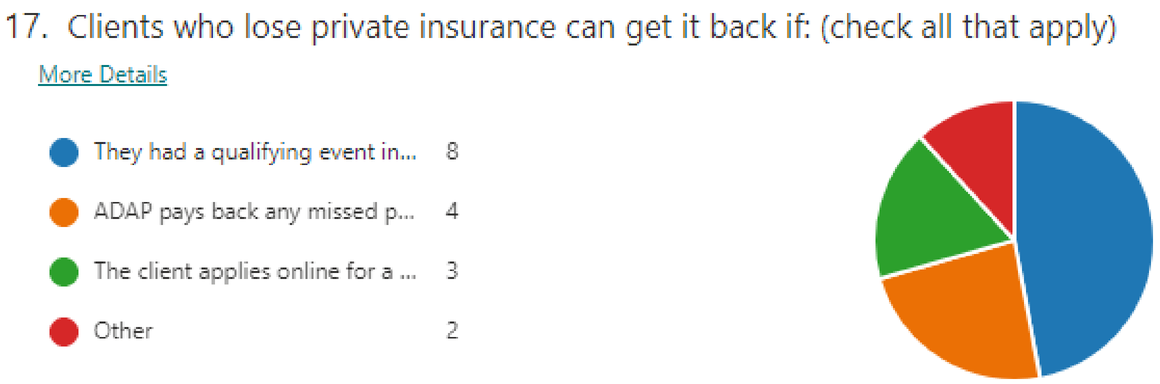


16. Documenting a PO Box is sufficient proof of residency for ADAP.

More Details

● True	0
● False	11

Responses varied (and showed general confusion) about the ways people can get private insurance back if they lose it:

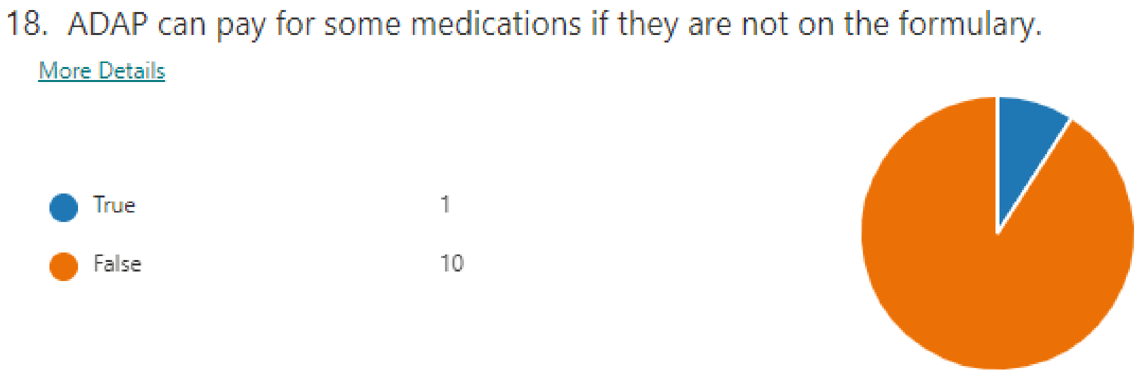


17. Clients who lose private insurance can get it back if: (check all that apply)

More Details

● They had a qualifying event in...	8
● ADAP pays back any missed p...	4
● The client applies online for a ...	3
● Other	2

Nearly all respondents knew that ADAP cannot pay for medications that are not on the formulary:



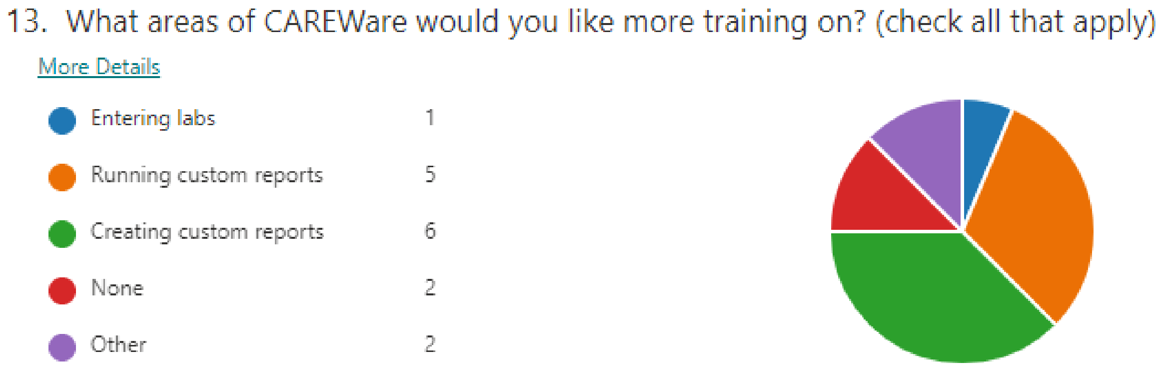
18. ADAP can pay for some medications if they are not on the formulary.

More Details

●	True	1
●	False	10

CAREWare

Generally, the vast majority of respondents were aware of proper CAREWare documentation procedures and where to look for information. Most respondents want training on creating and running custom reports:

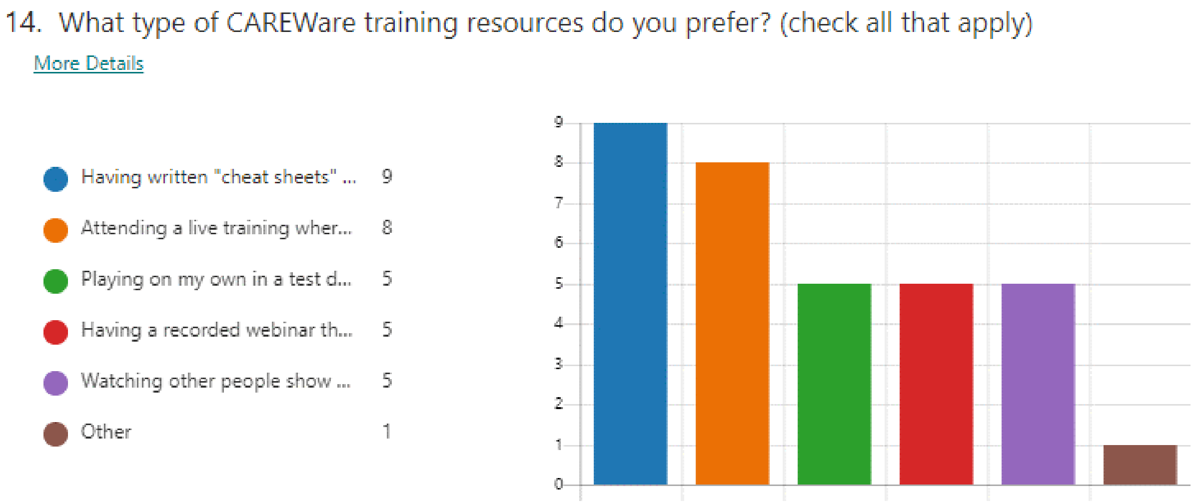


13. What areas of CAREWare would you like more training on? (check all that apply)

More Details

●	Entering labs	1
●	Running custom reports	5
●	Creating custom reports	6
●	None	2
●	Other	2

Written cheat sheets and live trainings are the most popular CAREWare training resources:



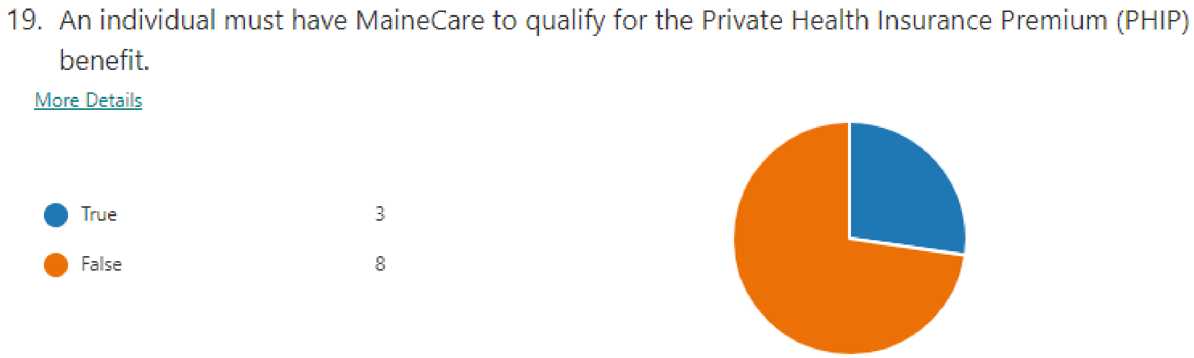
14. What type of CAREWare training resources do you prefer? (check all that apply)

More Details

●	Having written "cheat sheets" ...	9
●	Attending a live training wher...	8
●	Playing on my own in a test d...	5
●	Having a recorded webinar th...	5
●	Watching other people show ...	5
●	Other	1

MaineCare

Only 27% of respondents knew that people must have MaineCare in order to qualify for the Private Health Insurance Premium Benefit (PHIP):

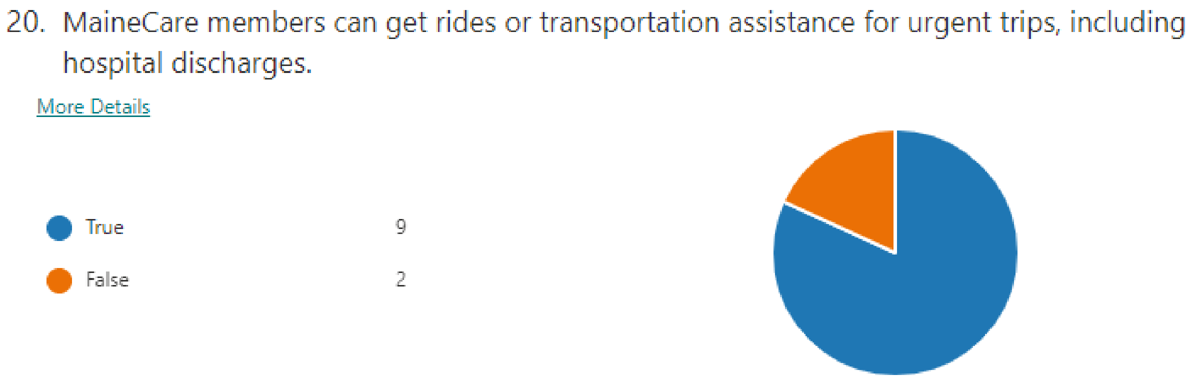


19. An individual must have MaineCare to qualify for the Private Health Insurance Premium (PHIP) benefit.

More Details

●	True	3
●	False	8

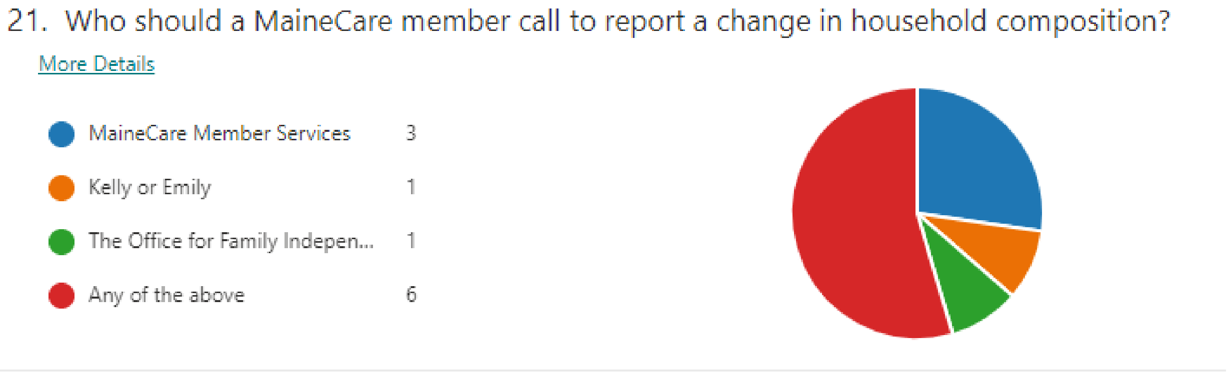
Most respondents (82%) knew that MaineCare members can get rides or transportation assistance for urgent trips:



20. MaineCare members can get rides or transportation assistance for urgent trips, including hospital discharges.

●	True	9
●	False	2

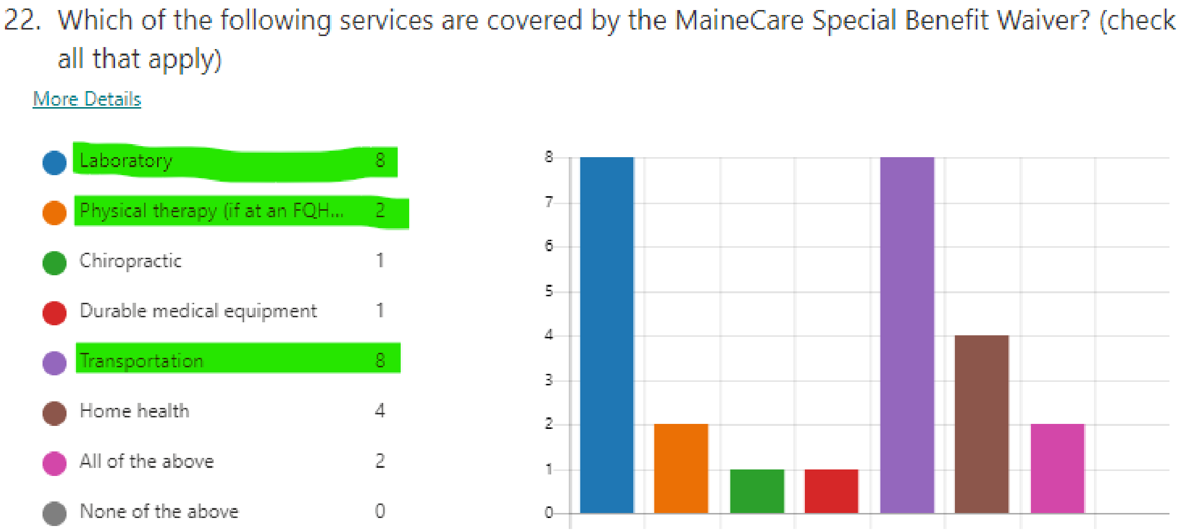
Previous trainings underscored that case managers could contact MaineCare Member Services, the Office for Family Independence (OFI), or Special Benefit Waiver (SBW) staff to report changes in household composition. However, guidance has changed and now OFI alone is the preferred contact:



21. Who should a MaineCare member call to report a change in household composition?

●	MaineCare Member Services	3
●	Kelly or Emily	1
●	The Office for Family Indepen...	1
●	Any of the above	6

Most respondents knew that the SBW covers labs and transportation, but fewer were aware that physical therapy is covered at federally-qualified health centers. Some responses indicated that not all case managers are aware of what the SBW does and does not cover:



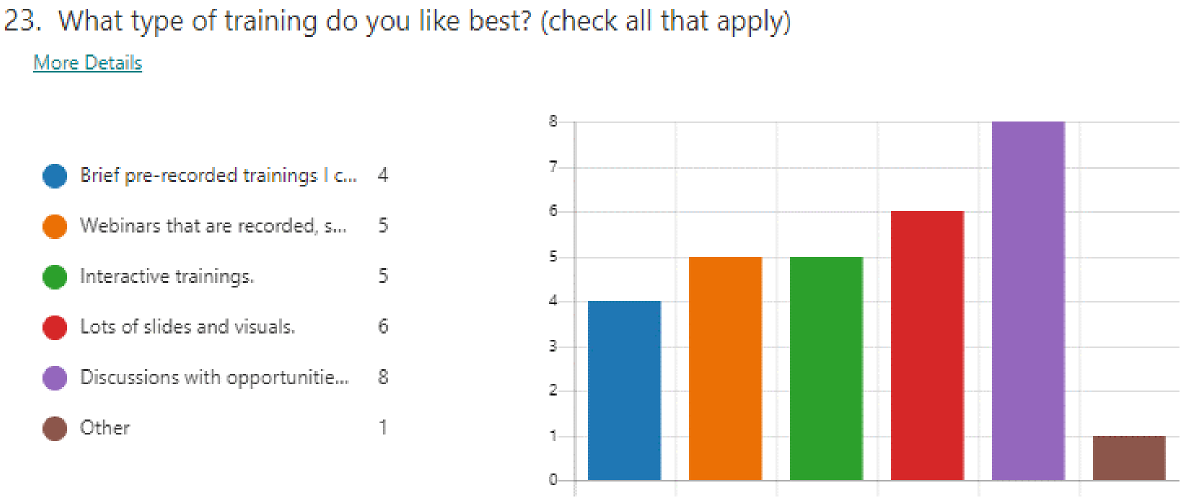
22. Which of the following services are covered by the MaineCare Special Benefit Waiver? (check all that apply)

More Details

Laboratory	8
Physical therapy (if at an FQH...	2
Chiropractic	1
Durable medical equipment	1
Transportation	8
Home health	4
All of the above	2
None of the above	0

Training Preferences

The most-preferred type of training was discussions with opportunities to ask questions, followed by lots of slides and visuals.

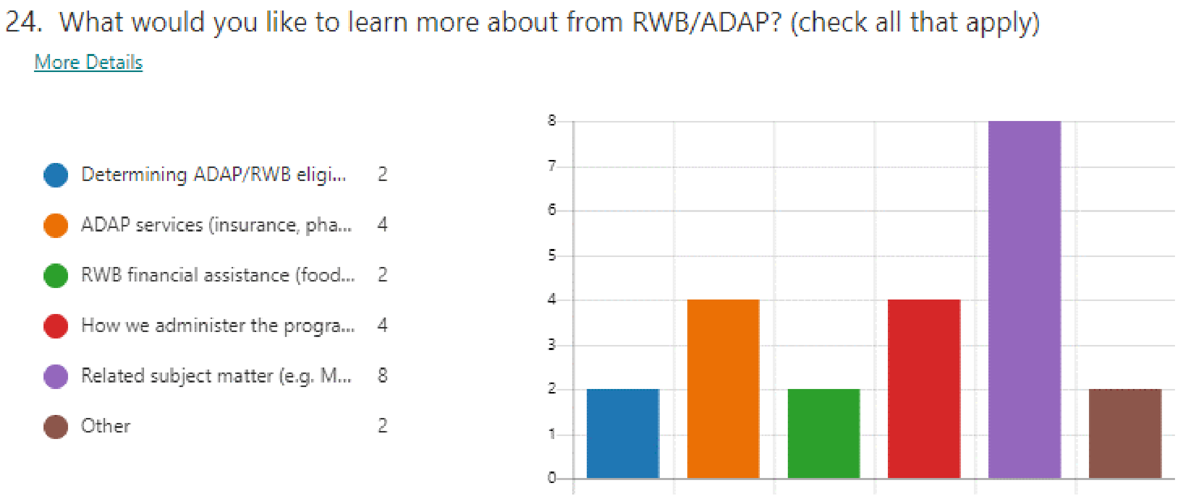


23. What type of training do you like best? (check all that apply)

More Details

Brief pre-recorded trainings I c...	4
Webinars that are recorded, s...	5
Interactive trainings.	5
Lots of slides and visuals.	6
Discussions with opportunitie...	8
Other	1

Most respondents are interested in training on related subject matter (such as MaineCare, low-income dental care, interpreter services, pre-natal care while living with HIV, etc.).

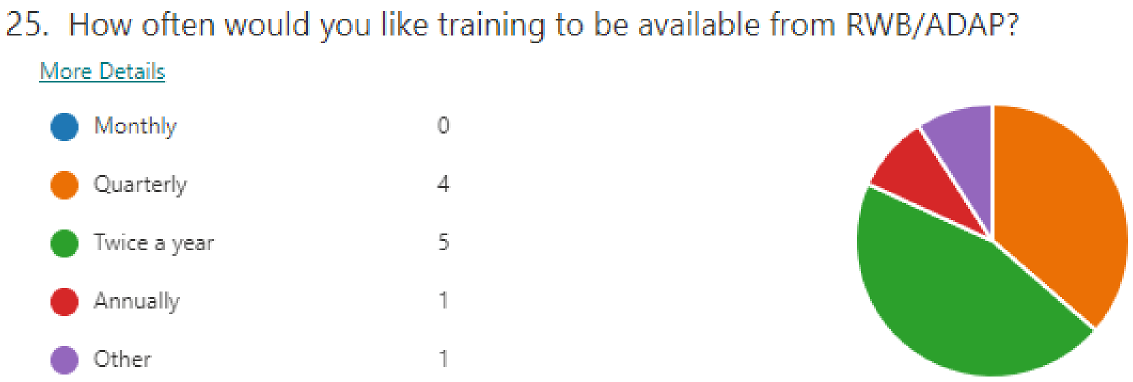


24. What would you like to learn more about from RWB/ADAP? (check all that apply)

More Details

●	Determining ADAP/RWB eligi...	2
●	ADAP services (insurance, pha...	4
●	RWB financial assistance (food...	2
●	How we administer the progra...	4
●	Related subject matter (e.g. M...	8
●	Other	2

About half of respondents would like quarterly training while about half would like training twice a year:



25. How often would you like training to be available from RWB/ADAP?

More Details

●	Monthly	0
●	Quarterly	4
●	Twice a year	5
●	Annually	1
●	Other	1

Key Informant Data

What would you identify as the top two or three challenges the clients on your caseload must face?

- Housing (7)
- Financial stability (5)
- Transportation (4)
- Food (3)
- Mental health (3)
- Systems navigation/knowledge of resources (2)
- Ability to use technology
- Aging
- Communication
- Finding a good PCP
- Internet access
- Stigma

What is the top unmet need you see for your clients?

- Housing (5)
- Transportation (2)
- Financial insecurity (2)
- Food insecurity
- In-home support services

One respondent wrote, "I'm concerned about the number of clients not getting their labs drawn regularly."

What more do you think the HIV service community in Maine could do to help people living with HIV become virally suppressed or stay virally suppressed?

- Reduce stigma (3)
    - more public education, outreach
- Improved access to transportation (2)
- Meet all basic needs first (2)
    - increase caps for assistance to account for inflation
- Increase case management capacity (2)
    - more frequent contact between clients and CMs, hire more CMs
- Free, drop-in medication counseling times
- Inspire hope
- More stigma-free testing access, pop-up sites
- Make medications more accessible
    - Pharmacies in rural areas may not stock ARVs and only order as needed

What more do you think the HIV service community in Maine could do to help prevent new HIV infections?

- Outreach/education (6)
    - Increase mobile testing
    - More outreach to younger people
    - Awareness programs in provider offices, schools, etc.
    - Media campaigns
    - In-person trainings with care providers
- More HIV testing (2)
- Early treatment for people testing positive
- More advertising for PREP and referrals for partners
- Double down on harm reduction
- Better/more accessible treatment for substance use disorders
- On-site needle exchange

What do you think the HIV service community in Maine could do to reduce disparities and health inequities?

- Transportation
- More telehealth options
- Widespread education and training efforts
- Cultural competency training
- Educating primary care providers
- Expanding health insurance coverage
- Talk about it, address it, and have more people of color in the room and in the State level
- Reaching out to all clients on a minimum of a weekly basis, rather than expecting clients to reach out to their medical case managers, as there are some clients who will not reach out, even when they need help
- Provide unconditional support and guidance to new agencies, promote and actively engage in increasing access to care
- ADAP needs to be more expansive and have looser regulations

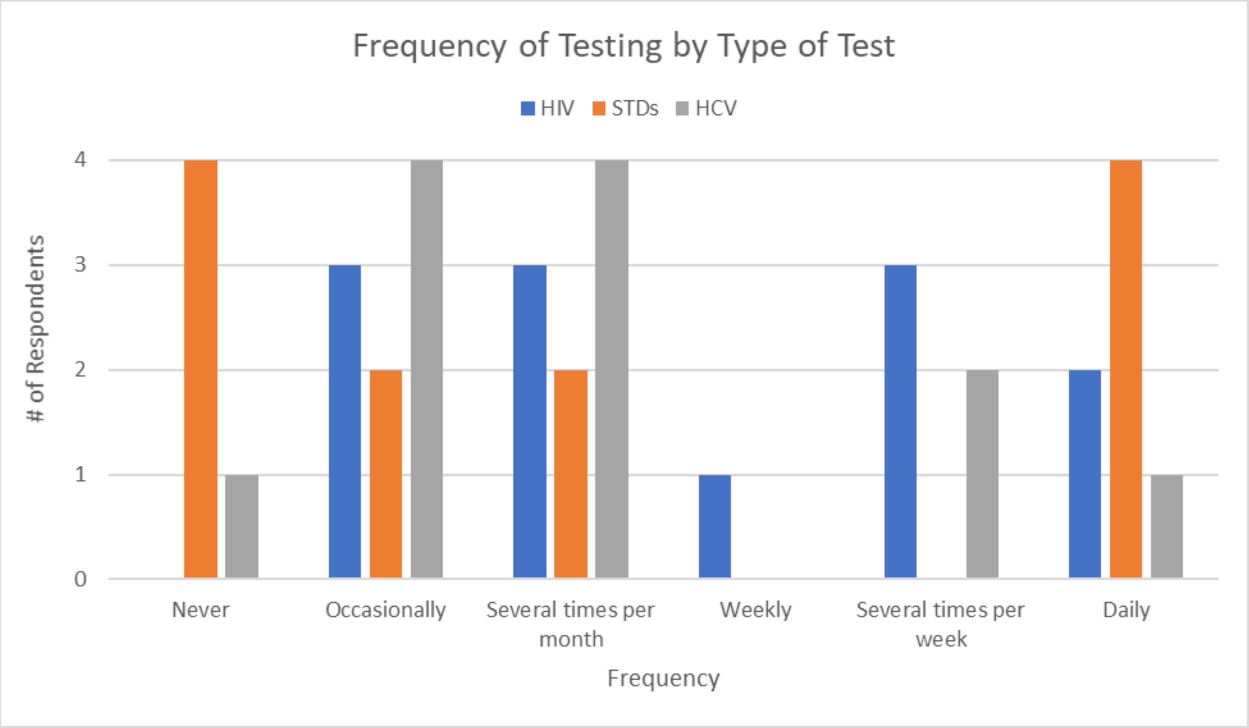
How do you think the HIV service community in Maine could be better coordinated to allow for integrated access to services your clients need?

- Increased communication (5)
- Increased coordination (3)
    - Several suggestions related to integrated provider meetings/opportunities for communication/coordination between community partners and RW
- More remote access to services
- Low-barrier services with an emphasis on being more welcoming and inclusive
- MaineCare allowing for CM transportation in areas where Logisticare is less reliable

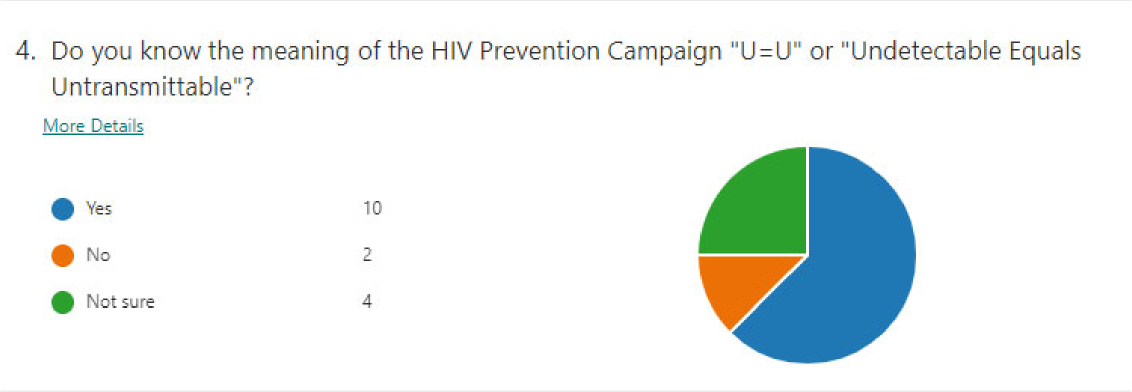
HIV Prevention Partner Survey

Services

Three respondents indicated that they never test people fro HIV, STDs, or HCV. One respondent was a new employee still in training. Of the remaining respondents, all perform HIV testing at least occasionally, most respondents perform at least some HCV testing, and the widest variation was among those who provide STD testing:



While most respondents indicated that they know the meaning of the U=U Campaign, it appears to be an area where more training may be needed:

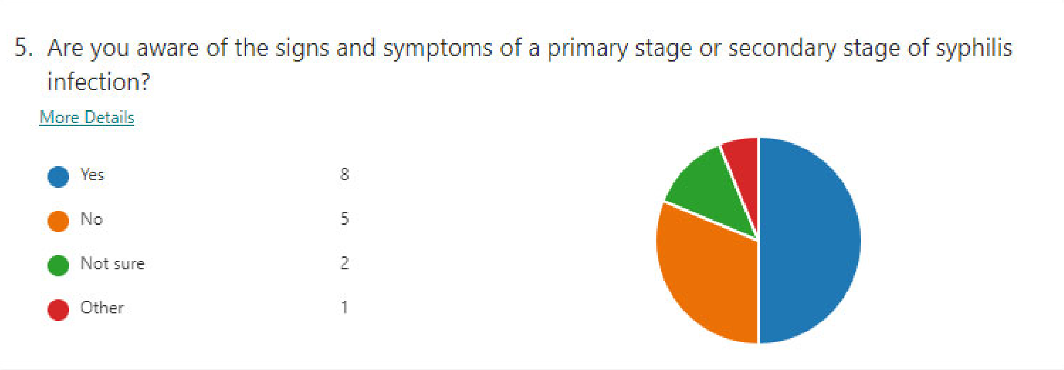


4. Do you know the meaning of the HIV Prevention Campaign "U=U" or "Undetectable Equals Untransmittable"?

More Details

● Yes	10
● No	2
● Not sure	4

The same may be said about signs and symptoms of syphilis:

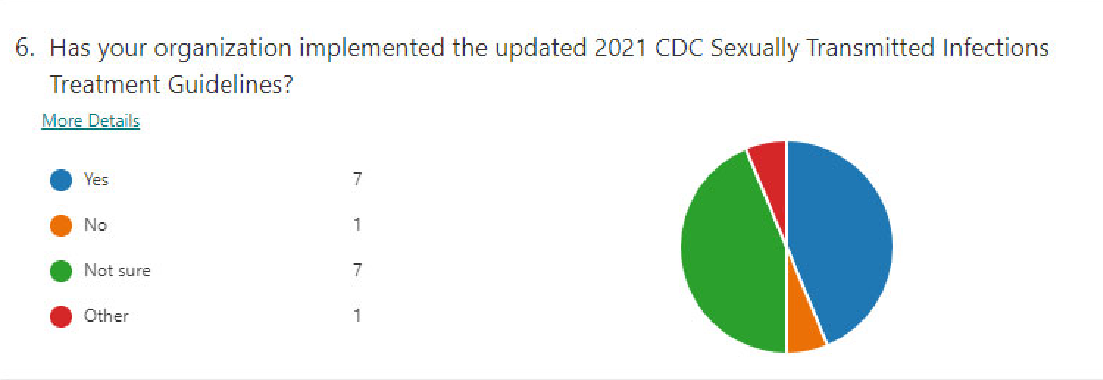


5. Are you aware of the signs and symptoms of a primary stage or secondary stage of syphilis infection?

More Details

●	Yes	8
●	No	5
●	Not sure	2
●	Other	1

Less than half of respondents (7/16) indicated that their organization has implemented the updated 2021 CDC Sexually Transmitted Infections Treatment Guidelines:



6. Has your organization implemented the updated 2021 CDC Sexually Transmitted Infections Treatment Guidelines?

More Details

●	Yes	7
●	No	1
●	Not sure	7
●	Other	1

At a minimum, most organizations offer external condoms and lubricant to their clients:

7. What safer sex materials do you/your organization offer to clients? (check all that apply)

More Details

●	External condoms	14
●	Internal condoms	9
●	Dental dams	9
●	Lubricant	13
●	Latex-free condoms	12
●	Other	1

Most respondents (88%) indicated that their organization offers harm reduction services.

Some ways respondents/their organizations make people with diverse backgrounds feel comfortable include:

- Offering compassionate care (10)
- Staff training (5)
- Cultivating a welcoming space (5)
  - Some examples include signage, universal bathrooms, gender neutral color schemes
- Offering interpreter services (4)
- Offering translated materials (2)
- Asking pronouns (2)
- Offering LGBTQ-specific materials (1)
- Offering items to meet basic needs (1)

About 63% of respondents (10/16) indicated that they ask a sexual history with all clients. Some of the ways they elicit answers about sexual history include:

- Risk assessment (8)
- Asking what type of sex they have (6)
- Asking what type of partners they have (5)
- Using open-ended questions (4)
- Asking about sexual orientation (2)
- Asking about gender identity (2)
- Asking about non-consensual contact (2)
- Asking number of partners (2)

In addition, three respondents indicated that they do not conduct in-depth sexual histories with clients.

Referrals

All respondents (100%) indicated that they know where to refer people for further testing and/or treatment for HIV/HCV/STDs while 88% (14/16) indicated that they know where to refer clients who need harm reduction services.

All respondents indicated some level familiarity with local resources to make referrals for social supports, as needed.

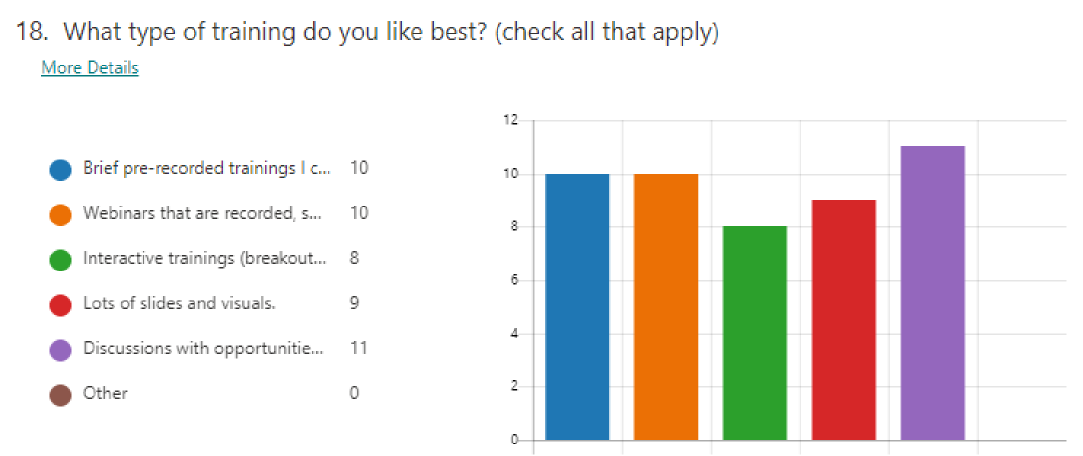
Most respondents (63%) indicated that there are not services they want to be able to refer clients to but don’t know where they might be available. The remaining respondents indicated the following unmet need areas:

- Additional housing support (2)
- Detox/treatment programs (2)
- Mental and behavioral health (2)

- Assistance with vehicle-related expenses (2)
- Utilities assistance (1)
- Dental care (1)
- Day shelters (1)
- Help for those who are transitioning (1)
- Q+ health referrals (1)
- Bridge programs (1)
- Harm reduction-based grief support (1)

Training Preferences

The most popular training types were discussions with opportunities for questions and recorded webinars, followed by brief pre-recorded trainings, webinars that are recorded for people to watch later, if needed:

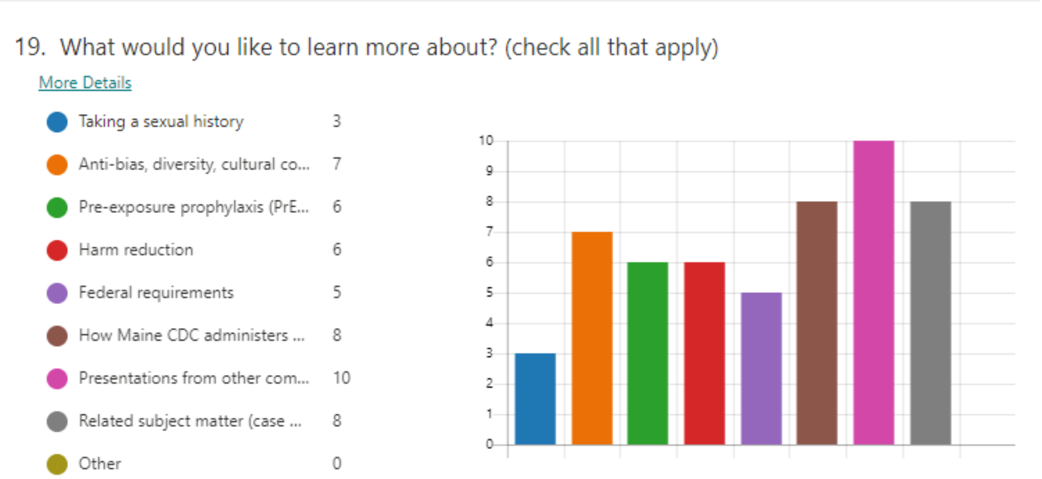


18. What type of training do you like best? (check all that apply)

More Details

● Brief pre-recorded trainings I c...	10
● Webinars that are recorded, s...	10
● Interactive trainings (breakout...	8
● Lots of slides and visuals.	9
● Discussions with opportunitie...	11
● Other	0

The most popular topics for training were presentations from other community organizations and related subject matter (such as case management, Ryan White/ADAP):

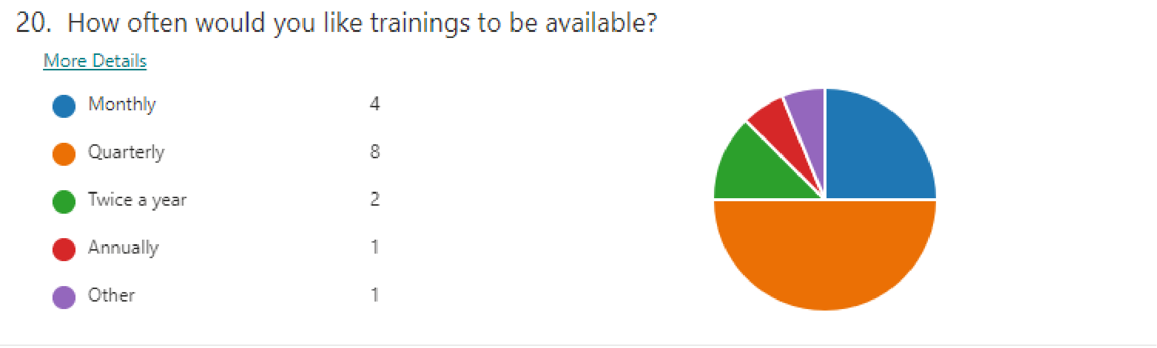


19. What would you like to learn more about? (check all that apply)

More Details

● Taking a sexual history	3
● Anti-bias, diversity, cultural co...	7
● Pre-exposure prophylaxis (PrE...	6
● Harm reduction	6
● Federal requirements	5
● How Maine CDC administers ...	8
● Presentations from other com...	10
● Related subject matter (case ...	8
● Other	0

Half (8/16) of respondents would like quarterly trainings:



20. How often would you like trainings to be available?

More Details

● Monthly	4
● Quarterly	8
● Twice a year	2
● Annually	1
● Other	1

Only 4 respondents (25%) indicated that their organization used volunteers for HIV/STD prevention services. Volunteer recruitment varies from local colleges to simple word of mouth. Each organization provides its own individualized trainings for volunteers.

Key Informant Data

What would you identify as the top two or three challenges your clients face?

- Housing (8)
- Financial security (7)
- Mental/behavioral health (3)
- Stigma (3)
- Transportation (3)
- Follow-up (2)
- Food insecurity (2)
- Lack of treatment/recovery options (2)
- Dental care
- Understanding the role of their case manager
- Referrals
- PrEP/PEP access and awareness
- Insurance
- Work/childcare
- Partner pressure
- Perception of risk
- Addiction
- Health care
- 24/7 SSP access

What is the top unmet need you see for your clients?

- Affordable housing (7)
- Mental/behavioral health (5)
- Health care (2)
- Affordability
- Lack of referral options
- Life skills
- Stability
- Transportation
- Treatment/recovery options

What more do you think the HIV service community in Maine could do to help people living with HIV become virally suppressed or stay virally suppressed?

- Housing (3)
- More accessible health care (3)
- Adherence
- Identify early infections
- Rapid linkage to care
- Flexible funding
- Increased harm reduction services
- Reduced barriers to care
- Mobile treatment vans
- Shipping meds
- Telehealth
- Assistance with prescription medication
- Increase the number of mental health providers
- Increase the number of dental providers

What more do you think the HIV service community in Maine could do to help prevent new HIV infections?

- Increased prevention outreach and education (4)
- Promote/expand access to PrEP and PEP (3)
- Make safer sex supplies more available (2)
- Social media
- Expand self-test kit distribution
- Advocate for increased screening in clinic/primary care settings
- Increase access to clean syringes
- Increase the number of SSPs
- Increase SSP funding
- Allow SSPs to ship supplies
- More messaging about free services
- Make health care more accessible
- Housing
- Testing at all local colleges and large community events

What do you think the HIV service community in Maine could do to reduce disparities and health inequities?

- Continued education (5)
    - One respondent specifically identified Equity, Diversity, and Inclusion trainings
    - Another respondent specifically identified education to reduce stigma of HIV and active substance use
- More accessible health care (2)
- Free services
- Expanded resources for New Mainers
- Counseling and coaching

- Housing
- Offer mini grants to build campaigns specific to communities served
- "Engage with communities of color and work intentionally with the organizations that serve them to better understand the barriers they face to accessing healthcare and other services"

How do you think the HIV service community in Maine could be better coordinated to allow for integrated access to services your clients need?

- Integrated care settings (5)
- Reduce stigma
- More robust referral networks
- Increase awareness
- Streamlined multi-lingual online resources
- Capacity to support clients with computer literacy
- Housing
- Streamline follow-up/confirmation testing statewide
- Survey providers twice per year
- Improved communication
- "An all-in-one reference library with vetted and culturally diverse options for treatments"

What are the biggest barriers your organization has with implementing HIV or STD prevention interventions?

- Funding (4)
- Staffing challenges (4)
- No-shows (2)
- Stigma (2)
- Patient refusal
- Syphilis testing technology
- Decentralized services
- Recruitment for services
- Policy challenges
- Lack of relationships with other service providers
- Technical assistance
- Addressing the roots of spread
- Politics

What are the biggest barriers your organization faces when serving people at increased risk for HIV (men who have sex with men, people who use injection drugs, transgender individuals, and other groups)?

- Stigma (4)
- Recruitment for services (4)
- Funding (3)
- Cultural norms around risk-taking
- Making successful interventions

- Policy challenges
- Access
- Sufficient treatment/recovery options
- Workforce
- Community education

2022 Health Care Provider Survey

Please describe how likely your practice is to offer the following services:

	Never	Very Seldom	Sometimes	Frequently	Always
How often does your practice offer HIV testing to all of your patients between the ages of 13 and 64?	0%	9%	36%	36%	18%
How often does your practice perform routine HIV testing on patients at higher risk for HIV infection? Routine testing is defined as testing that occurs in regular intervals, e.g. 3 months, 6 months, 12 months.	9%	36%	18%	9%	27%
How often does your practice prescribe HIV Pre-Exposure Prophylaxis (PrEP) to patients at higher risk for HIV infection?	45%	36%	0%	9%	9%
How often does your practice prescribe HIV Post-Exposure Prophylaxis (PEP) to patients who have had a recent high-risk exposure to HIV?	36%	36%	0%	18%	9%
How often does your practice offer Hepatitis C Virus (HCV) testing to patients between the ages of 18 and 79?	0%	0%	18%	64%	18%
How often does your practice routinely test patients for Chlamydia and Gonorrhea (CT/GC)?	0%	0%	36%	36%	27%
How often does your practice offer extragenital (rectal and pharyngeal) CT/GC testing of patients?	9%	55%	9%	18%	9%
How often does your practice routinely test patients for syphilis?	9%	27%	36%	27%	0%
How often do providers interview their patients about the patient's sexual health history?	0%	9%	18%	45%	27%
How often does your practice treat patients for HCV?	45%	18%	18%	9%	9%
How often does your practice treat patients for HIV?	73%	9%	9%	0%	9%
How often does your practice treat patients for substance use disorders using medically-assisted treatment?	45%	9%	18%	9%	18%

How likely is your practice to incorporate injection treatments for HIV (e.g. Cabenuva)?

- 27% Will not incorporate injection treatments for HIV
- 45% Unlikely to incorporate injection treatments for HIV
- 18% May incorporate injection treatments for HIV
- 0% Very likely to incorporate injection treatments for HIV
- 9% Will definitely incorporate injection treatments for HIV

General Awareness Questions

General Awareness Questions	**Yes**	**No**
Are providers in your practice aware of the signs and symptoms of a primary stage or secondary stage of syphilis infection?	91%	9%
Do providers in your practice know the meaning of the HIV prevention campaign "Undetectable Equals Untransmittable"?	64%	36%
Has your practice implemented the updated 2021 CDC Sexually Transmitted Infections Treatment Guidelines?	82%	18%
Is your practice aware of the State of Maine AIDS Drug Assistance Program (ADAP)?	64%	36%
Is your practice aware of the State of Maine Ryan White Part B Program?	55%	45%
Is your practice aware of the Maine CDC Disease Intervention Specialists who follow up with patients diagnosed with gonorrhea, syphilis, and HIV?	73%	27%
Is your practice aware it can order free sexual health and educational materials from the Maine CDC? (materials may be ordered at https://www.maine.gov/dhhs/mecdc/infectious-disease/hiv-std/order-form-wn-hiv-std.shtml)	64%	36%
Does your practice offer Free Care, services at a discounted cost, or services at a sliding scale for uninsured patients or patients who have difficulty affording medical care?	100%	0%
Is your practice using the HIV Treatment Guidelines in managing your HIV-positive patients?	73%	27%
Does your practice have a referral system in place for newly diagnosed HIV positive patients to access medical case management services?	82%	18%

Where do you seek guidance on disease management for HIV, STDs, and Viral Hepatitis? (check all that apply)

- 82% US CDC
- 82% State of Maine CDC
- 64% Colleagues
- 64% Medical Literature
- 36% Internet Query

How often does your practice assess mental health needs?
(check all that apply)

- 82% Every time a patient presents at your practice
- 55% During a patient's annual physical
- 45% When a patient expresses concerns about their mental health
- 45% When a clinician is concerned about a patient's mental health

Narrative Questions

What are the biggest barriers your practice has with implementing HIV or STD prevention interventions (regular screening, prescribing PrEP, etc.)?
Transportation, lack of awareness, and staff capacity were the most common responses.

What are the biggest barriers your practice faces when serving people at increased risk for HIV (men who have sex with men, people who use injection drugs, transgender individuals, and other groups)?
Transportation was the most common response.

When needed, what are the steps you take to connect patients to social support services (like shelters, food pantries, case management, syringe service programs, etc.)?

- About half (45%) of respondents indicated that they have designated staff on site for this.
- Another 36% indicated that they have systems in place to provide referrals.
- The remaining respondent indicated that although they make referrals, there are not enough local programs.

Summary

In general, HIV Case Managers are knowledgeable about the HIV Treatment Guidelines and ADAP/Ryan White Part B Program policies and expectations, showing improvement from survey responses in 2017 despite significant turnover during that time. Ongoing training efforts appear to be working.

Training preference data show overlap between HIV Case Manager and Prevention Providers in terms of type of trainings, topics, and frequency. There may be opportunities to provide trainings for both groups simultaneously to better encourage collaboration and breakdown silos.

Housing and financial stability were the biggest challenges for clients identified by both HIV Case Managers and Prevention Providers, followed by transportation and mental health.

Affordable housing was the top unmet need identified by both HIV Case Managers and Prevention Providers.

The most common suggestions from HIV Case Managers and Prevention Providers for helping people living with HIV to become and stay virally suppressed were to reduce stigma and increase access to affordable housing.

The most common suggestions from HIV Case Managers and Prevention Providers for prevention new HIV infections were to increase outreach/education and promote/expand access to PrEP and PEP.

Continued education/training was the most common suggestion for reducing disparities and health inequalities from HIV Case Managers and Prevention Providers.

Increased communication and integrated care settings were the most common suggestions for better coordinating services from HIV Case Managers and Prevention Providers.

Health Care Provider survey results may indicate a need for increased outreach and education, particularly in the areas of:

- Best practices and ways to access PrEP and PEP
- Best practices related to extragenital testing for chlamydia and gonorrhea
- Best practices related to routine HIV testing
- The U=U campaign
- Resources available from Maine CDC’s Infectious Disease Prevention Program

Office of MaineCare Services

HIV/AIDS Waiver – 2020 Provider Survey Analysis

Background:

The Department of Health and Human Services, Office of MaineCare Services (OMS) operates an HIV/AIDS program under a waiver approved by the U.S. Centers for Medicare & Medicaid Services (CMS). This waiver allows the Department to provide limited MaineCare (Maine Medicaid) coverage to HIV-positive Maine residents who have an individual gross income less than or equal to 250% of the Federal Poverty Level (FPL), as well as providing care management to all HIV-positive MaineCare members, those with an individual income at or below 138% of the FPL. The HIV/AIDS waiver program began in July 2002 and CMS has approved it for renewal through December 31, 2028.

Survey Objective:

The goal of the Provider Survey is to gather feedback and find areas for improvement so that the program effectively supports providers and thereby improves care for members. In the past year, an influx of immigrants and the COVID-19 pandemic significantly increased the demands on providers. Impacts included an increase in patients' behavioral health concerns, provider adoption and/or expansion of telehealth options, workforce shortages, and delay of routine preventive care. In addition, COVID disproportionally affected the clinical outcomes of the Black, Indigenous, and People of Color (BIPOC) communities. Each year, OMS adds new questions to the survey to address emerging clinical and social issues. In this year's survey, as part of OMS' efforts to increase the focus on health equity in all our programs, we added questions about barriers to care and how we might address them. OMS is particularly interested in providers' awareness and use of Community Health Workers (CHW) to assist their patients in obtaining the full spectrum of care they need. We share this survey analysis with CMS as part of the annual report for the MaineCare waiver, as well as with the HIV Advisory Committee (HIVAC) and the Maine CDC's Integrated HIV Prevention and Planning committee.[1]

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[1] The HIV Advisory Committee was established to advise the Office of the Governor and state, federal and private sector agencies, officials and committees on HIV-related and AIDS-related policy, planning, budget, or rules. The HIV Advisory Committee also assesses emerging HIV-related issues and trends, initiates and responds to legislation, and prepares and presents an annual report on the status of HIV in Maine.

Survey Process:

OMS conducted the 16th annual provider survey at the beginning of 2021. Surveys were mailed to infectious disease specialists and primary care providers who, at the time of the mailing, were treating MaineCare and waiver members with HIV/AIDS. This year, OMS also offered the survey online, through SurveyMonkey. Three hundred nine surveys were mailed, and 76 providers responded (5 of those providers responded online). This data shows a response rate of approximately 25%, compared to 34% last year. This reduced response rate was likely due to the impact of COVID-19. The lower response rate may mean that the feedback is less representative of the whole group of providers.

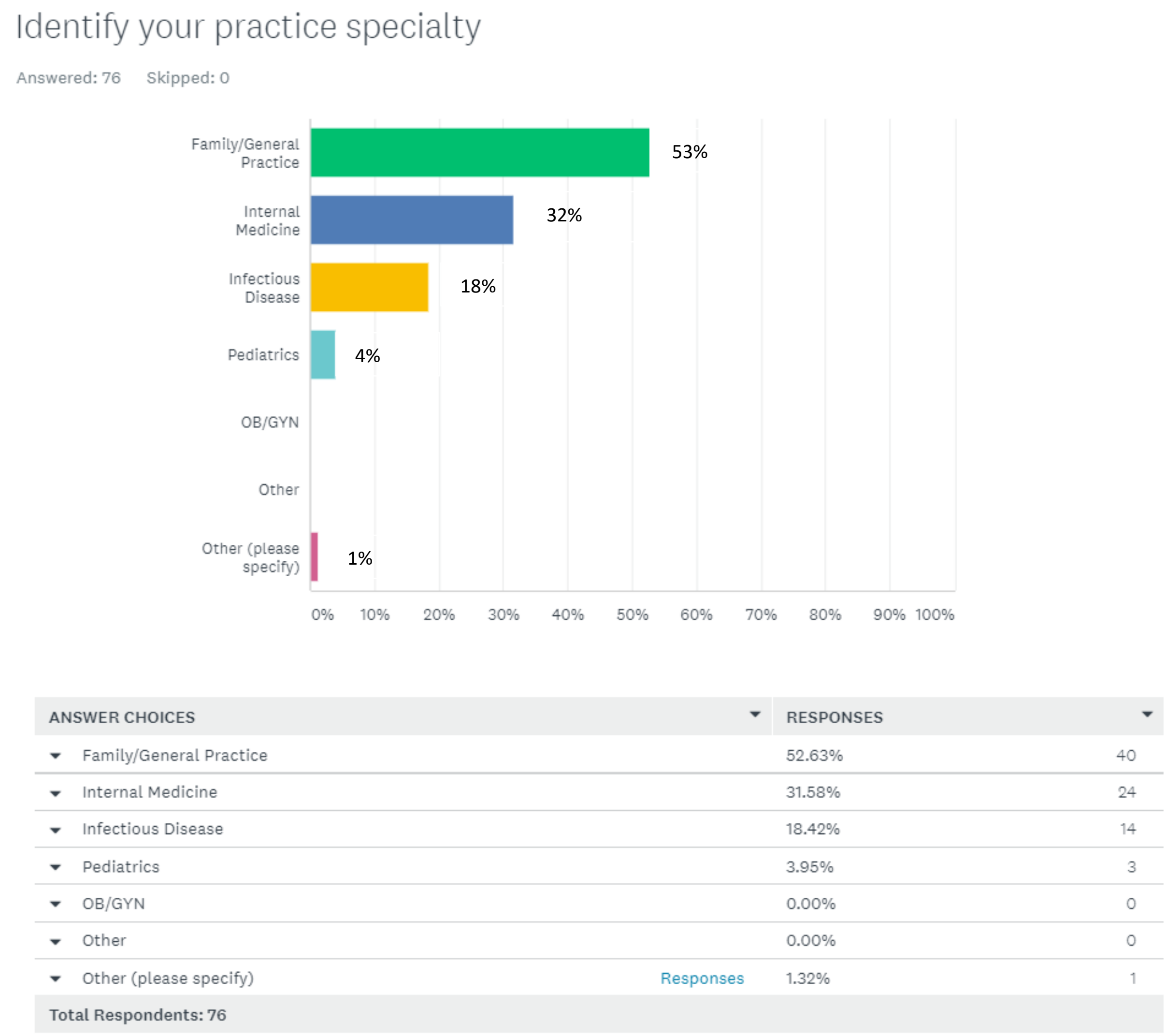
The survey questions covered the following areas:

- Medical practice specialty
- Number of HIV/AIDS patients managed or co-managed, and number of patients who are new Mainers (newly established in the US, such as immigrants and refugees)
- Provider awareness of current treatment guidelines and new recommendations for HIV/AIDS patients
- Provider awareness of funding and training opportunities through the Maine AIDS Education and Training Center (MEAETC)
- Provider awareness of the MaineCare HIV/AIDS waiver
- Provider awareness of the Ryan White/AIDS Drug Assistance Program (ADAP)
- Barriers affecting adherence/compliance with medication
- Provider awareness and usage of CHWs
- Providers' feedback on how the HIV/AIDS waiver could best support them
- Providers' preferences on receiving letters and updates via an HIV-specific listserv

Note: Not all participants answered all questions, and some participants selected multiple answers on a question; therefore, the number of responses vary from question to question. The percentages in the charts are rounded to the nearest whole number based on the number of responses.

Results:

Figure 1: Practice Specialties



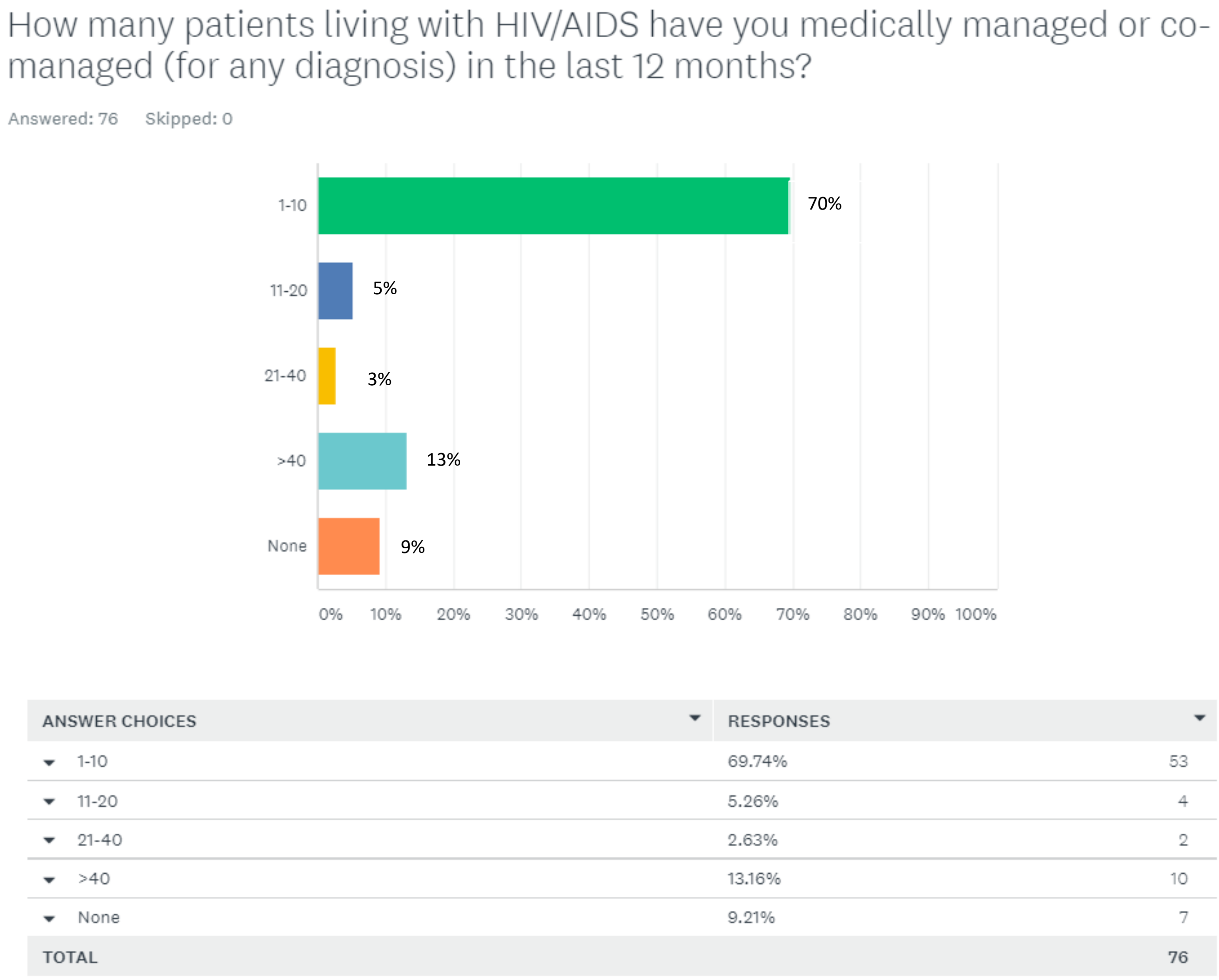
Identify your practice specialty

Answered: 76 Skipped: 0

ANSWER CHOICES		RESPONSES	
Family/General Practice		52.63%	40
Internal Medicine		31.58%	24
Infectious Disease		18.42%	14
Pediatrics		3.95%	3
OB/GYN		0.00%	0
Other		0.00%	0
Other (please specify)	Responses	1.32%	1
Total Respondents: 76			

Figure 1 shows that of the providers who responded, the majority (53%) were family/general practice, compared to 57% last year.

Figure 2: Number of Current HIV/AIDS Patients



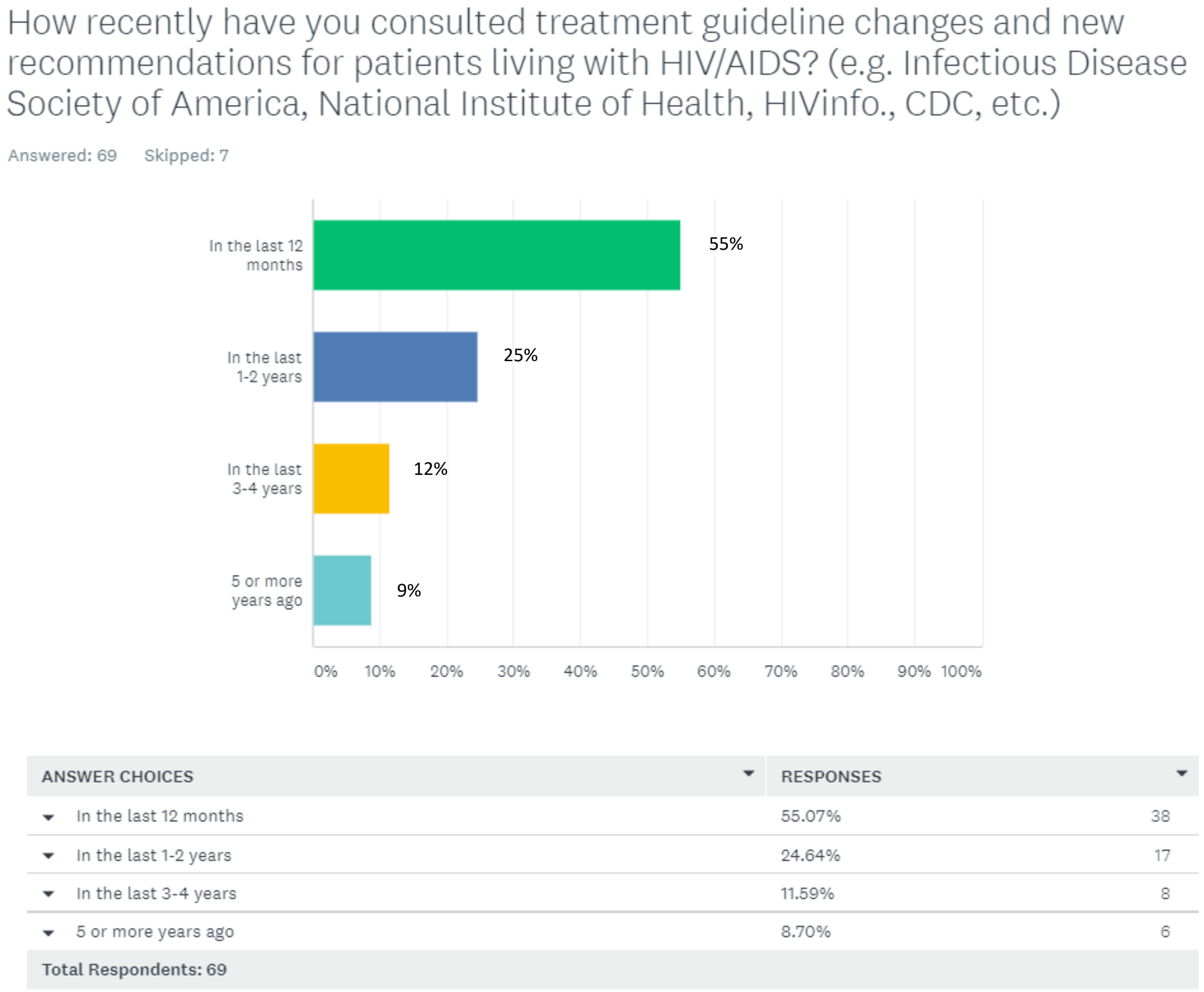
How many patients living with HIV/AIDS have you medically managed or co-managed (for any diagnosis) in the last 12 months?

Answered: 76 Skipped: 0

ANSWER CHOICES	RESPONSES	
1-10	69.74%	53
11-20	5.26%	4
21-40	2.63%	2
>40	13.16%	10
None	9.21%	7
TOTAL		76

Figure 2 shows that regardless of specialty, many providers (70%) indicated that they currently manage between one and ten patients with HIV/AIDS, compared to 65% last year.

Figure 3: Consultation of Current Treatment Guidelines and New HIV/AIDS Recommendations



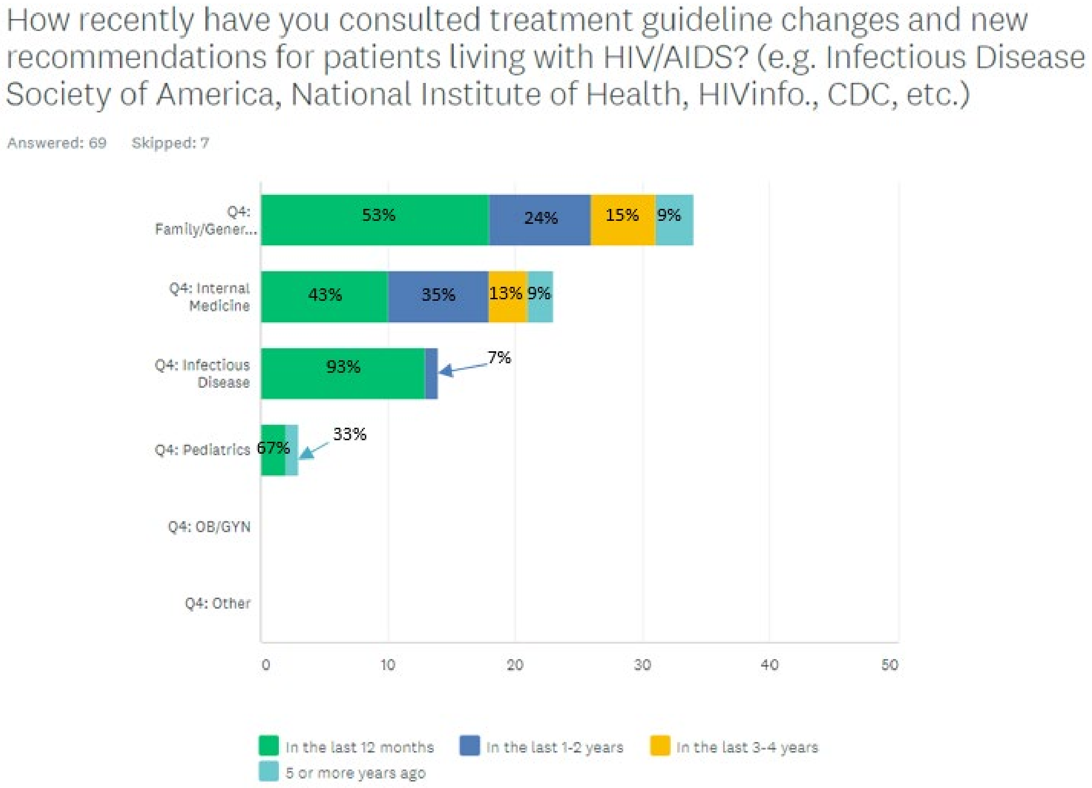
How recently have you consulted treatment guideline changes and new recommendations for patients living with HIV/AIDS? (e.g. Infectious Disease Society of America, National Institute of Health, HIVinfo., CDC, etc.)

Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
In the last 12 months	55.07%	38
In the last 1-2 years	24.64%	17
In the last 3-4 years	11.59%	8
5 or more years ago	8.70%	6
Total Respondents: 69		

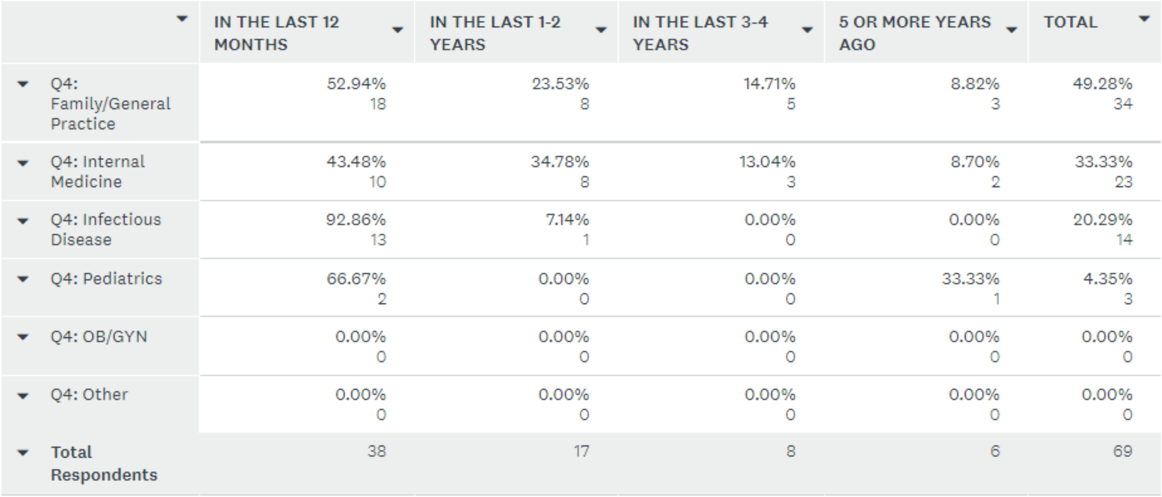
Figure 3 shows providers’ timeframe for consulting current treatment guidelines and new recommendations for HIV/AIDS patients. More than half (55%) indicate they have reviewed the guidelines in the last 12 months; this is a 15% decrease from the previous year. Nine percent of providers indicated that it has been five or more years since they reviewed treatment guidelines and recommendations, compared to 8% last year.

Figure 3a: Practice Type and Consultation of New HIV/AIDS Guidelines and Recommendations



How recently have you consulted treatment guideline changes and new recommendations for patients living with HIV/AIDS? (e.g. Infectious Disease Society of America, National Institute of Health, HIVinfo., CDC, etc.)

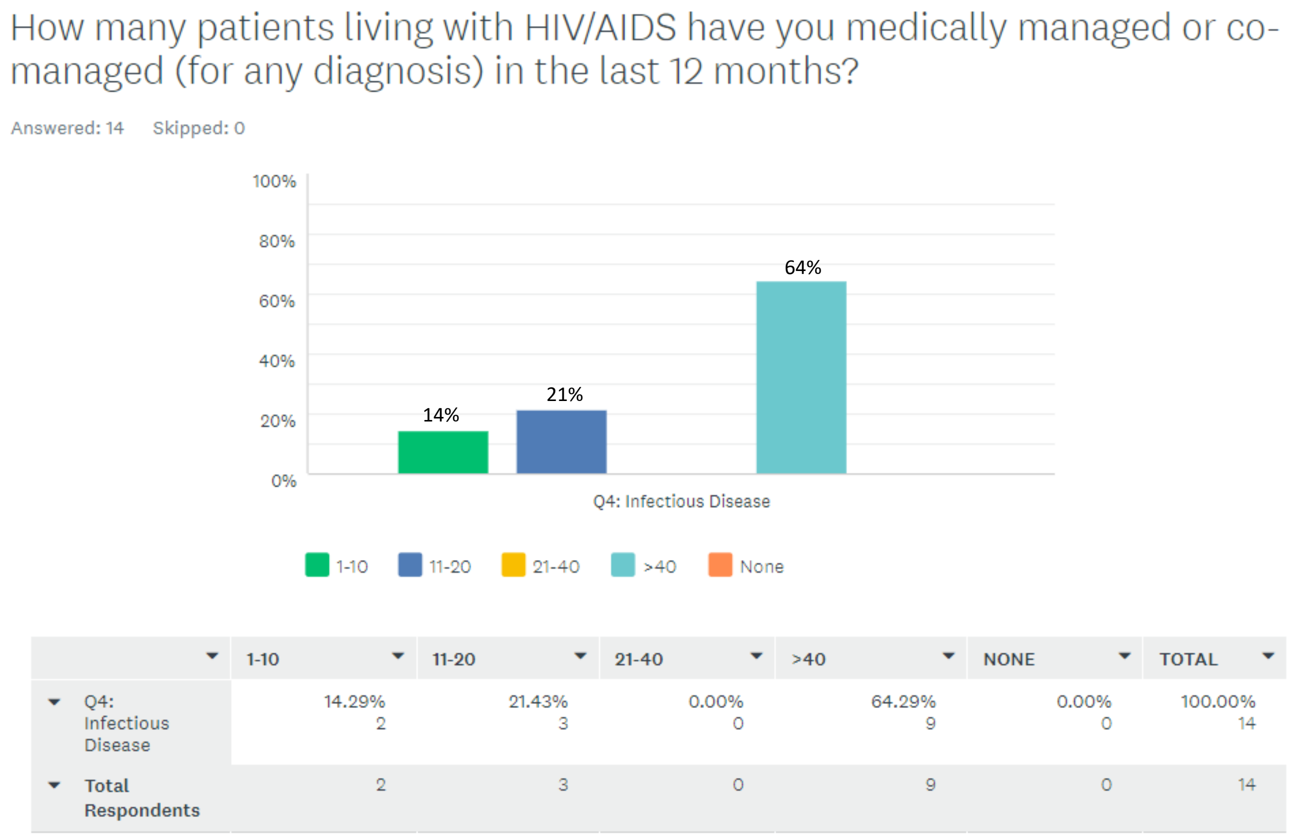
Answered: 69 Skipped: 7



	IN THE LAST 12 MONTHS	IN THE LAST 1-2 YEARS	IN THE LAST 3-4 YEARS	5 OR MORE YEARS AGO	TOTAL
Q4: Family/General Practice	52.94% 18	23.53% 8	14.71% 5	8.82% 3	49.28% 34
Q4: Internal Medicine	43.48% 10	34.78% 8	13.04% 3	8.70% 2	33.33% 23
Q4: Infectious Disease	92.86% 13	7.14% 1	0.00% 0	0.00% 0	20.29% 14
Q4: Pediatrics	66.67% 2	0.00% 0	0.00% 0	33.33% 1	4.35% 3
Q4: OB/GYN	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0
Q4: Other	0.00% 0	0.00% 0	0.00% 0	0.00% 0	0.00% 0
Total Respondents	38	17	8	6	69

Figure 3a shows providers' timeframe for consulting current treatment guidelines and new recommendations for HIV/AIDS patients by provider specialty. Ninety-three percent of infectious disease specialists that responded indicated that they had reviewed the new HIV/AIDS guidelines and recommendations within the last 12 months. Other specialties had lower rates of review within the previous 12 months.

Figure 3b: Current HIV/AIDS Patients for Infectious Disease Specialists



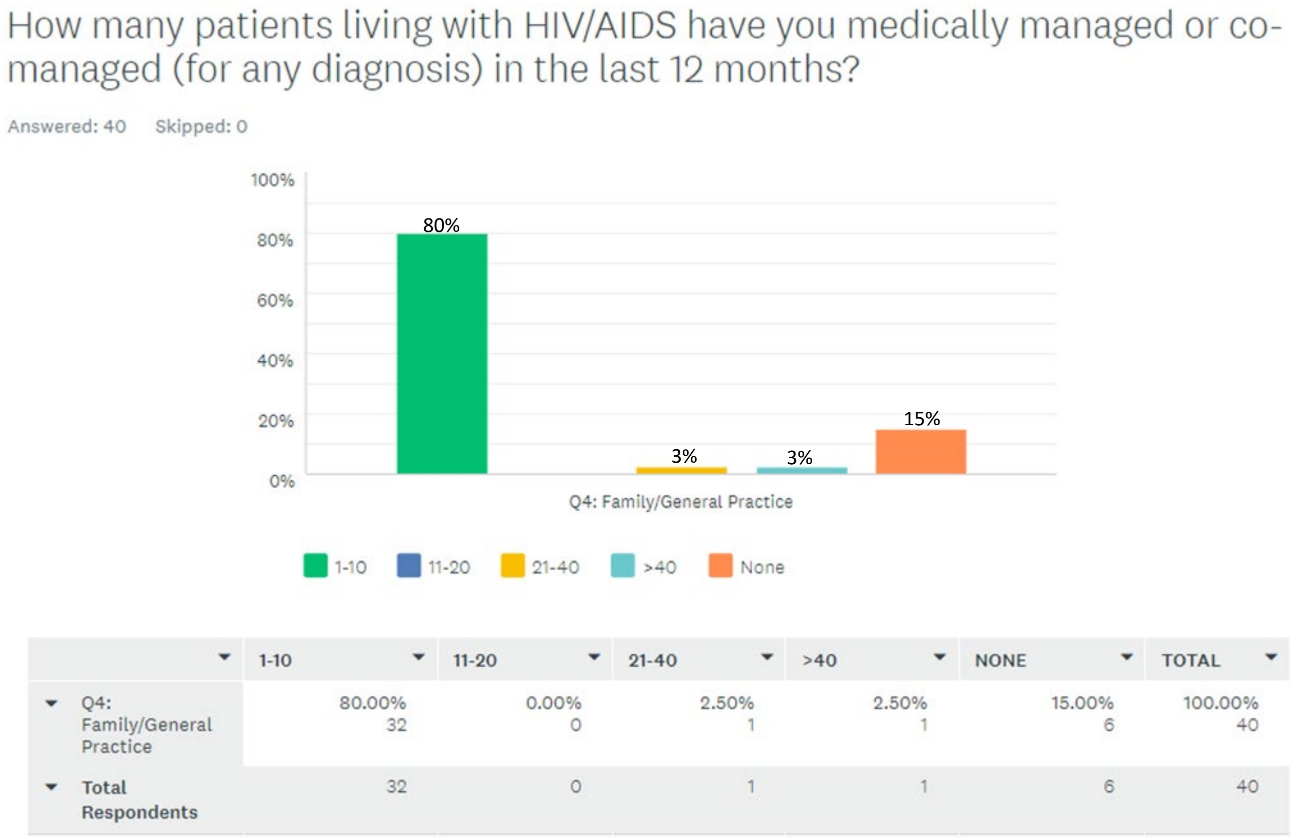
How many patients living with HIV/AIDS have you medically managed or co-managed (for any diagnosis) in the last 12 months?

Answered: 14 Skipped: 0

	1-10	11-20	21-40	>40	NONE	TOTAL
Q4: Infectious Disease	14.29% 2	21.43% 3	0.00% 0	64.29% 9	0.00% 0	100.00% 14
Total Respondents	2	3	0	9	0	14

Figure 3b shows how many patients are managed by the infectious disease specialists who responded to the survey. Nine out of 14 infectious disease specialists indicated that they currently manage over 40 patients, compared to seven of twelve the previous year.

Figure 3c: Current HIV/AIDS Patients for General/Family Practice



How many patients living with HIV/AIDS have you medically managed or co-managed (for any diagnosis) in the last 12 months?

Answered: 40 Skipped: 0

	1-10	11-20	21-40	>40	NONE	TOTAL
Q4: Family/General Practice	80.00% 32	0.00% 0	2.50% 1	2.50% 1	15.00% 6	100.00% 40
Total Respondents	32	0	1	1	6	40

Figure 3c shows the number of patients treated by the family/general practice respondents. The majority (80%) of family/general practice respondents indicated that they currently manage 1-10 patients with HIV/AIDS, compared to last year, where more providers reported seeing patients in the higher ranges. Three percent of the general/family practice providers who responded indicated that they currently manage over 40 patients with HIV/AIDS, compared to two percent the previous year.

Figure 4: Barriers Providers Perceive to Medication Adherence/Compliance

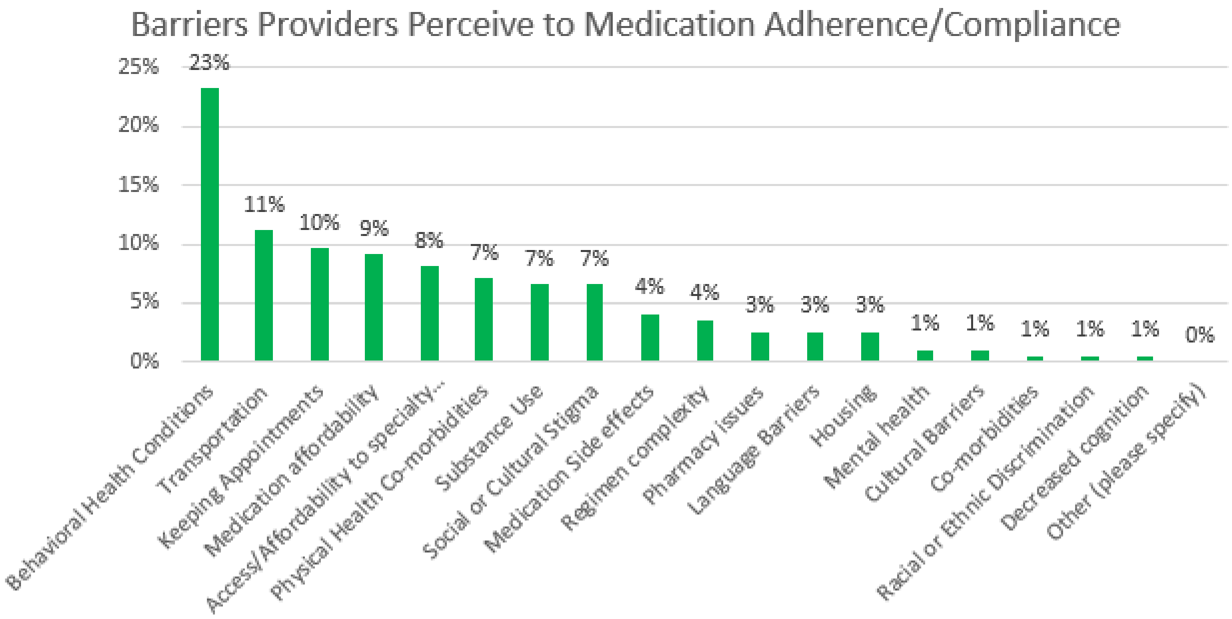
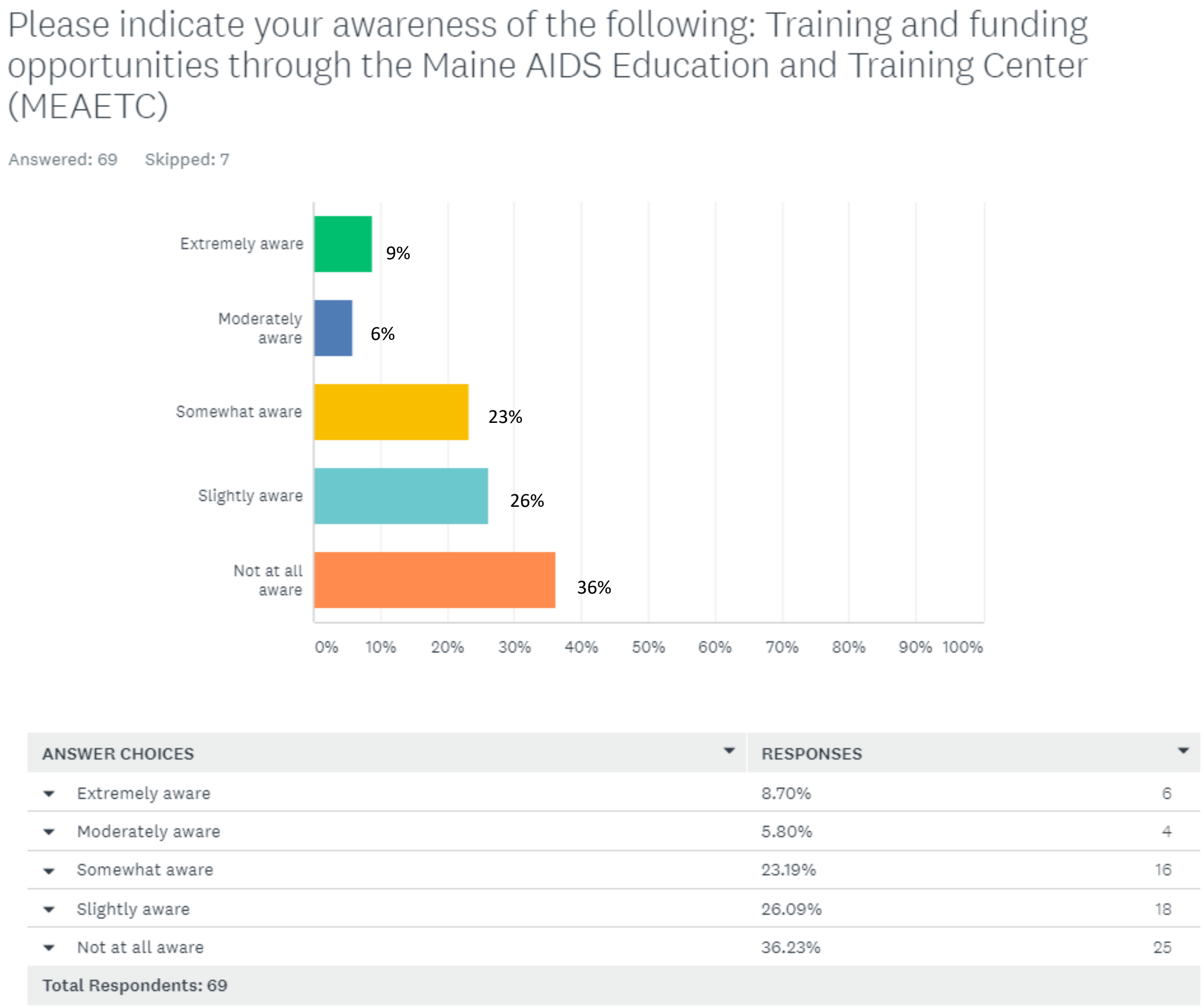


Figure 4 shows what providers feel are the most common barriers related to medication adherence/compliance for their patients with HIV/AIDS. Twenty-three percent of providers indicated behavioral health conditions, 11% indicated transportation, and 10% identified keeping appointments as a top adherence/compliance barrier. These barriers largely match those providers identified in 2019, which were behavioral health (20%), keeping appointments (15%), and transportation (12%). Since 2015, providers have consistently ranked behavioral health conditions the number one barrier to treatment adherence. Transportation and keeping appointments have been in the top three most commonly cited barriers since 2016.

Figure 5: Awareness of HIV Training and Funding Opportunities



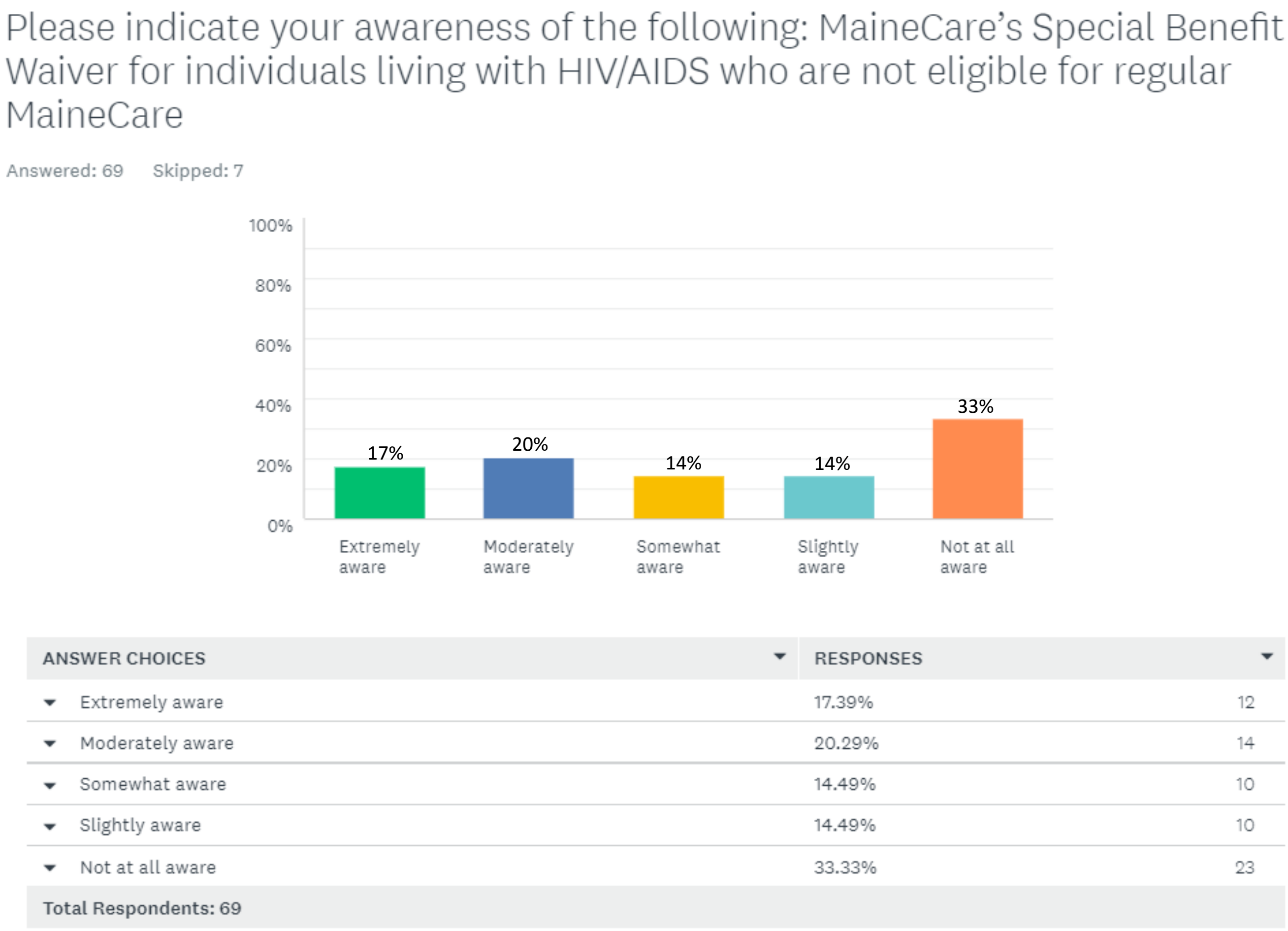
Please indicate your awareness of the following: Training and funding opportunities through the Maine AIDS Education and Training Center (MEAETC)

Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
Extremely aware	8.70%	6
Moderately aware	5.80%	4
Somewhat aware	23.19%	16
Slightly aware	26.09%	18
Not at all aware	36.23%	25
Total Respondents: 69		

Figure 5 shows that 64% of providers have some familiarity with HIV training and funding opportunities through the Maine AIDS Education and Training Center (MEAETC), compared to 73% the previous year. Thirty-six percent of providers were not aware of the MEAETC, compared to 27% the previous year.

Figure 6: Awareness of the Special Benefit Waiver



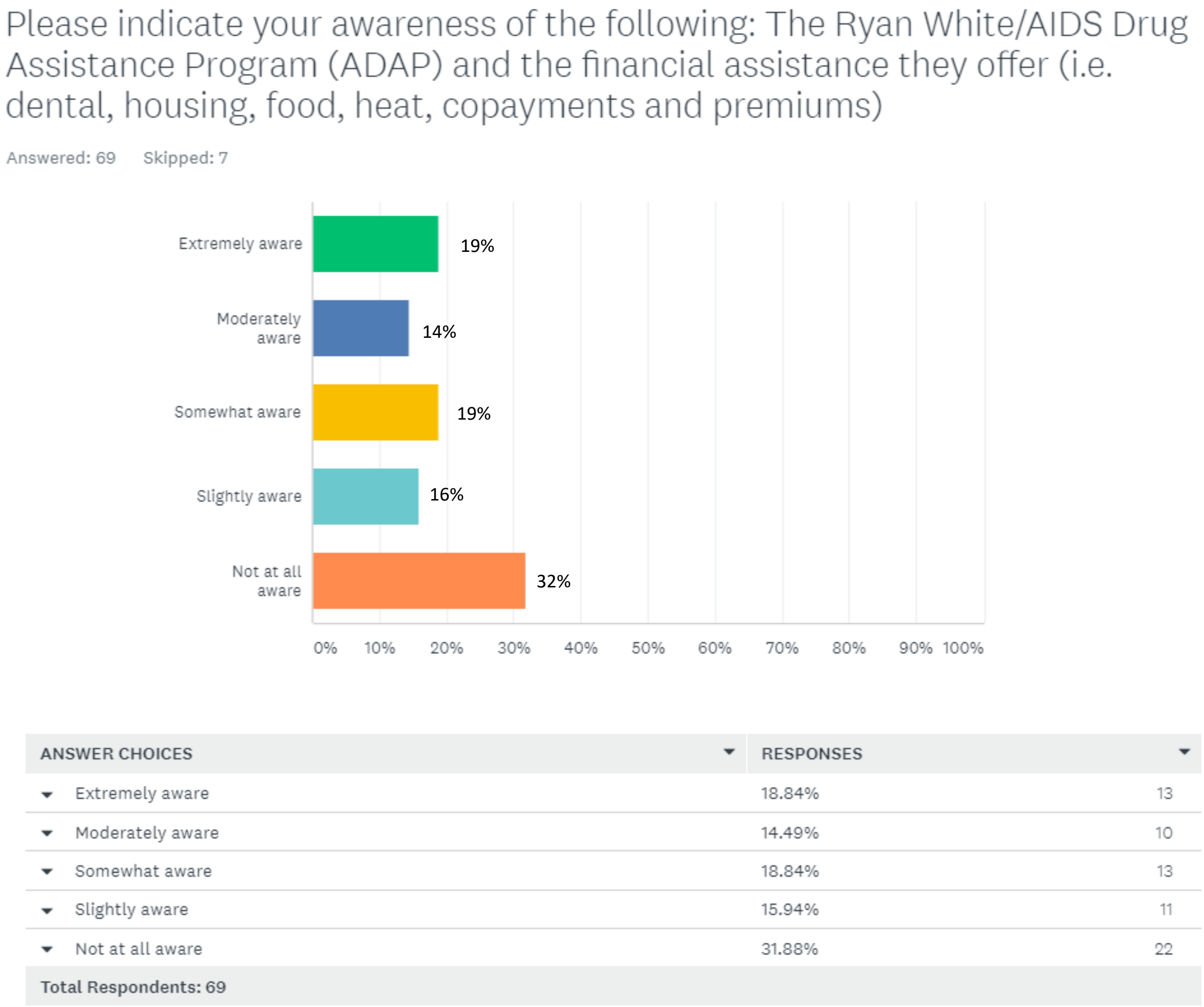
Please indicate your awareness of the following: MaineCare's Special Benefit Waiver for individuals living with HIV/AIDS who are not eligible for regular MaineCare

Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
Extremely aware	17.39%	12
Moderately aware	20.29%	14
Somewhat aware	14.49%	10
Slightly aware	14.49%	10
Not at all aware	33.33%	23
Total Respondents: 69		

Figure 6 shows that most respondents (67%) have some familiarity with Maine's HIV/AIDS waiver, compared to 75% last year. Thirty-three percent of respondents were not at all aware of the waiver program, compared to 25% last year.

Figure 7: Awareness of Ryan White/ADAP Programs



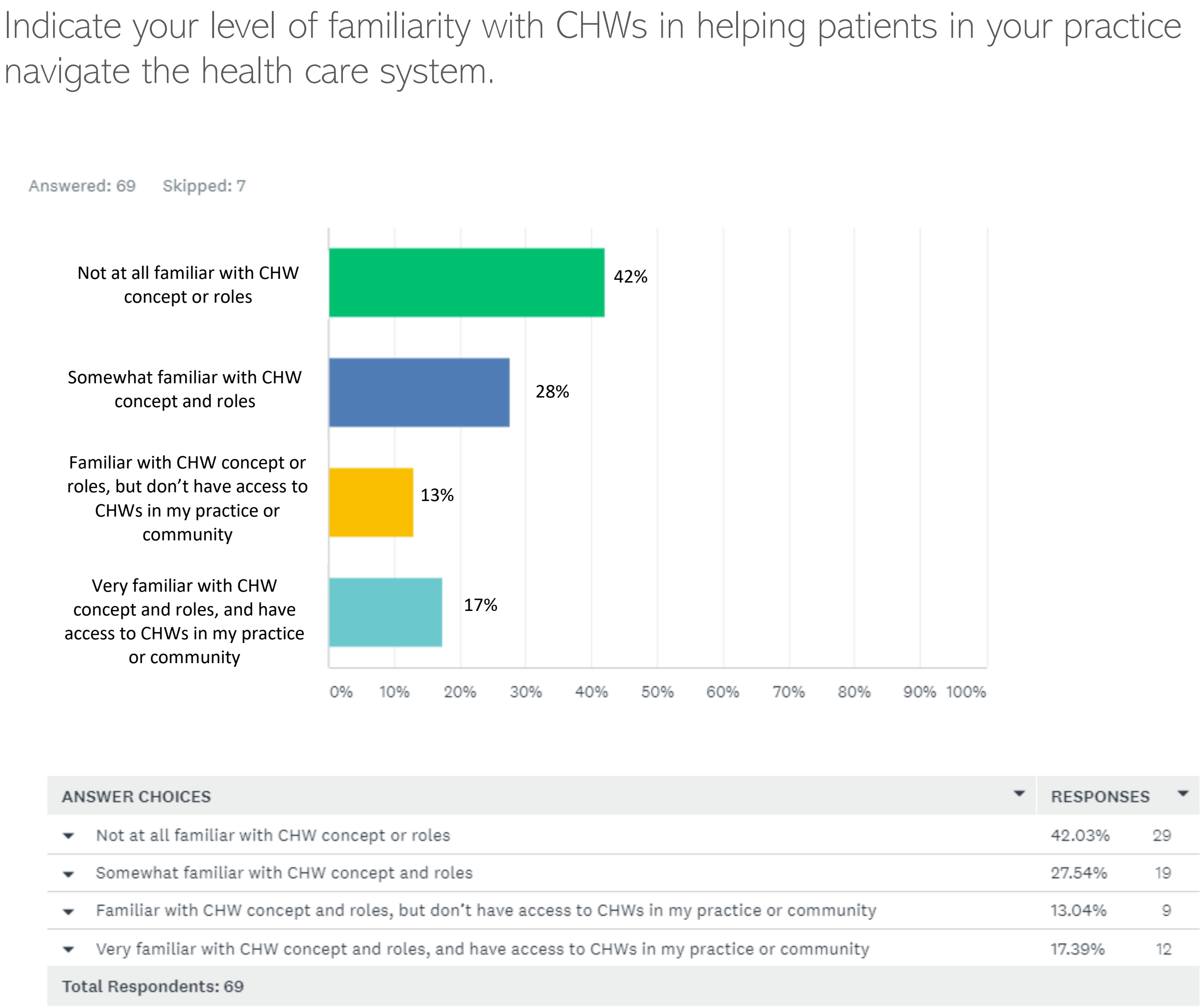
Please indicate your awareness of the following: The Ryan White/AIDS Drug Assistance Program (ADAP) and the financial assistance they offer (i.e. dental, housing, food, heat, copayments and premiums)

Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
Extremely aware	18.84%	13
Moderately aware	14.49%	10
Somewhat aware	18.84%	13
Slightly aware	15.94%	11
Not at all aware	31.88%	22
Total Respondents: 69		

Figure 7 shows that 68% of providers are familiar with the Ryan White/AIDS Drug Assistance Program (ADAP), available through the Maine Center for Disease Control & Prevention (CDC), and the financial assistance it offers to people living with HIV/AIDS, compared to 74% last year. Thirty-two percent of providers indicated that they are not at all aware of this program, compared to 26% last year.

Figure 8: Familiarity with CHW concept and roles



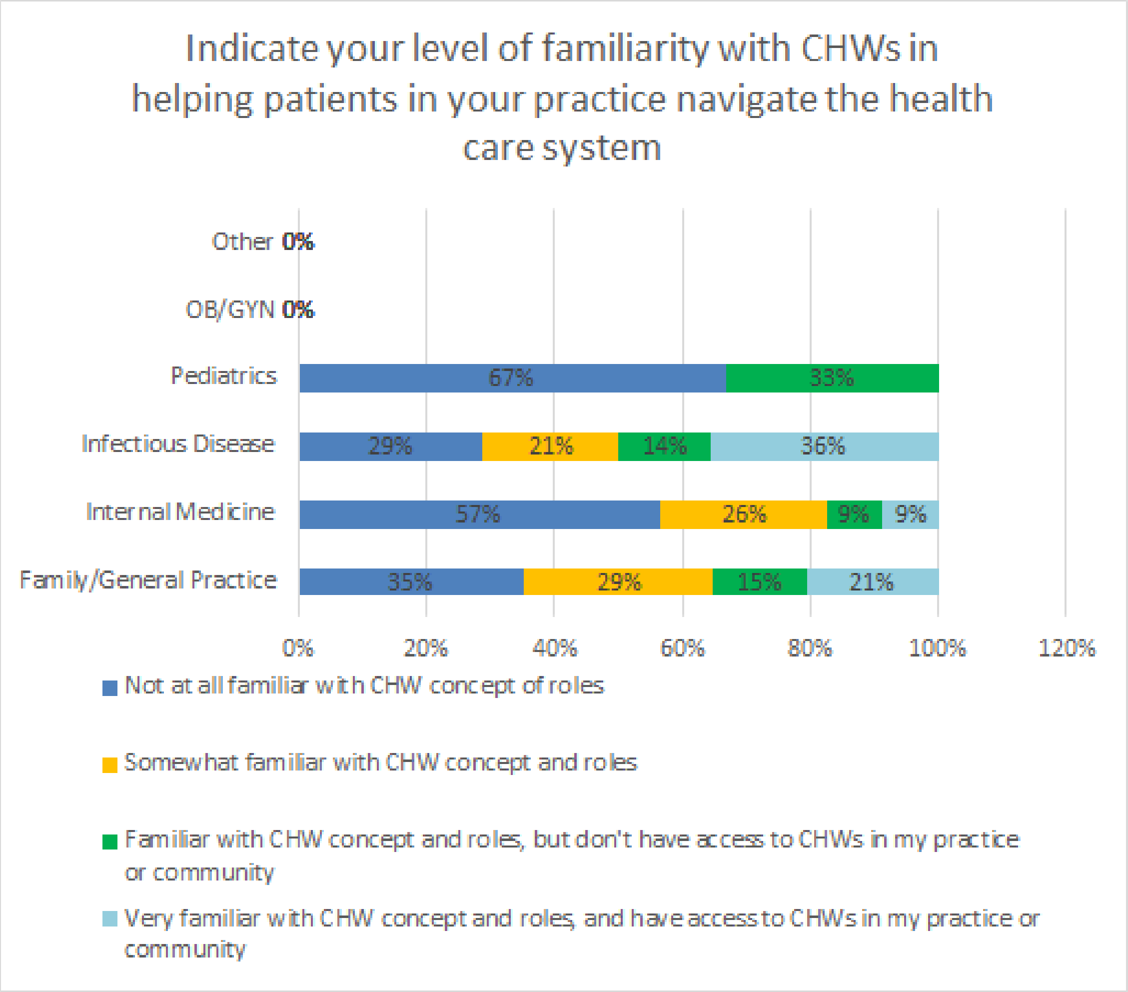
Indicate your level of familiarity with CHWs in helping patients in your practice navigate the health care system.

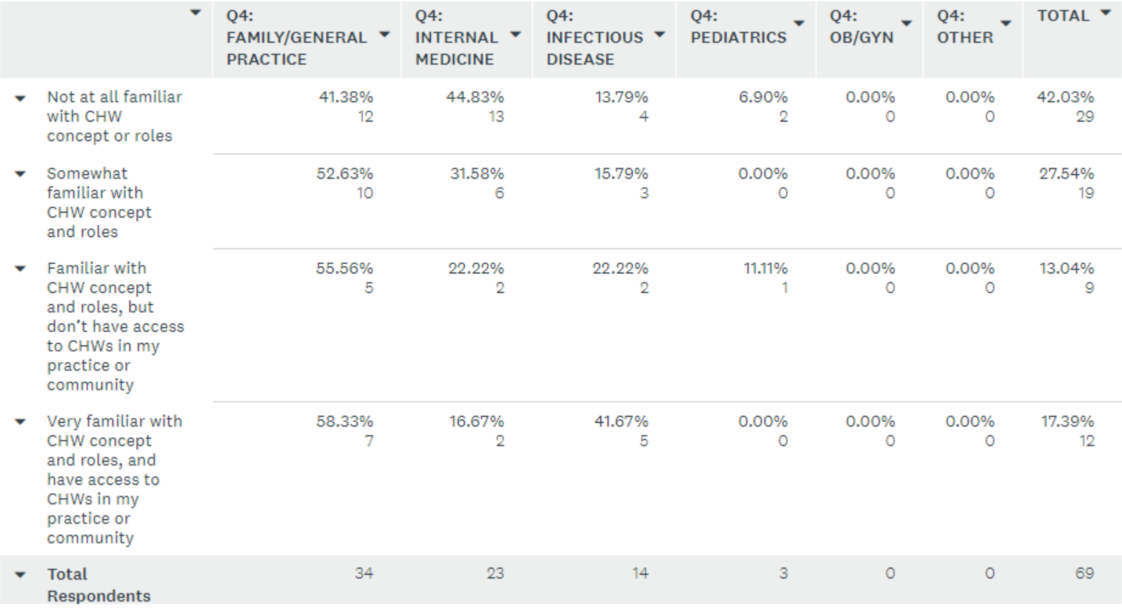
Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
Not at all familiar with CHW concept or roles	42.03%	29
Somewhat familiar with CHW concept and roles	27.54%	19
Familiar with CHW concept and roles, but don't have access to CHWs in my practice or community	13.04%	9
Very familiar with CHW concept and roles, and have access to CHWs in my practice or community	17.39%	12
Total Respondents: 69		

Figure 8 displays information regarding providers' familiarity with CHWs. These healthcare professionals provide culturally competent care directly in a community setting. This year's survey is the first to ask about provider familiarity of and referral to CHW services. Providers showed varying degrees of knowledge, with 58% responding that they are at least somewhat familiar with the concept and roles of a CHW.

Figure 8a: Familiarity of various provider type with CHW and roles

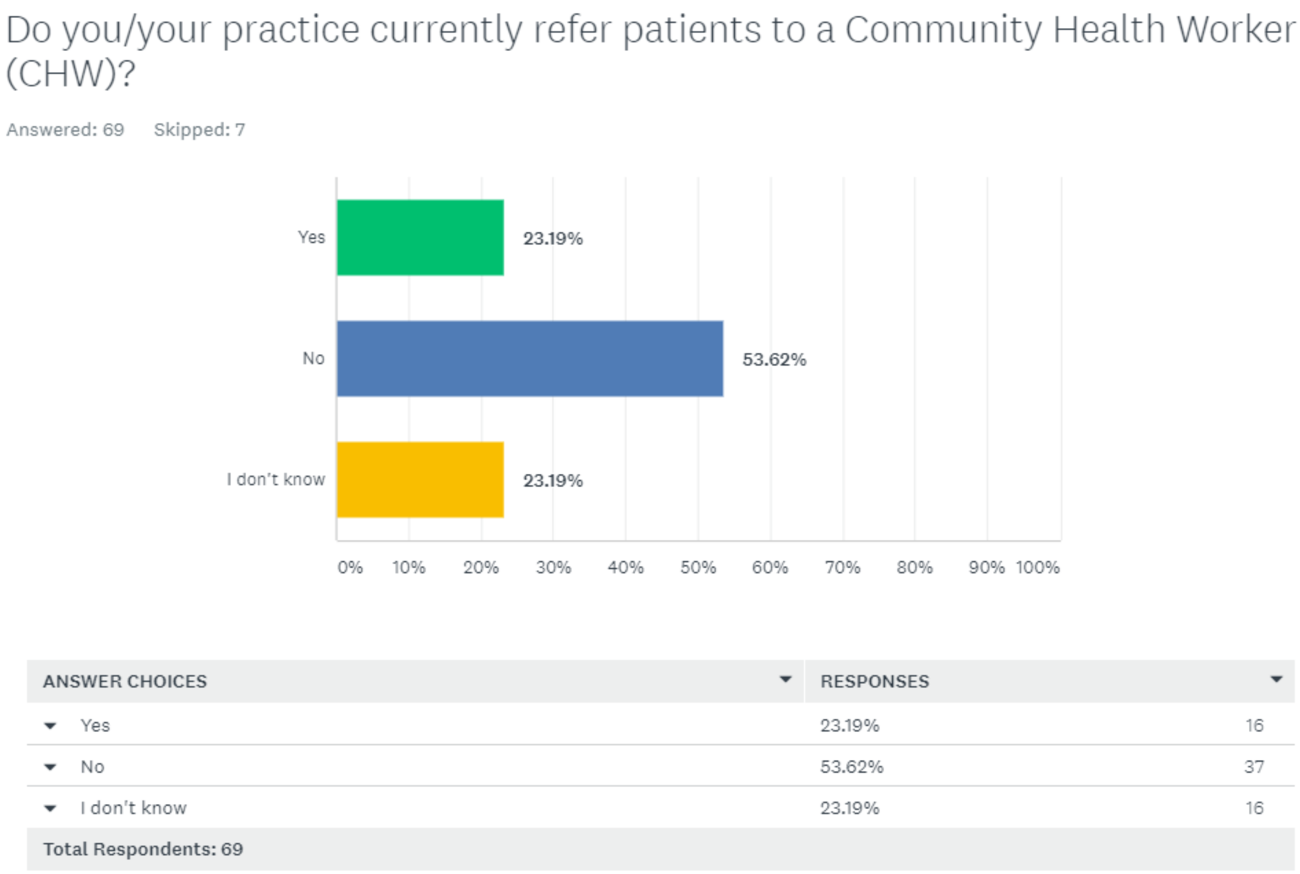




	Q4: FAMILY/GENERAL PRACTICE	Q4: INTERNAL MEDICINE	Q4: INFECTIOUS DISEASE	Q4: PEDIATRICS	Q4: OB/GYN	Q4: OTHER	TOTAL
Not at all familiar with CHW concept or roles	41.38% 12	44.83% 13	13.79% 4	6.90% 2	0.00% 0	0.00% 0	42.03% 29
Somewhat familiar with CHW concept and roles	52.63% 10	31.58% 6	15.79% 3	0.00% 0	0.00% 0	0.00% 0	27.54% 19
Familiar with CHW concept and roles, but don't have access to CHWs in my practice or community	55.56% 5	22.22% 2	22.22% 2	11.11% 1	0.00% 0	0.00% 0	13.04% 9
Very familiar with CHW concept and roles, and have access to CHWs in my practice or community	58.33% 7	16.67% 2	41.67% 5	0.00% 0	0.00% 0	0.00% 0	17.39% 12
Total Respondents	34	23	14	3	0	0	69

Figure 8a shows survey respondents' current familiarity with CHWs by provider type. Similar to Figure 8, this shows a varying level of familiarity and displays the wide range of provider knowledge by provider type. The infectious disease practices seem to have the most familiarity with and use of CHWs.

Figure 8b: Current referral to a CHW



Do you/your practice currently refer patients to a Community Health Worker (CHW)?

Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
Yes	23.19%	16
No	53.62%	37
I don't know	23.19%	16
Total Respondents: 69		

Figure 8b shows survey respondents' current referral habits to CHWs. It is notable that many providers (54%) do not currently refer patients to a CHW.

Figure 8c: Current referral to a CHW by provider focus

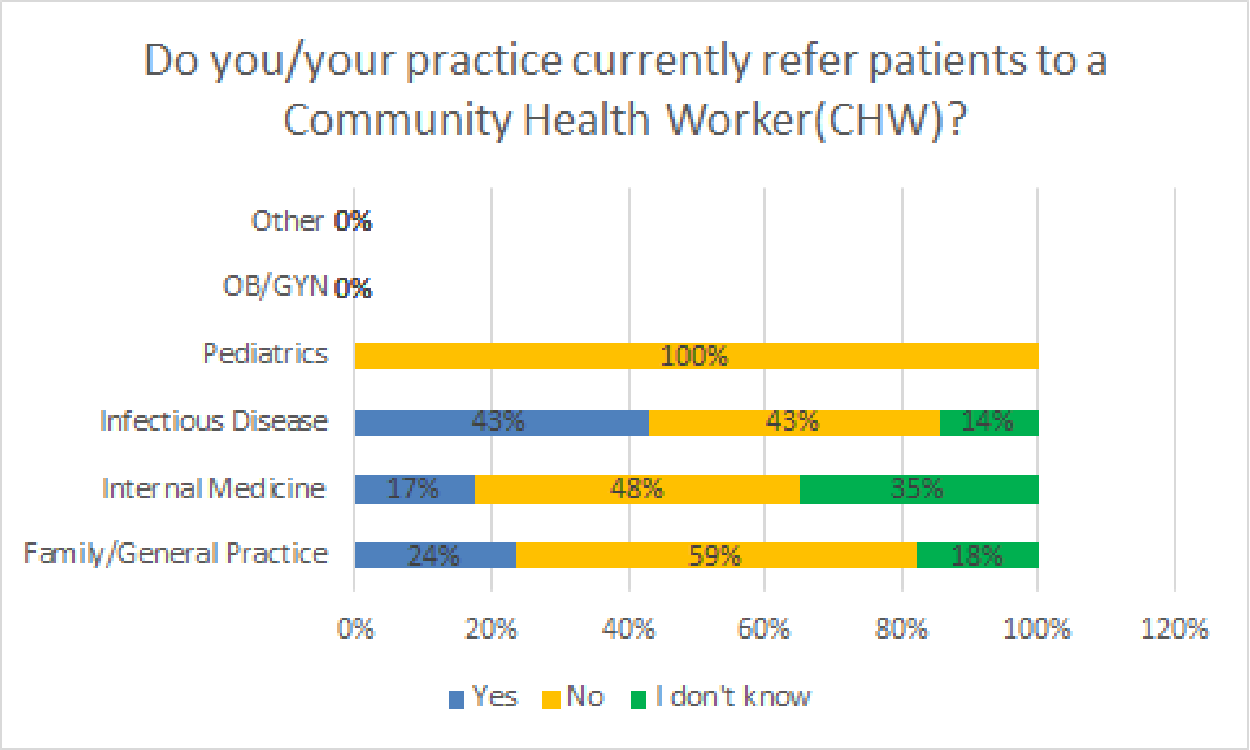
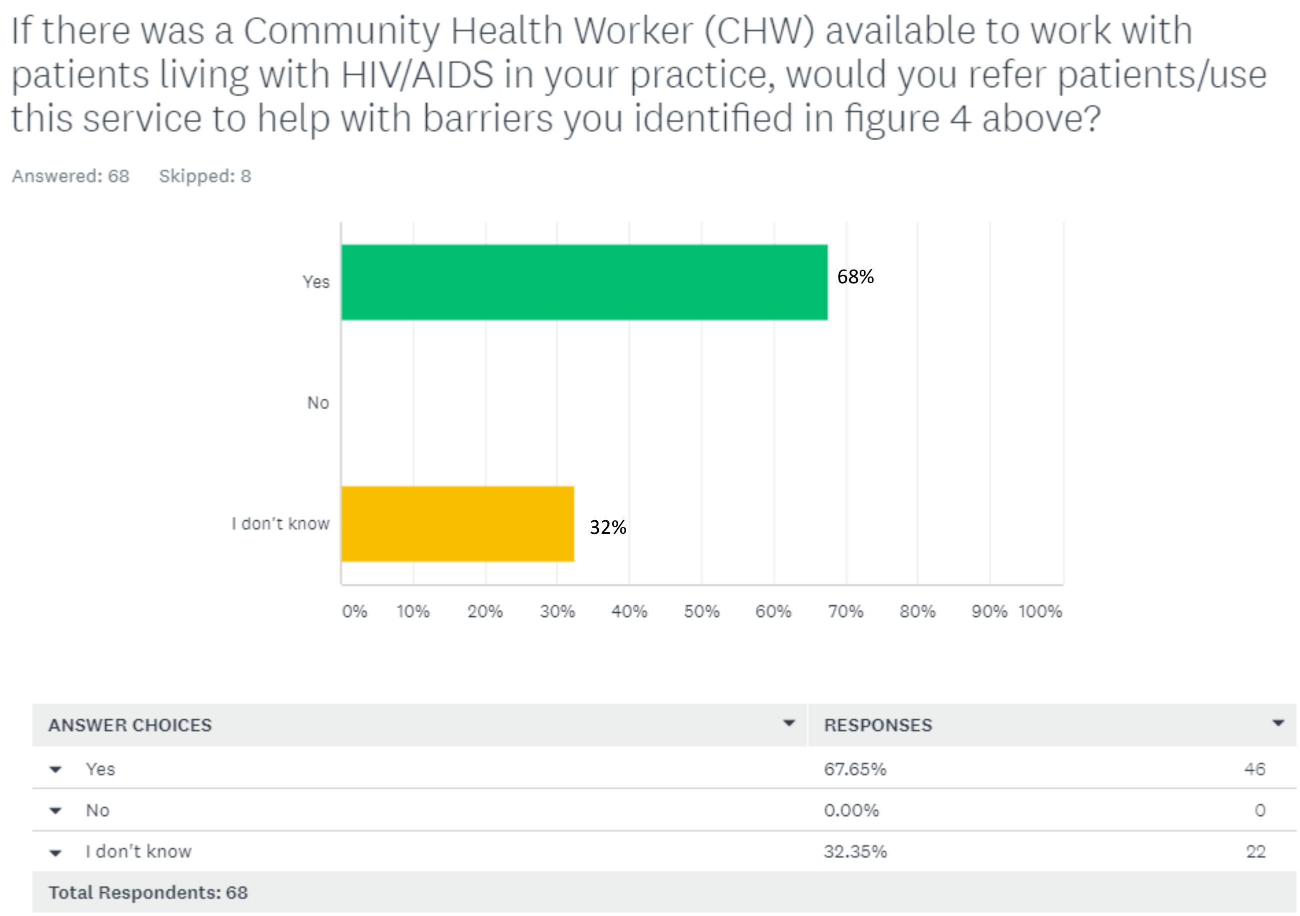


Figure 8c shows providers current CHW referral habits by provider type. Notably, the majority of respondents (37/69) do not currently refer patients to a CHW. Similar to the above finding on providers familiarity of CHW services, infectious disease practices are most likely to have referred patients to CHW services.

Figure 8d: Provider willingness to refer patients to a CHW



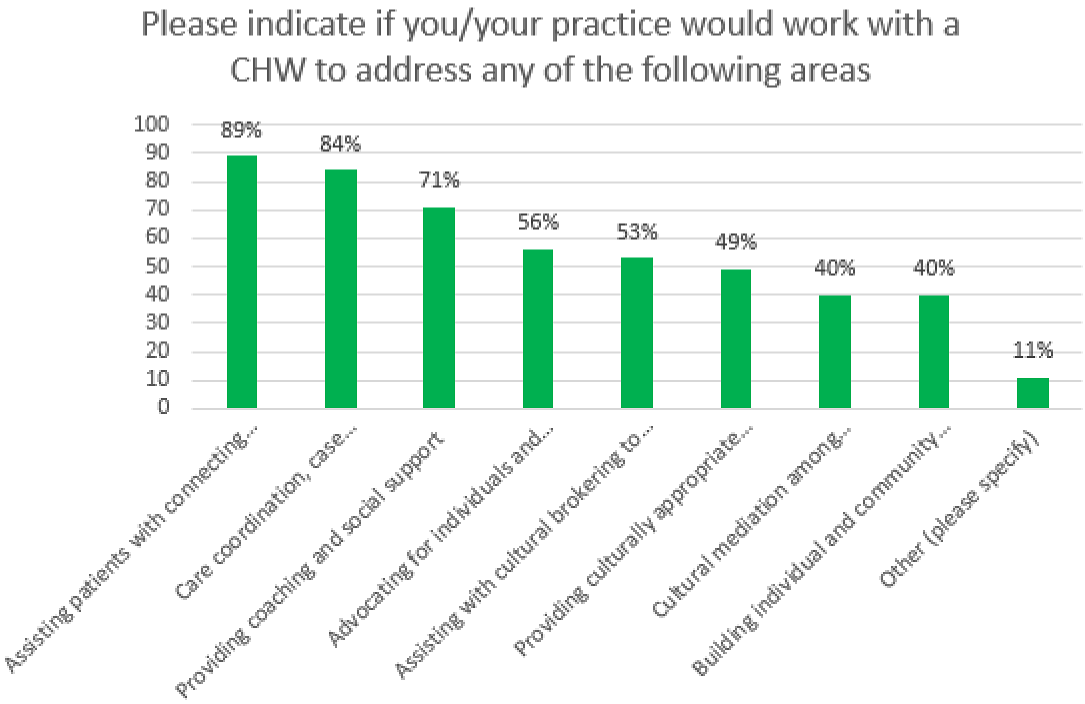
If there was a Community Health Worker (CHW) available to work with patients living with HIV/AIDS in your practice, would you refer patients/use this service to help with barriers you identified in figure 4 above?

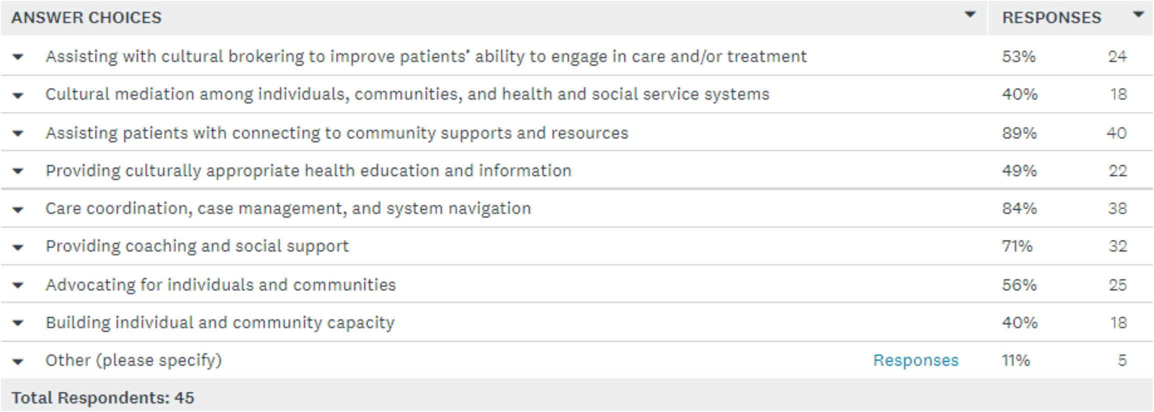
Answered: 68 Skipped: 8

ANSWER CHOICES	RESPONSES	
Yes	67.65%	46
No	0.00%	0
I don't know	32.35%	22
Total Respondents: 68		

Figure 8d displays the responses to if providers would refer patients to CHWs to help address the barriers to treatment adherence that they identified earlier in the survey if CHWs were available (see Figure 4 above). Sixty-eight percent of respondents indicated yes. Of note, there were no respondents that indicated that they would not refer to a CHW, showing that this is potentially a large opportunity to promote the services of CHWs.

Figure 8e: Focus of CHW work

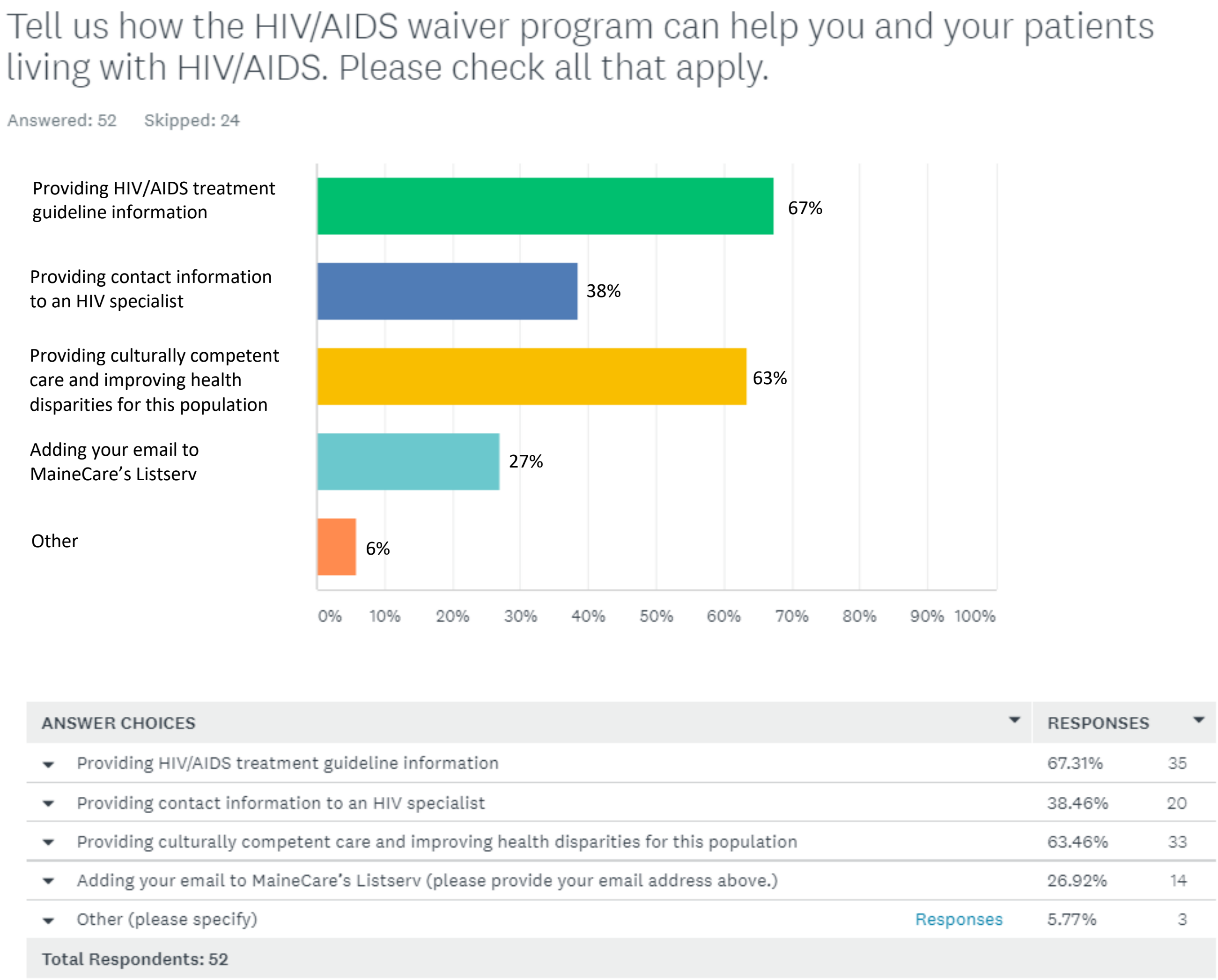

Please indicate if you/your practice would work with a CHW to address any of the following areas



ANSWER CHOICES		RESPONSES	
Assisting with cultural brokering to improve patients' ability to engage in care and/or treatment		53%	24
Cultural mediation among individuals, communities, and health and social service systems		40%	18
Assisting patients with connecting to community supports and resources		89%	40
Providing culturally appropriate health education and information		49%	22
Care coordination, case management, and system navigation		84%	38
Providing coaching and social support		71%	32
Advocating for individuals and communities		56%	25
Building individual and community capacity		40%	18
Other (please specify)	Responses	11%	5
Total Respondents: 45			

Figure 8e shows for the providers who are willing to refer to a CHW, what areas would be helpful to their practice. The two categories with the highest responses were "assisting patients with connecting to community support and resources" (89%) and "care coordination, case management, and system navigation" (84%).

Figure 9: Support for Providers and Patients



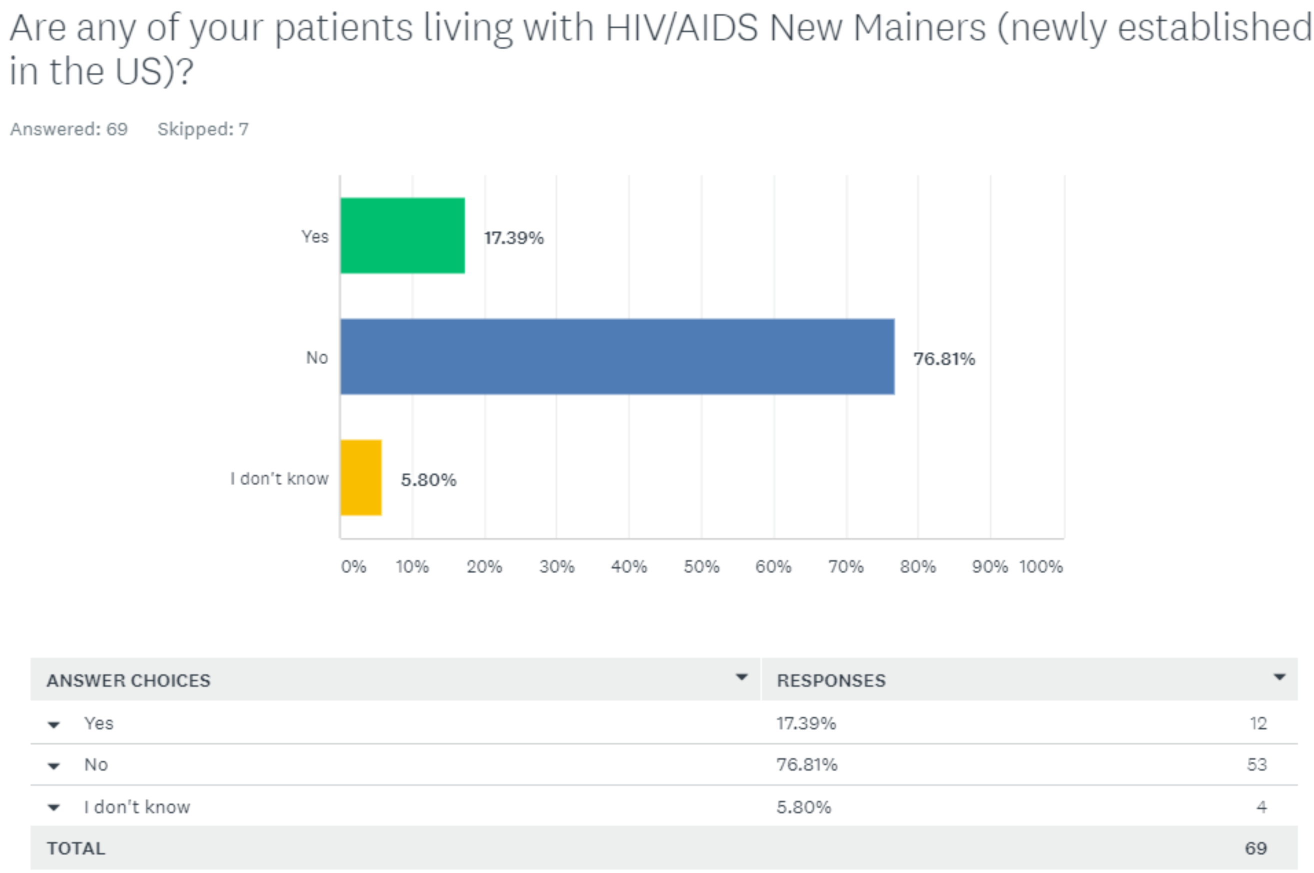
Tell us how the HIV/AIDS waiver program can help you and your patients living with HIV/AIDS. Please check all that apply.

Answered: 52 Skipped: 24

ANSWER CHOICES	RESPONSES	
Providing HIV/AIDS treatment guideline information	67.31%	35
Providing contact information to an HIV specialist	38.46%	20
Providing culturally competent care and improving health disparities for this population	63.46%	33
Adding your email to MaineCare's Listserv (please provide your email address above.)	26.92%	14
Other (please specify) Responses	5.77%	3
Total Respondents: 52		

Figure 9 indicates how providers would like the HIV/AIDS waiver program to support them. This question was added this year. Of the 76 providers who responded, 27% indicated that they wanted to be added to MaineCare's e-mail distribution list; 67% of respondents said that the program should provide treatment guideline information; 63% would like support providing culturally competent care and improving health disparities within the population; 38% of providers would like the HIV/AIDS waiver program to provide contact information for an HIV specialist.

Figure 10: New Mainers



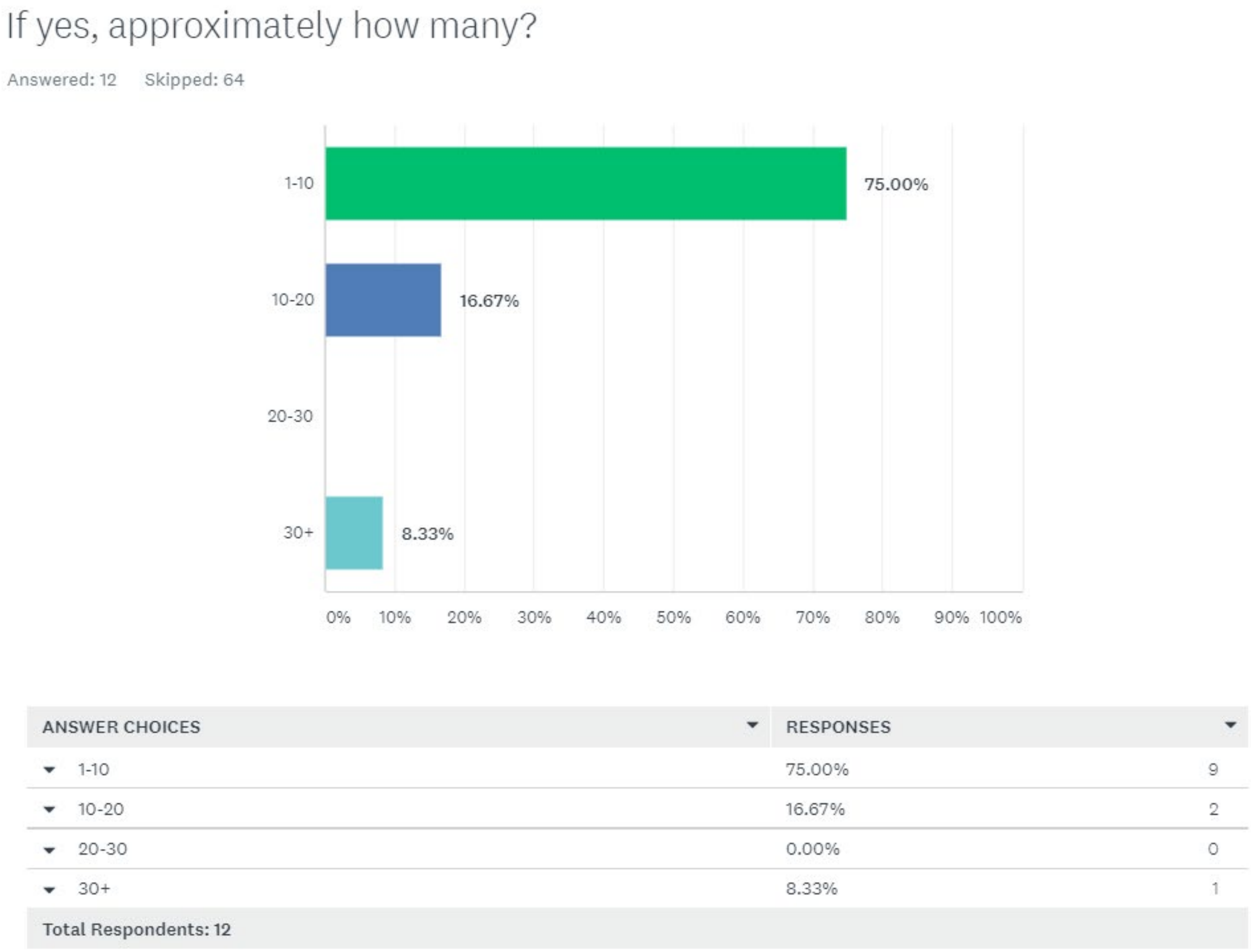
Are any of your patients living with HIV/AIDS New Mainers (newly established in the US)?

Answered: 69 Skipped: 7

ANSWER CHOICES	RESPONSES	
Yes	17.39%	12
No	76.81%	53
I don't know	5.80%	4
TOTAL		69

Figure 10 shows provider responses regarding whether their HIV/AIDS patients are New Mainers (immigrants newly established in the United States). Most providers (77%) said their patients were not New Mainers.

Figure 10a: Number of New Mainers



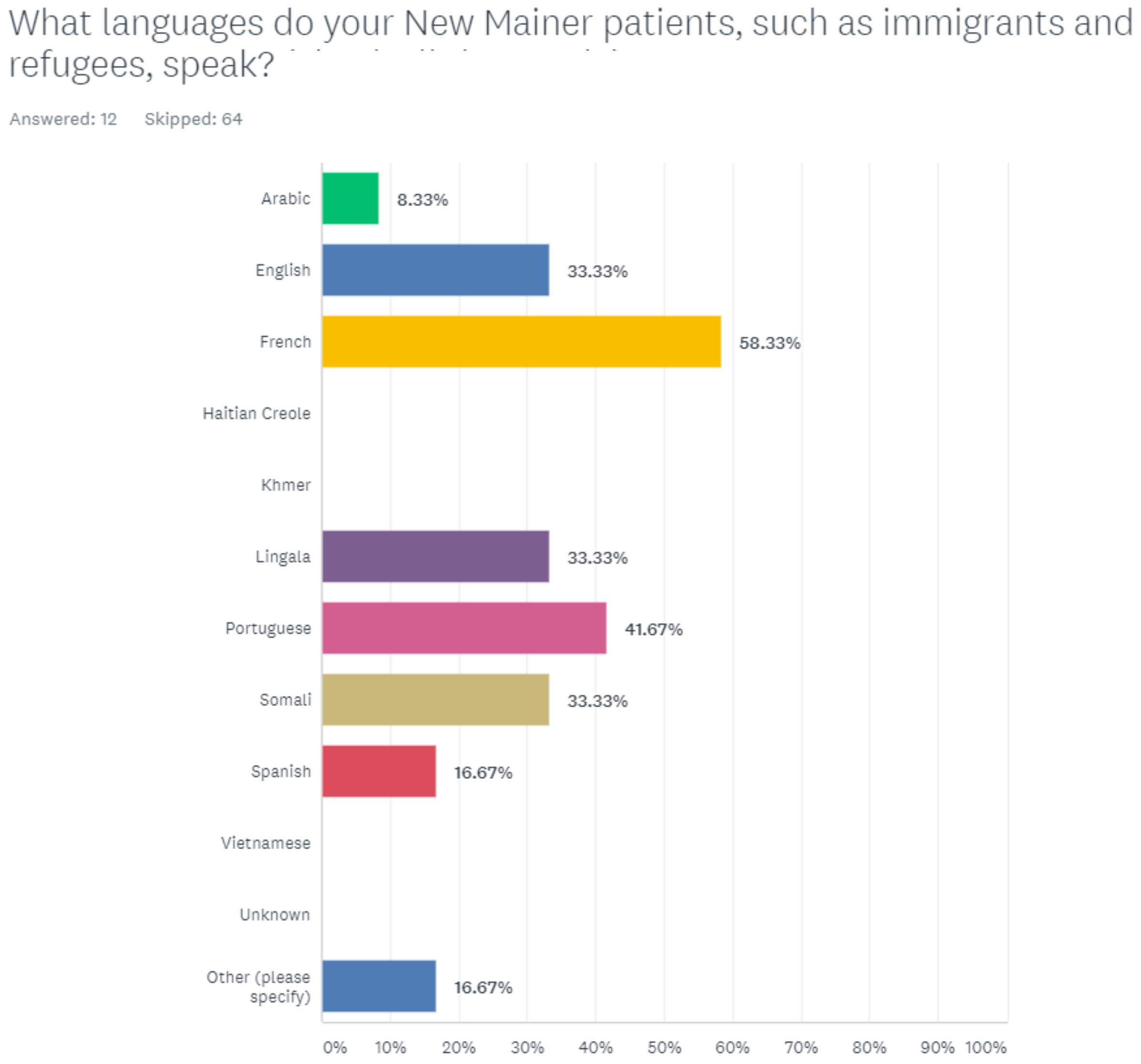
If yes, approximately how many?

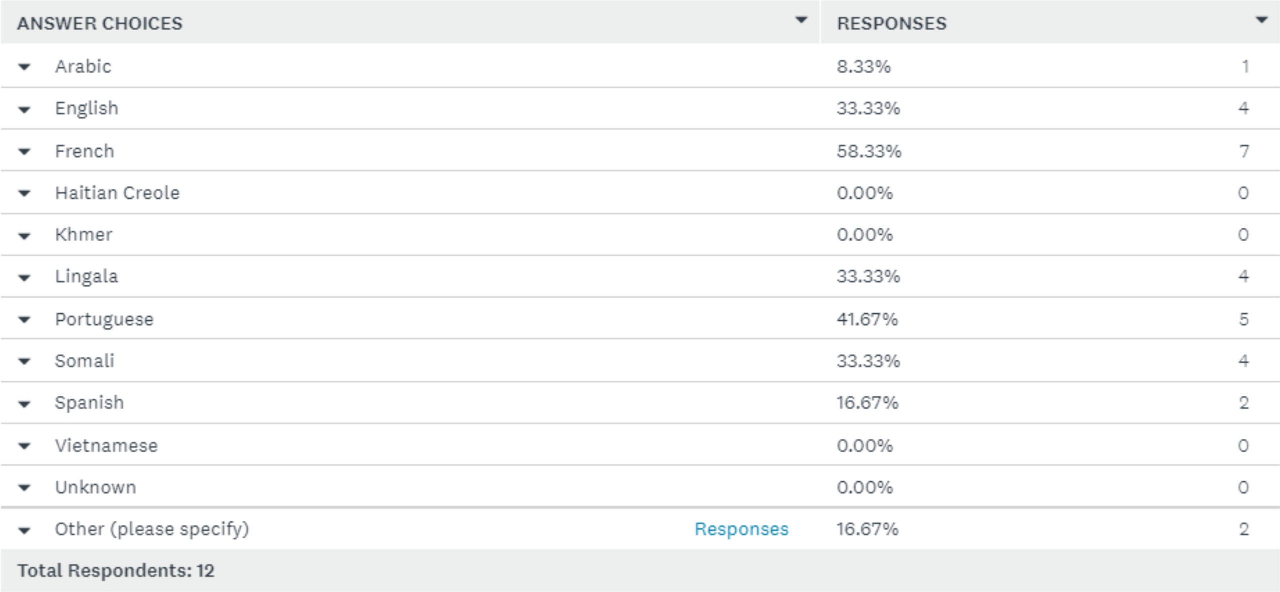
Answered: 12 Skipped: 64

ANSWER CHOICES	RESPONSES	
1-10	75.00%	9
10-20	16.67%	2
20-30	0.00%	0
30+	8.33%	1
Total Respondents: 12		

Figure 10a depicts a further breakdown of the New Mainer population to show approximately how many New Mainers providers are currently managing. Most respondents (9 out of 12) reported managing 1-10 New Mainers, whereas only one provider manages more than 30.

Figure 10b: Languages of HIV/AIDS New Mainers





ANSWER CHOICES		RESPONSES	
Arabic		8.33%	1
English		33.33%	4
French		58.33%	7
Haitian Creole		0.00%	0
Khmer		0.00%	0
Lingala		33.33%	4
Portuguese		41.67%	5
Somali		33.33%	4
Spanish		16.67%	2
Vietnamese		0.00%	0
Unknown		0.00%	0
Other (please specify)	Responses	16.67%	2
Total Respondents: 12			

Figure 10b shows a breakdown of languages New Mainer patients speak based on respondents' experiences inside their respective practices. Only respondents who indicated they have a New Mainer in their practice were asked this question. These 12 providers indicated that the most spoken language (58%) was French, followed by Portuguese (42%). Additionally, many New Mainers speak more than one language.

Key Findings and Next Steps:

The primary goal of the HIV/AIDS waiver program is to improve care and treatment adherence for MaineCare members living with HIV/AIDS. Evidence of the program's success is shown by the fact that 82% of members in 2020 have reached viral suppression (<200 MLs). We celebrate this finding at the same time OMS continues to pursue further opportunities to improve the program to support HIV/AIDS care and care management.

The 2020 Provider Survey responses highlight opportunities for additional program support including:

- Assisting members in finding behavioral health providers and services and access to transportation. Providers indicated these as the top barriers for patients living with HIV/AIDS that prevent maintaining adherence to treatment and obtaining their health goals. These issues are also identified as barriers by respondents to the 2020 Member Survey).
- Directing providers to the latest HIV treatment guidelines.

- Promoting the Maine AIDS Education and Training Center (MEAETC) and other support programs for offering educational opportunities about HIV/AIDS to providers.
- Promoting the availability of Community Health Workers (CHW) and the services they offer.
- Providing culturally competent care and improving health disparities for this population.

The following sections address these opportunities in more detail.

Member Barriers to Adherence/Compliance to Treatment: Behavioral Health Conditions

Twenty-three percent of providers indicated behavioral health conditions as a top barrier to patient adherence/compliance. This finding has been consistent for the past six annual provider surveys. The 2020 MaineCare Member Survey revealed that 53% of members reported experiencing poor mental health five or more days a month. OMS' Nurse Coordinator called these members to learn more about why they reported poor mental health. Most members attributed their poor mental health status to COVID (isolation and/or fear of getting the disease), physical ailments, and pain. Additionally, many of these members reported to OMS that it is just "normal" for them to experience poor mental health throughout the month, especially during the winter months. The members also indicated that behavioral health problems persist, in part, because care is not available; providers have long waiting lists and no open capacity to see new patients. In addition, when the Nurse Coordinator contacts a member about a missed appointment or missed medication pick-up, the member often cites poor mental health as the reason. Based on these results, OMS in collaboration with the broader Department and our community partners, are considering how best to support providers and members in receiving the behavioral health care they need. One promising approach is for practices to utilize CHWs (see below) to help connect members to the necessary services.

Member Barriers to Adherence/Compliance to Treatment: Transportation

Eleven percent of providers indicated transportation is a top barrier to patient treatment adherence/compliance. The 2020 Member Survey showed that 51% of members reported not being able to access necessary medical care, tests, treatments, and prescriptions due to transportation. Though members have access to MaineCare's Non-Emergency Transportation (NET) program, which provides free rides to MaineCare covered services, in 2020, the COVID-19 pandemic led to both a shortage of drivers and the cancellation of many elective or non-emergency appointments. Both members and providers cancelled elective or non-emergency appointments. This increase in cancellations had an impact on driver availability, especially if the cancellation were not made timely enough to allow for rescheduling of the driver. In 2021, the supply of drivers remained lower than before the pandemic, which has placed a strain on the current capacity of the NET program. OMS is working with NET providers to increase their ability to serve our members.

Provider Education

The provider survey results highlighted a need for more provider education. While most respondents (55%) indicate they have reviewed the HIV treatment guidelines in the last 12 months, this is a 15% decrease from the previous year. OMS is working with the New England HIV AIDS Education Training Center to offer a 30-minute webinar on treatment guidelines. This training will occur in early 2022 and will be available as a resource in the future. Additionally, a number of respondents had little or no familiarity with training and funding opportunities through the Maine AIDS Education and Training Center, MaineCare's Special Benefit Waiver, and the Ryan White/AIDS Drug Assistance Program. To address this, OMS mailed 50 education packets after the survey was closed out to providers. Packets included information on these programs and resources and information on the HIV/AIDS Treatment Guidelines Application.

In addition to the resources and training opportunities listed above, the HIV/AIDS program is exploring other options such as using an existing provider email distribution list to send frequent updates and resources; collaborating with the Maine CDC to create, compile, and share information on the treatment guidelines; and collaborating with the MEAETC to address the lack of familiarity on these and other identified topics.

Community Health Workers (CHWs)

Forty-two percent of respondents were not at all familiar with CHWs, but 68% said if there was a CHW available, they would refer patients to them. Respondents anticipated that a CHW would help patients connect to community support and resources, as well as help with care coordination, case management, and system navigation. A review of 61 studies concluded that CHW programs are effective, particularly for low-income groups, in improving cancer prevention and reducing cardiovascular risk. Eight studies of the 61 reviewed supported addressed cost effectiveness and found the programs cost effective.[2] HIV program staff are collaborating with OMS' Delivery System Reform programs, as well as partnering with the Maine Center for Disease Control and Prevention on a grant to support CHWs targeted for the BIPOC HIV population in a Federally Qualified Health Center in Portland, the largest city in the state. OMS plans to use the findings from this grant to inform the HIV waiver program providers about potential options to leverage CHWs for their patients. Finally, the Department has a Federal grant for CHW activities to address health disparities uncovered by the COVID epidemic.

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[2] Kim K, Choi JS, Choi E, Nieman CL, Joo JH, Lin FR, Gitlin LN, Han HR. Effects of Community-Based Health Worker Interventions to Improve Chronic Disease Management and Care Among Vulnerable Populations: A Systematic Review. Am J Public Health. 2016 Apr;106(4):e3-e28. doi: 10.2105/AJPH.2015.302987. Epub 2016 Feb 18. PMID: 26890177; PMCID: PMC4785041.

Department of Health and Human Services

State of Maine
2022 HIV/STD Prevention Needs Assessment Survey Report

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Data & Quality Specialist
Ryan White Part B Program

Contents

Introduction

The 2022 HIV/STD Prevention Needs Assessment Survey was available online and as a printed instrument distributed to the following community-based organizations:
- Health Equity Alliance
- Horizon Program at MaineGeneral Medical Center
- Regional Medical Center at Lubec
- City of Portland
- Gilman Clinic
- Frannie Peabody Center
- Maine Access Immigrant Network

Staff members tabled at the following events with printed surveys and QR codes to encourage online completion by phone:
- Frannie Peabody Center AIDS Walk
- Lewiston/Auburn Pride
- Southern Maine Pride (Portland)
- Bangor Pride
- HIV Testing Day (Portland)

All respondents were offered a $10 Hannaford card for their time.

A total of 546 responses were received.

All survey responses were entered into REDCap and analyzed using Excel.

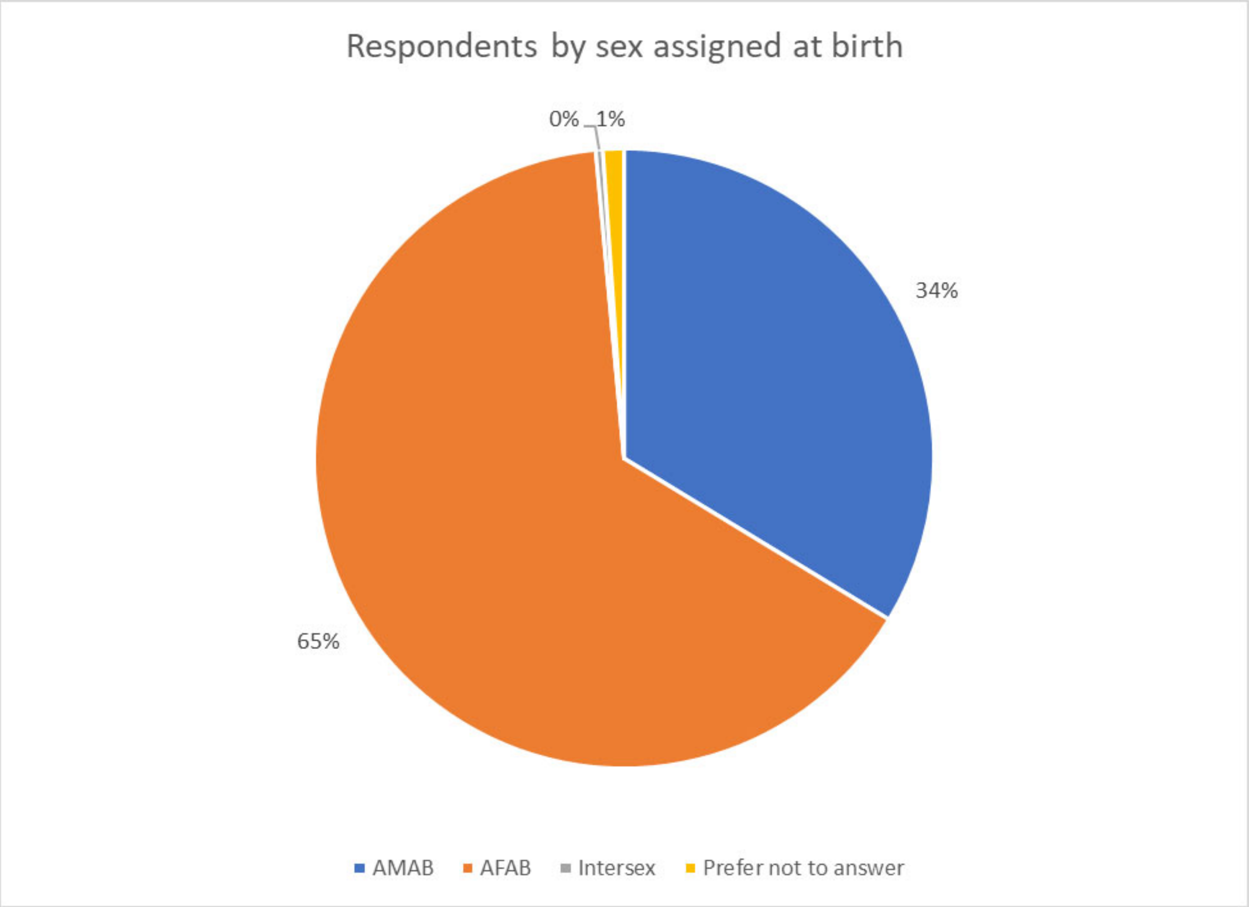
Anecdotal responses and analysis of data reveal flaws in the survey instrument when it comes to defining terms, such as monogamy, long-term, safe sex, and protected sex. It may also be important to distinguish between prescribed injection drug use and injecting non-prescription drugs.

Future surveys should also attempt to align timeframes for questions whenever possible. (For example, there is a question about being diagnosed with an STI or viral hepatitis in the past two years, but most other questions, including number of sexual partners, use the past year as a frame of reference.)

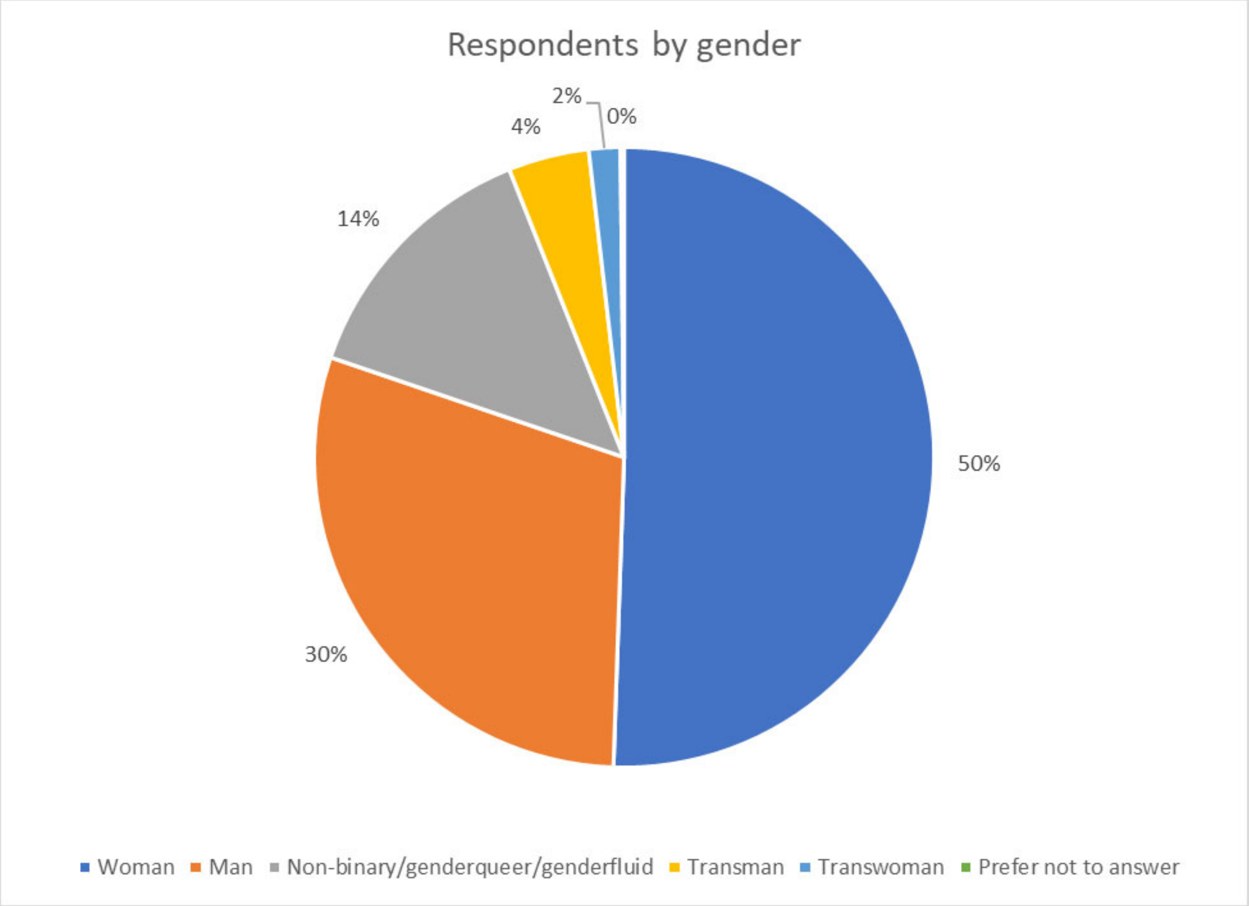
Demographics

Sex assigned at birth and gender

About one-third of respondents were assigned male at birth, compared to about 65% who were assigned female.

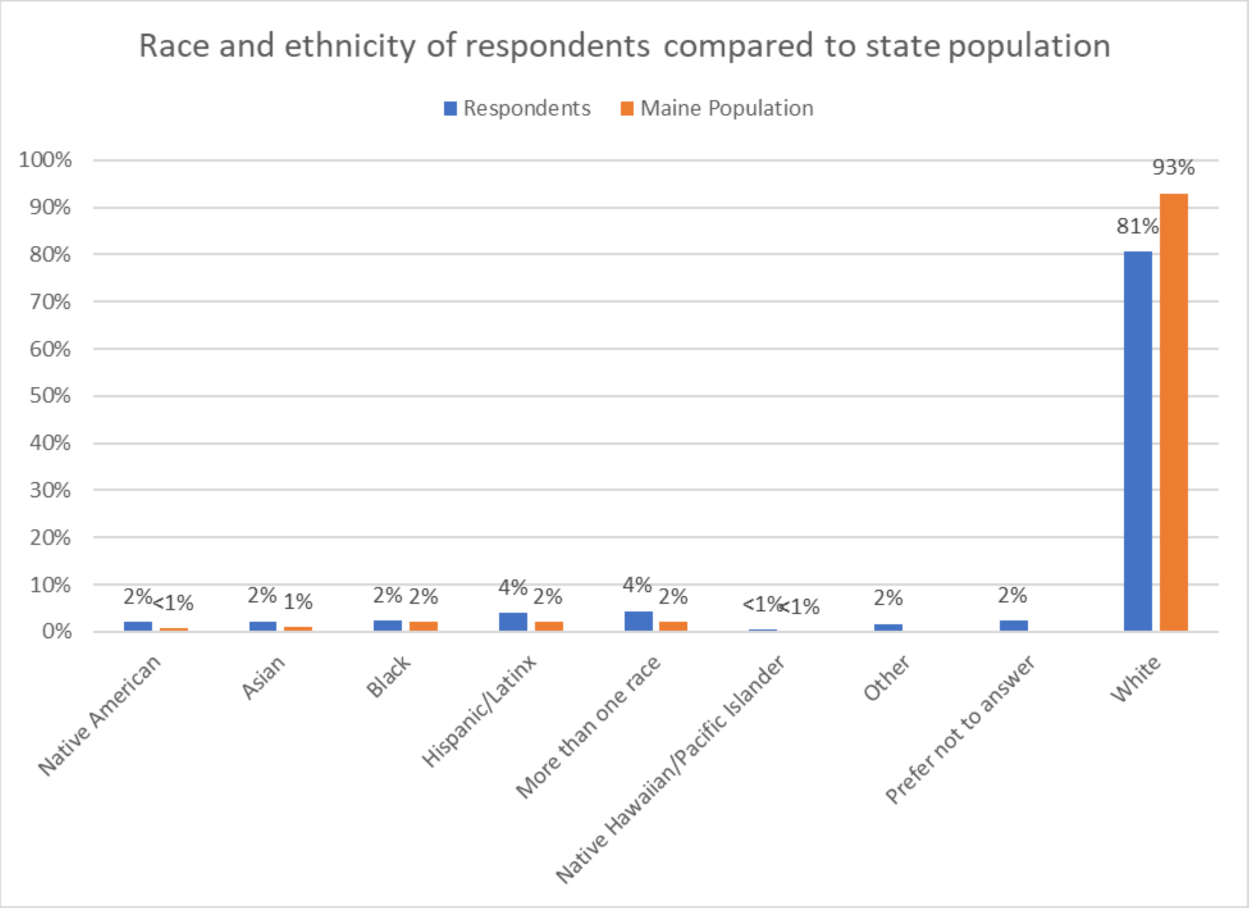


About half of respondents identified as women, about one-third as men, and about 20% as non-binary or transgender.



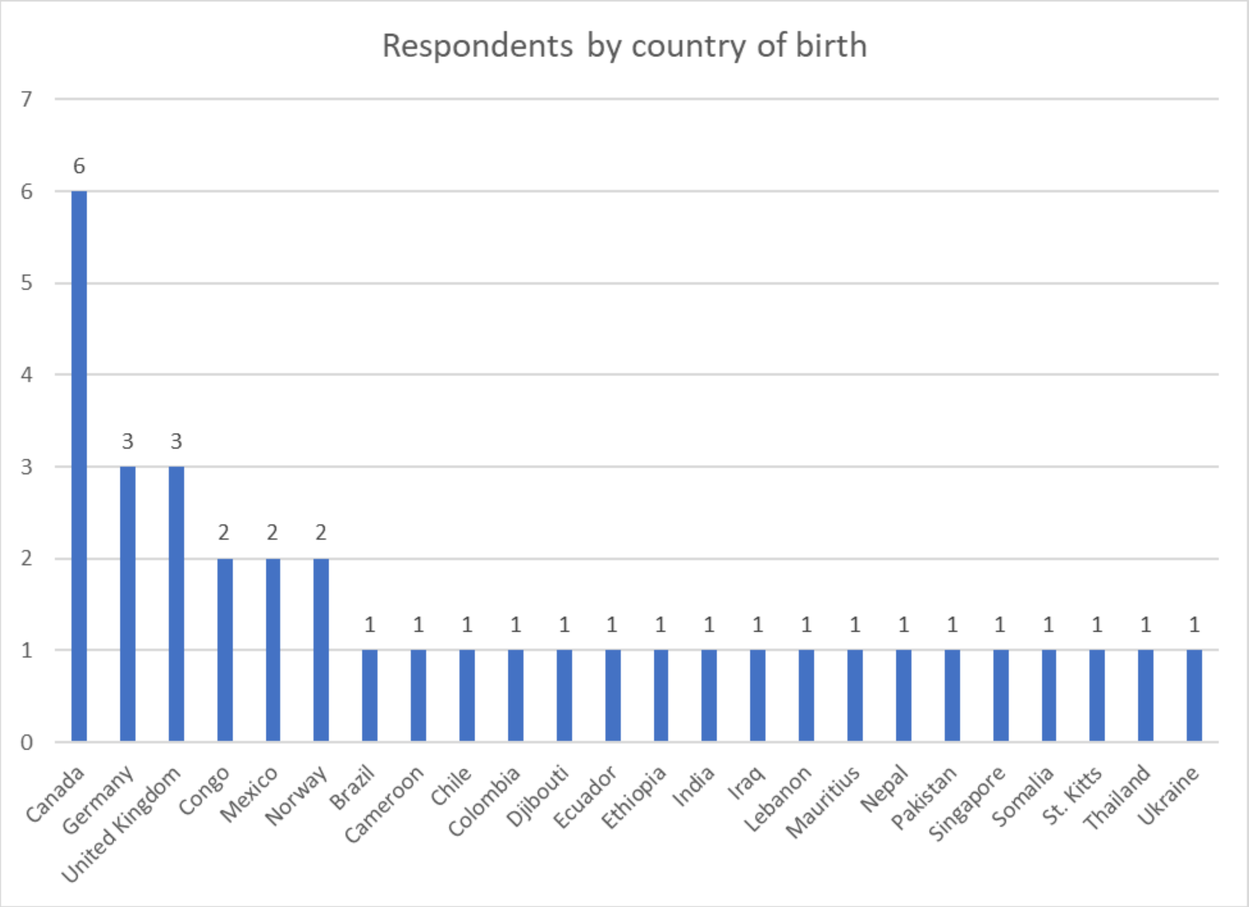
Race and ethnicity

While most respondents (81%) were white only, they were more racially and ethnically diverse than the general population of Maine, according to the U.S. Census:

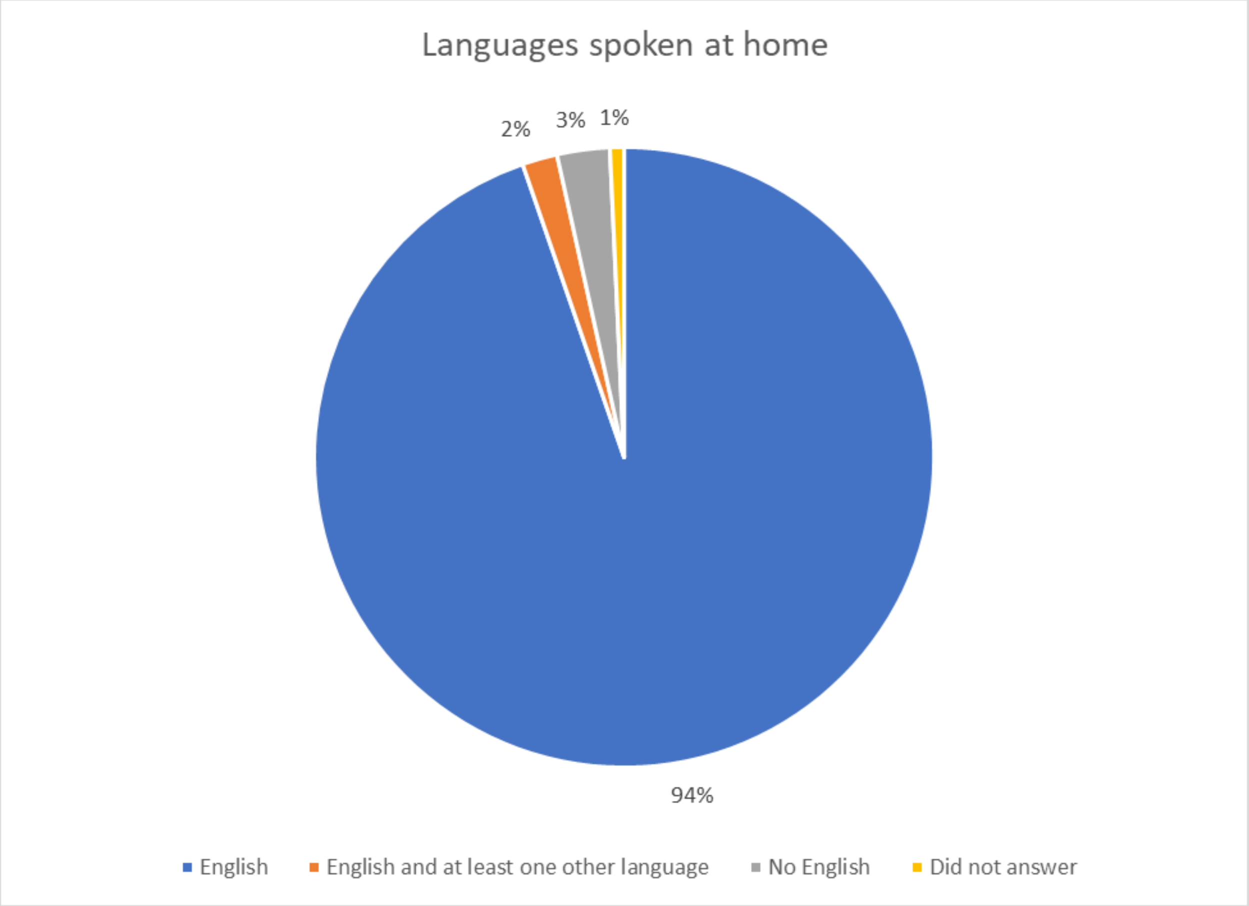


Country of birth and languages spoken at home

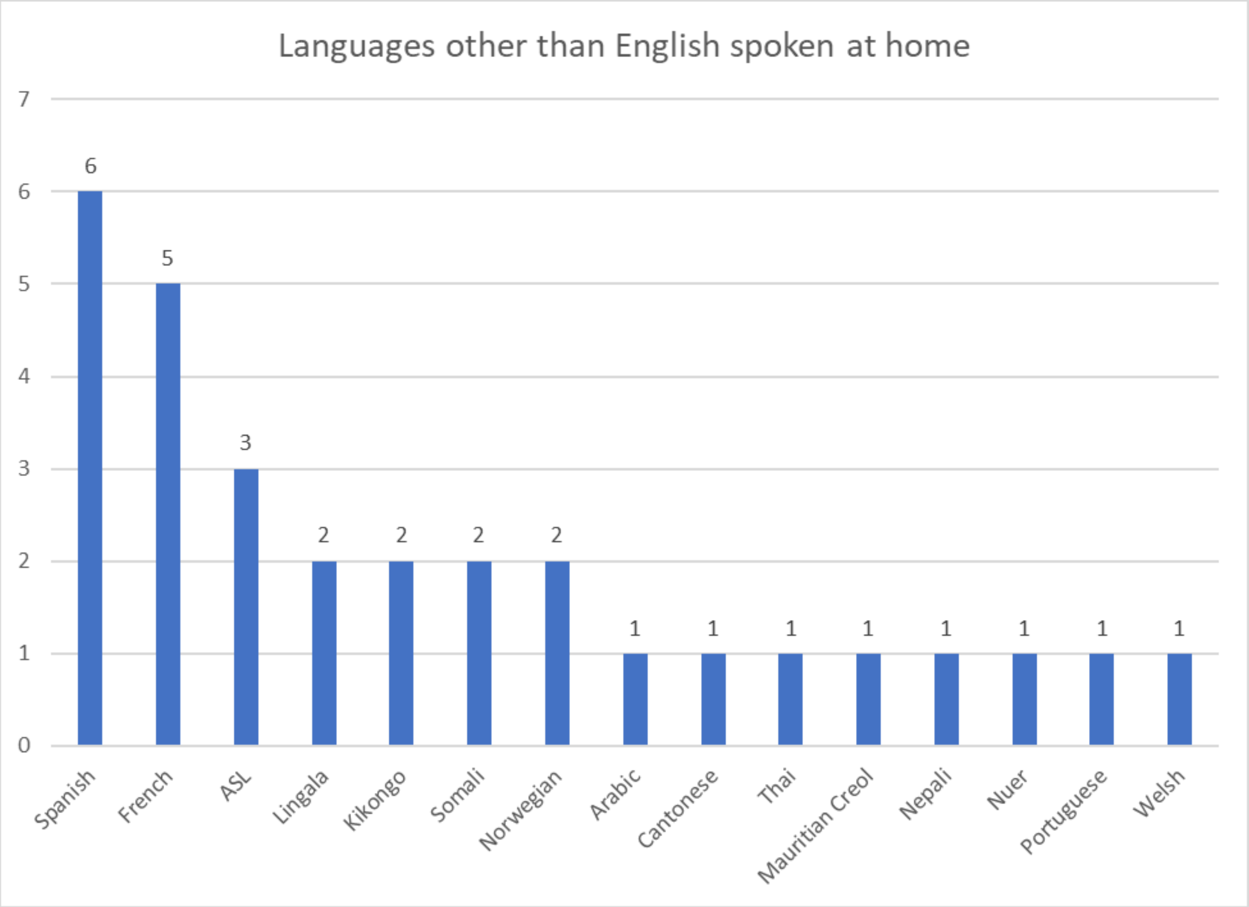
According to the U.S. Census, about 4% of the population in Maine was born in another country, compared to about 7% of survey respondents.



Nearly all respondents (96%) indicated that English is one of the languages spoken at home:

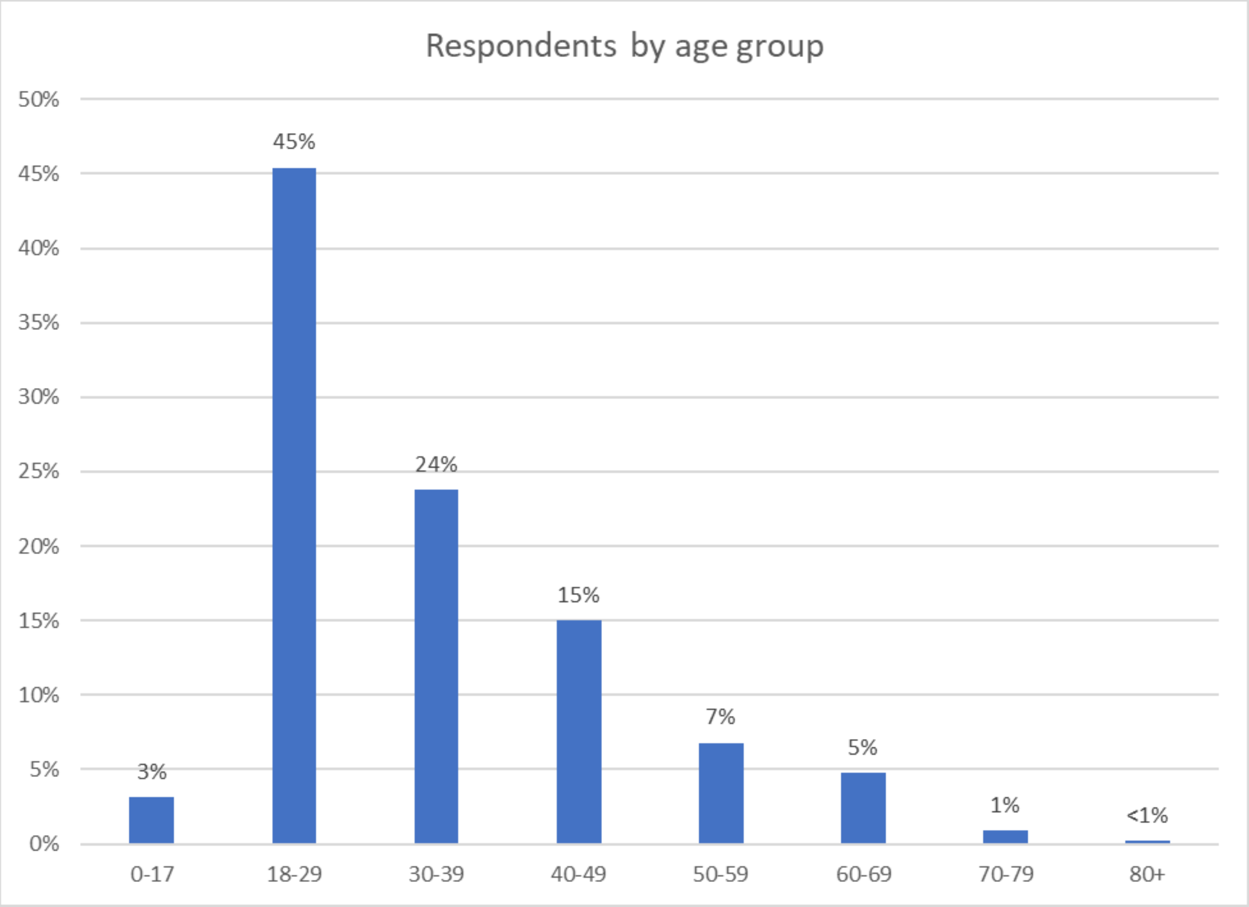


The most common languages other than English that respondents identified speaking at home were Spanish, French, and American Sign Language (ASL).



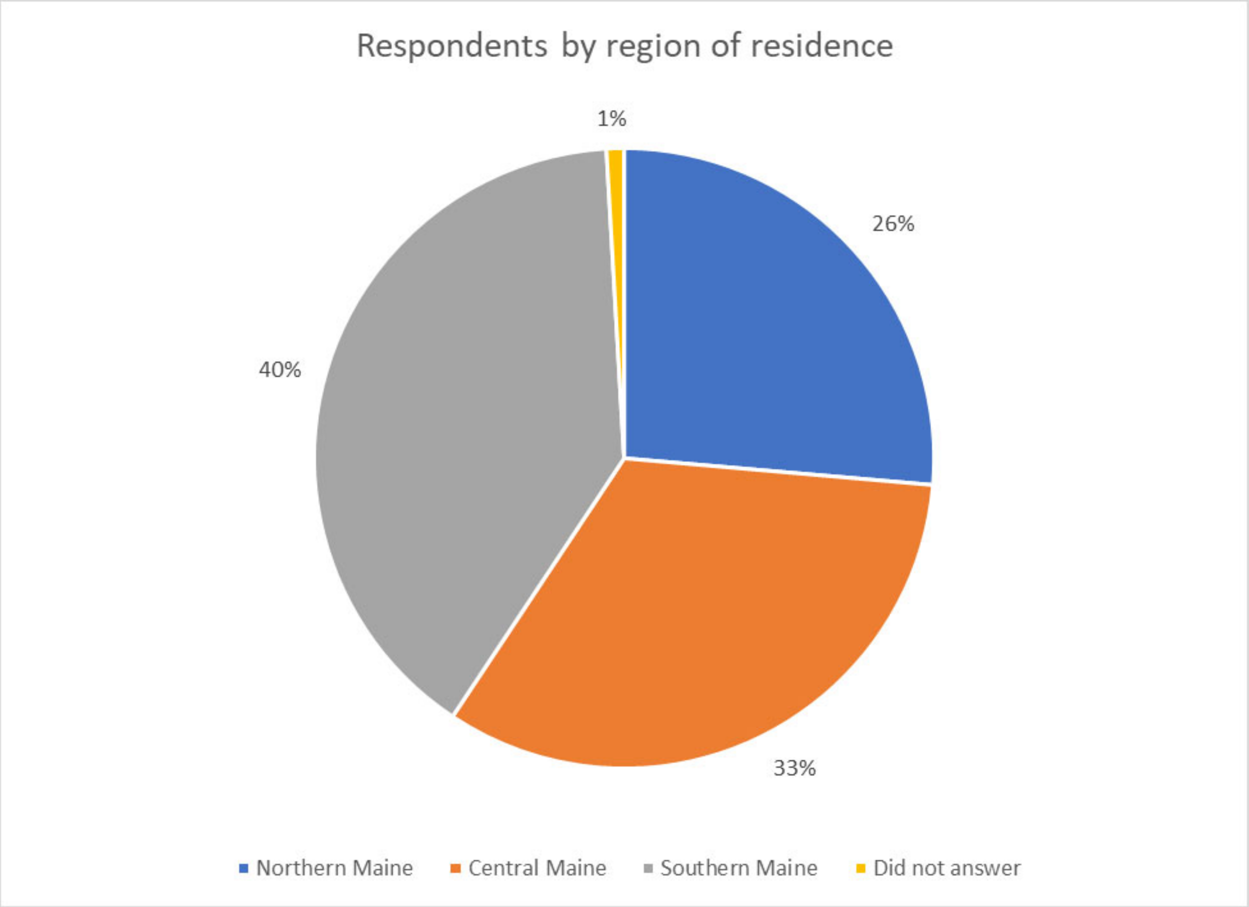
Age

Almost half of respondents (48%) were younger than 30. About 13% were age 50 or older.



Region of residence

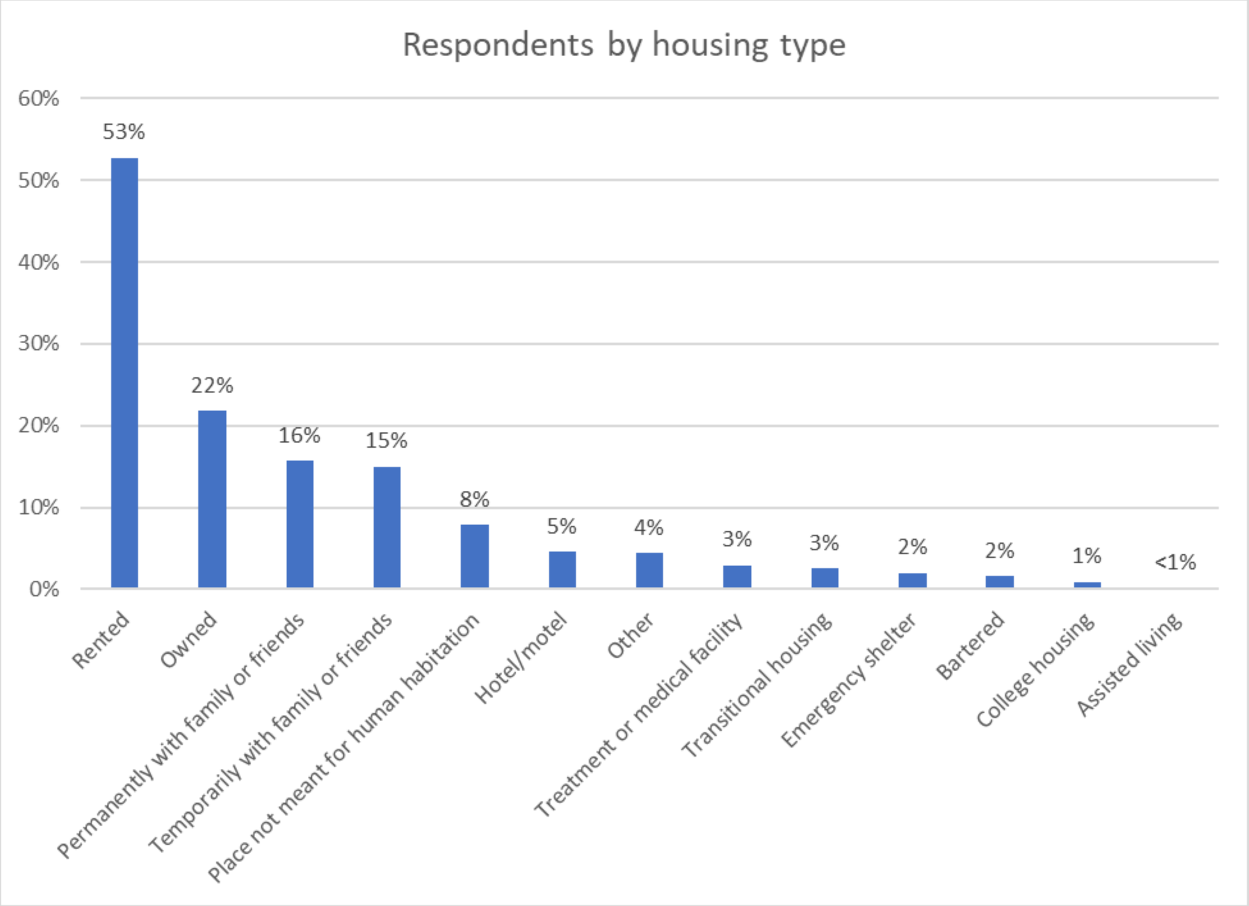
About 40% of respondents lived in Southern Maine (Cumberland and York counties), about one-third in Central Maine (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset, and Waldo counties), and about one-quarter in Northern Maine (Aroostook, Hancock, Penobscot, Piscataquis, and Washington counties).



Housing status

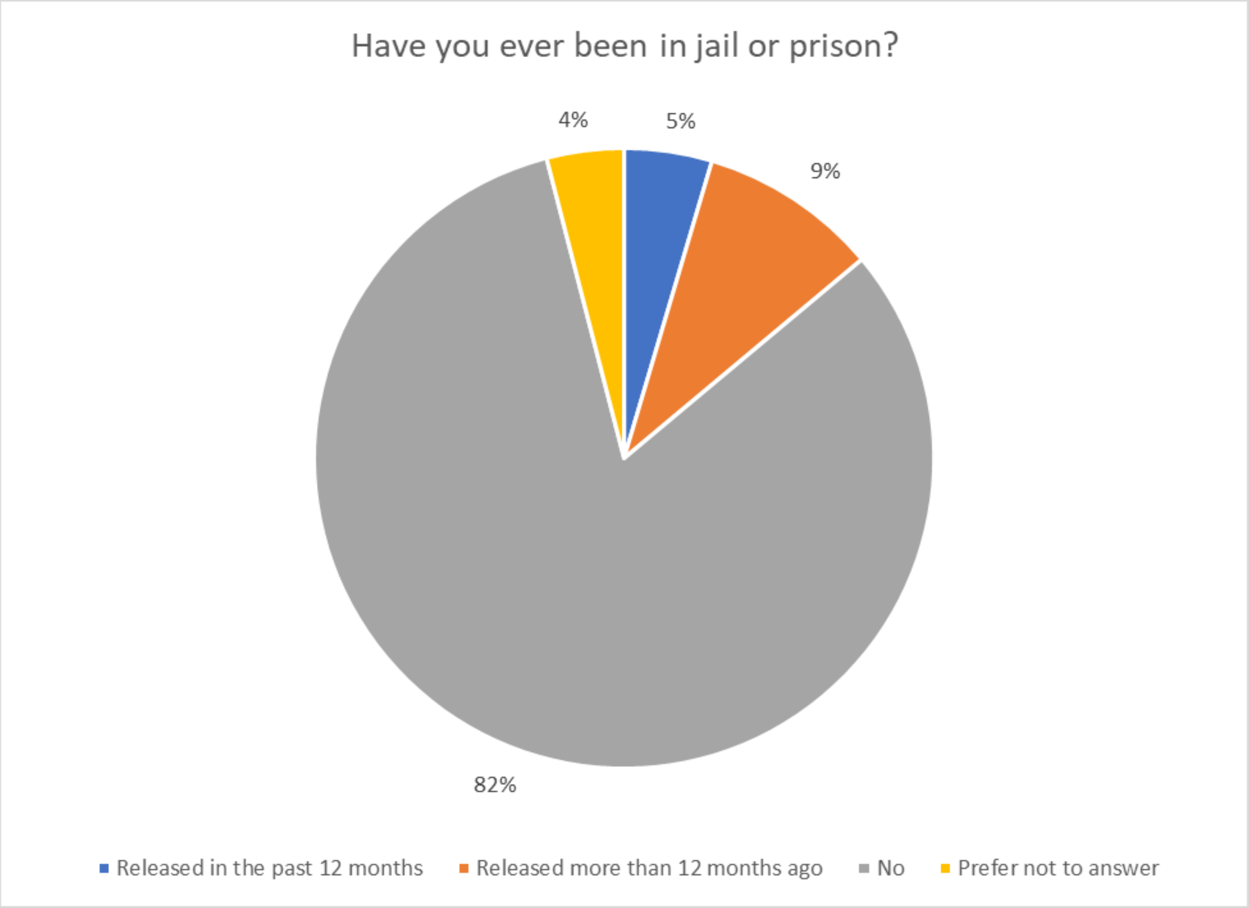
Respondents were asked to identify all housing situations they have lived in for the last 12 months. Eight percent of respondents reported three or more housing situations in the past year.

Of the 43 individuals who reported three or more housing situations in the past year, 58% reported staying in a place not meant for human habitation, 44% reported staying in a hotel, and 21% reported staying in an emergency shelter.



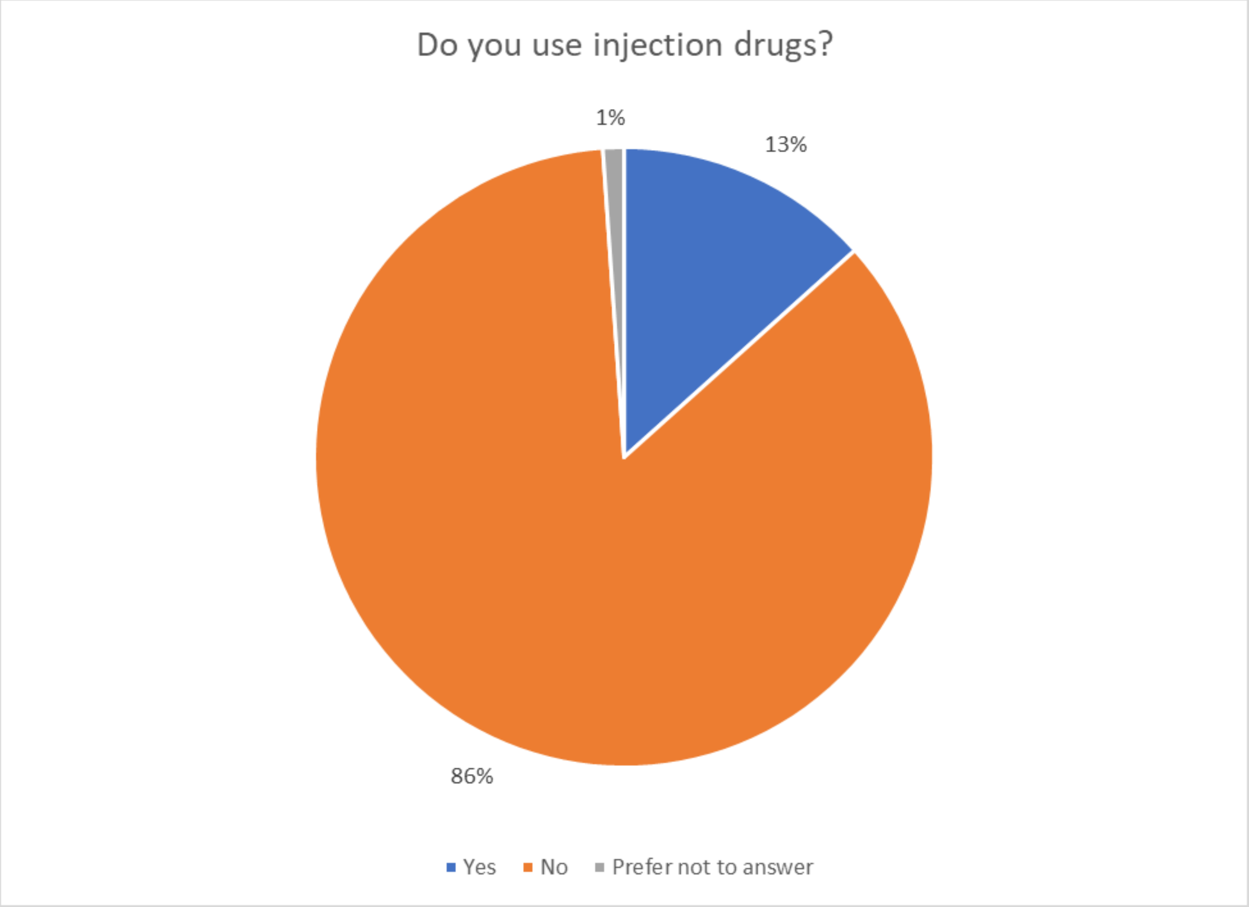
Incarceration

About 14% of respondents indicated that they had ever been incarcerated.



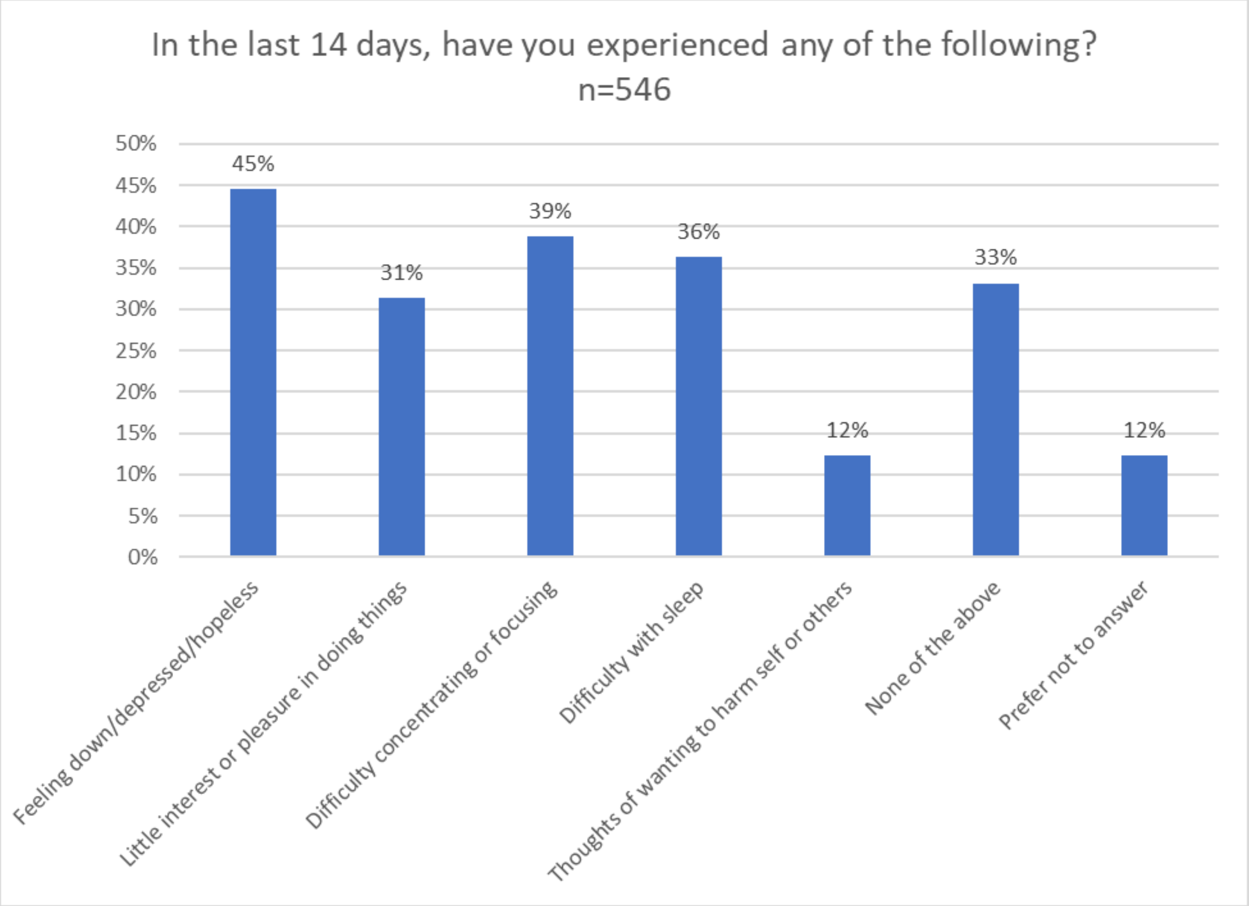
Injection drug use

About 13% of respondents reported injection drug use.



Mental health

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. Although one-third of respondents reported "none of the above," ratings were still high among all risk populations for various symptoms.


In the last 14 days, have you experienced any of the following?
n=546
50%
45%
40%
35%
30%
25%
20%
15%
10%
5%
0%
45%
31%
39%
36%
12%
33%
12%
Feeling down/depressed/hopeless
Little interest or pleasure in doing things
Difficulty concentrating or focusing
Difficulty with sleep
Thoughts of wanting to harm self or others
None of the above
Prefer not to answer

Discrimination

The most-frequently reported types of discrimination were based on gender identity and sexual practices. About 10% of respondents indicated fear of using HIV prevention services at least sometimes.

How often do you experience the following?	Never	Very Seldom	Sometimes	Often	Always	N/A
Ill-treatment or discrimination by your medical provider due to your gender identity	62%	13%	10%	5%	1%	8%
Ill-treatment or discrimination by your medical provider due to your sexual practices	64%	14%	12%	2%	1%	7%
Ill-treatment or discrimination by your medical provider due to your racial or ethnic identity	80%	6%	4%	2%	1%	8%
Ill-treatment or discrimination by your medical provider due to your HIV status	73%	2%	2%	1%	<1%	22%
Ill-treatment or discrimination by your landlord or prospective landlord because of your HIV status	72%	2%	2%	1%	<1%	22%
Fear of using HIV prevention services (such as HIV testing, condoms, PrEP) because of how you feel you would be treated by family, friends, or community members	70%	7%	7%	1%	2%	17%

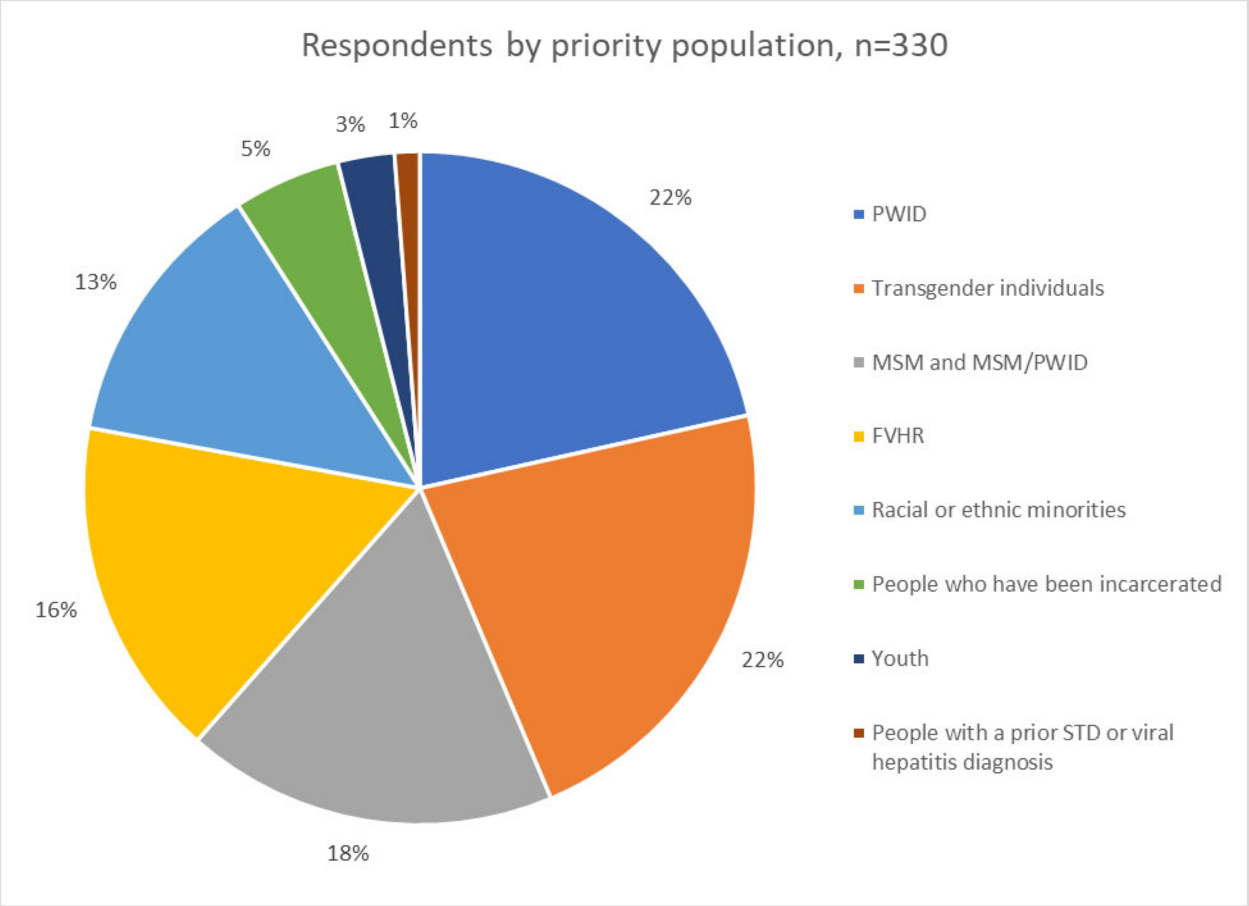
Priority populations and risk

The following priority populations were identified in the most recent Request for Proposals (RFP) for Community HIV Outreach and Testing Services:

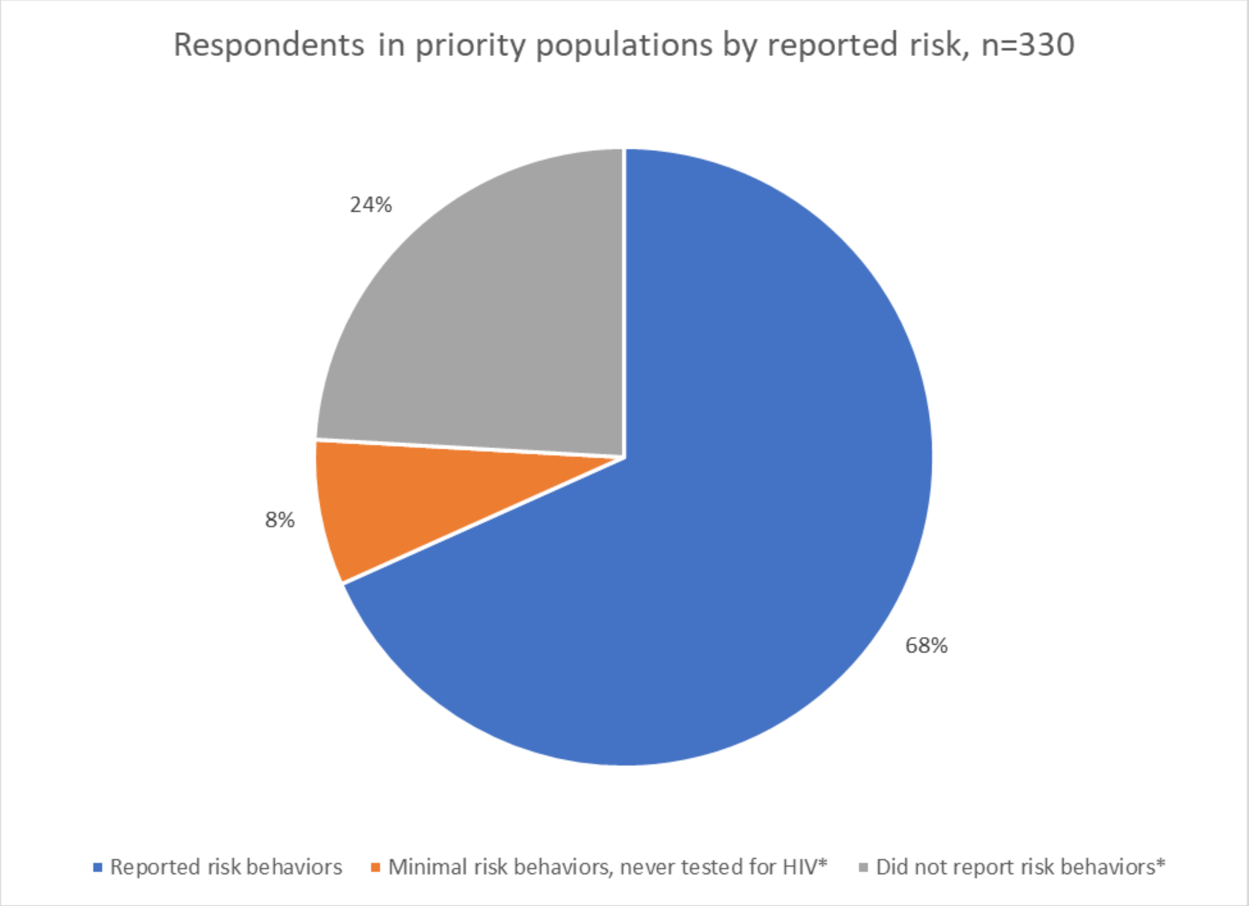
- Males who have sex with males (MSM)
- People who inject drugs (PWID)
- Females at Very High Risk (FVHR), including women who:
    - Have had unprotected anal or vaginal sex with a partner who is MSM and/or PWID;
    - Have traded unprotected anal or vaginal sex for money, goods, and/or survival needs;
    - Are currently or recently infected with gonorrhea, syphilis, and/or viral hepatitis; and/or
    - Have been sexually assaulted within the past 12 months
- Transgender individuals
- Adults and adolescents 24 years-old or younger
- People living with HIV/AIDS (PLWH)
- Individuals who are in drug treatment
- Individuals with partners diagnosed with HIV, STDs, or viral hepatitis
- Individuals with partners who are MSM or PWID
- Individuals who have been incarcerated
- Individuals who have been sexually assaulted
- Individuals engaged in sex work
- Individuals who have had a prior STD or viral hepatitis diagnosis
- Individuals who are pregnant
- Racial and ethnic minorities
- Asylum seekers, asylees, or refugees

It is important to note that the survey did not include questions that would identify young adults between the ages of 18 and 24, individuals who are in drug treatment, individuals with partners who are MSM or PWID, individuals who have been sexually assaulted, individuals who are pregnant, or asylum seekers, asylees, or refugees.

A total of 330 respondents (60%) met the criteria to be included in one of the priority populations.

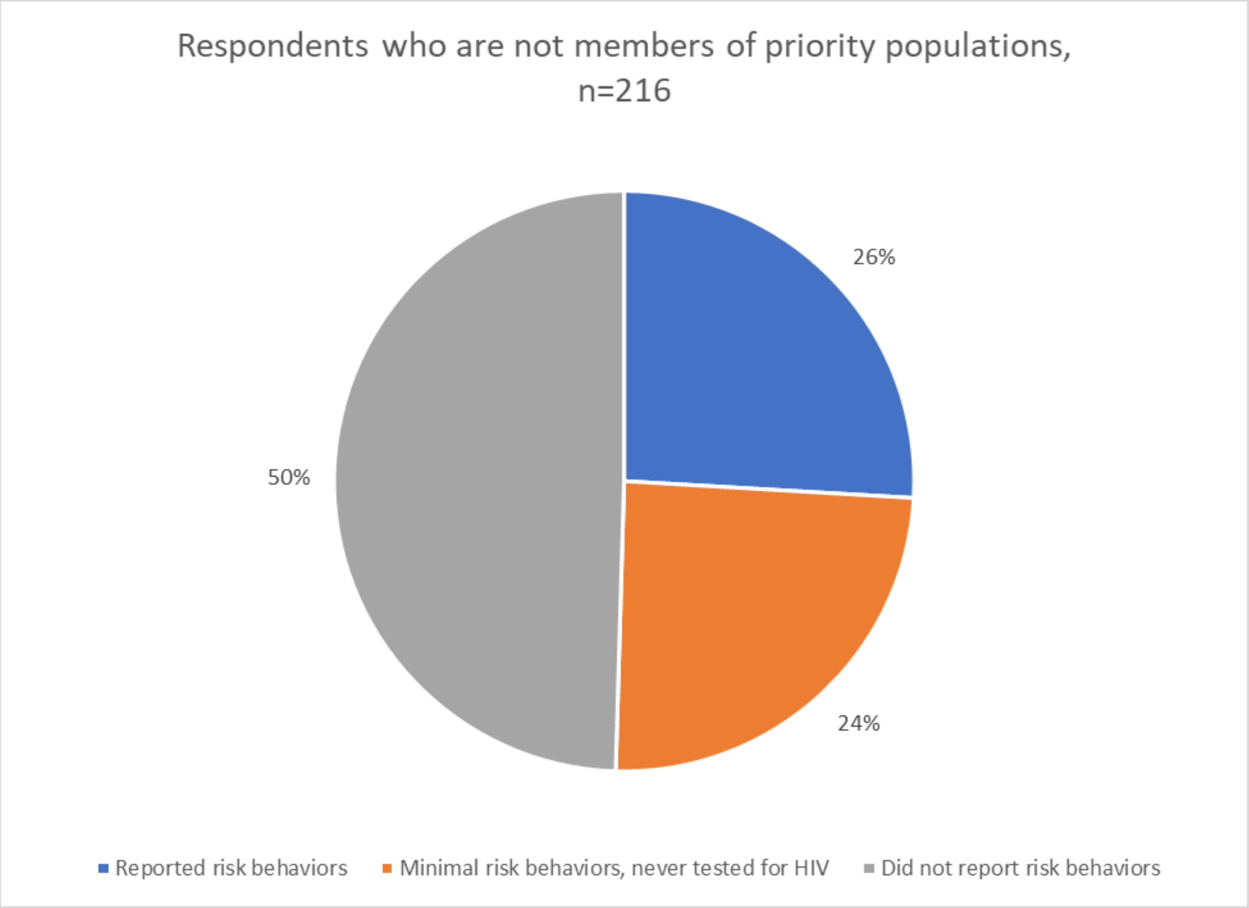


Prioritization is based on risk behaviors and vulnerable populations. About one-quarter of those in priority populations did not report any risk behaviors for HIV/STDs.



* These respondents are included in priority populations because they are members of a vulnerable demographic group.

A total of 216 respondents (40%) did not meet any criteria to be included in priority populations. About half of these did not report any risk behaviors for HIV/STDs.



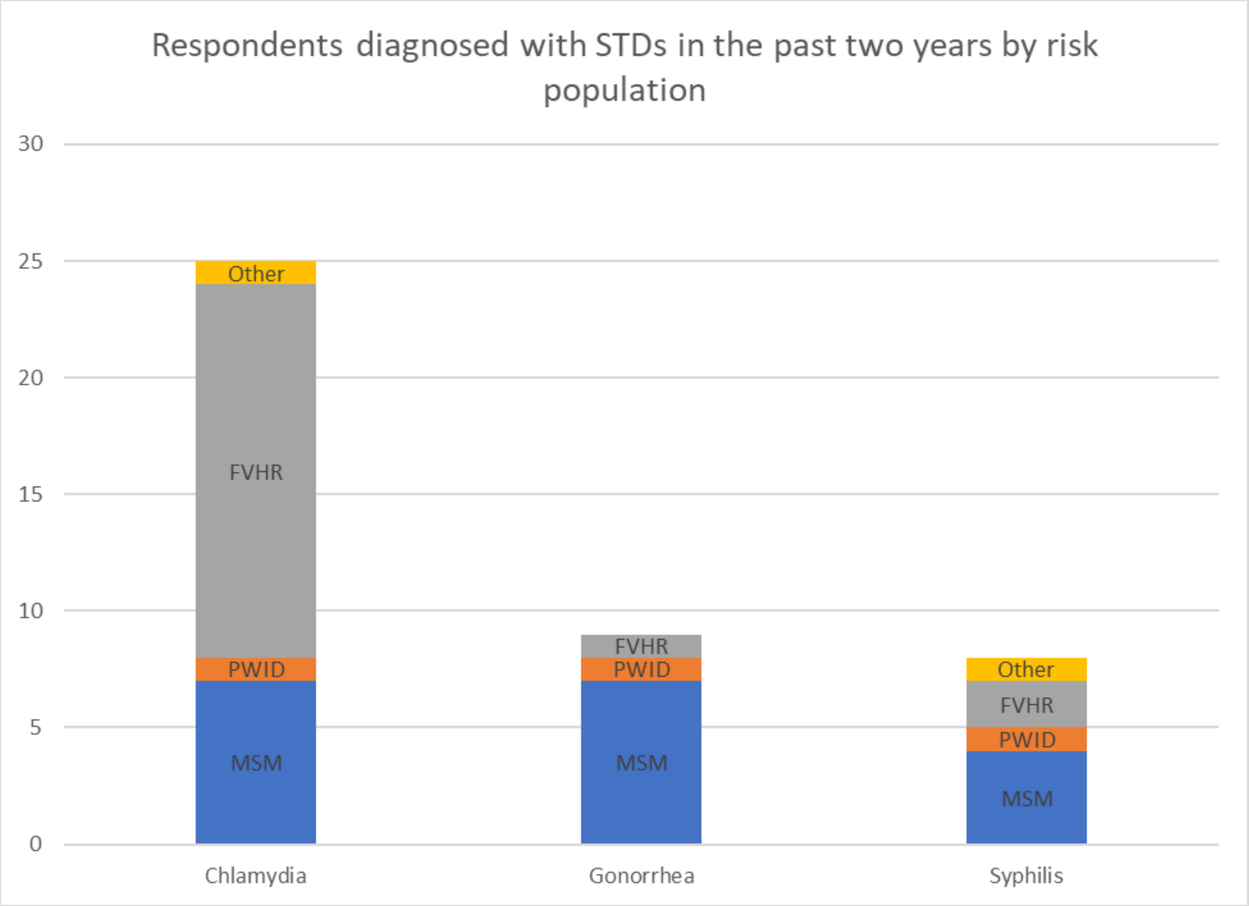
The table below shows the percentage of respondents among each priority population who indicated that they thought they might be at risk for HIV/STDs versus the percentage of respondents who reported behaviors that would be consider a risk for HIV/STDs.

Priority population	% perceived risk	% reported risk behaviors
MSM and MSM/PWID	59%	100%
FVHR	43%	100%
PWID	31%	100%
People with a prior STD or viral hepatitis diagnosis	25%	100%
People who have been incarcerated	12%	82%
No priority population	15%	50%
Transgender individuals	25%	47%
Racial or ethnic minorities	14%	33%
Youth	11%	11%
Total	**26%**	**66%**

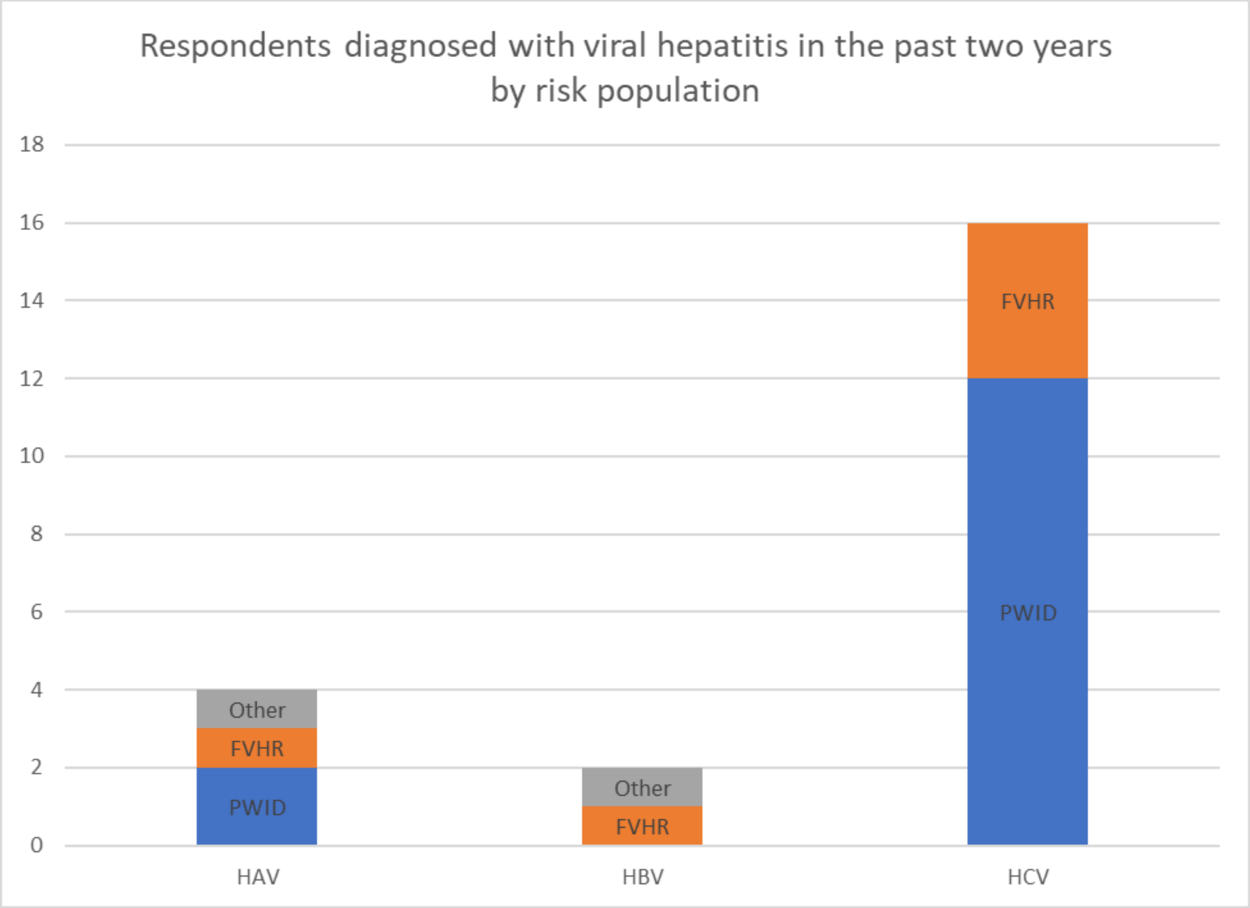
The prioritized population with the most STD diagnoses in the past two years was FVHR, with nearly one-third of FVHR respondents reporting a diagnosis with chlamydia. In addition, FVHR respondents report two cases of syphilis and one of gonorrhea.

Seven MSM respondents reported a chlamydia diagnosis, seven a gonorrhea diagnosis, and four a syphilis diagnosis.

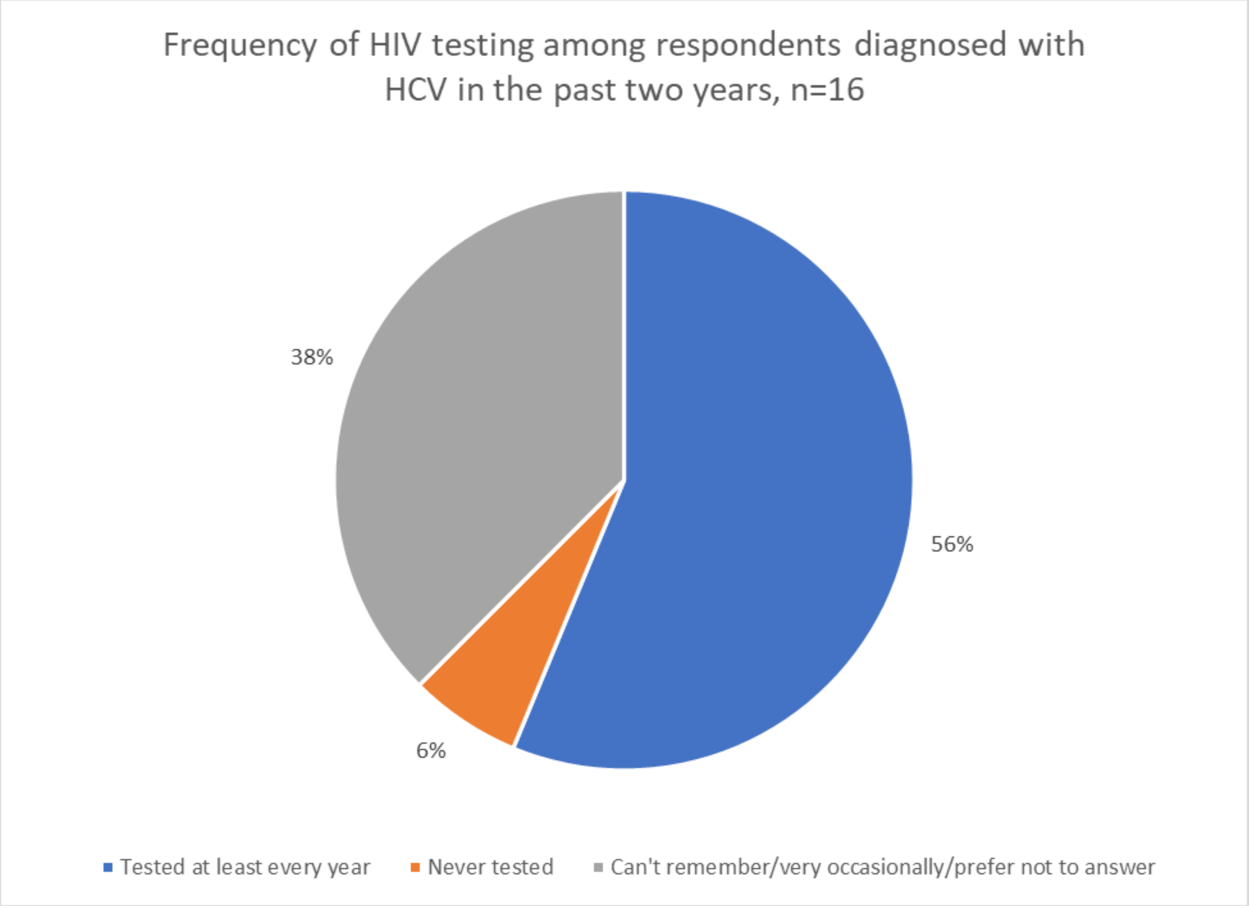
Three different PWID respondents reported being diagnosed with one of the three-reportable STDs in the last two years, one each with chlamydia, gonorrhea, and syphilis.



No MSM reported being diagnosed with viral hepatitis in the past two years. Hepatitis C was the most commonly reported viral hepatitis diagnosis among respondents, reported by 12 PWID and four FVHR.



There were sixteen respondents (3%) who reported being diagnosed with Hepatitis C in the past two years. Of these, 56% reported being tested for HIV at least every year while 46% have never tested, can’t remember the last time they were tested, very occasionally tested, or preferred not to answer.



Responses by priority populations

MSM

There were 59 respondents (11%) who reported being assigned male at birth (AMAB) and who report sex with men as a risk behavior. Four of these MSM respondents (7%) also reported injection drug use as a risk behavior.

Fourteen of these respondents (24%) currently identify as non-binary or transgender.

Only five respondents (8%) indicated a race or ethnicity other than white/not Hispanic.

Two-thirds of MSM respondents (66%) were age 39 or younger, and more than one-third (37%) were age 18-29.

Four respondents (7%) reported staying in a place not meant for human habitation at some point in the past year. Four respondents (7%) reported three or more living situations in the past year.

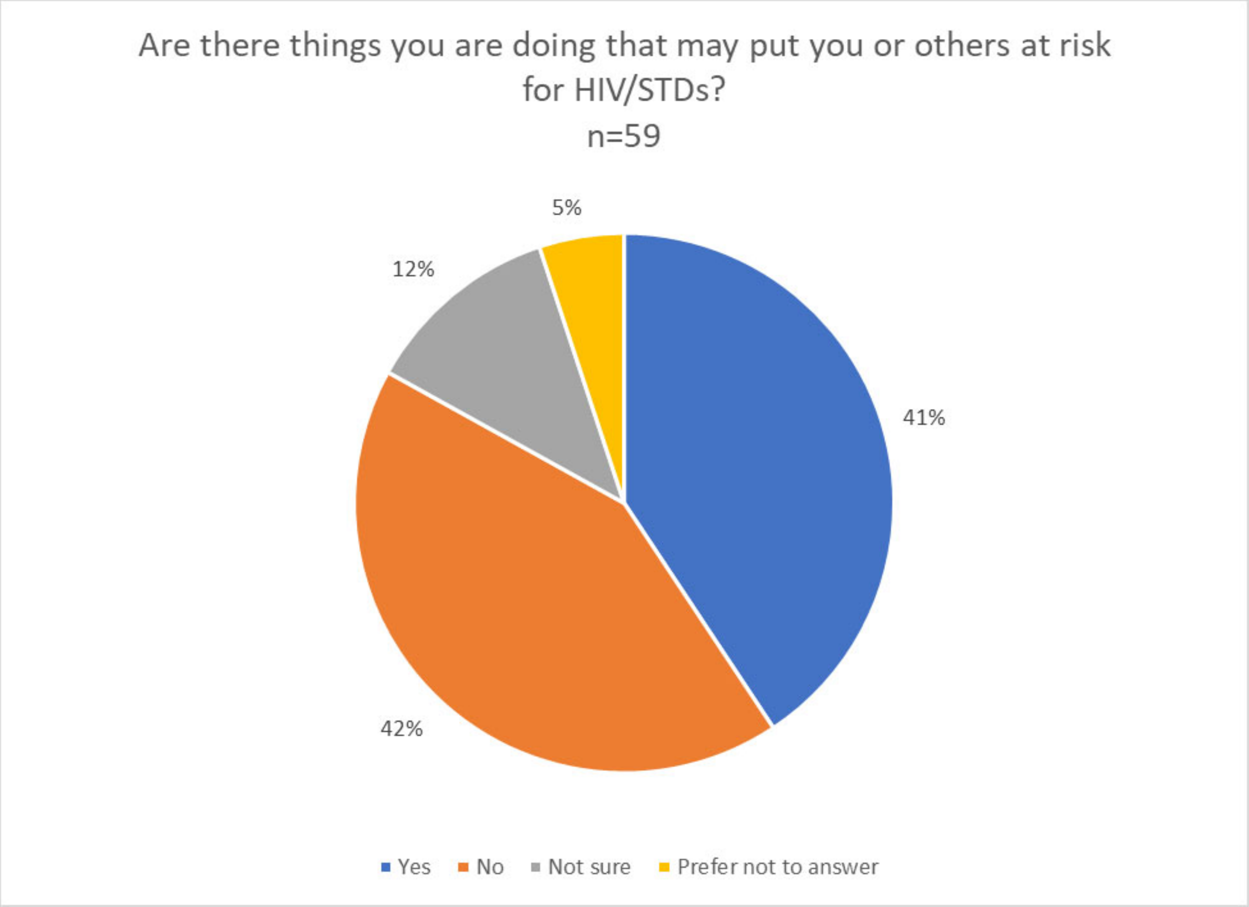
Ten respondents (17%) reported being incarcerated.

Other infections

Seven MSM respondents (12%) reported being diagnosed with chlamydia in the last two years; seven respondents (12%) reported being diagnosed with gonorrhea in the last two years; four (7%) reported being diagnosed with syphilis in the last two years. Two individuals reported being diagnosed with all three.

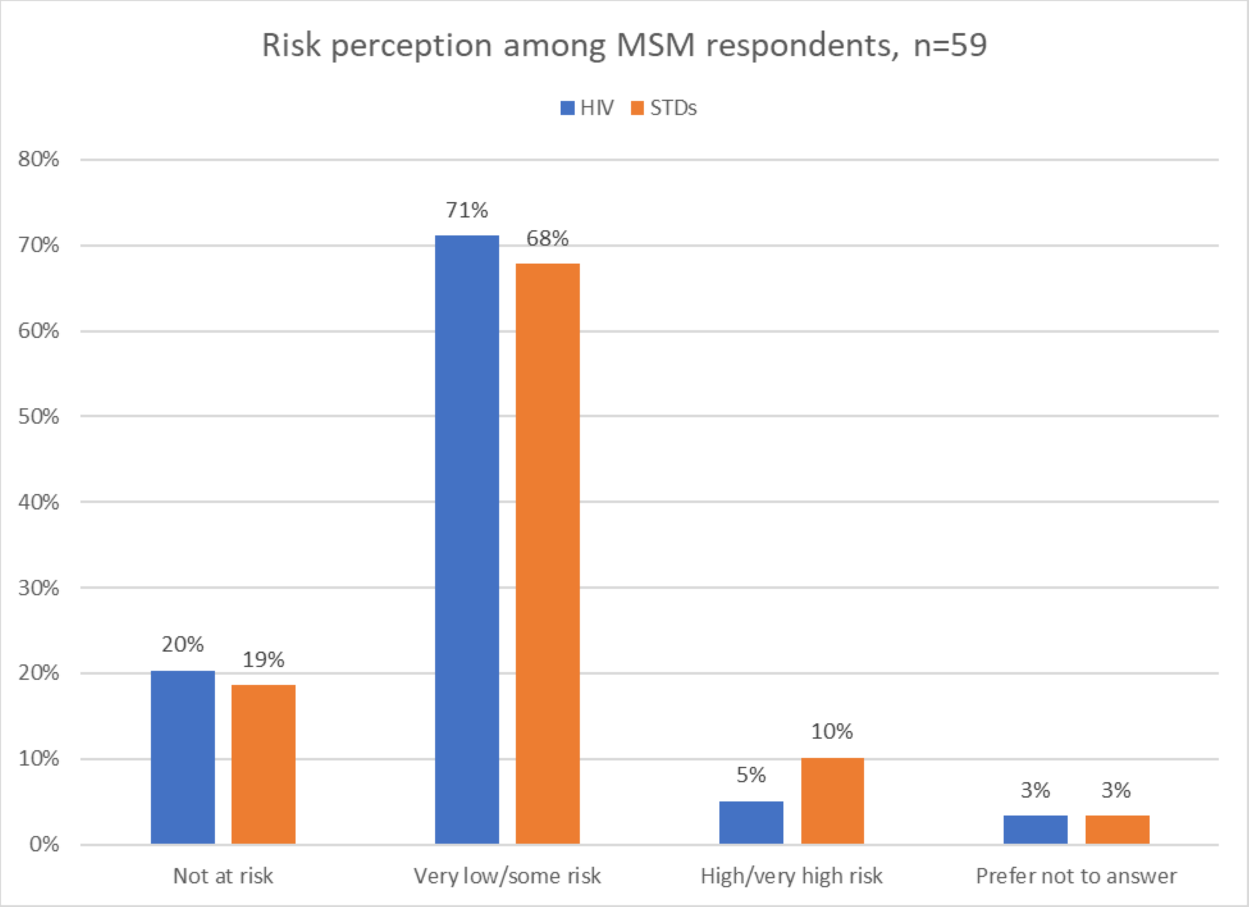
No respondents reported being diagnosed with Hepatitis A, B, or C in the past two years.

Risk perception and HIV testing



Of the 22 MSM respondents who indicated they were at some risk, high risk, or very high risk for HIV infection, 15 (68%) reported that they were doing things that may put themselves or others at risk for HIV/STDs.

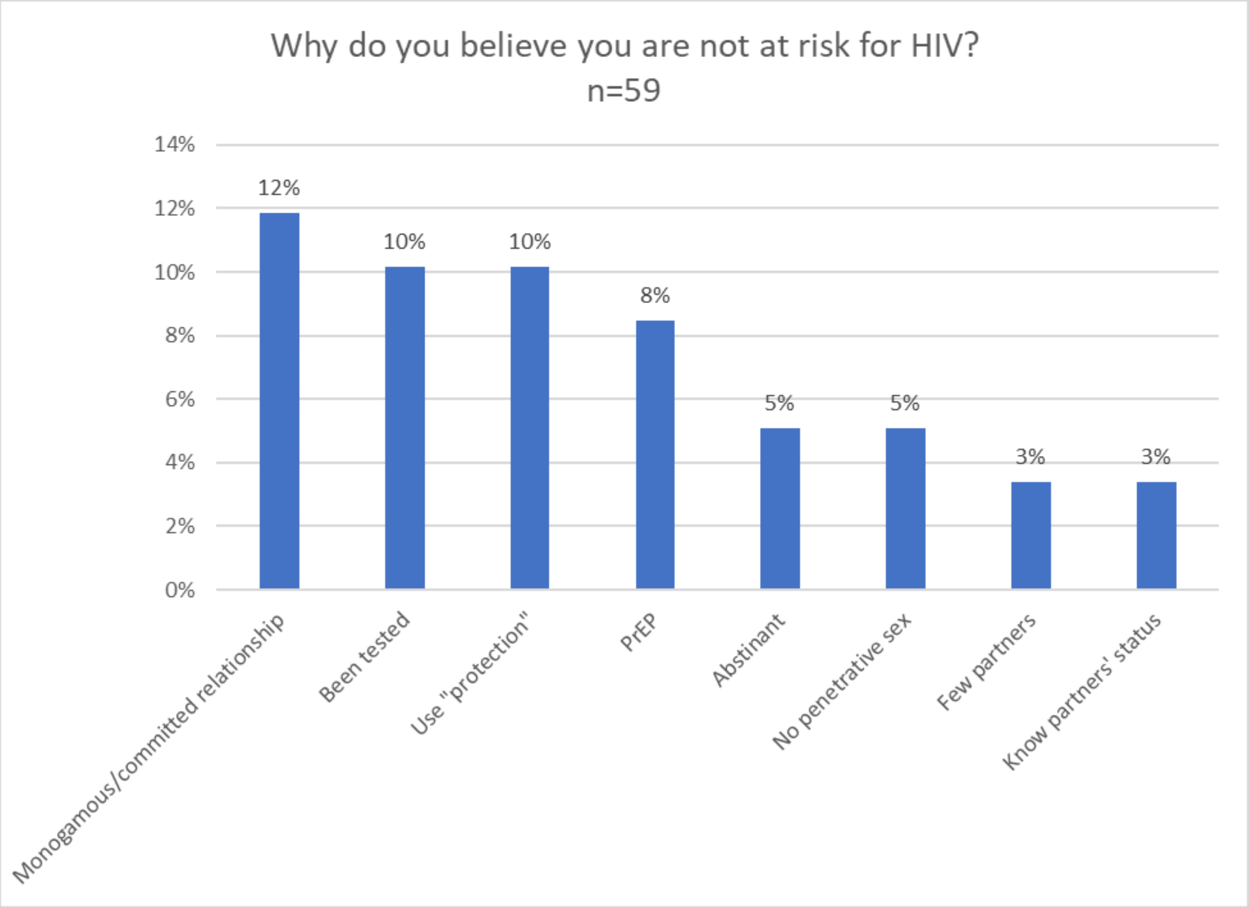
Of the 26 respondents who indicated that were at some risk, high risk, or very high risk for STDs, 16 (62%) reported that they were doing things that may put themselves or others at risk for HIV/STDs.



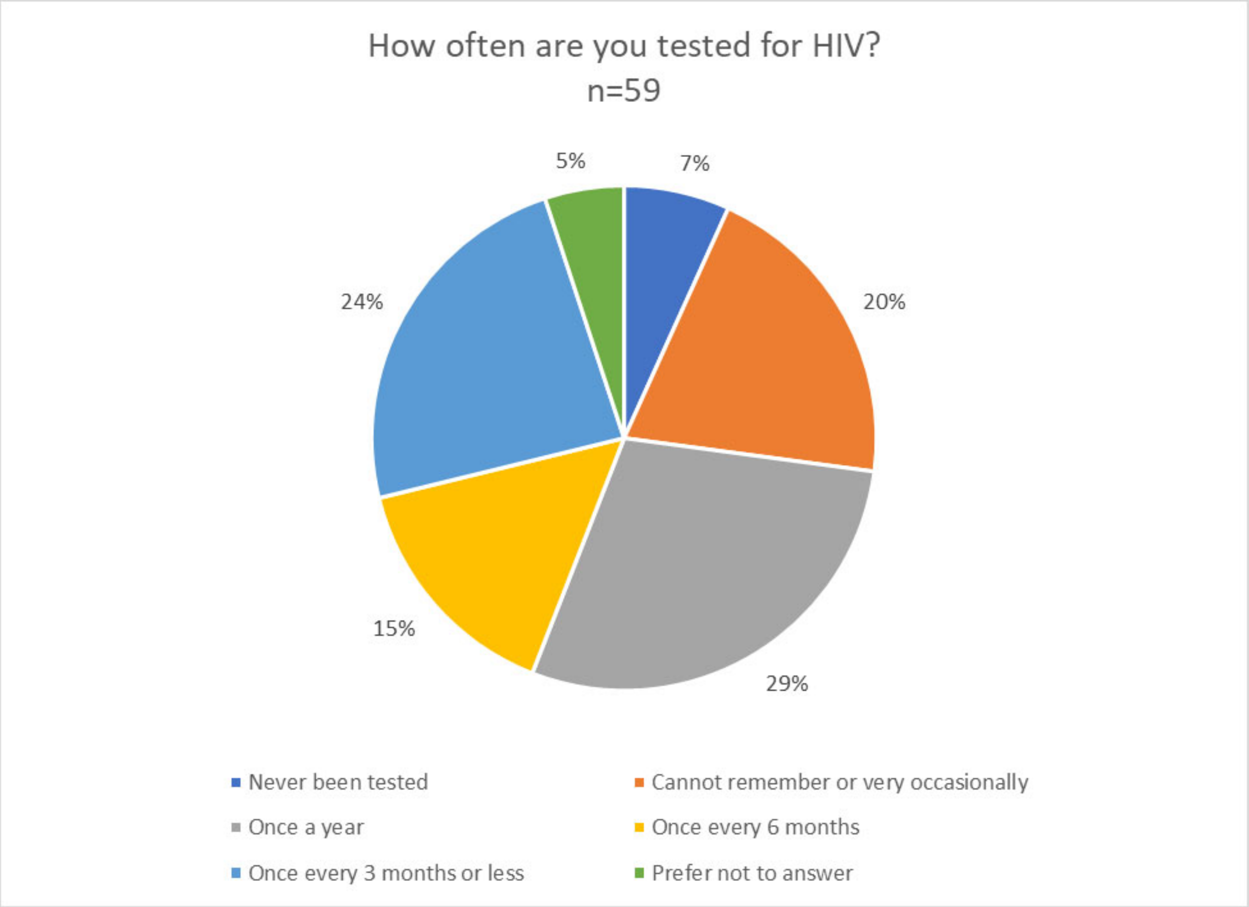
There were four MSM respondents who reported high risk for STDs but low or some risk for HIV. Two of these individuals reported being on PrEP, while the other two individuals reported being on PrEP in the past but not at the time of the survey.

The survey included a narrative question, “Why do you believe you are not at risk for HIV?” Responses were aggregated by theme. The most common response among MSM was that they were in a monogamous or committed relationship (12%), followed by knowing their own status (10%), and using “protection” (10%).

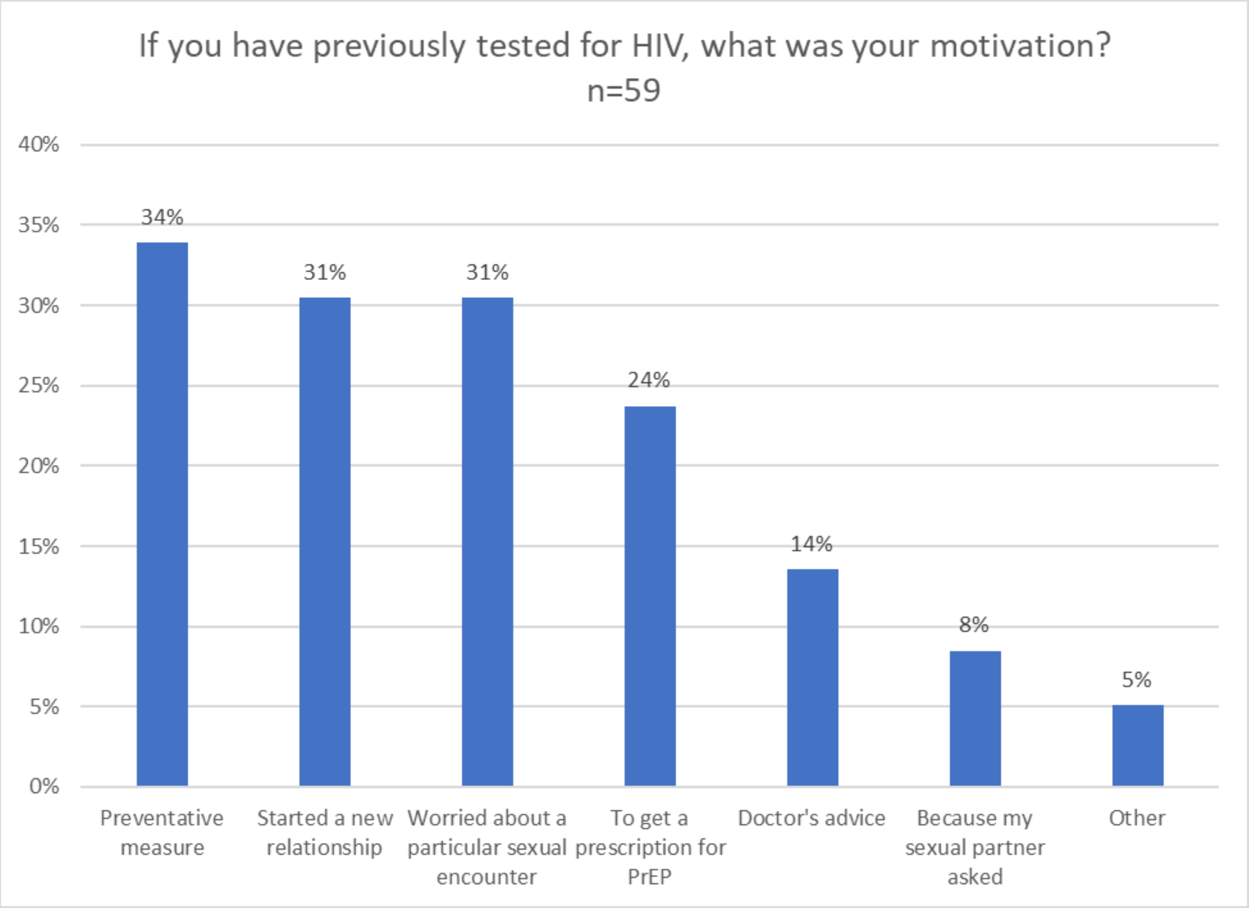
“Protection” and “safe sex” were used vaguely without explicitly stating condoms were being used.



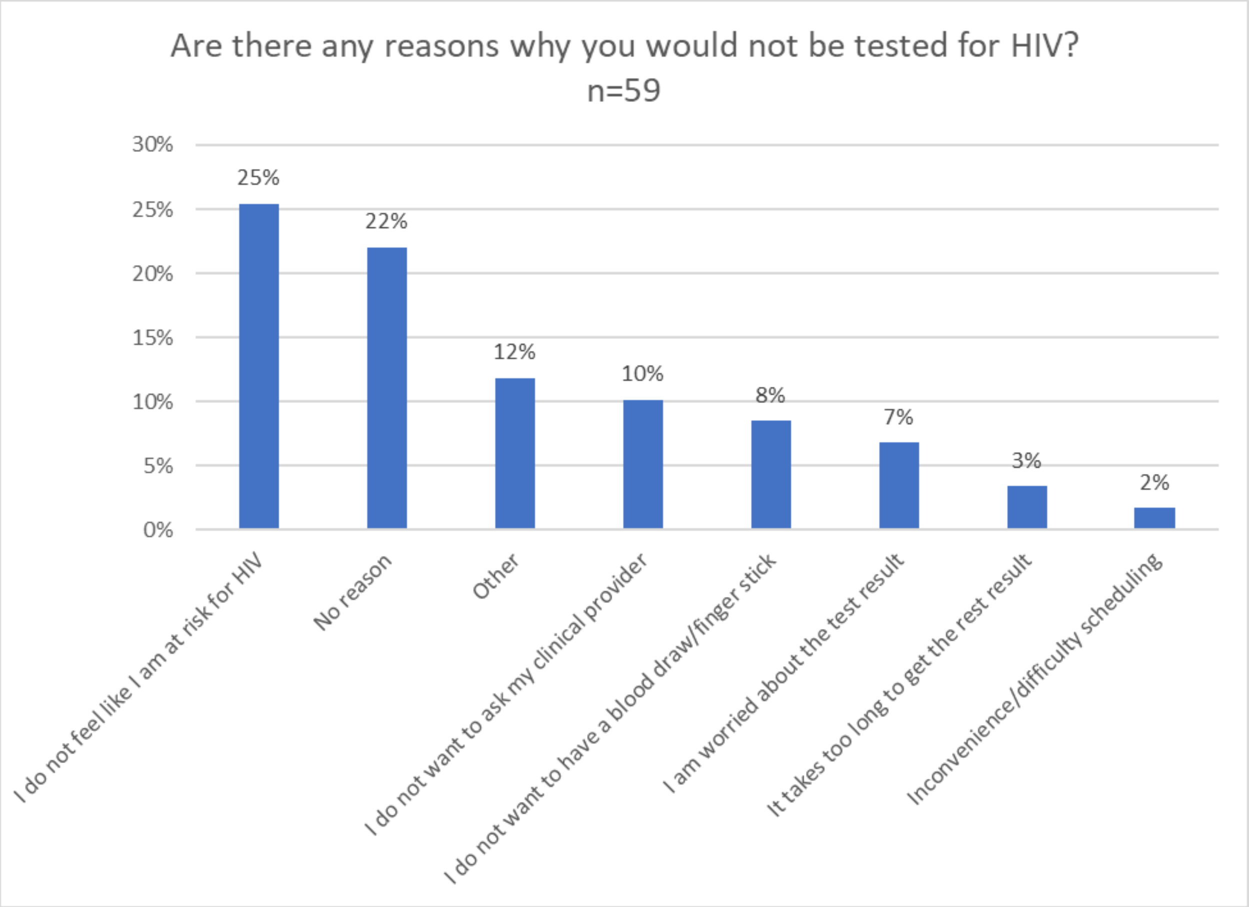
Most MSM respondents (68%) report being tested for HIV at least once per year.



Respondents could select multiple options for the reason they have been previously tested for HIV. The most common response (34%) was testing as a preventative measure, followed by testing at the start of a new relationship (31%), and being worried about a particular sexual encounter (31%). Almost one-quarter of respondents (24%) indicated that they tested to get a prescription for PrEP.



Respondents could select multiple options for any reasons they would not be tested for HIV. The most common response (25%) among MSM was "I do not feel like I am at risk for HIV." Of those 15 respondents, five (one-third) answered yes to the question about doing things that put themselves or others at risk, four reported some risk for HIV and another reported that they believe they are at "some risk" for HIV.



Most MSM respondents (69%) reported awareness of free HIV testing programs through Frannie Peabody Center, Portland Public Health, Maine Family Planning, or Health Equity Alliance, and 85% reported willingness to be tested for HIV at one of these sites.

Only two respondents provided reasons why they would not be willing to test at one of the identified sites; both indicated that they neeed more information about the testing sites.

Six respondents (10%) reported using an HIV home test, but 88% would be willing to use one in the future.

About 10% of MSM respondents (six individuals) indicated that they sometimes fear using HIV prevention services because of how they feel they would be treated by family, friends, or community members, and 7% (four individuals) of respondents reported often or always feeling this way.

Provider comfort

Most MSM respondents (76%) indicated that they are comfortable speaking with their medical provider about their sexual history.

Almost one-quarter of MSM respondents (24%) indicated that they sometimes or often experience ill-treatment or discrimination by their medical provider due to their sexual practices.

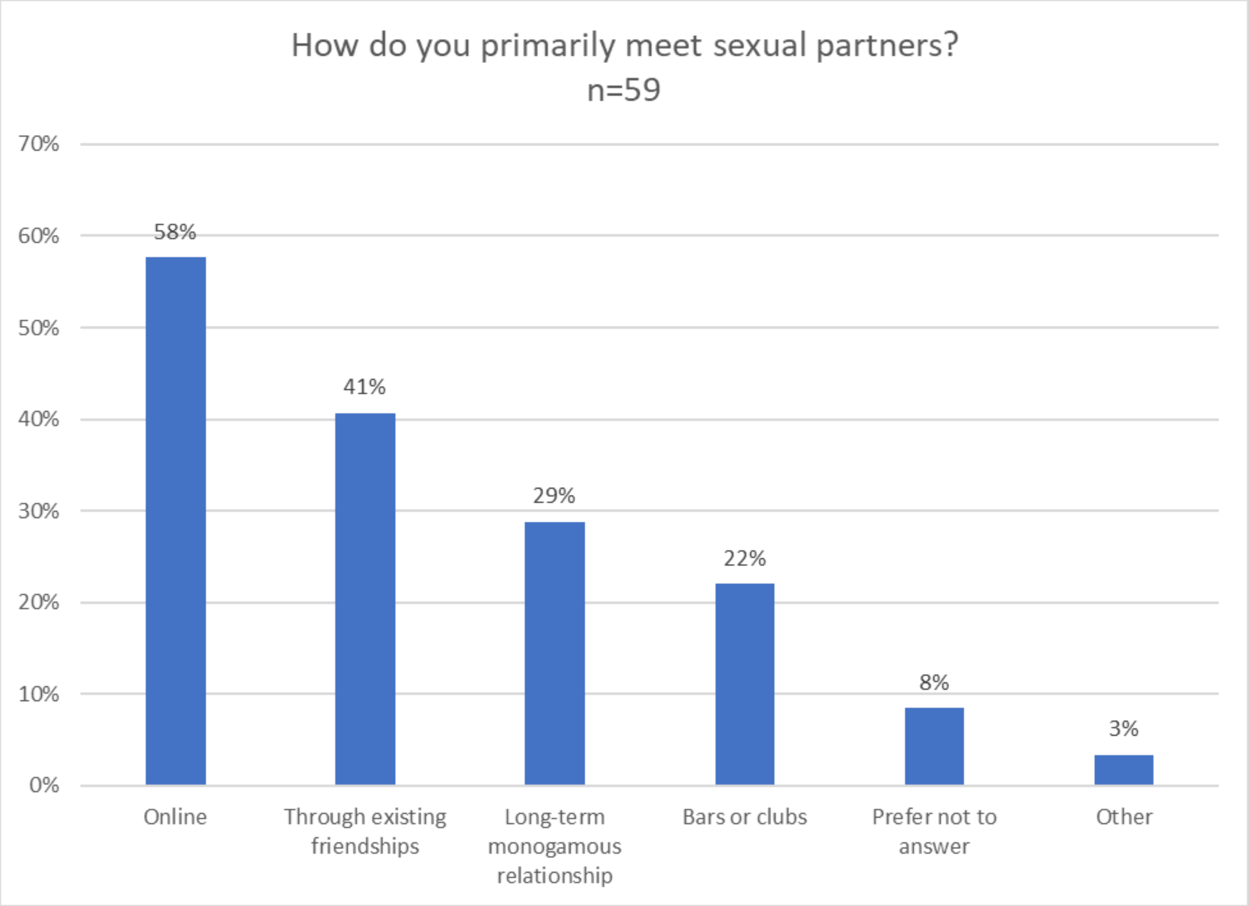
Less than half (42%) indicated that their medical provider had ever recommended HIV testing.

Four respondents (7%) reported needing an interpreter at least sometimes to speak with their medical provider, but 12 respondents (20%) indicated that they had ever had difficulty communicating with their medical provider.

Sexual history

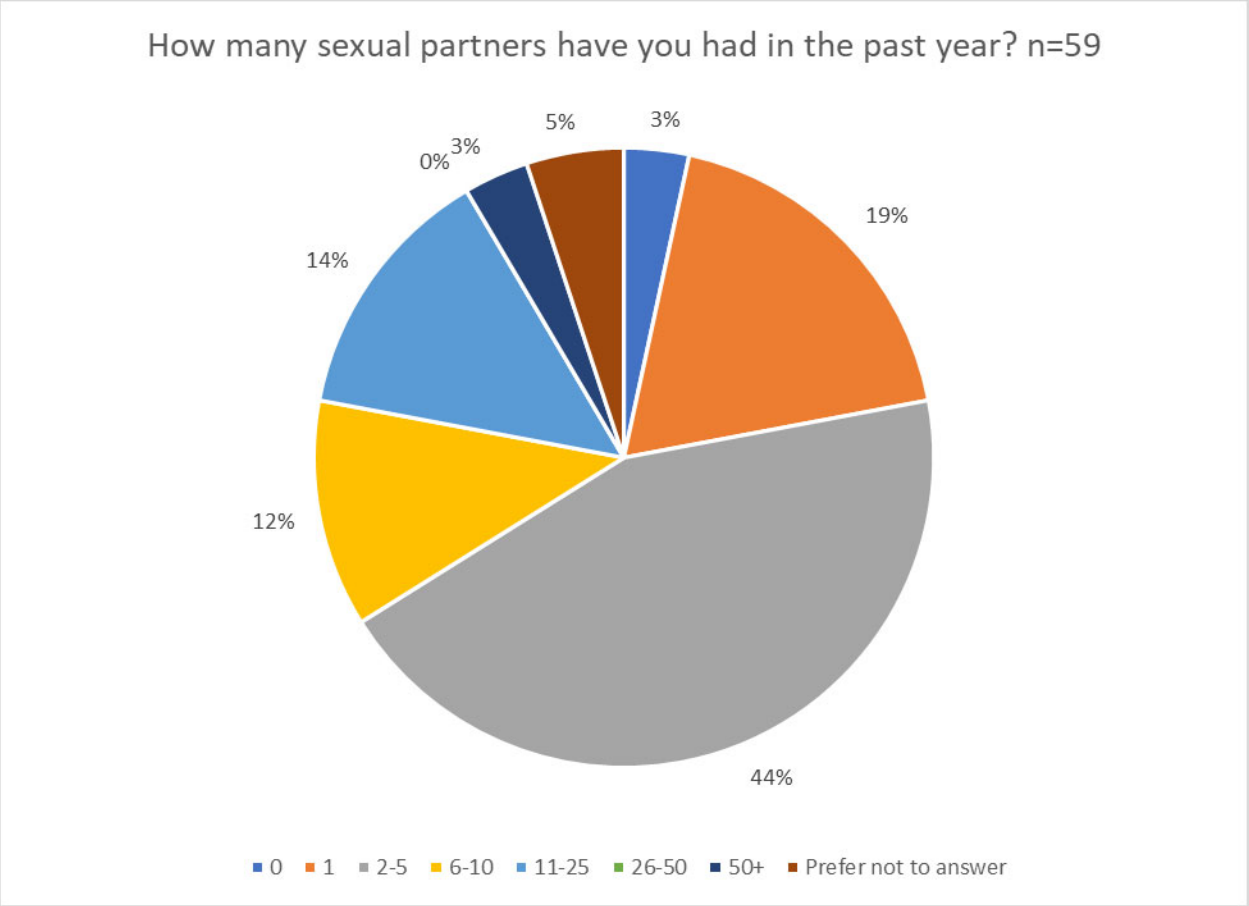
In addition to sex with men, 13 respondents (22%) reported sex with women, and 14 respondents (24%) reported sex with transgender individuals as risk factors for HIV infection.

Respondents could select multiple choices to identify how they meet sexual partners. The most common response (58%) was online.



Of the 17 respondents who indicated that they were in a long-term monogamous relationship, one reported 6-10 sexual partners in the past year and one reported 11-25. This may indicate a need to use defined timeframes (rather than "long-term") and to define the term "monogamy" on future surveys.

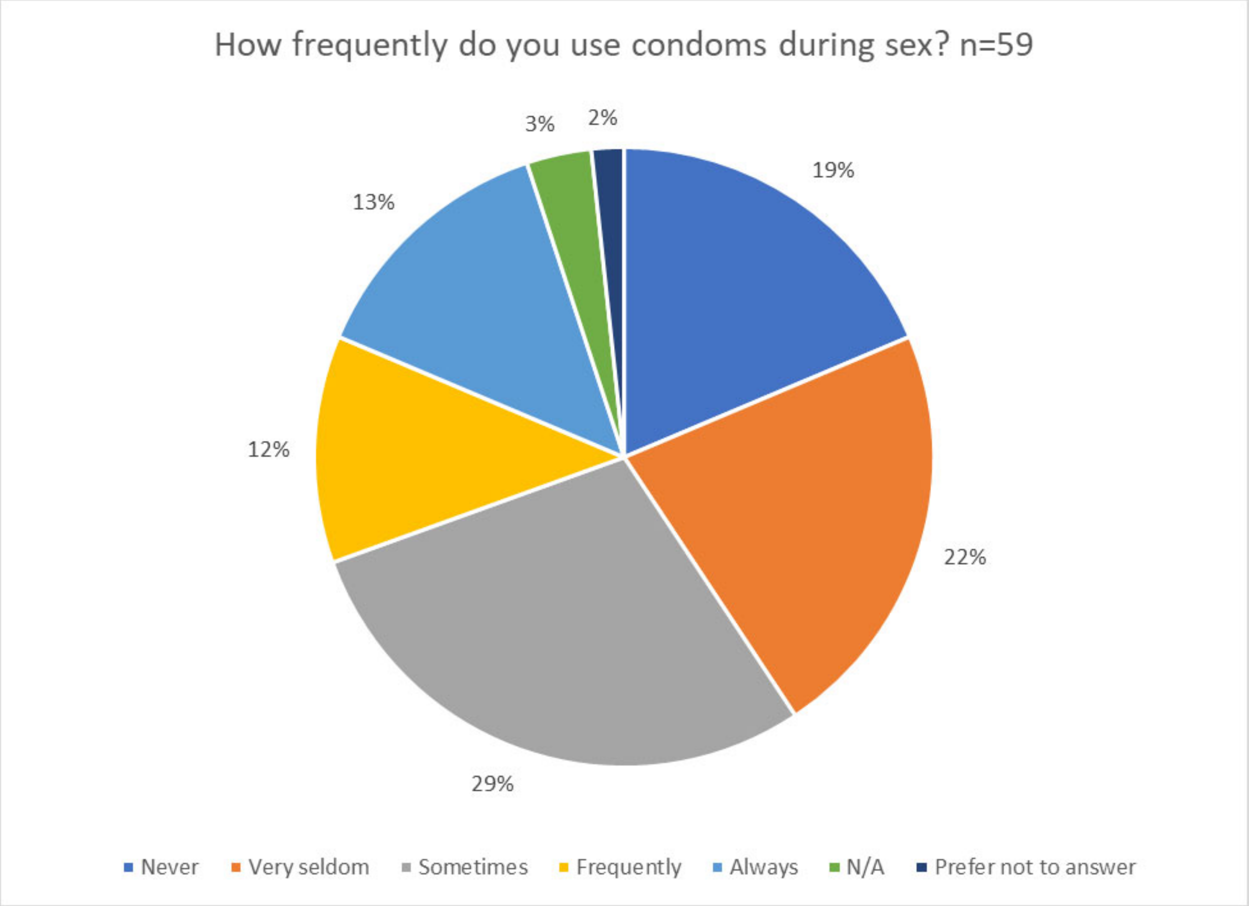
About 38% of those who reported meeting partners online (13 individuals) identified the sites/apps they use. The most common was Grindr (11 respondents). Four respondents identified Scruff and four identified Tinder; three respondents identified other sites/social media platforms.



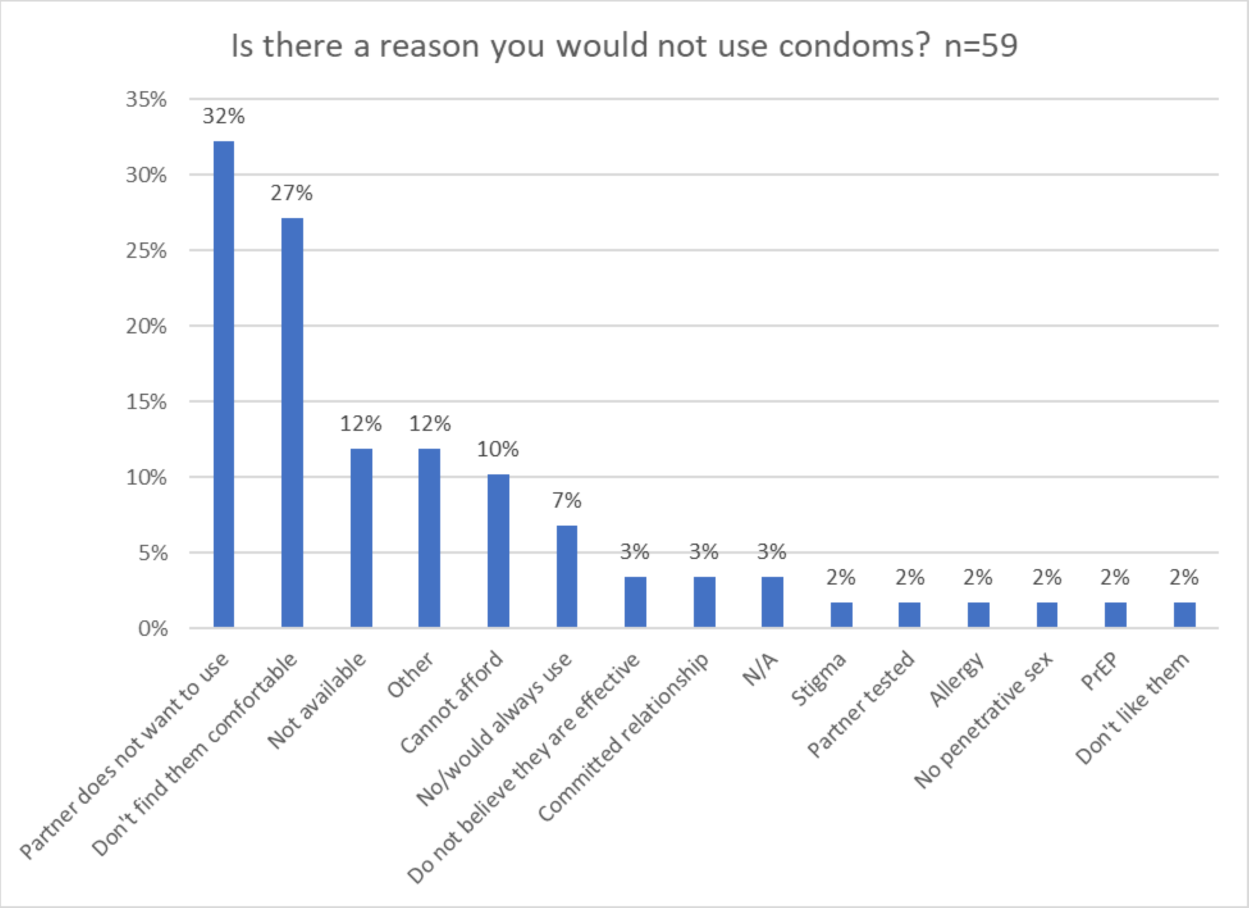
Twelve respondents (20%) indicated that they had ever exchanged sex for money, substances, or goods.

Condom use

Most respondents (69%) reported that they use condoms sometimes, very seldom, or never, compared to 25% who frequently or always use condoms.

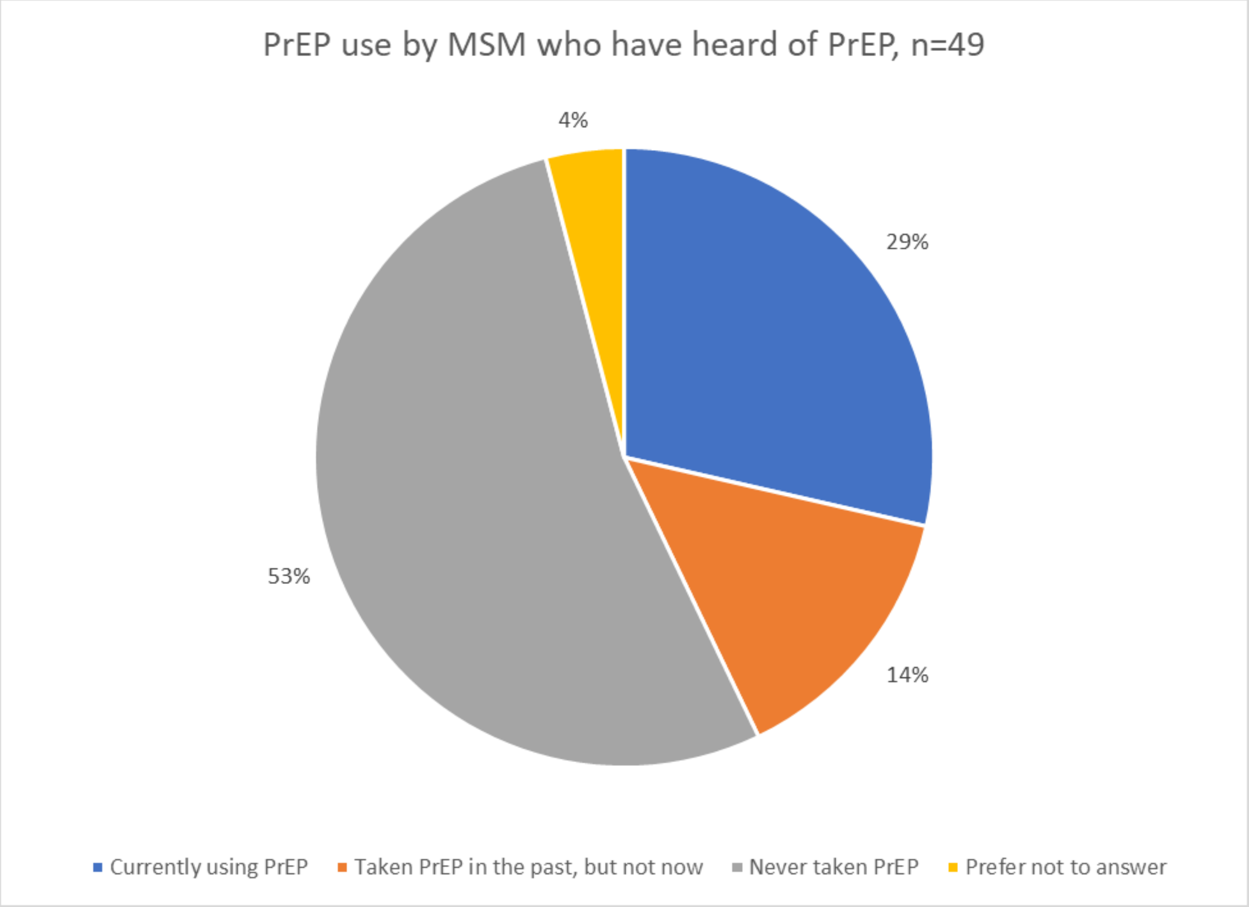


Respondents could select multiple choices to indicate why they would not use condoms. The most common response (32%) was that the respondent's partner did not want to use them, followed by 27% who indicated that they do not find condoms comfortable.

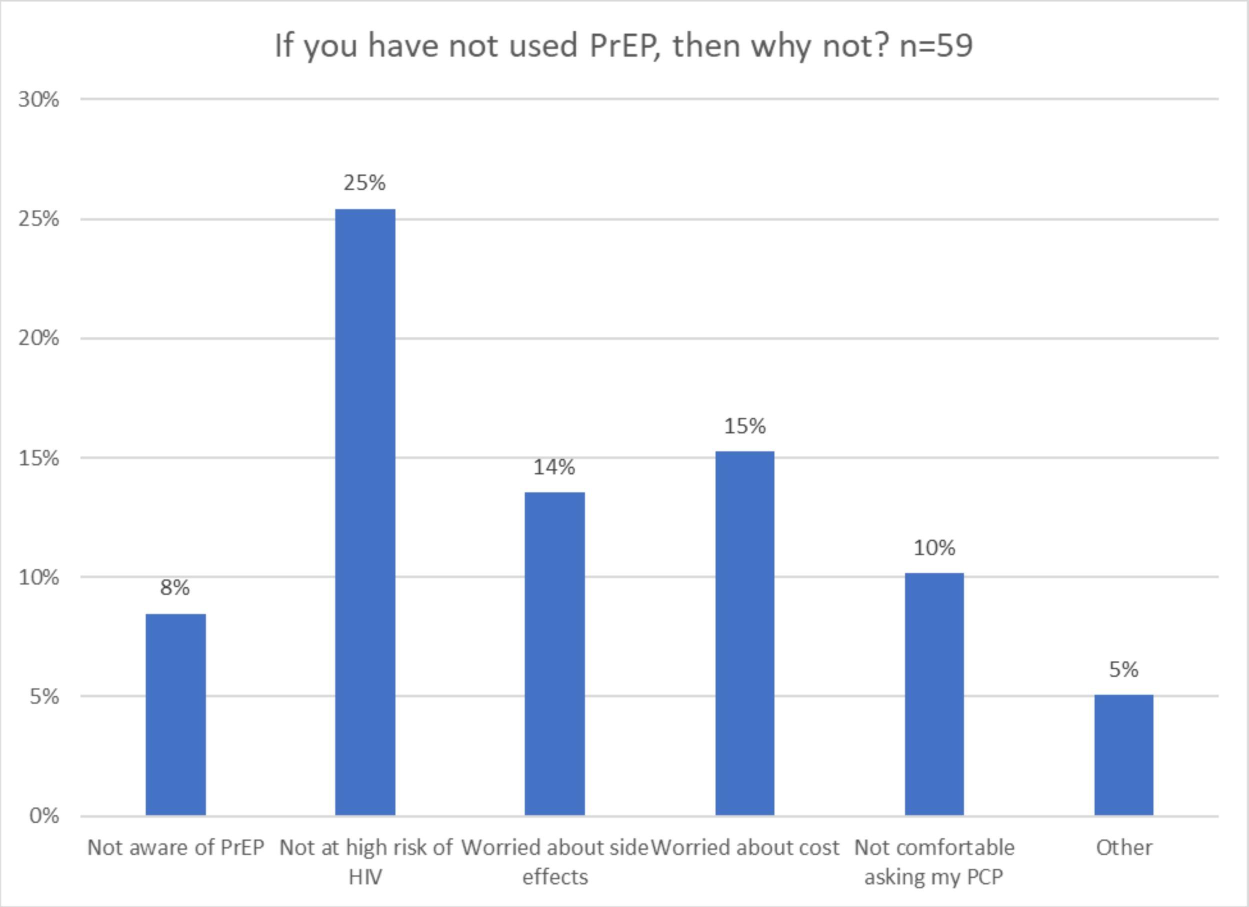


PrEP and PEP

Most respondents (83%) have heard of Pre-Exposure Prophylaxis (PrEP), but less than half of respondents (49%) have heard of Post-Exposure Prophylaxis (PEP).



Respondents could select multiple choices to indicate why they have not used PrEP. The most common response (25%) was, “I do not believe I am at high risk for HIV infection.”



Most respondents (66%) would be willing to take PrEP if it was available through a pharmacy without consulting a medical provider.

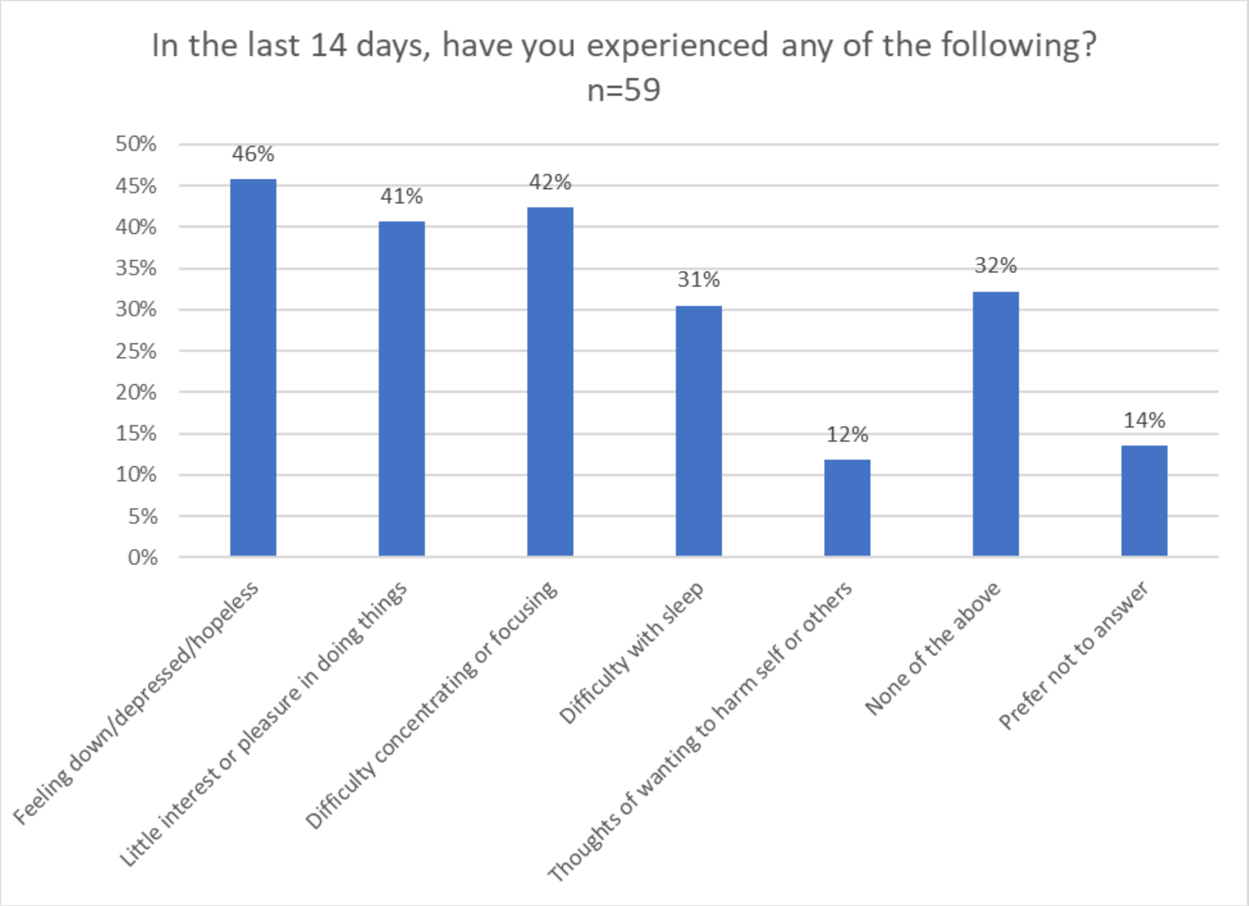
Five respondents (8%) indicated that they had requested PrEP from a provider and been refused. Of these five, one reports currently taking PrEP, two report taking PrEP in the past but not at the time of the survey, and two reported never taking PrEP.

Only two respondents reported ever taking PEP, and only one of these completed the full 28-day course.

Support services

Most MSM respondents (61%) indicated that it takes an hour or less to travel one-way to most services they want (e.g. case management, support groups, etc.). Four respondents (7%) indicated that it takes more than an hour to get to such services.

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. About one-third of MSM respondents indicated that they had not experienced any of symptoms on the list, but more than 40% reported feeling down/depressed/hopeless, little interest/pleasure in doing things, and difficulty concentrating or focusing. Seven respondents (12%) reported thoughts of harming themselves or others.

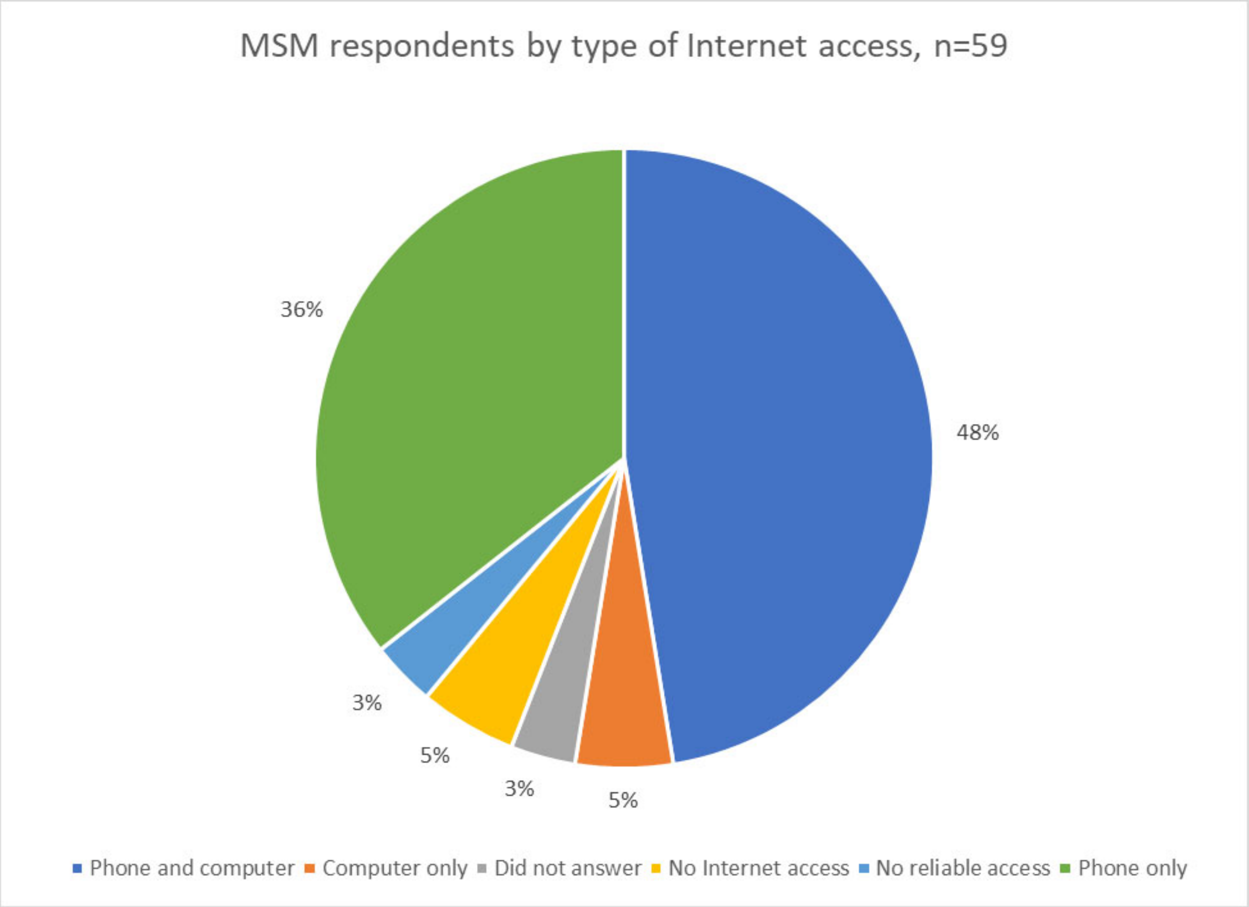


Respondents could select multiple choices to indicate if they needed more opportunities for social support. The most common response (46%) was “I don’t need any opportunities.” Eleven respondents (19%) indicated a need for peer supports, eight (14%) for weekly meetings, and seven (12%) for social retreats.

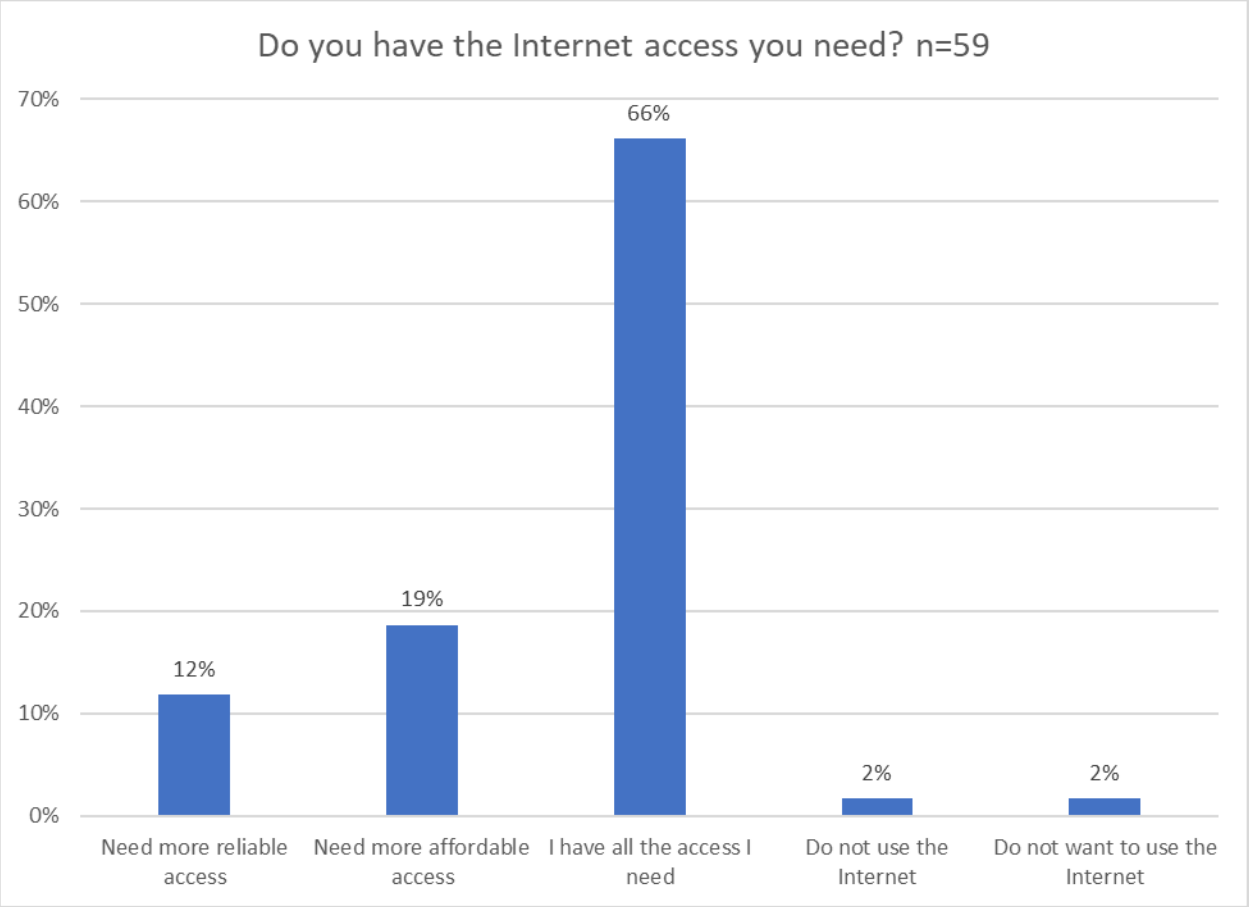
There was a narrative question about barriers that get in the way of accessing support services. The most common response (5%) was cost.

Internet access

Most MSM respondents (83%) can access the Internet by phone, and 92% have some form of reliable Internet access (phone, computer, or both).



Most MSM respondents (66%) indicated that they have all the Internet access they need. Sixteen respondents (27%) indicated that they needed more reliable and/or affordable Internet access.

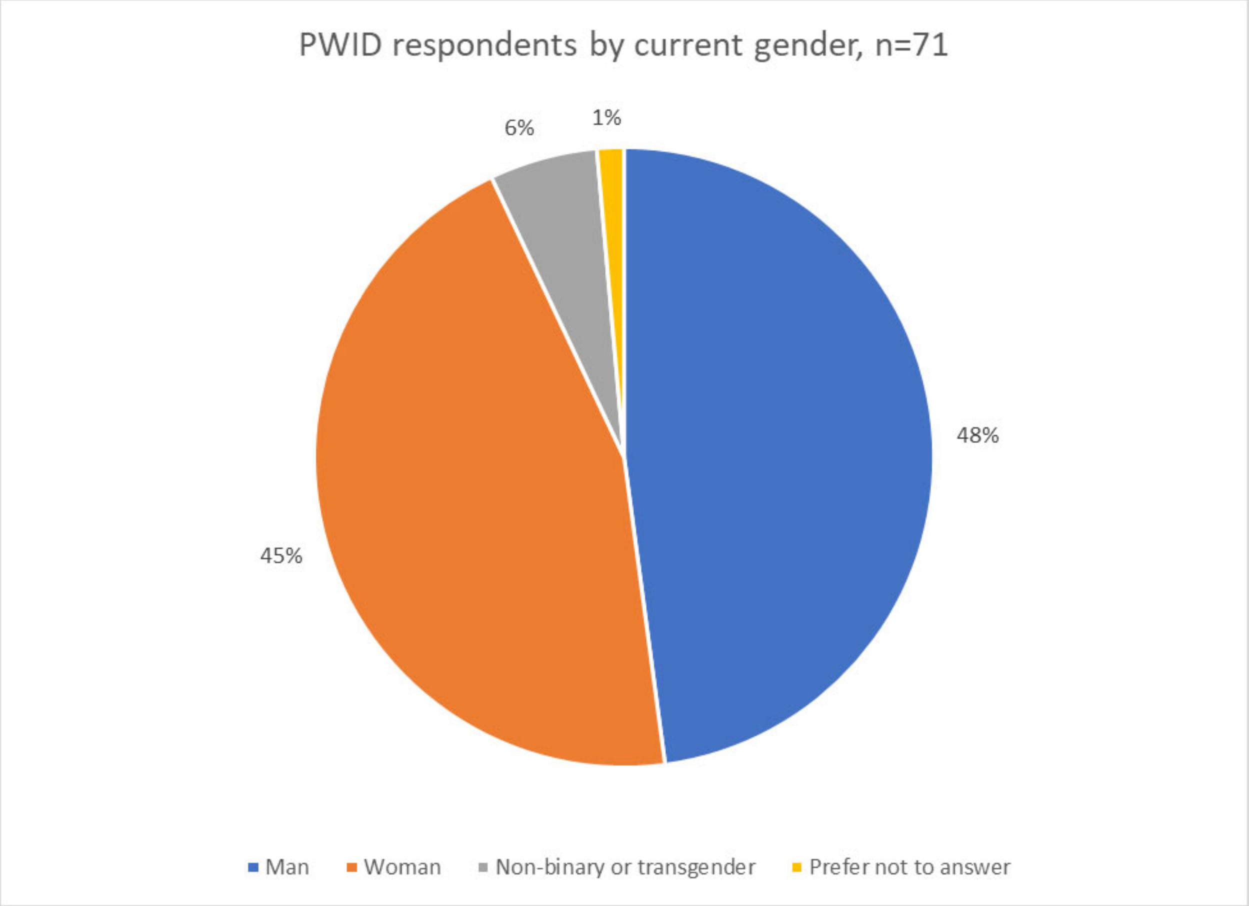


PWID

There were 71 respondents (13%) who reported that they inject drugs and/or that injecting drugs was a risk behavior for HIV.

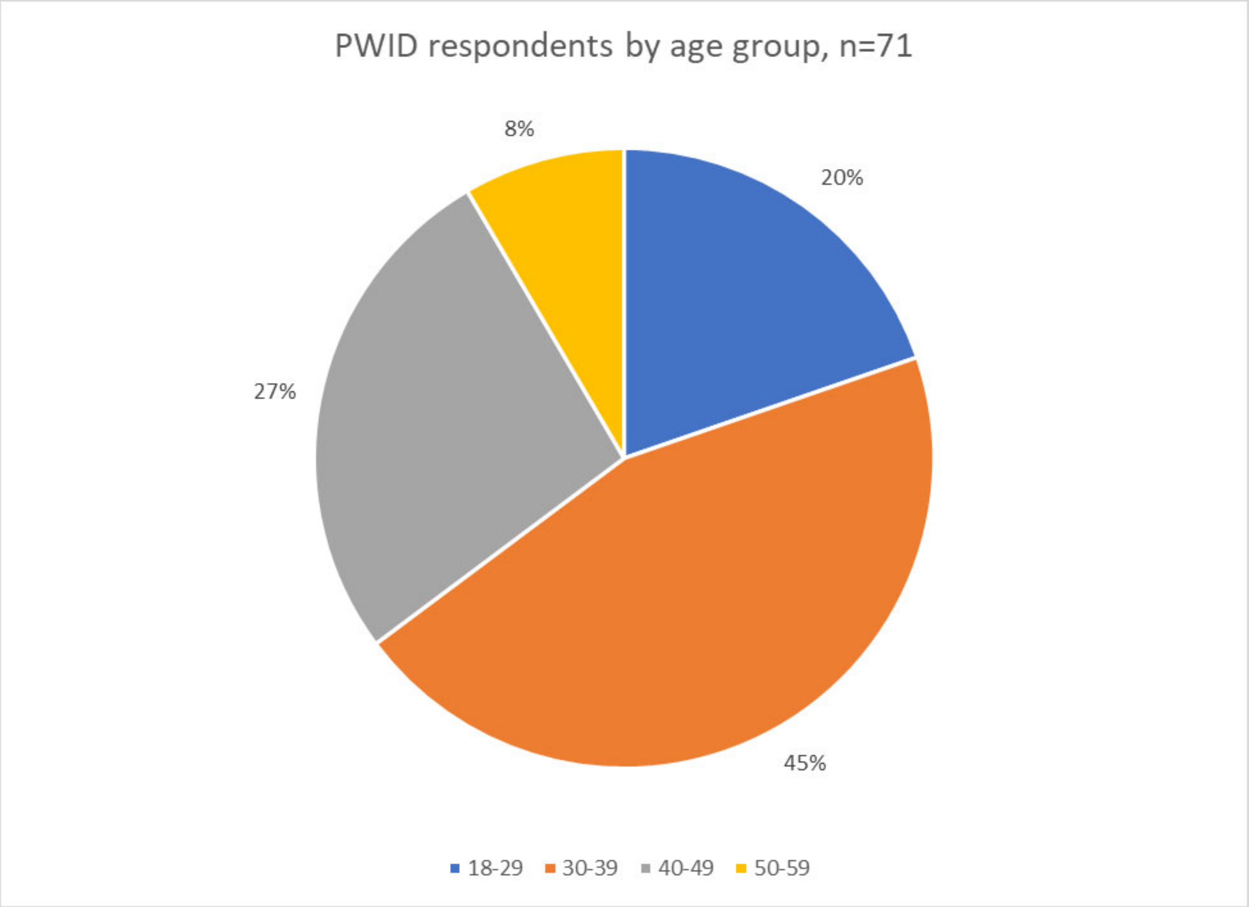
A total of 69 respondents indicated that they use injection drugs. The wording of the question may have included people who inject prescription drugs. A total of 41 respondents indicated injecting drugs as a risk behavior for HIV.

Almost half (48%) of PWID respondents identify as men and 46% identify as women.

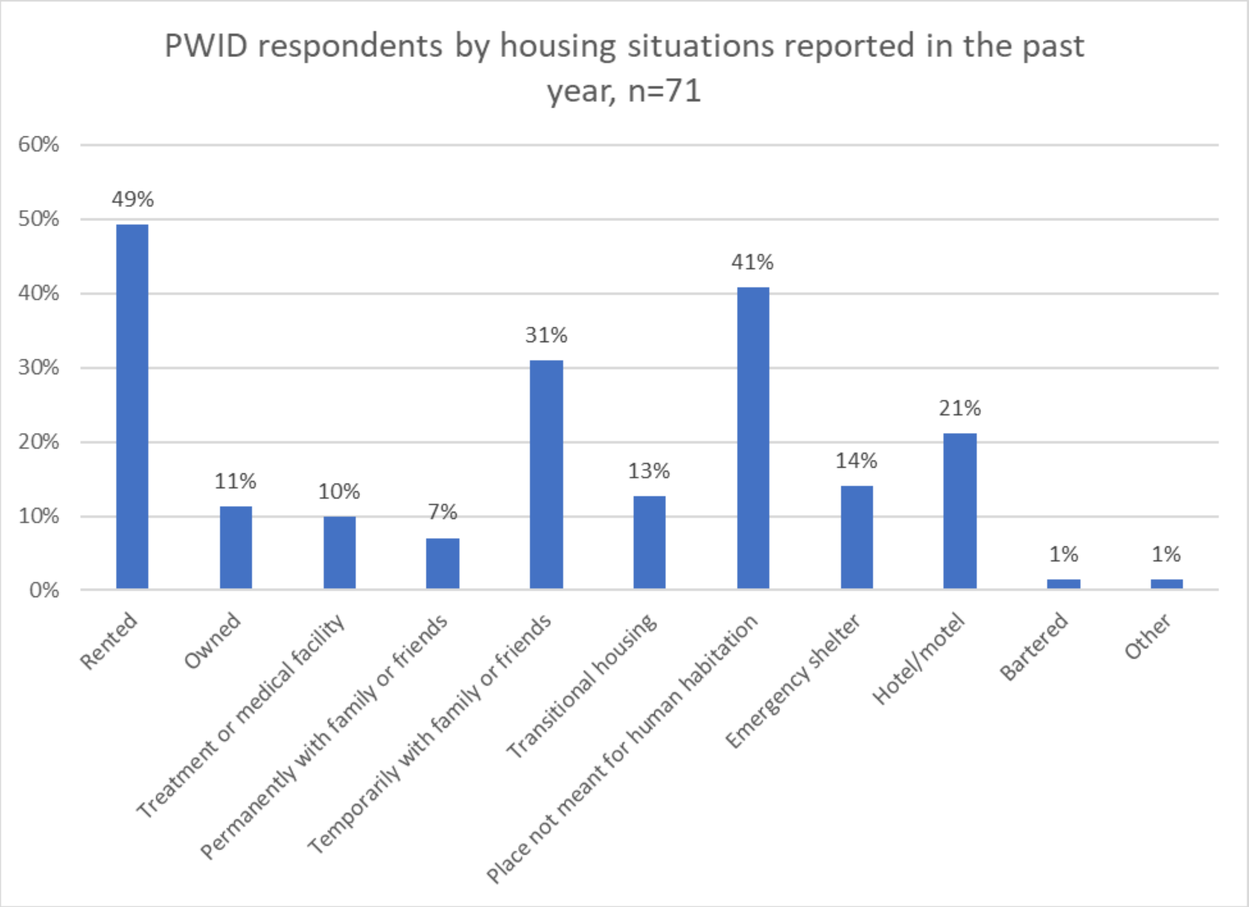


There were no Black PWID respondents. Six respondents identified as Native American, four reported more than one race, two identified as Hispanic/Latinx, and two as Asian. More than three-quarters of PWID respondents (76%) identified as white.

There were no PWID respondents under age 18 or over age 59. Most (72%) were between the ages of 30 and 49.



A total of 41% of respondents reported staying in a place not meant for human habitation at some point in the past year. Nearly one-third (30%) reported three or more living situations in the past year. Seven respondents (10%) reported staying in a treatment or medical facility in the past year.



A total of 46 respondents (65%) reported being incarcerated; less than half of these (41%) reported being released in the past 12 months.

How often do you do the following:	Never	Very seldom	Sometimes	Often	Always	Did not answer
Share syringes	72%	20%	6%	0%	0%	3%
Share drug use equipment or "works"	52%	24%	14%	1%	0%	8%
Use a syringe exchange site	14%	4%	8%	15%	51%	7%

A total of 13 respondents indicated that they very seldom or never used syringe exchange sites. Of these, five reported that they had never heard of a syringe exchange site, two reported not believing they were at risk for diseases from injection drug use, two reported that syringe exchange sites were difficult to access, and two reported that they were not comfortable using syringe exchanges.

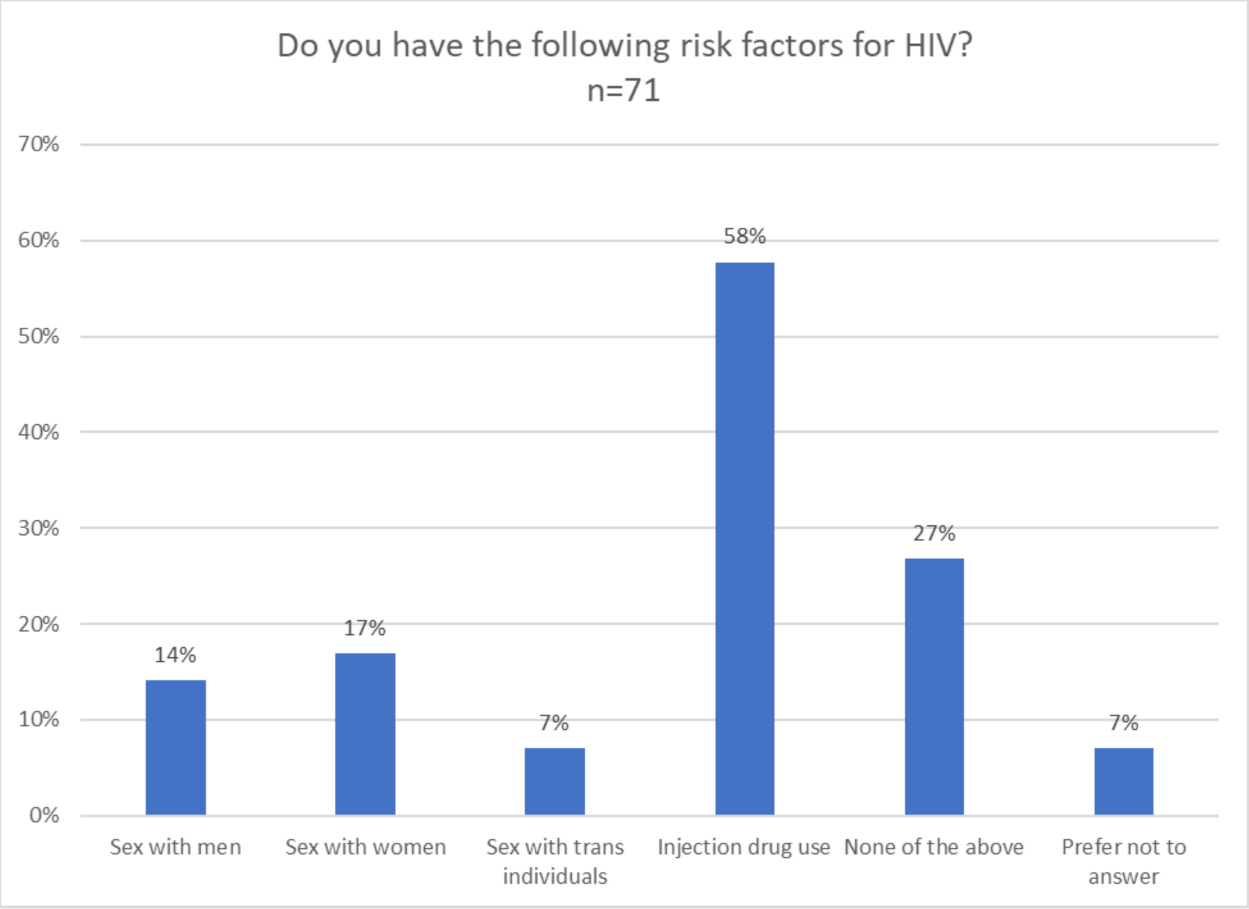
Other infections

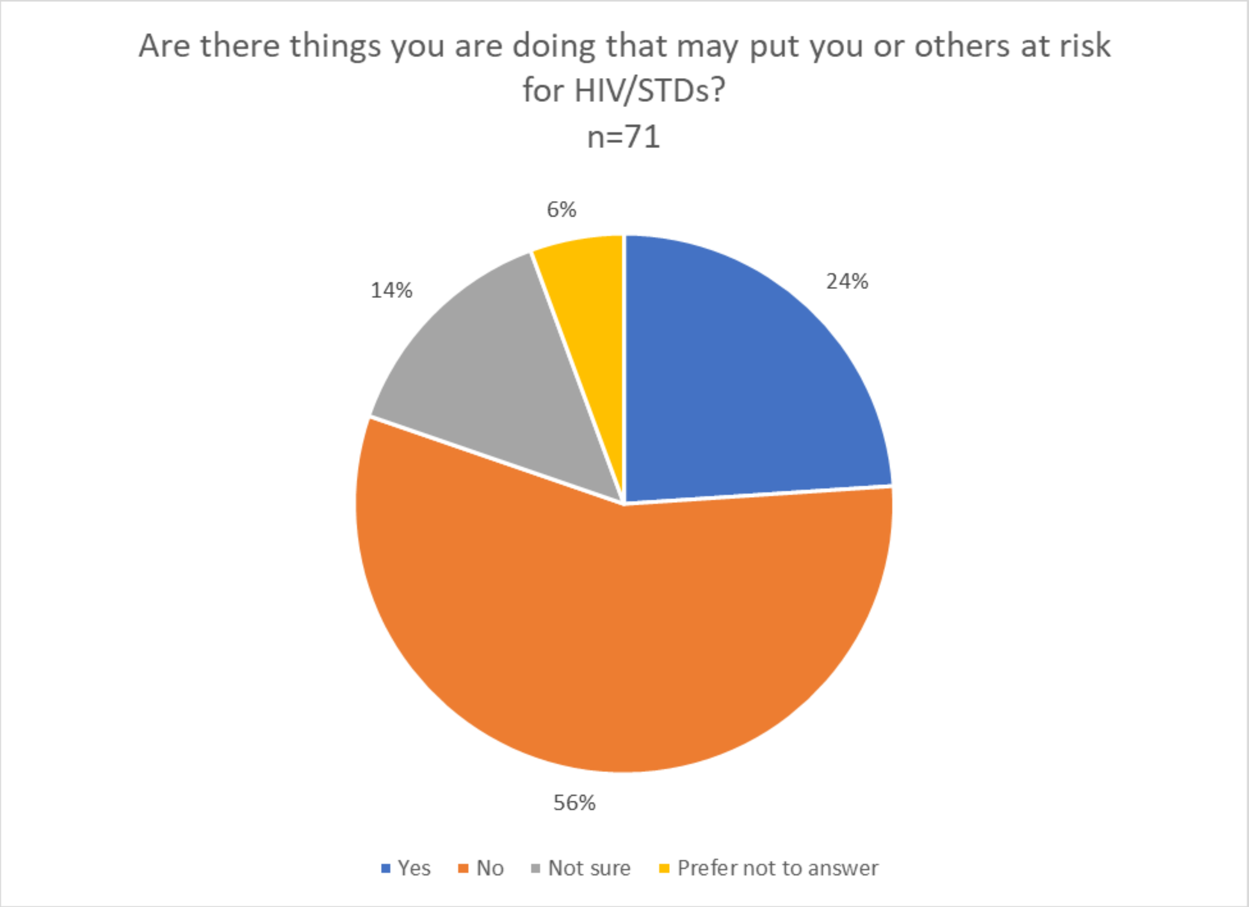
Three different PWID respondents reported being diagnosed with one of the three-reportable STDs in the last two years, one each with chlamydia, gonorrhea, and syphilis.

Two respondents were diagnosed with Hepatitis A in the last two years. Twelve respondents (17%) were diagnosed with Hepatitis C in the past two years.

Risk perception and HIV testing

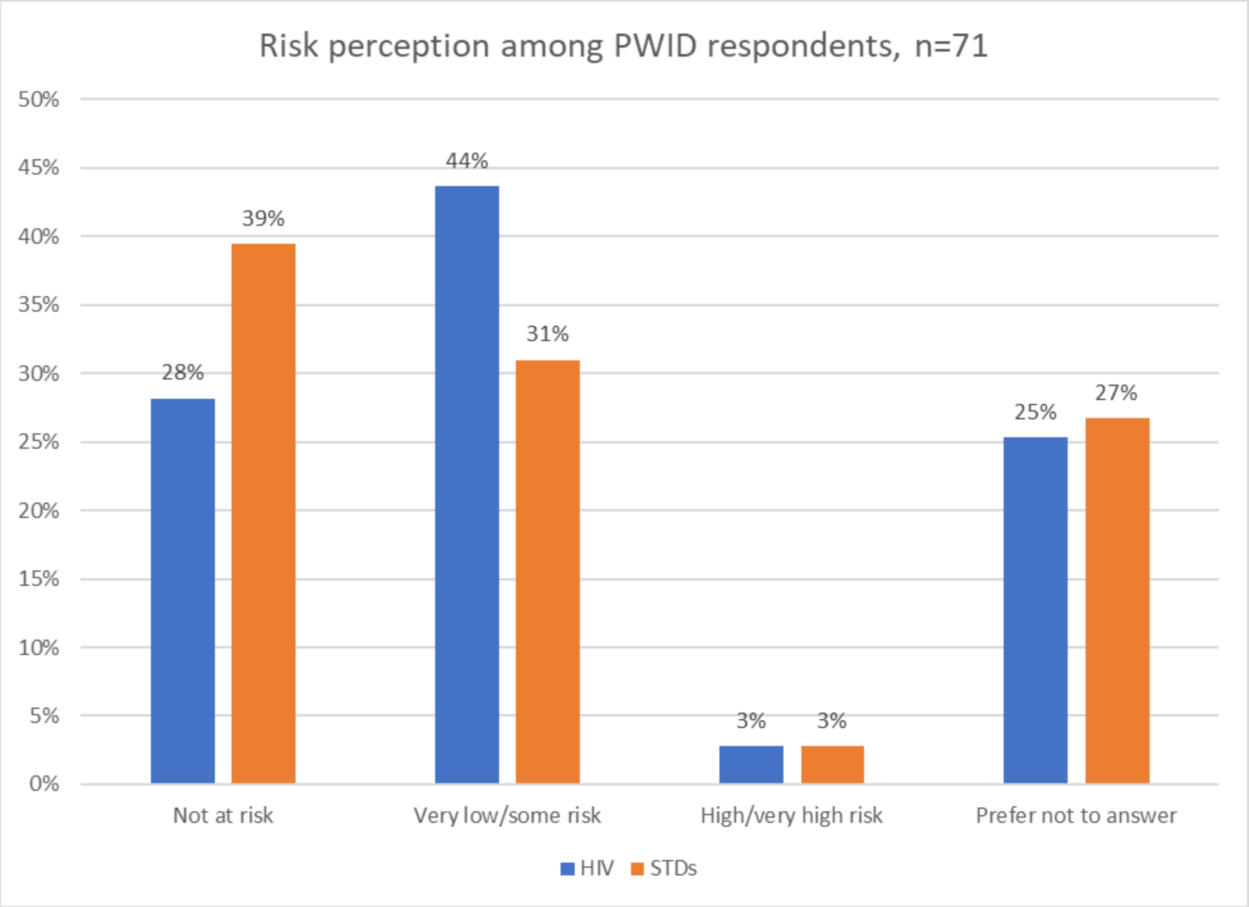
Only 58% of PWID respondents indicated that their injection drug use was a risk factor for HIV.





Of the 12 PWID respondents who indicated they were at some or high risk for HIV infection, 7 (58%) reported that they were doing things that may put themselves or others at risk for HIV/STDs.

Of the 10 PWID respondents who indicated they were at some or high risk for STDs, 8 (80%) reported that they were doing things that may put themselves or others at risk for HIV/STDs.

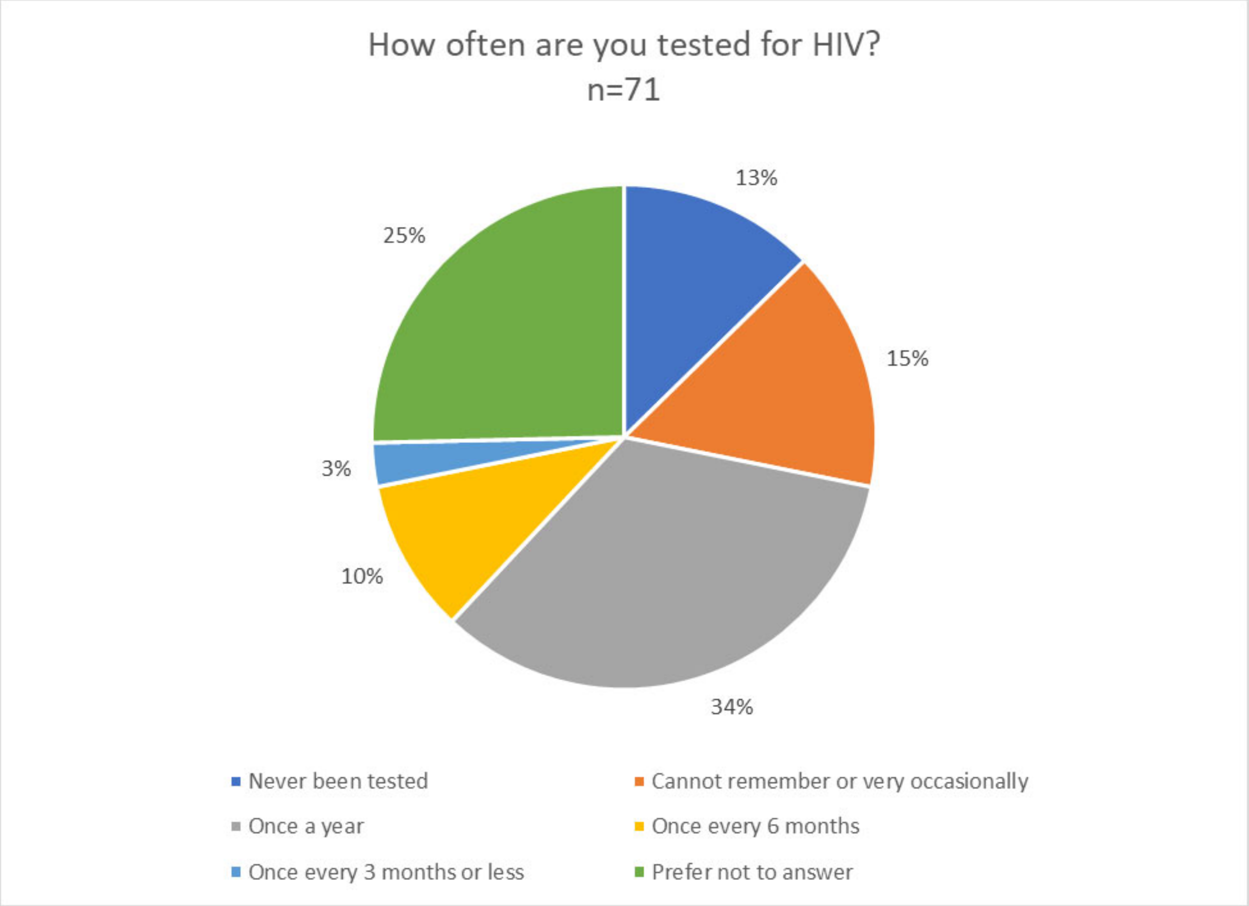


The survey included a narrative question, “Why do you believe you are not at risk for HIV?” Responses were aggregated by theme. The most common responses among PWID were that they were currently abstinent or asexual (8%) and that they don’t share injection equipment (8%).

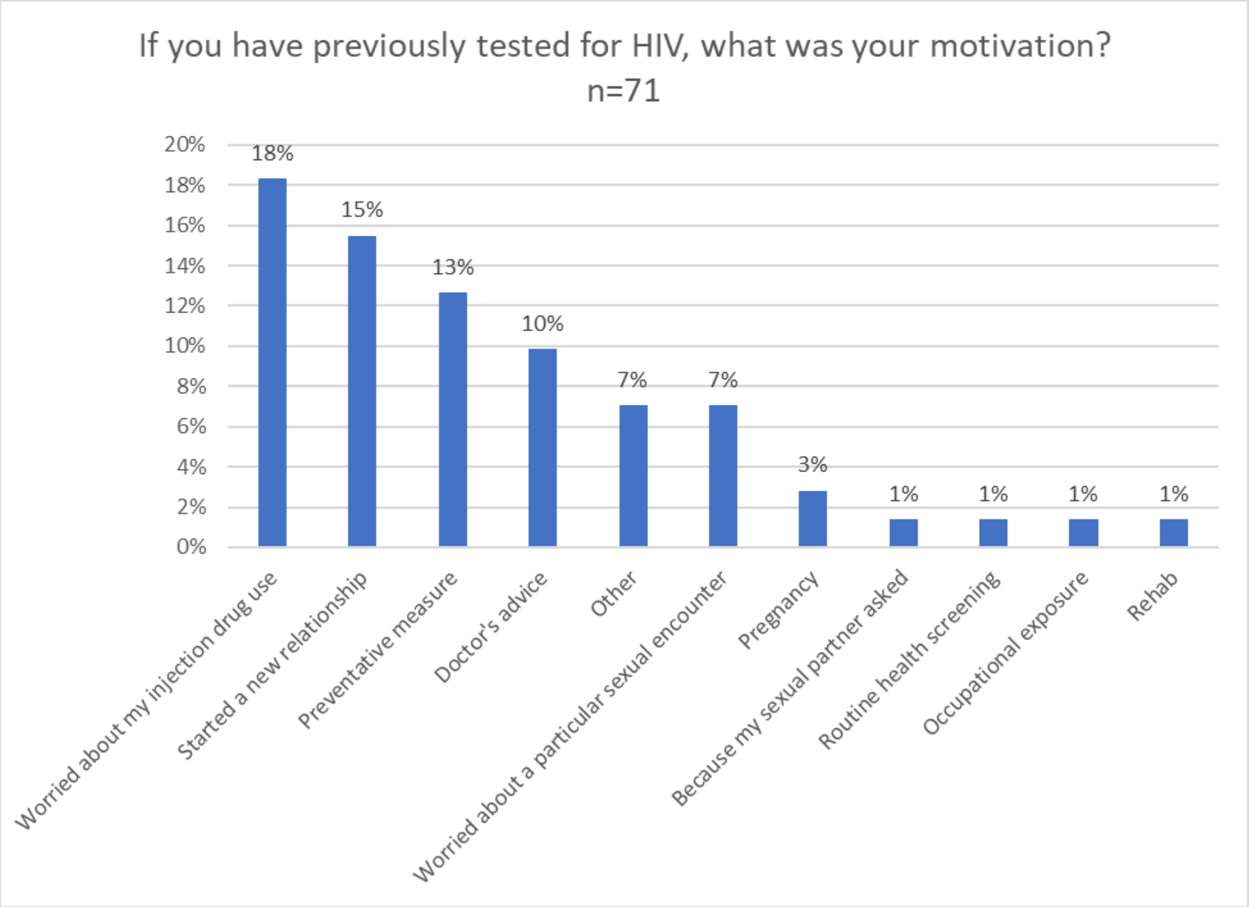
Of the six respondents who wrote in that they were not at risk for HIV because they don’t share injection equipment, three (50%) reported conflicting responses earlier in the survey. One reported very seldom sharing syringes and often sharing works, one reported sometimes sharing works, and one reported very seldom sharing works.

Four respondents (6%) indicated that they were in a monogamous or committed relationship.

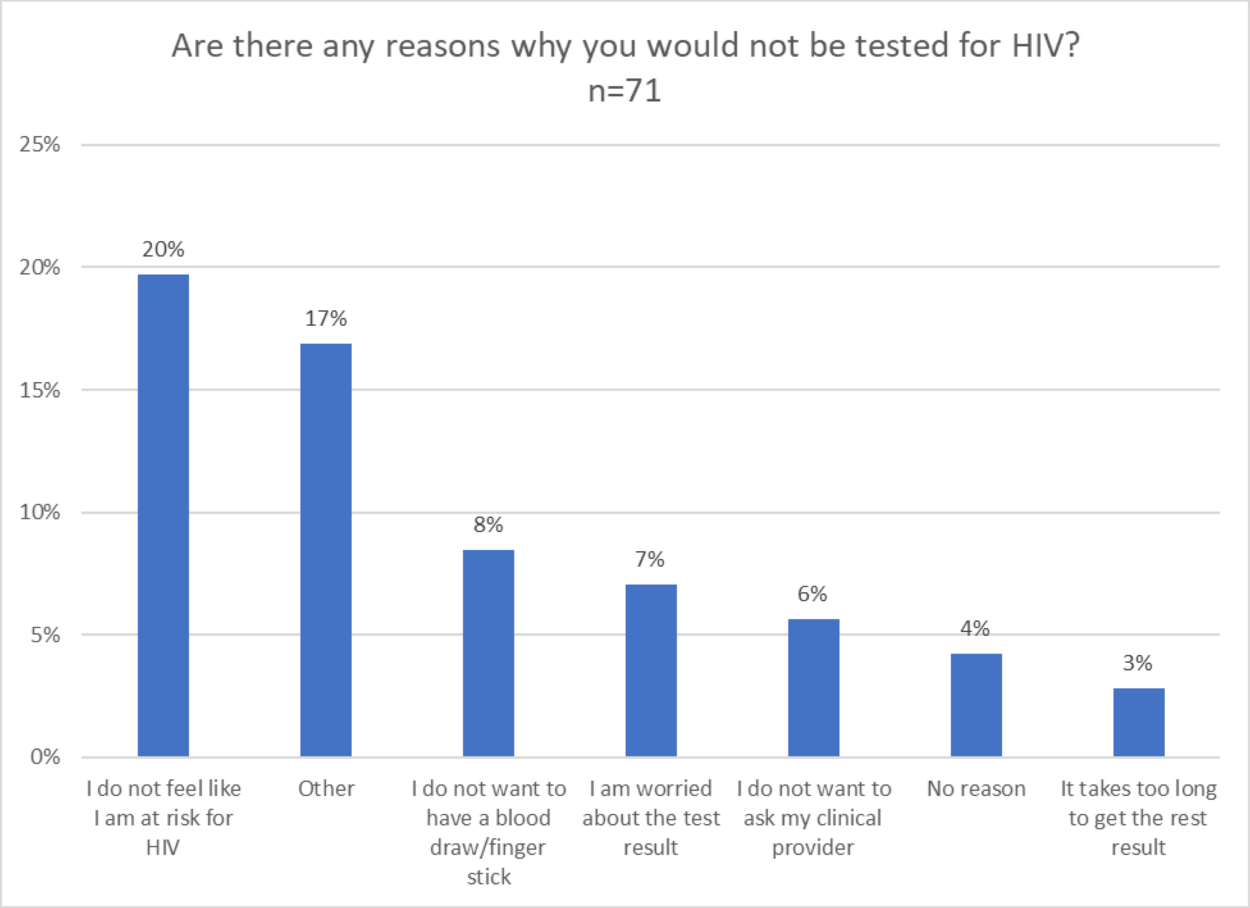
A total of 33 PWID respondents (46%) report being tested for HIV at least once per year while nine (13%) have never been tested.



Respondents could select multiple options for the reason they have been previously tested for HIV. The most common response (18%) was worry about their injection drug use.



Respondents could select multiple options for any reasons they would not be tested for HIV. The most common response (20%) among PWID was "I do not feel like I am at risk for HIV."



Most PWID respondents (61%) reported awareness of free HIV testing programs through Frannie Peabody Center, Portland Public Health, Maine Family Planning, or Health Equity Alliance, and 63% reported willingness to be tested for HIV at one of these sites.

Only three respondents provided reasons why they would not be willing to test at one of the identified sites; one reported not having transportatin and two reported having a bad experience with an HIV testing site.

Six respondents (8%) reported using an HIV home test; 63% would be willing to use one in the future.

About 10% of PWID respondents (seven individuals) indicated that they sometimes fear using HIV prevention services because of how they feel they would be treated by family, friends, or community members, and 4% (three individuals) of respondents reported often or always feeling this way.

Provider comfort

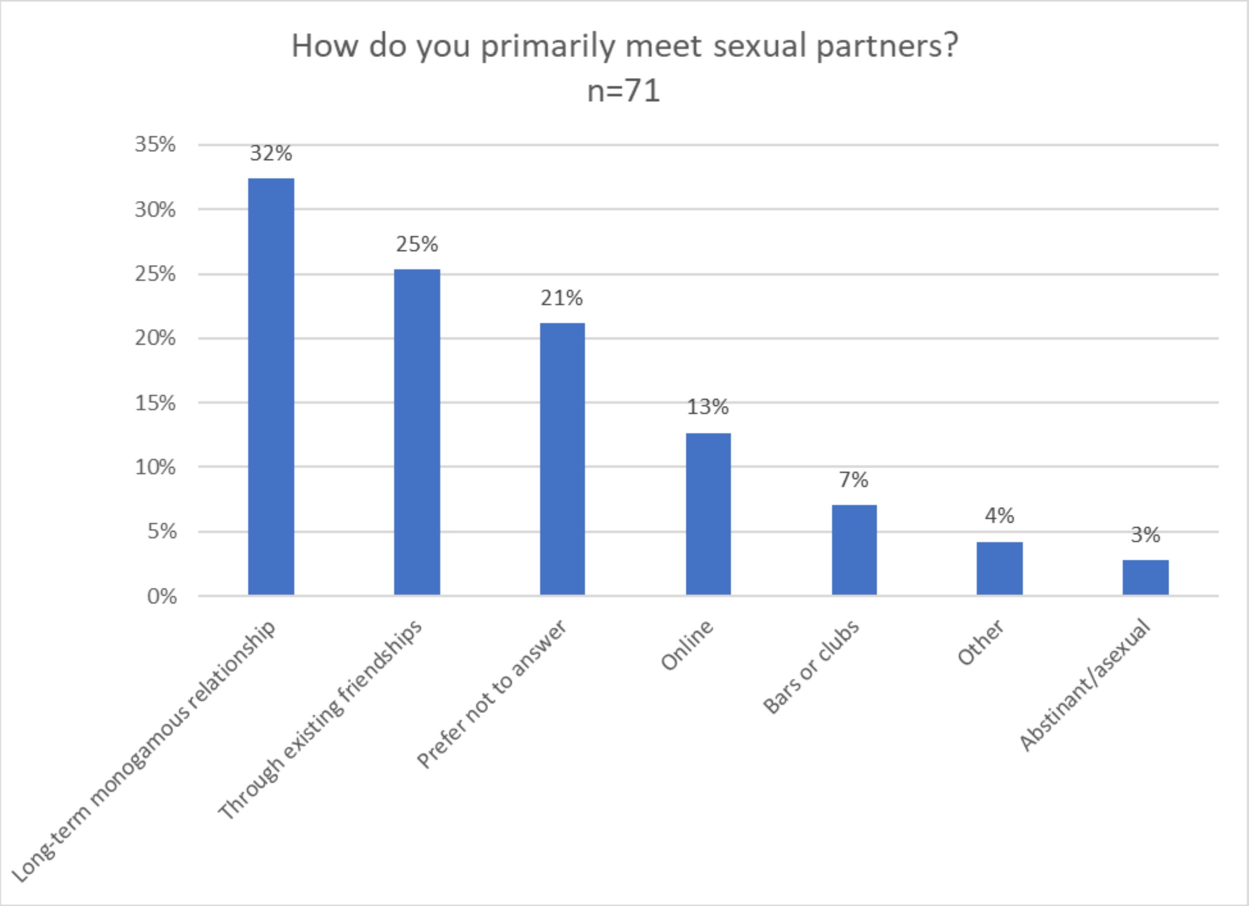
Most PWID respondents (77%) indicated that they are comfortable speaking with their medical provider about their sexual history, but only half (49%) reported feeling comfortable speaking with their medical provider about their injection drug use.

Just over one-quarter of respondents (27%) indicated that their medical provider had ever recommended HIV testing.

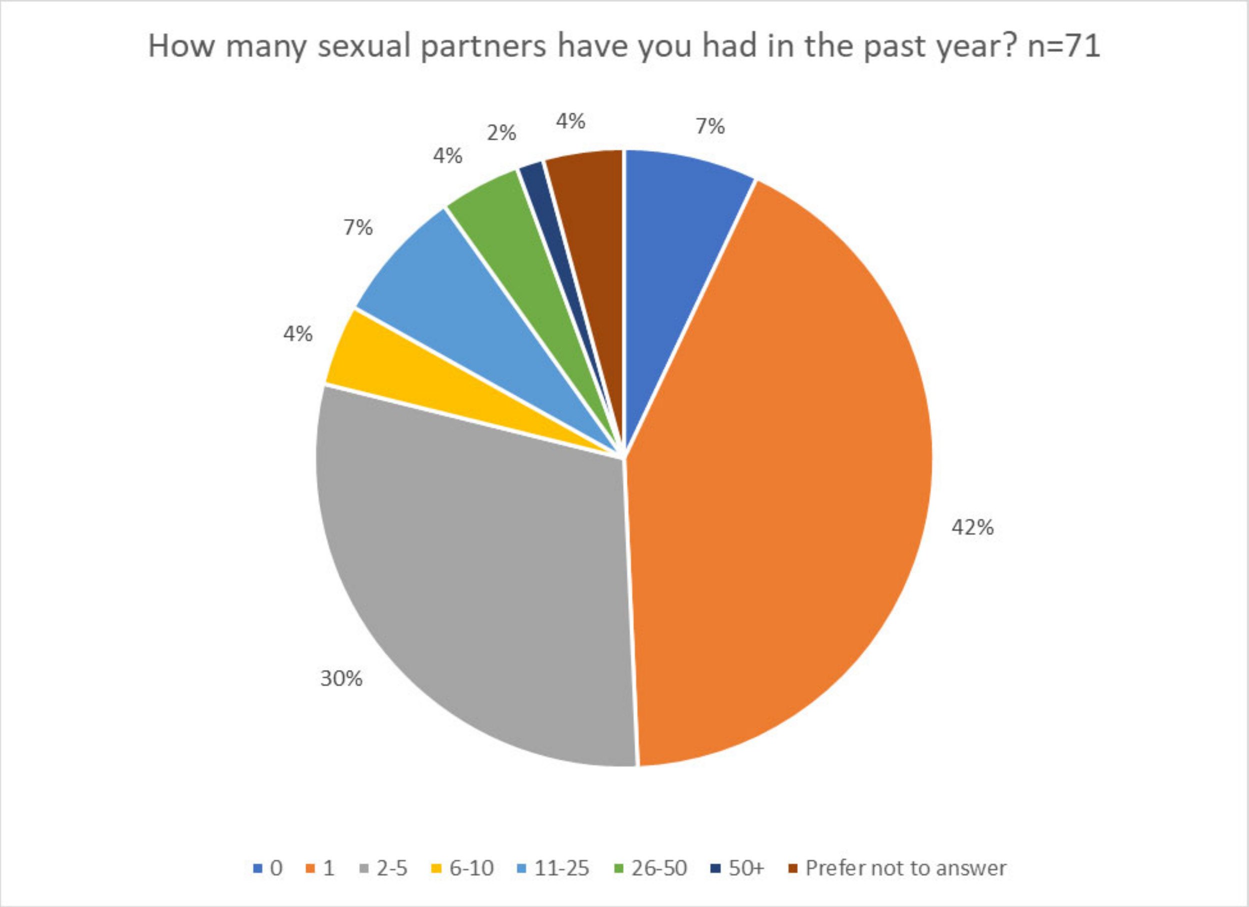
Nine respondents (13%) reported needing an interpreter at least sometimes to speak with their medical provider, but 20 respondents (28%) indicated that they had ever had difficulty communicating with their medical provider.

Sexual history

Respondents could select multiple choices to identify how they meet sexual partners. The most common response (32%) was that they were in a long-term monogamous relationship. One of these respondents indicated later in the survey that they had had 26-50 sexual partners in the past year.



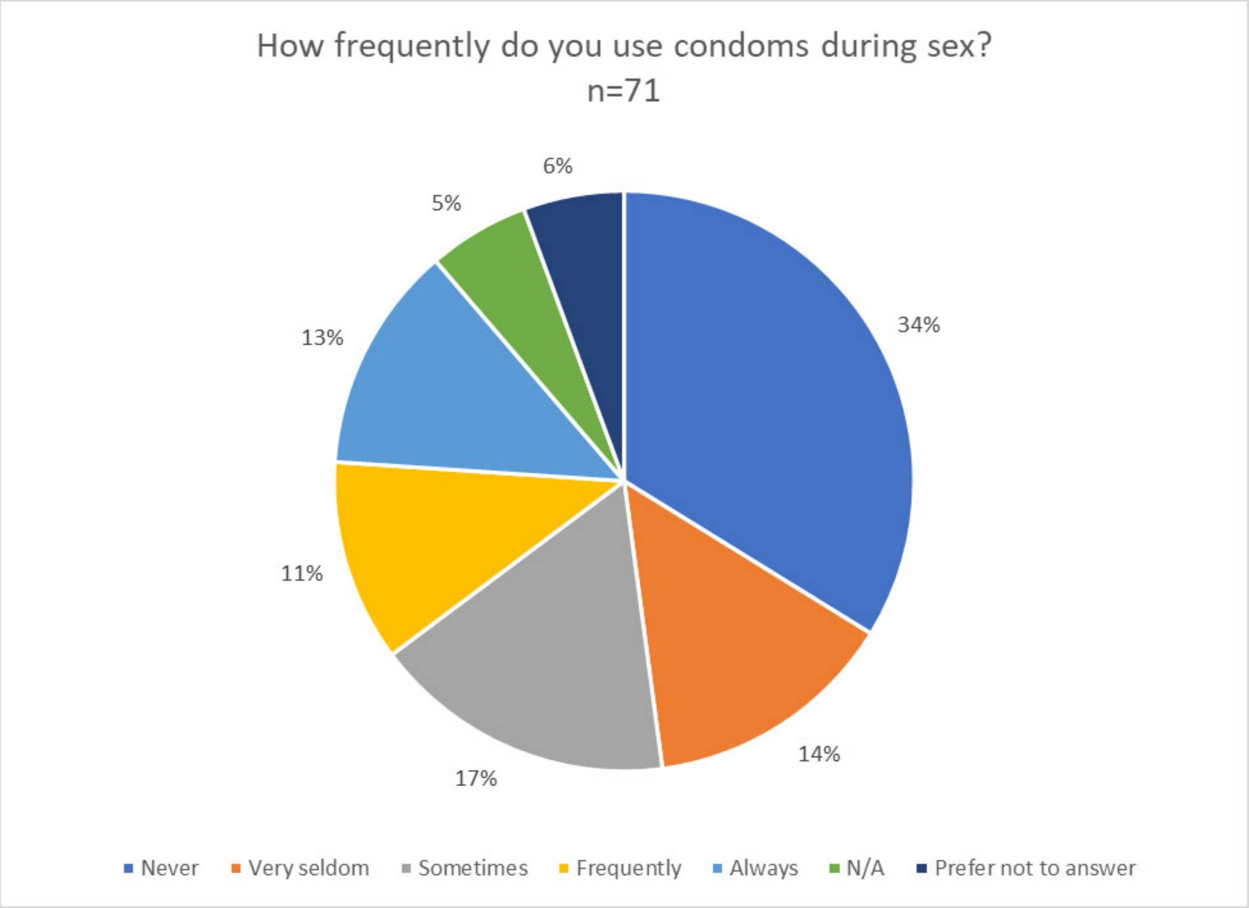
Only one respondent who reported meeting partners online gave more detail about the sites/apps used. This individual reported using Facebook to meet partners.



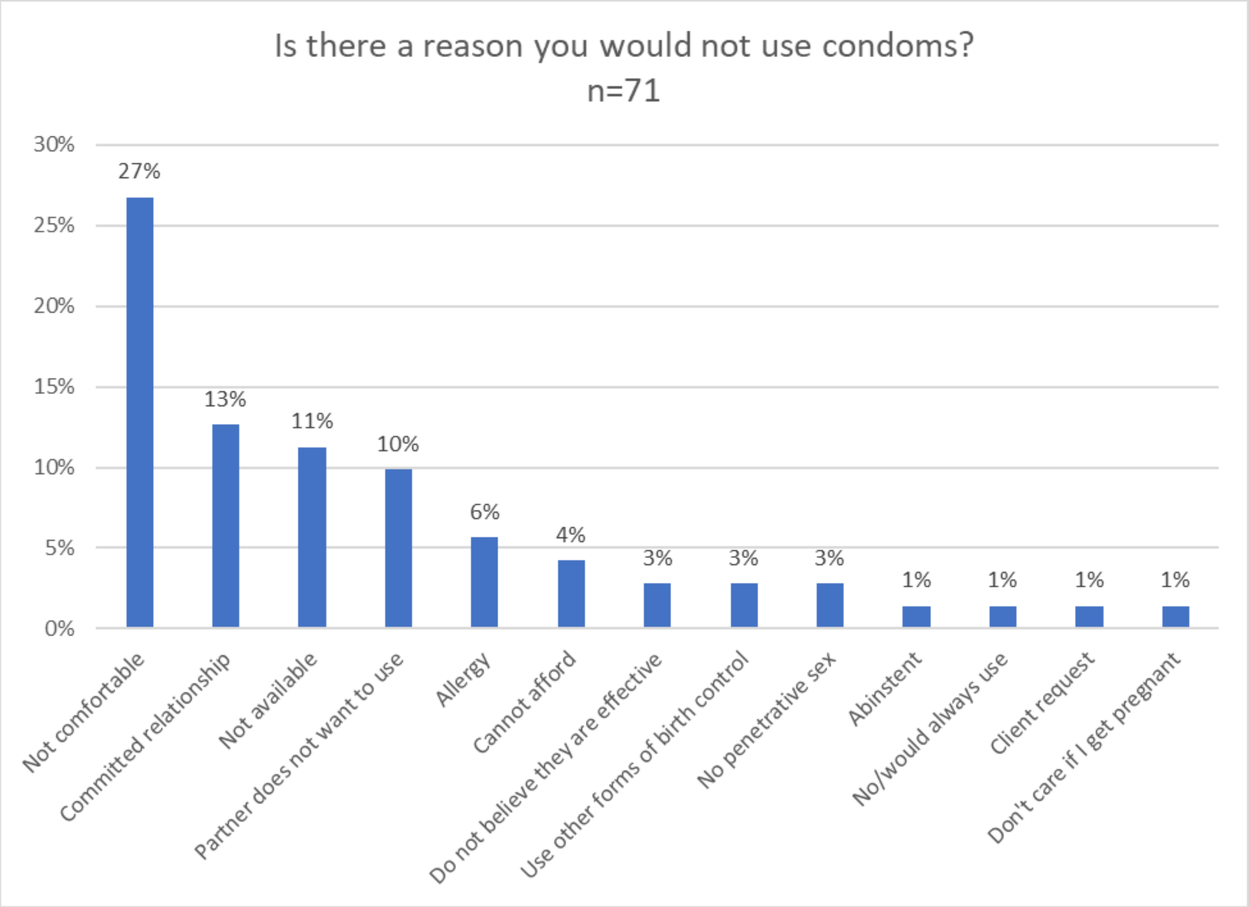
Thirteen respondents (18%) indicated that they had ever exchanged sex for money, substances, or goods.

Condom use

Most respondents (65%) reported that they use condoms sometimes, very seldom, or never, compared to 24% who frequently or always use condoms.



Respondents could select multiple choices to indicate why they would not use condoms. The most common response (27%) was that they do not find condoms comfortable.

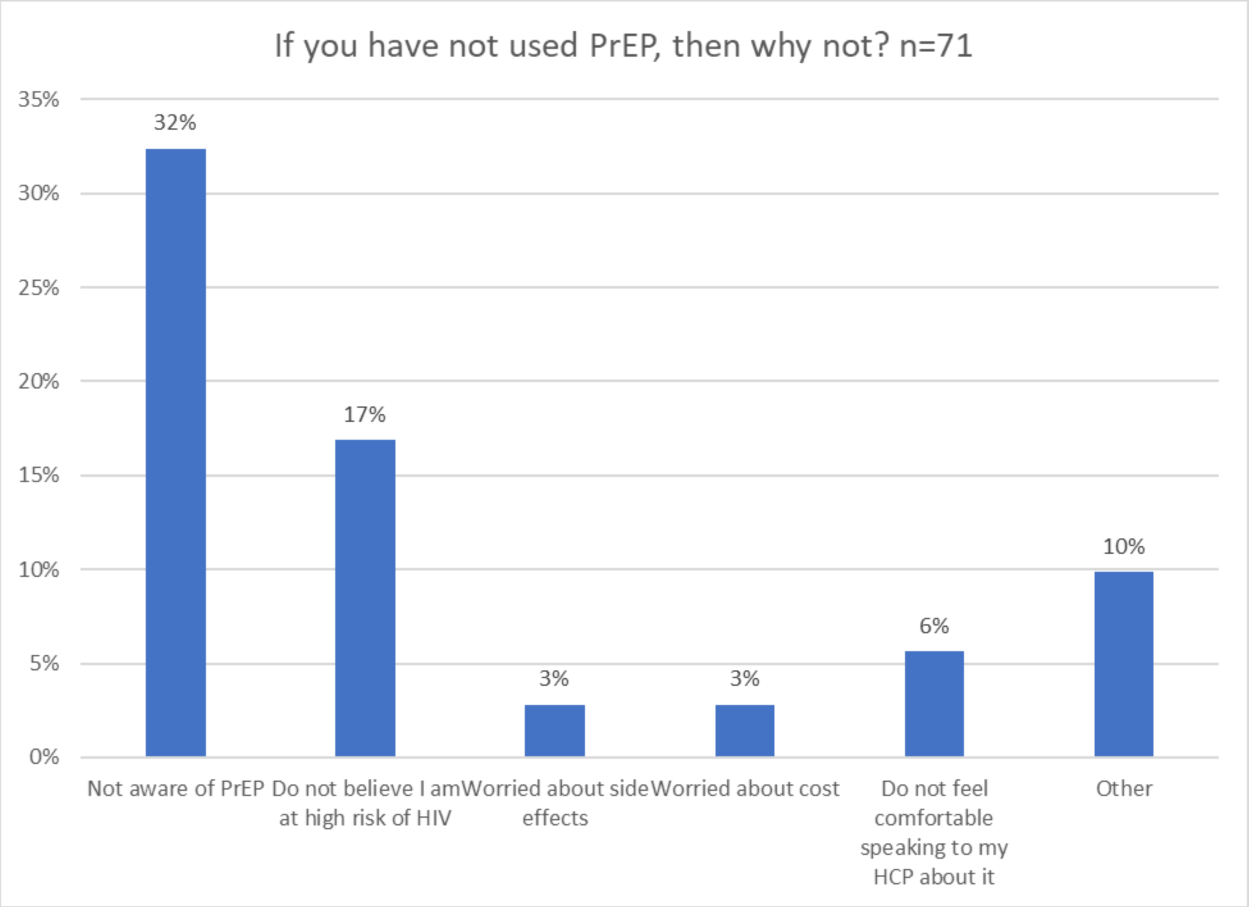


PrEP and PEP

Twenty respondents (28%) have heard of Pre-Exposure Prophylaxis (PrEP), but only 12 respondents (17%) have heard of Post-Exposure Prophylaxis (PEP).

Of those who have heard of PrEP, only one individual reports currently taking PrEP.

Respondents could select multiple choices to indicate why they have not used PrEP. The most common response (32%) was, “I was not aware of PrEP.”



A total of 38% of PWID respondents would be willing to take PrEP if it was available through a pharmacy without consulting a medical provider.

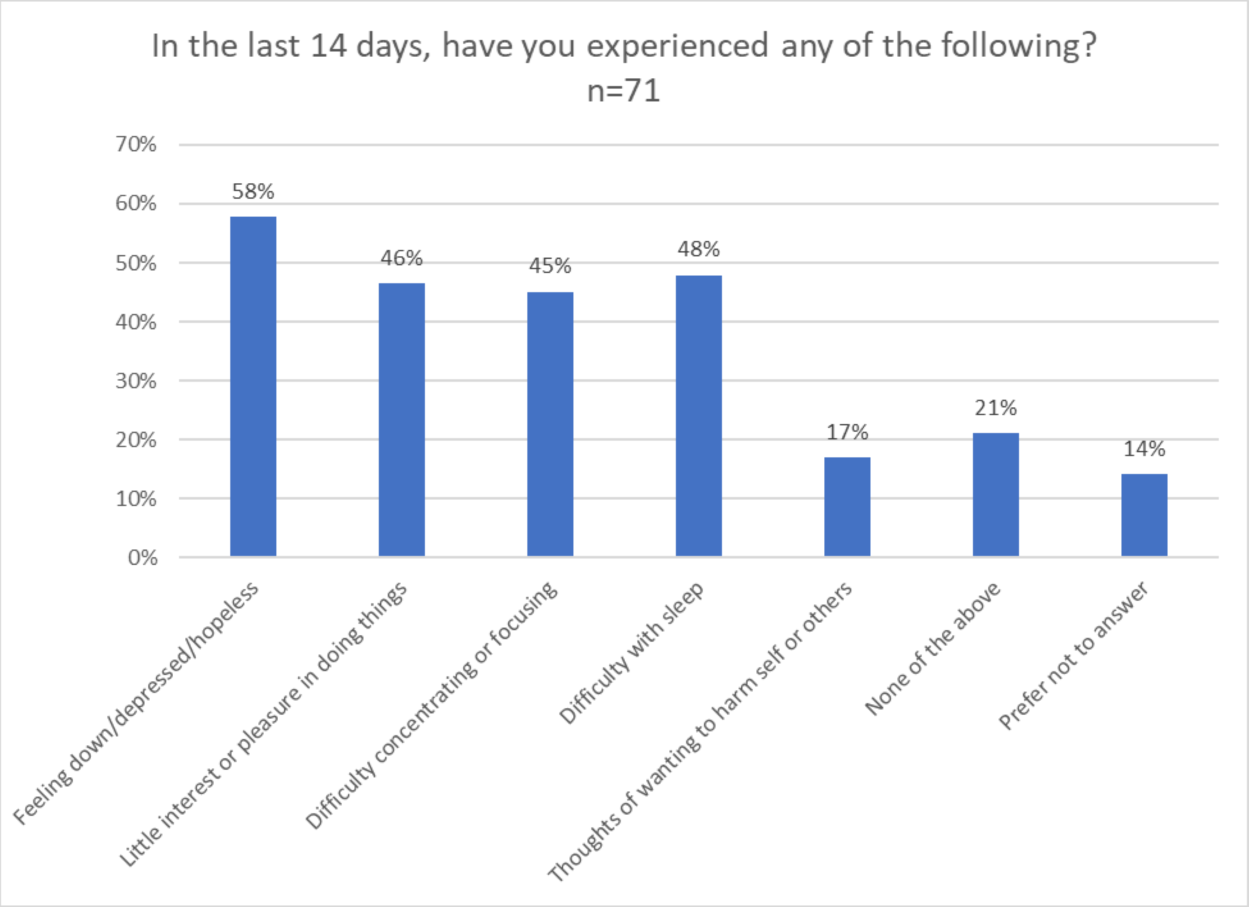
Five respondents (7%) indicated that they had requested PrEP from a provider and been refused. Of these five, one reports currently taking PrEP.

Four respondents reported ever taking PEP, and only two of these completed the full 28-day course.

Support services

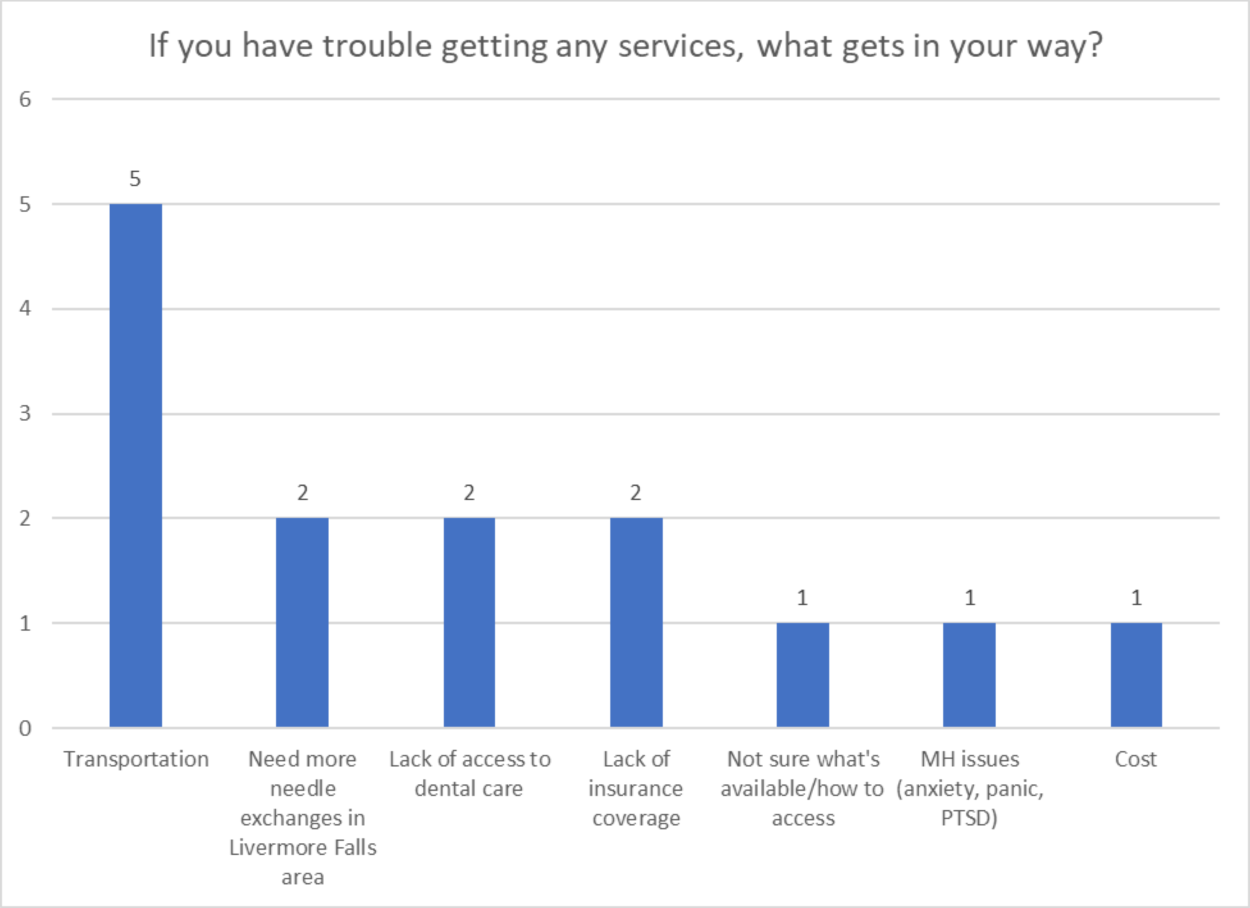
Most PWID respondents (61%) indicated that it takes an hour or less to travel one-way to most services they want (e.g. case management, support groups, etc.); 17% indicated that it takes more than an hour to get to such services.

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. About 21% of PWID respondents indicated that they had not experienced any of symptoms on the list, but more than half (58%) reported feeling down/depressed/hopeless. Twelve respondents (17%) reported thoughts of harming themselves or others.



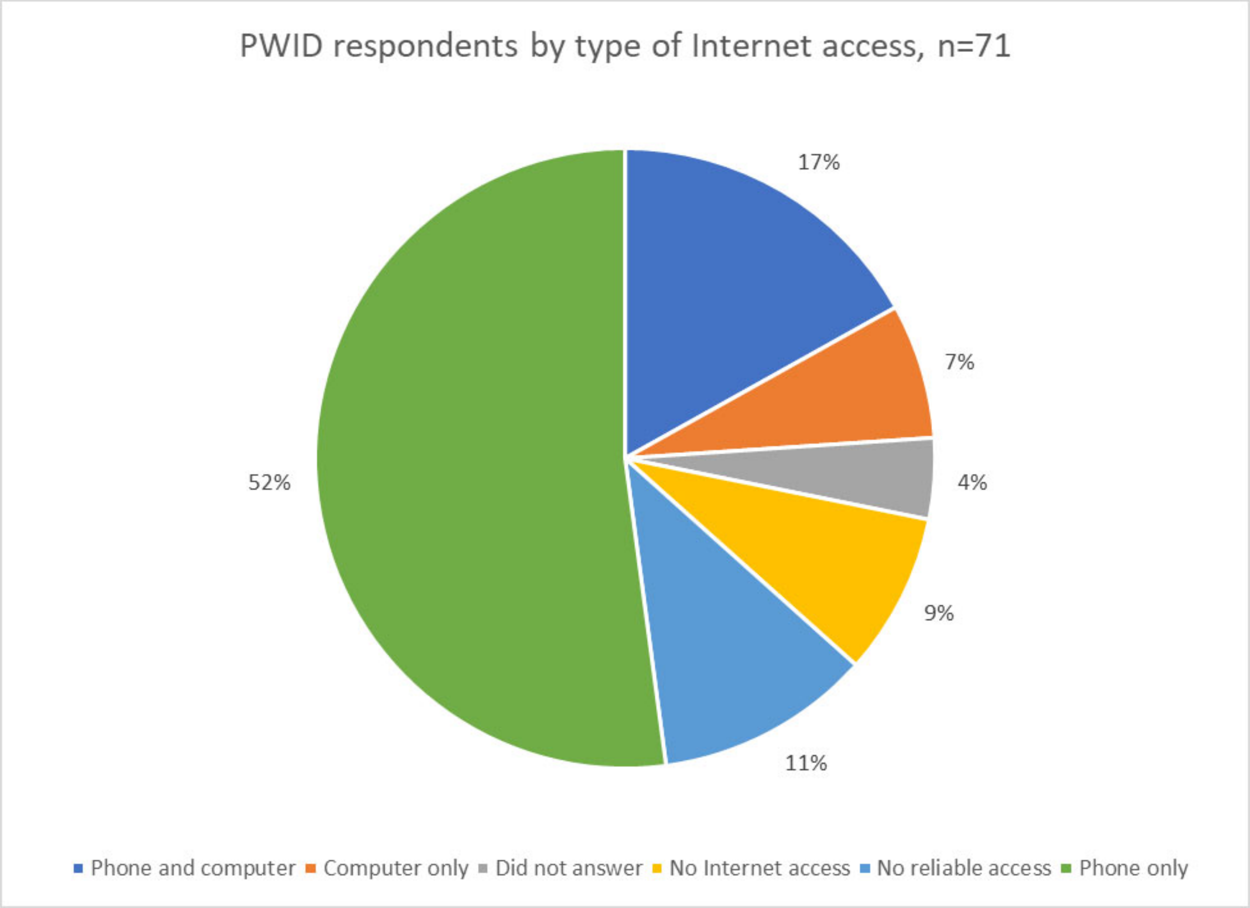
Respondents could select multiple choices to indicate if they needed more opportunities for social support. The most common response (41%) was "I don't need any opportunities," followed by learning retreats (17%), peer supports (15%), and community dinners (15%).

There was a narrative question about barriers that get in the way of accessing support services. While there were not many responses, there were some common themes:



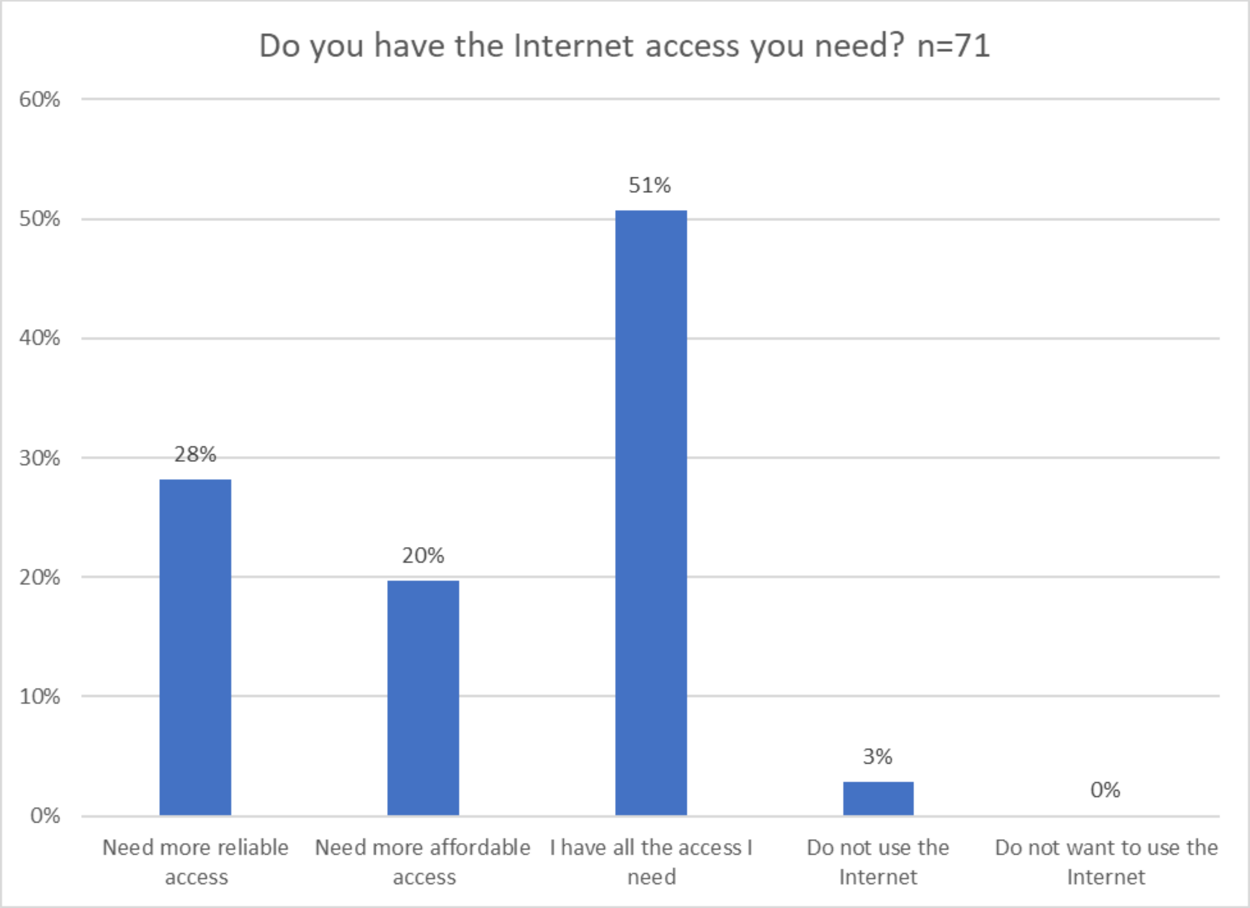
Internet access

Most PWID respondents (69%) can access the Internet by phone, and 76% have some form of reliable Internet access (phone, computer, or both).



Most PWID respondents (51%) indicated that they have all the Internet access they need. Four respondents (6%) indicated that they needed more reliable and affordable Internet, 16 (23%) reported needing more reliable access only, and ten (14%) reported needing more affordable access only.

No respondents selected "I do not want to use the Internet."



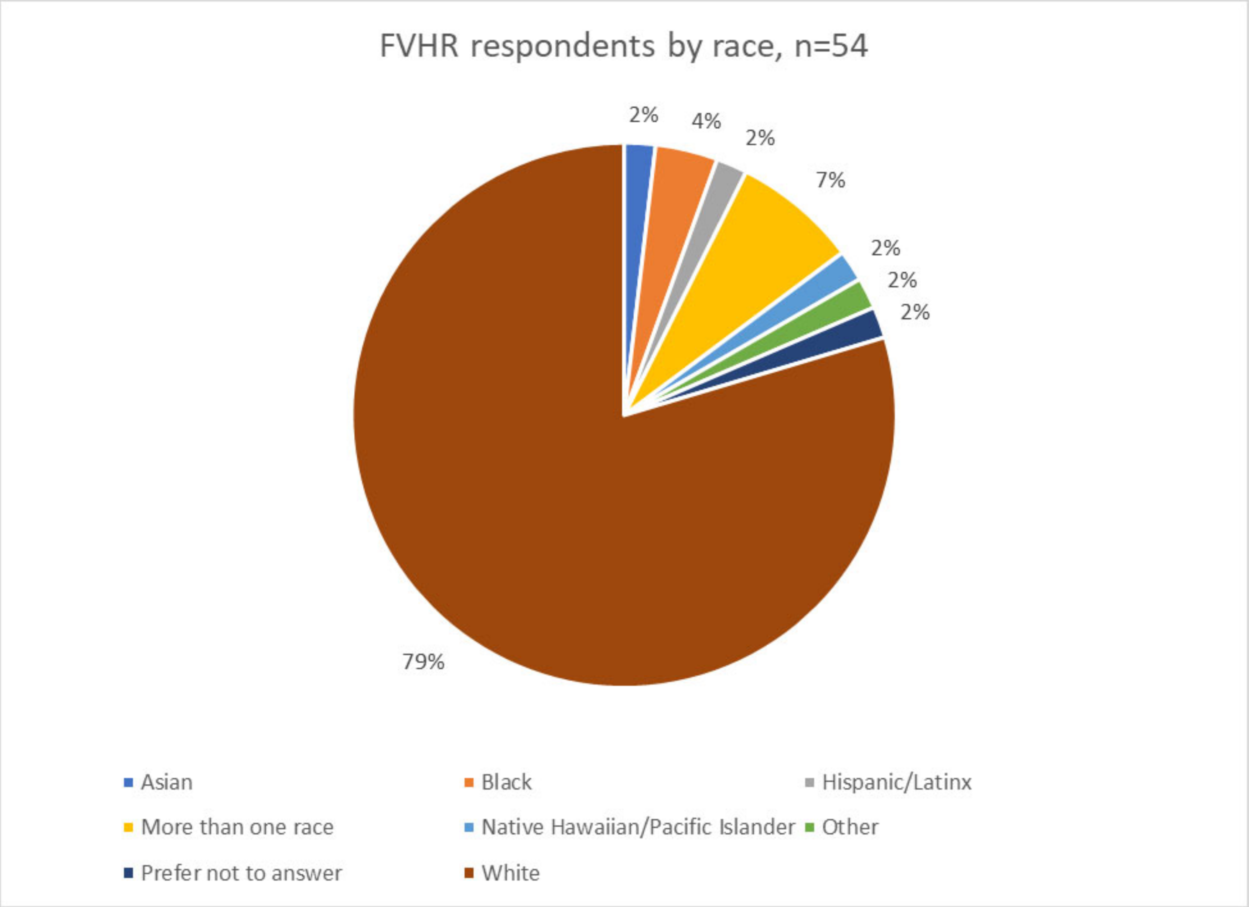
FVHR

The survey did not include questions to assess if a respondent's partners were MSM and/or PWID or if the respondent had been sexually assaulted in the past 12 months.

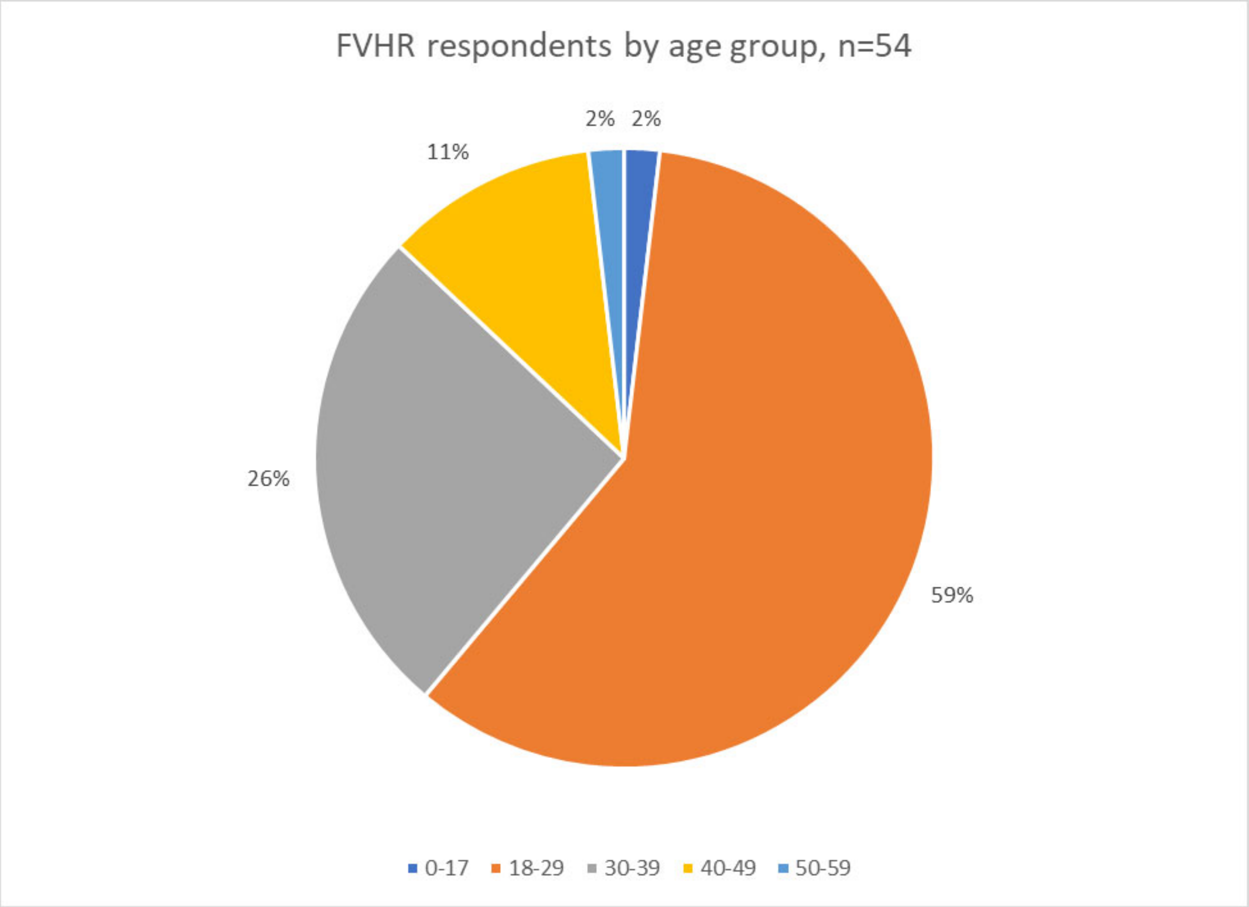
Respondents were classified as FVHR if they reported being assigned female at birth (AFAB) and reported exchanging sex for money, substances, or goods and/or reported a diagnosis of chlamydia, gonorrhea, syphilis, and/or viral hepatitis in the past two years. A total of 54 respondents (10%) met these classifications.

Most FVHR respondents (72%) currently identify as women. Thirteen respondents (24%) identify as non-binary/genderqueer/gender-fluid. Two respondents (4%) identify as transmen.

A total of 43 respondents (80%) identified as white and not Hispanic/Latinx. There were no Native American respondents.



There were no FVHR respondents older than age 59. Most respondents (85%) were between 18 and 39.



Three respondents (6%) reported staying in a place not meant for human habitation at some point in the past year. Four respondents (7%) reported three or more living situations in the past year.

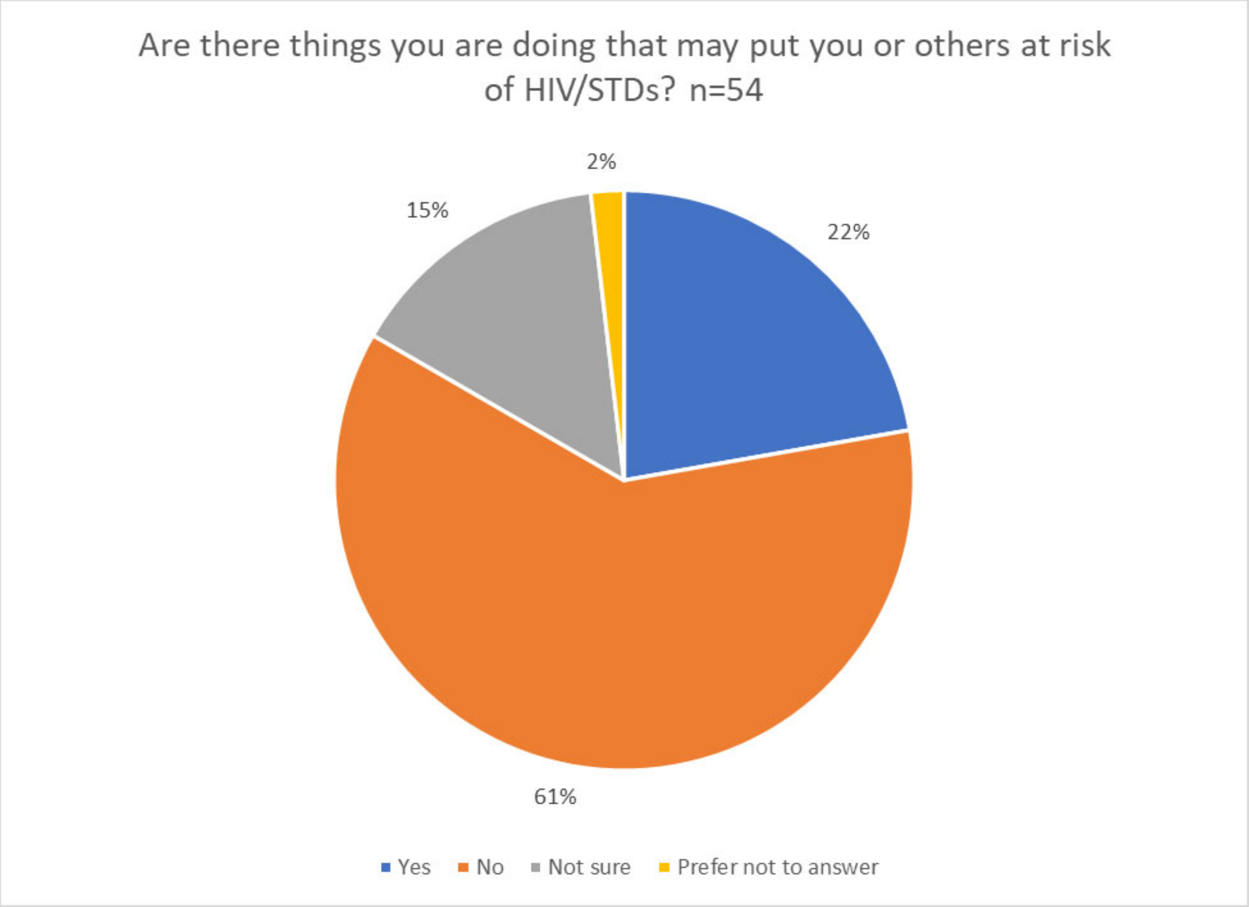
Five respondents (9%) reported being incarcerated; all but one were released more than 12 months before the survey.

Other infections

Nearly one-third of respondents (30%) report being diagnosed with chlamydia in the last two years. Four respondents (7%) report being diagnosed with Hepatitis C in the last two years. Two respondents (4%) reported being diagnosed with syphilis in the past two years. One of these individuals reported being diagnosed with chlamydia, gonorrhea, syphilis, Hepatitis A, Hepatitis B, and Hepatitis C.

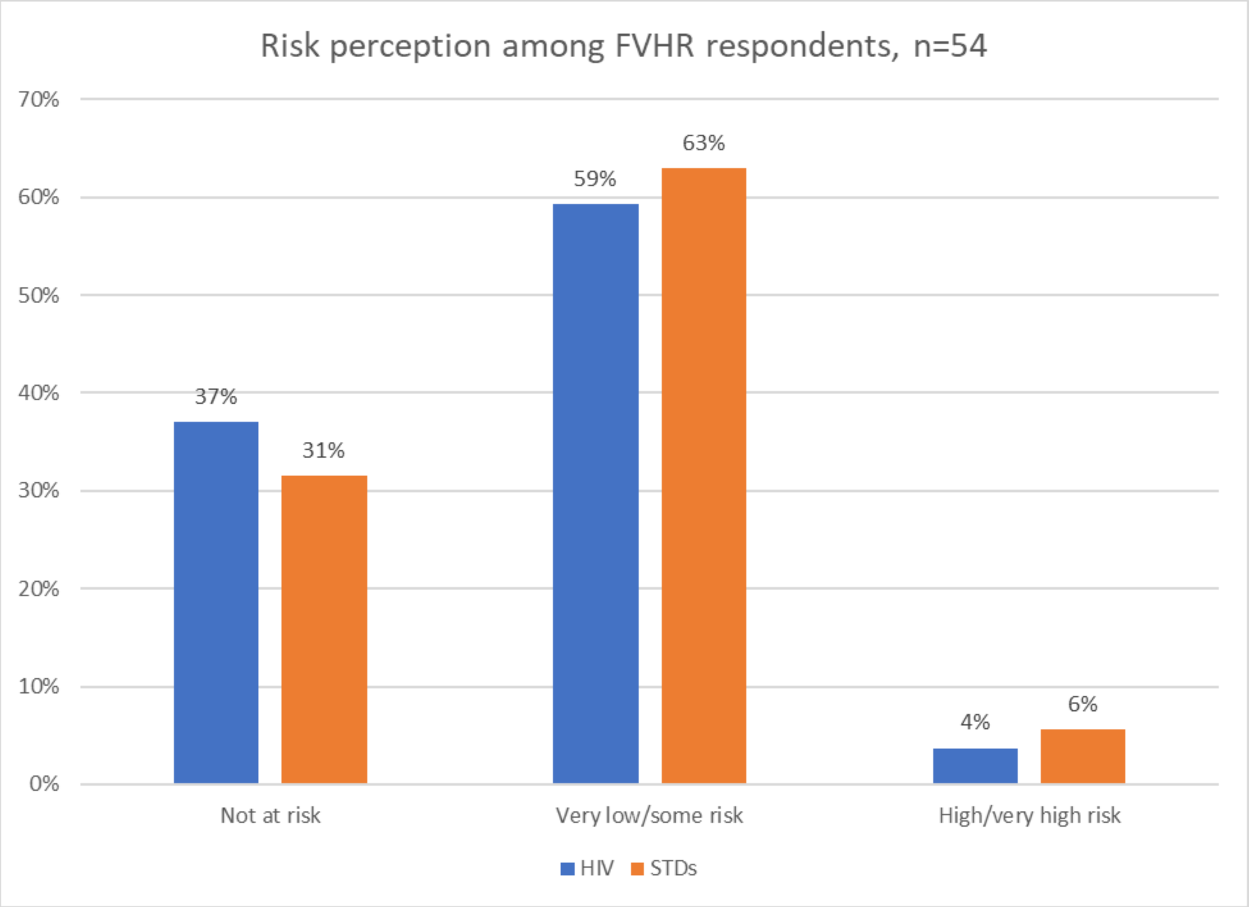
Risk perception and HIV testing

Two-thirds of FVHR respondents (67% or 36 individuals) reported exchanging sex for money, substances, or goods. Twenty respondents (37%) reported being diagnosed with at least one of the three reportable STDs and/or viral hepatitis in the past two years.

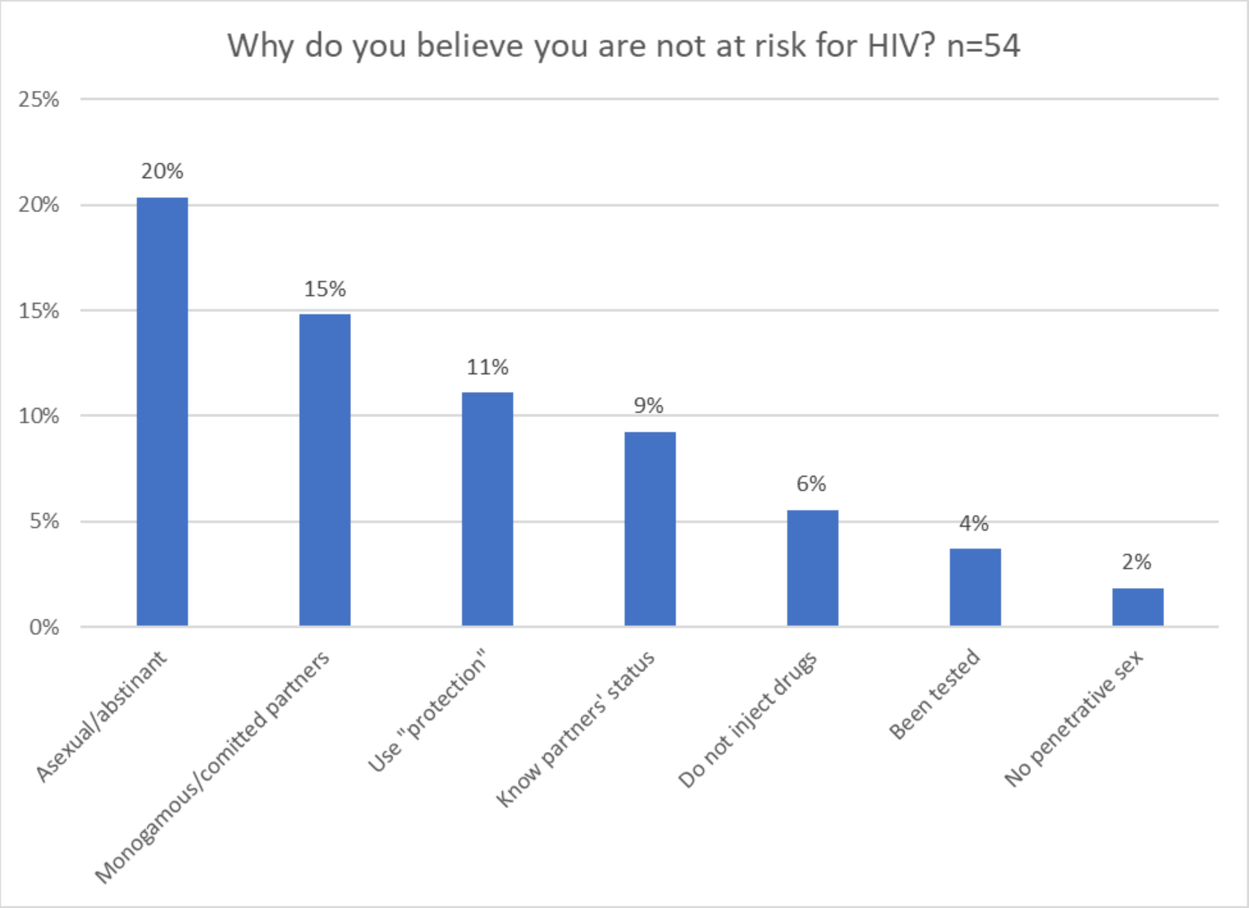


Of the 13 FVHR respondents who indicated they were at some, high, or very high risk for HIV infection, 7 (54%) reported that they were doing things that may put themselves or others at risk for HIV/STDs.

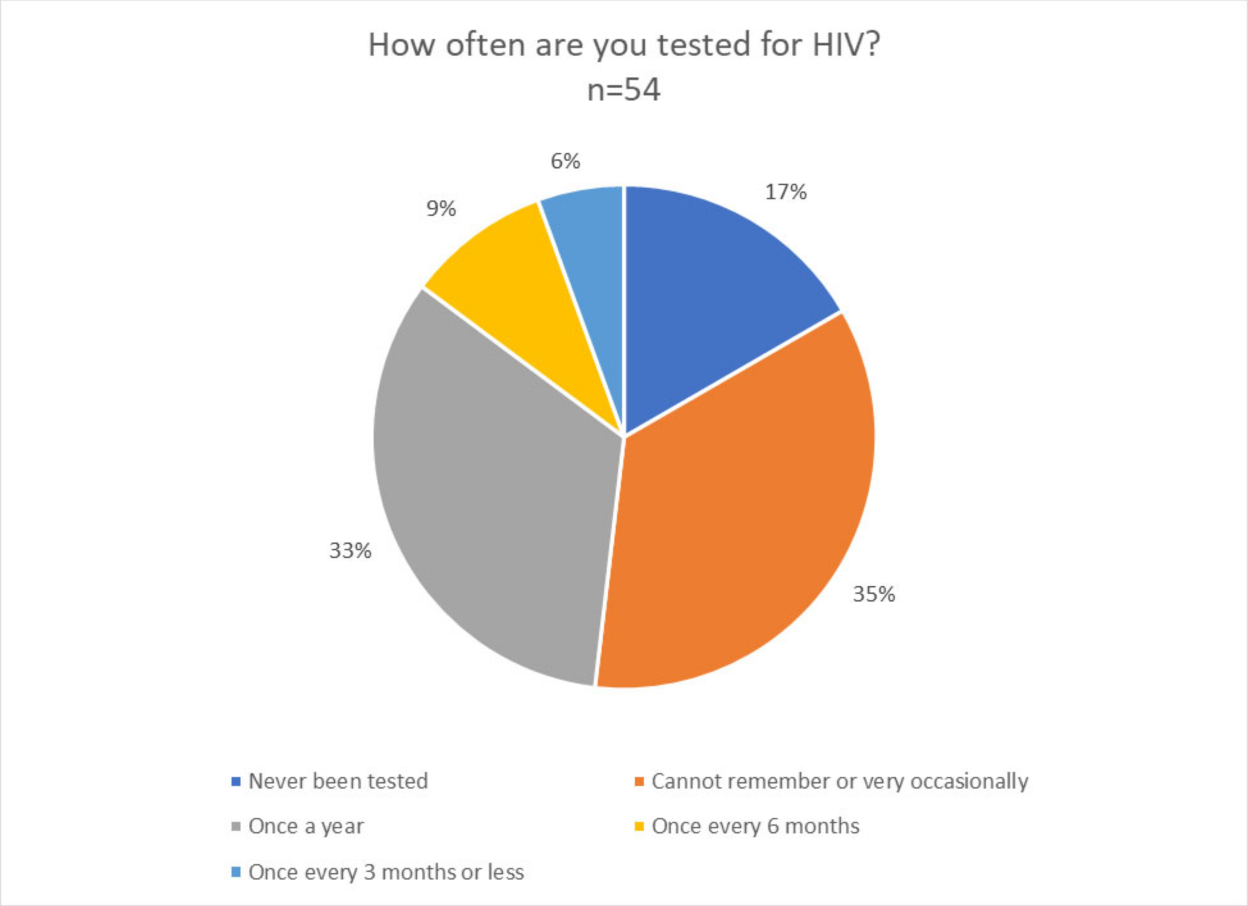
Of the 19 FVHR respondents who indicated they were at some, high, or very high risk for STDs, 8 (42%) reported that they were doing things that may put themselves or others at risk for HIV/STDs.



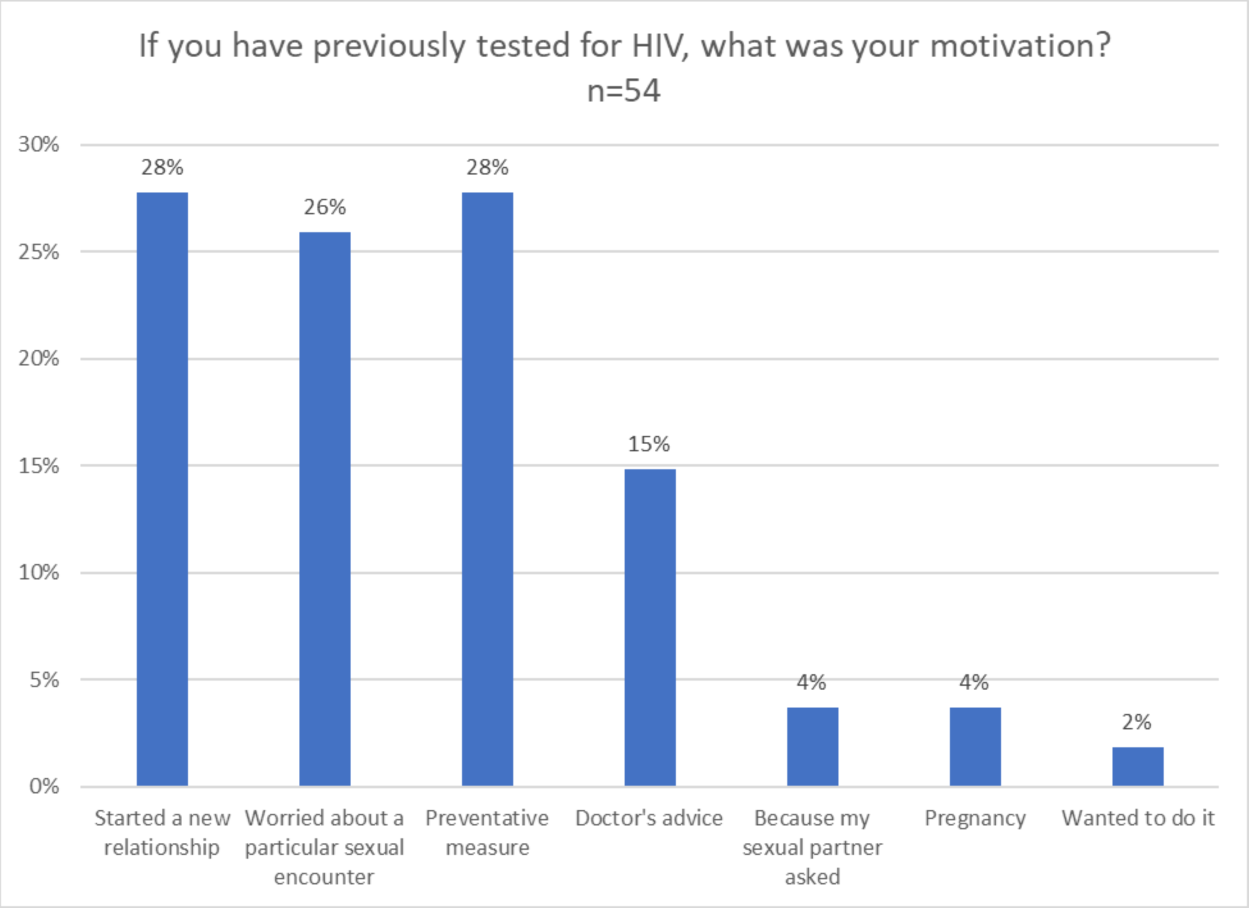
The survey included a narrative question, “Why do you believe you are not at risk for HIV?” Responses were aggregated by theme. The most common responses among FVHR were that they were currently abstinent or asexual (20%); three of these 11 respondents (27%) reported zero sexual partners in the past year later in the survey.



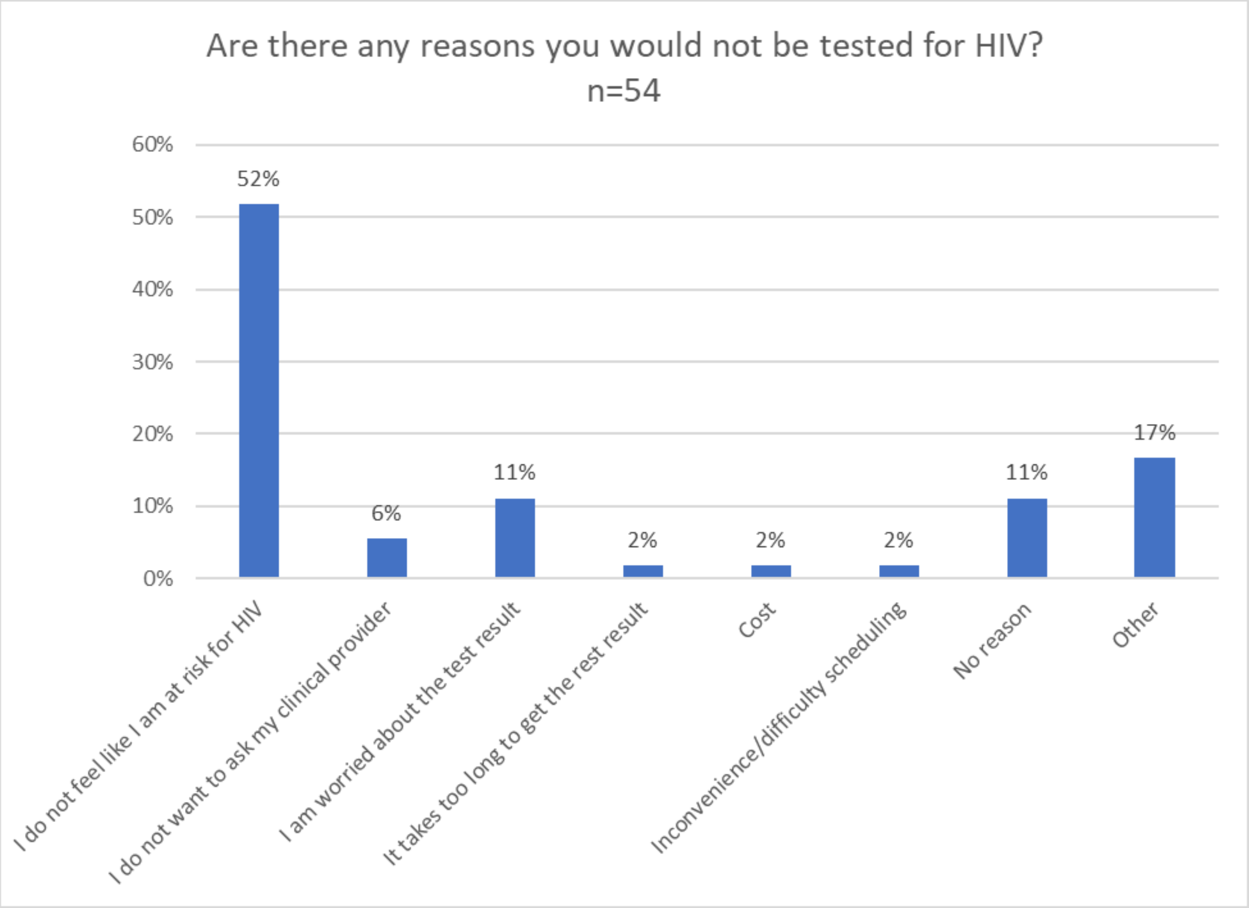
A total of 26 FVHR respondents (48%) report being tested for HIV at least once per year while nine (17%) have never been tested.



Respondents could select multiple options for the reason they have been previously tested for HIV.



Respondents could select multiple options for any reasons they would not be tested for HIV. The most common response (52%) among FVHR was "I do not feel like I am at risk for HIV."



Most FVHR respondents (63%) reported awareness of free HIV testing programs through Frannie Peabody Center, Portland Public Health, Maine Family Planning, or Health Equity Alliance, and 87% reported willingness to be tested for HIV at one of these sites.

Four respondents (7%) indicated they would need more information about testing sites, two respondents (4%) indicated that they did not have transportation to get to a test site, and one (2%) indicated that they would test through their primary care provider.

Three respondents (6%) reported using an HIV home test; 90% would be willing to use one in the future.

About 9% of FVHR respondents (five individuals) indicated that they fear using HIV prevention services at least some of the time because of how they feel they would be treated by family, friends, or community members.

Provider comfort

Six FVHR respondents (11%) reported always or often experiencing ill-treatment or discrimination by their medical provider due to their gender. An additional 16 (30%) reported sometimes experiencing this.

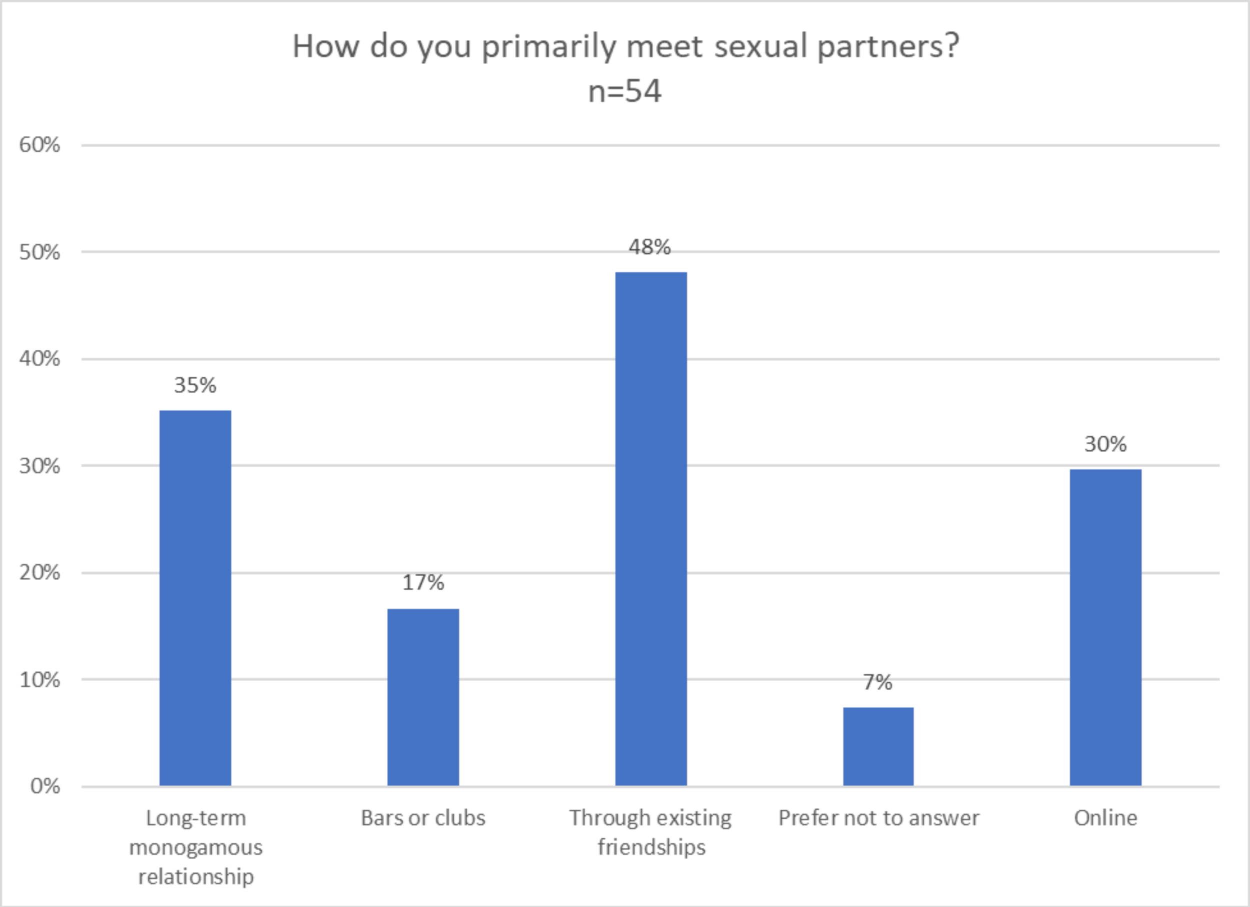
Most FVHR respondents (81%) indicated that they are comfortable speaking with their medical provider about their sexual history.

A total of 21 respondents (39%) indicated that their medical provider had ever recommended HIV testing.

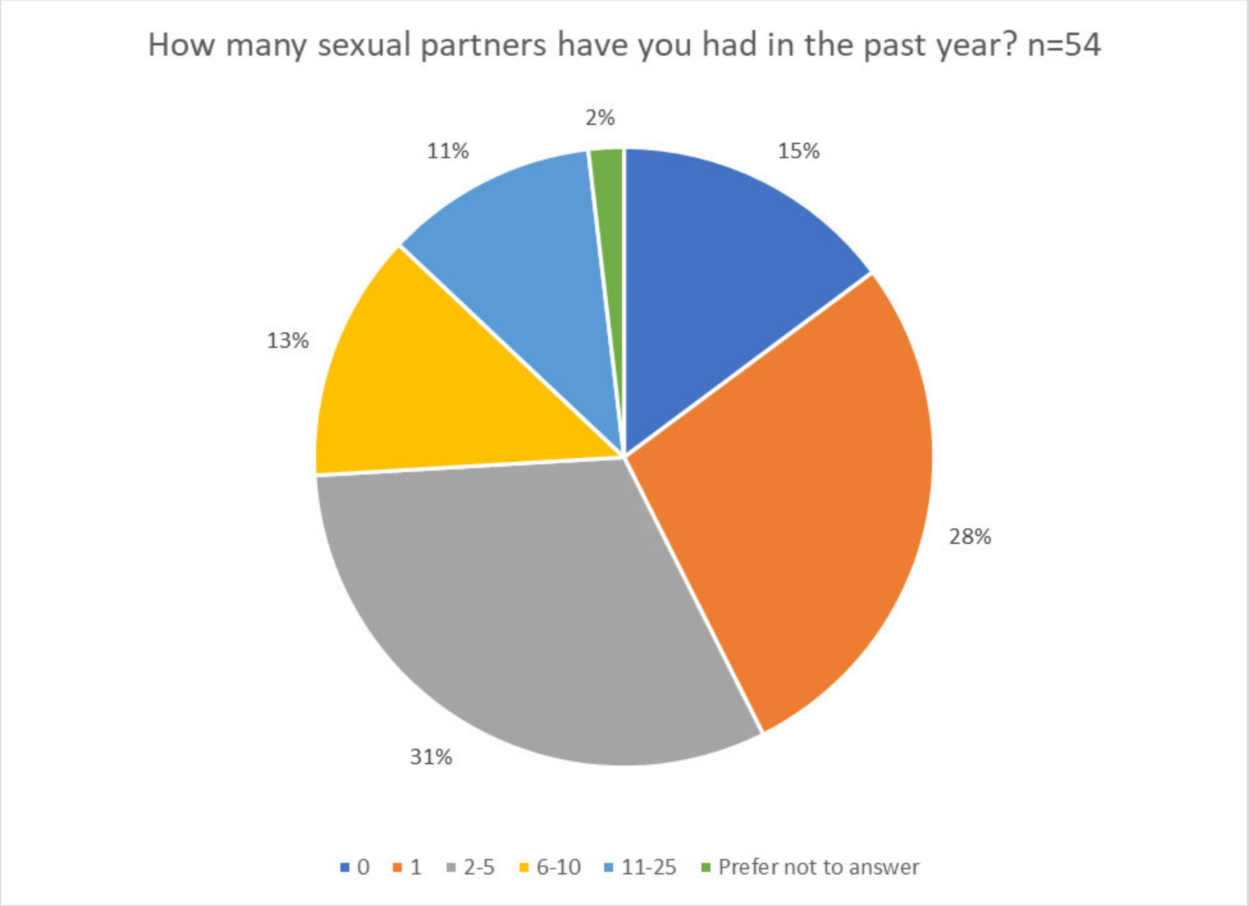
No respondents reported needing an interpreter to speak with their medical provider, but 10 respondents (19%) indicated that they had ever had difficulty communicating with their medical provider.

Sexual history

Respondents could select multiple choices to identify how they meet sexual partners. Of the 19 respondents who indicated that they were in a long-term monogamous relationship, 15 reported later in the survey that they had had six or more sexual partners in the past year.

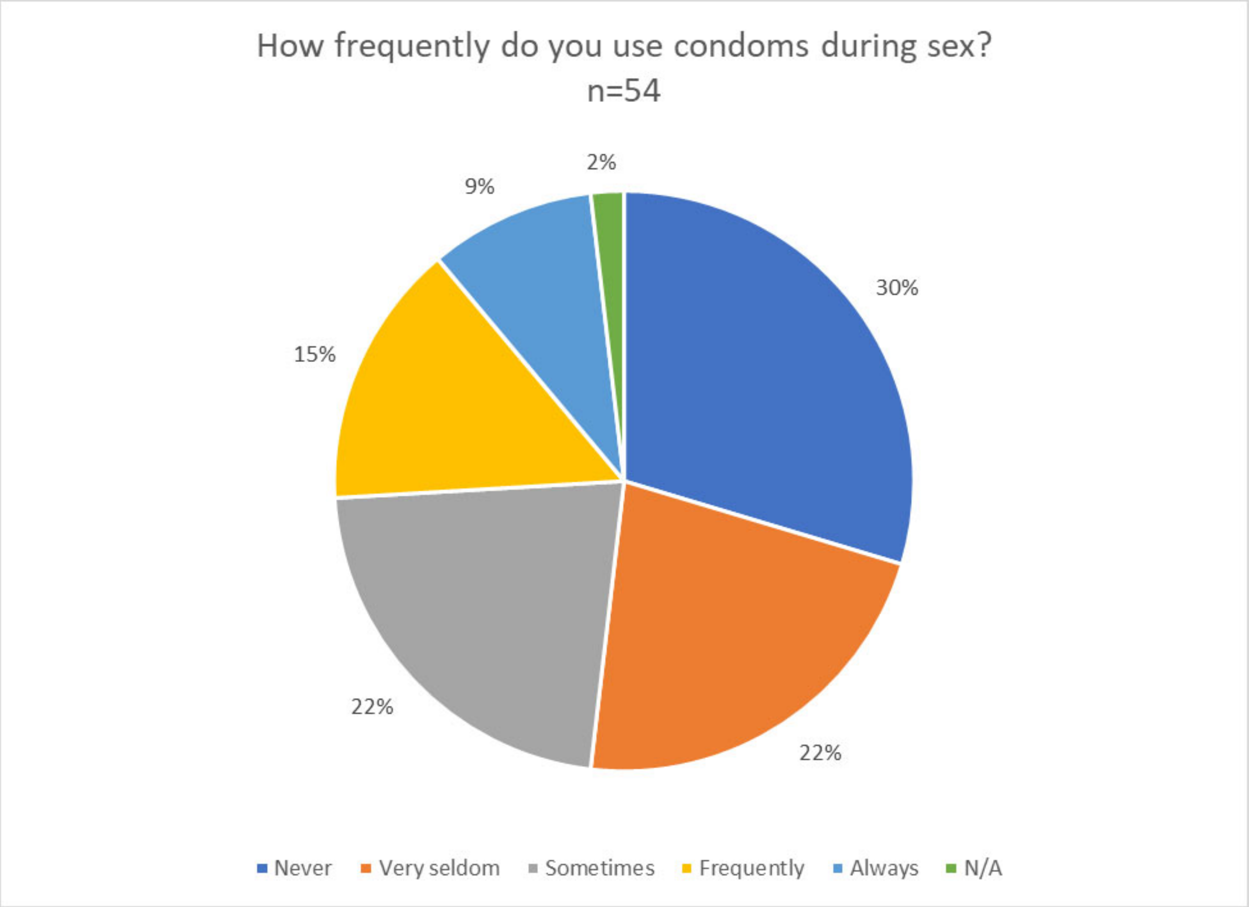


Five respondents (9%) identified the sites/apps they use to meet partners online. The most common response among these was Tinder (80%), followed by Hinge (40%), Bumble (20%), and social media sites (20%).

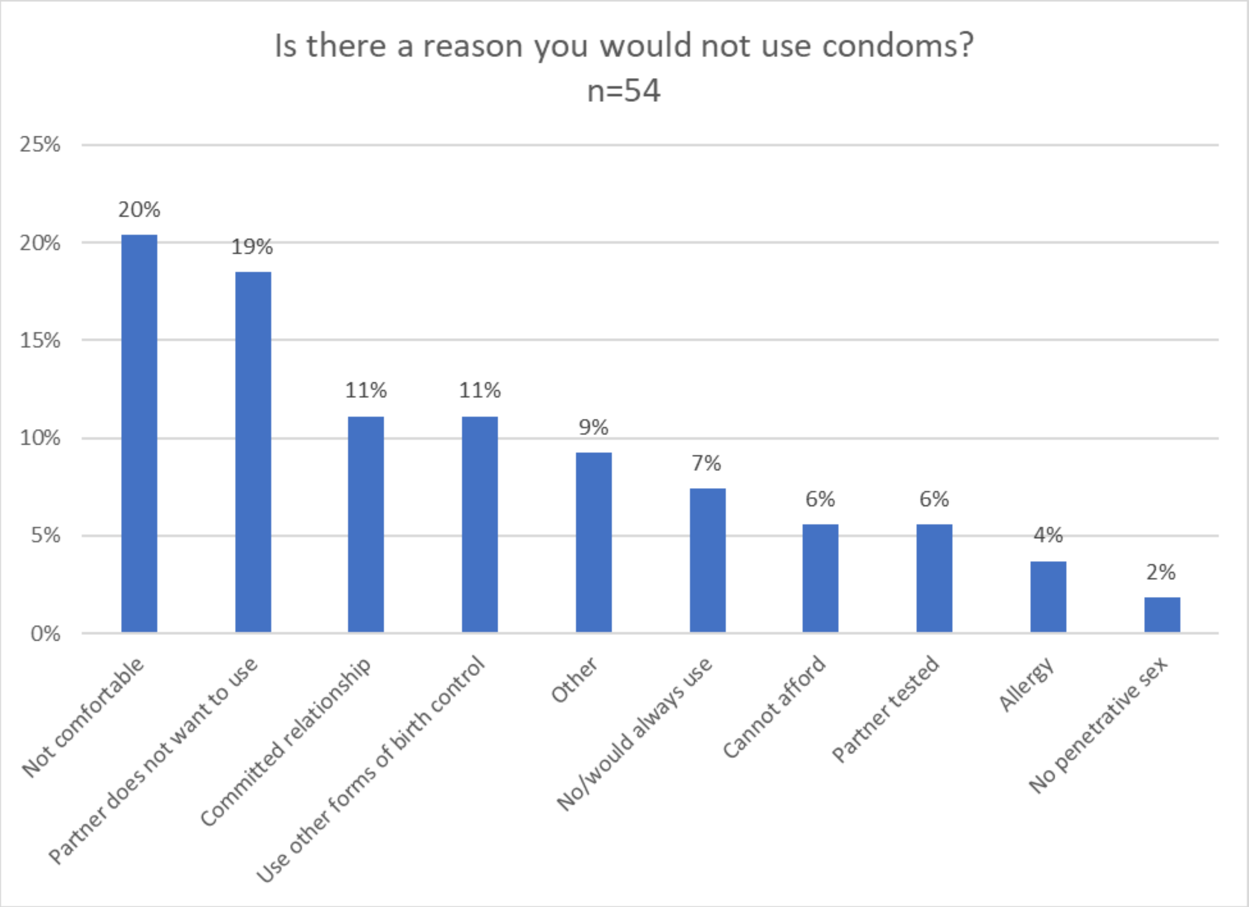


Condom use

Nearly one-third of FVHR respondents (30%) indicated that they never use condoms during sex, the most common response. Less than one-quarter (24%) reported frequently or always using them.



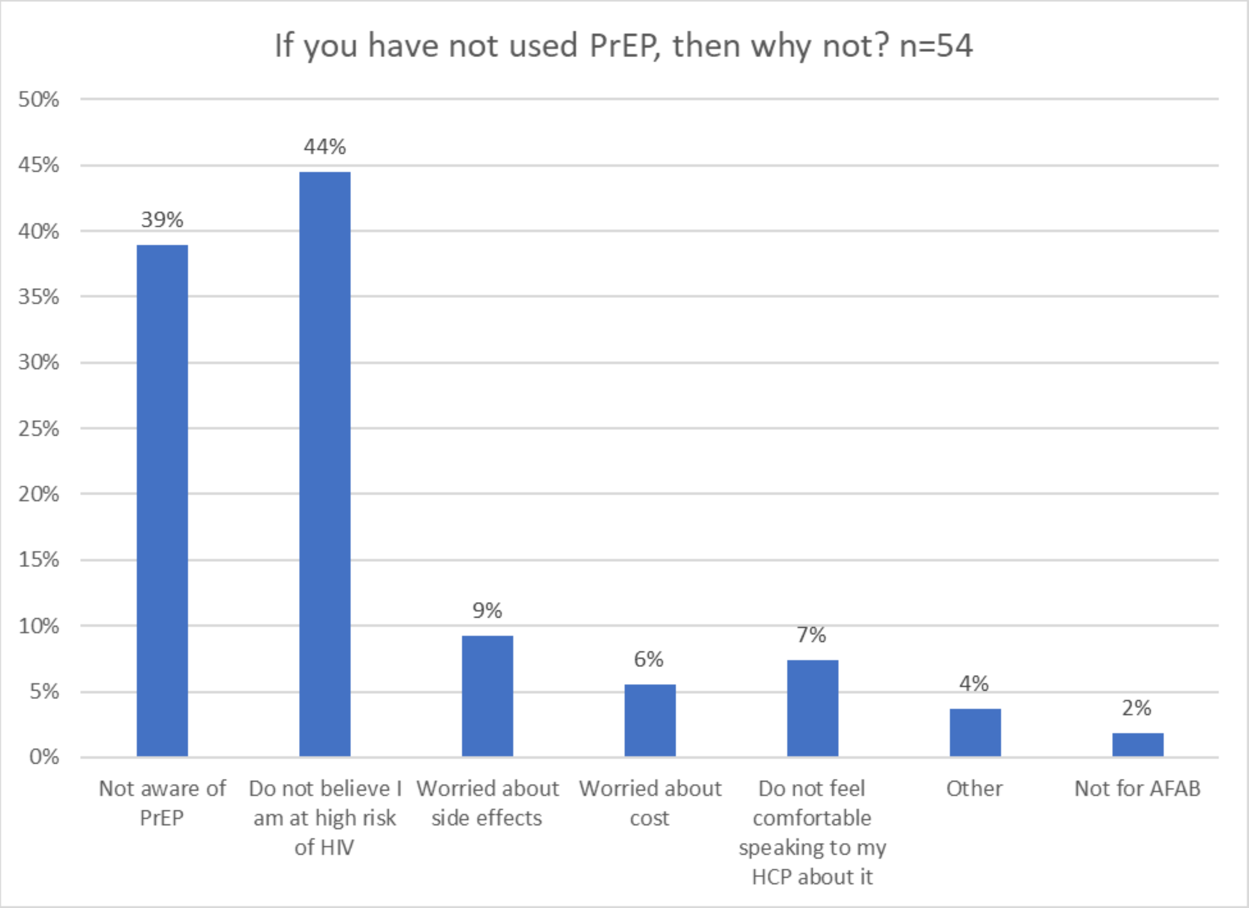
Respondents could select multiple choices to indicate why they would not use condoms. The most common response (20%) was that they do not find condoms comfortable.



PrEP and PEP

A total of 29 FVHR respondents (54%) have heard of Pre-Exposure Prophylaxis (PrEP), but only 19 respondents (35%) have heard of Post-Exposure Prophylaxis (PEP).

Respondents could select multiple choices to indicate why they have not used PrEP. The most common responses were that they do not believe they are at high risk of HIV (44%) and that they were not aware of PrEP (39%).



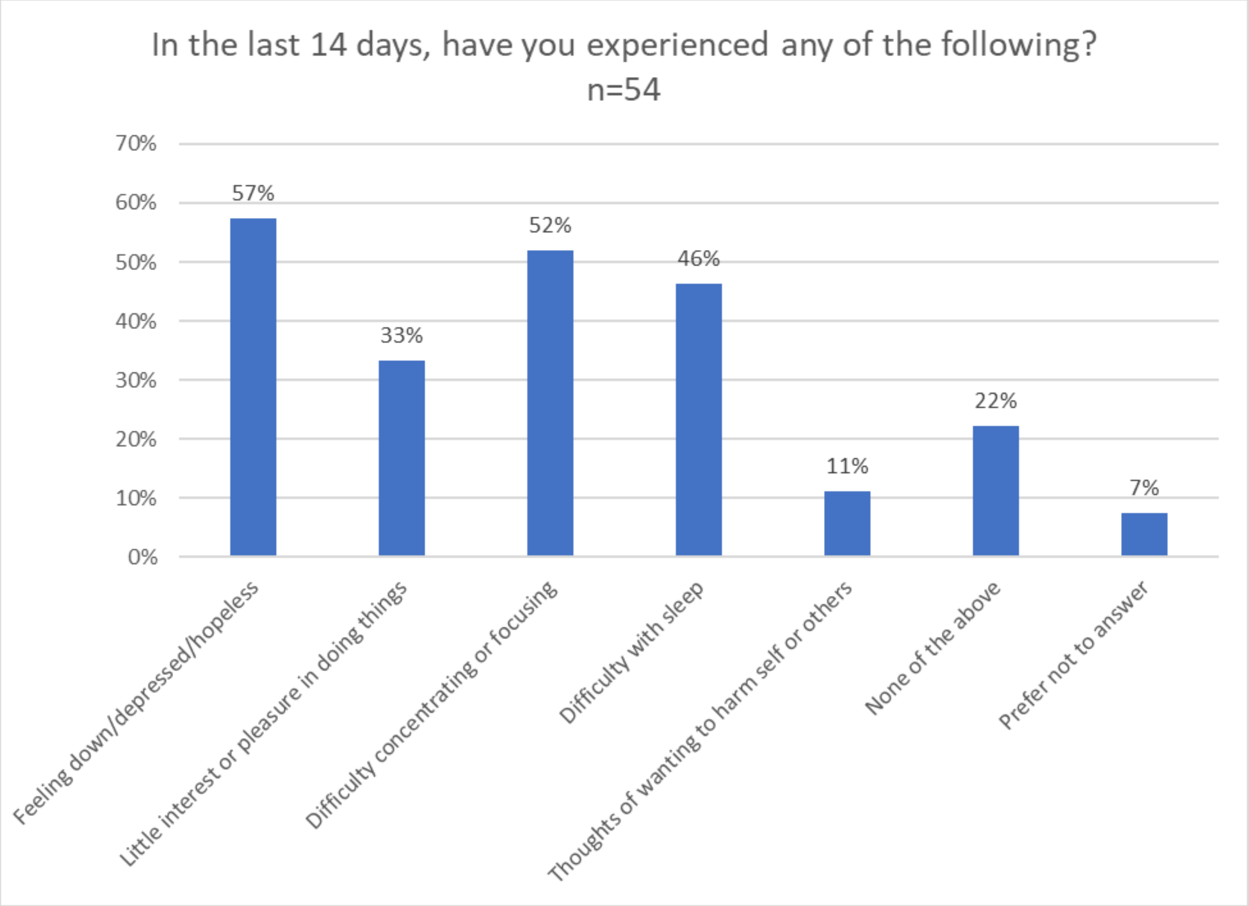
A total of 56% of FVHR respondents would be willing to take PrEP if it was available through a pharmacy without consulting a medical provider.

One respondent reported ever taking PEP and completed the full 28-day course.

Support services

Most FVHR respondents (78%) indicated that it takes an hour or less to travel one-way to most services they want (e.g. case management, support groups, etc.); 7% indicated that it takes between one and two hours to get to such services.

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. About 22% of FVHR respondents indicated that they had not experienced any of symptoms on the list, but more than half (57%) reported feeling down/depressed/hopeless and difficulty concentrating or focusing (52%). Six respondents (11%) reported thoughts of harming themselves or others.

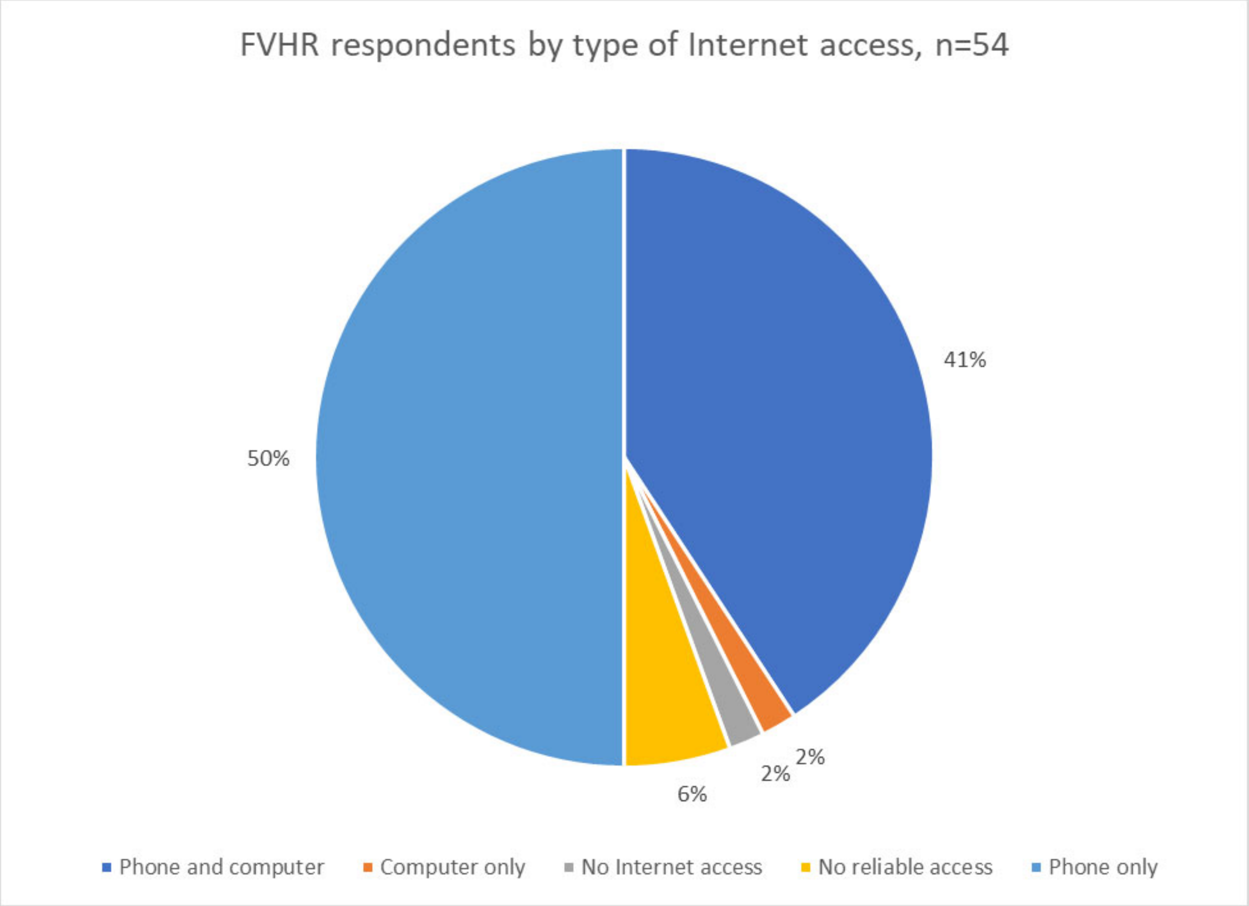


Respondents could select multiple choices to indicate if they needed more opportunities for social support. The most common response (52%) was "I don't need any opportunities," followed by peer supports (15%), and community dinners (15%), and weekly meetings (11%).

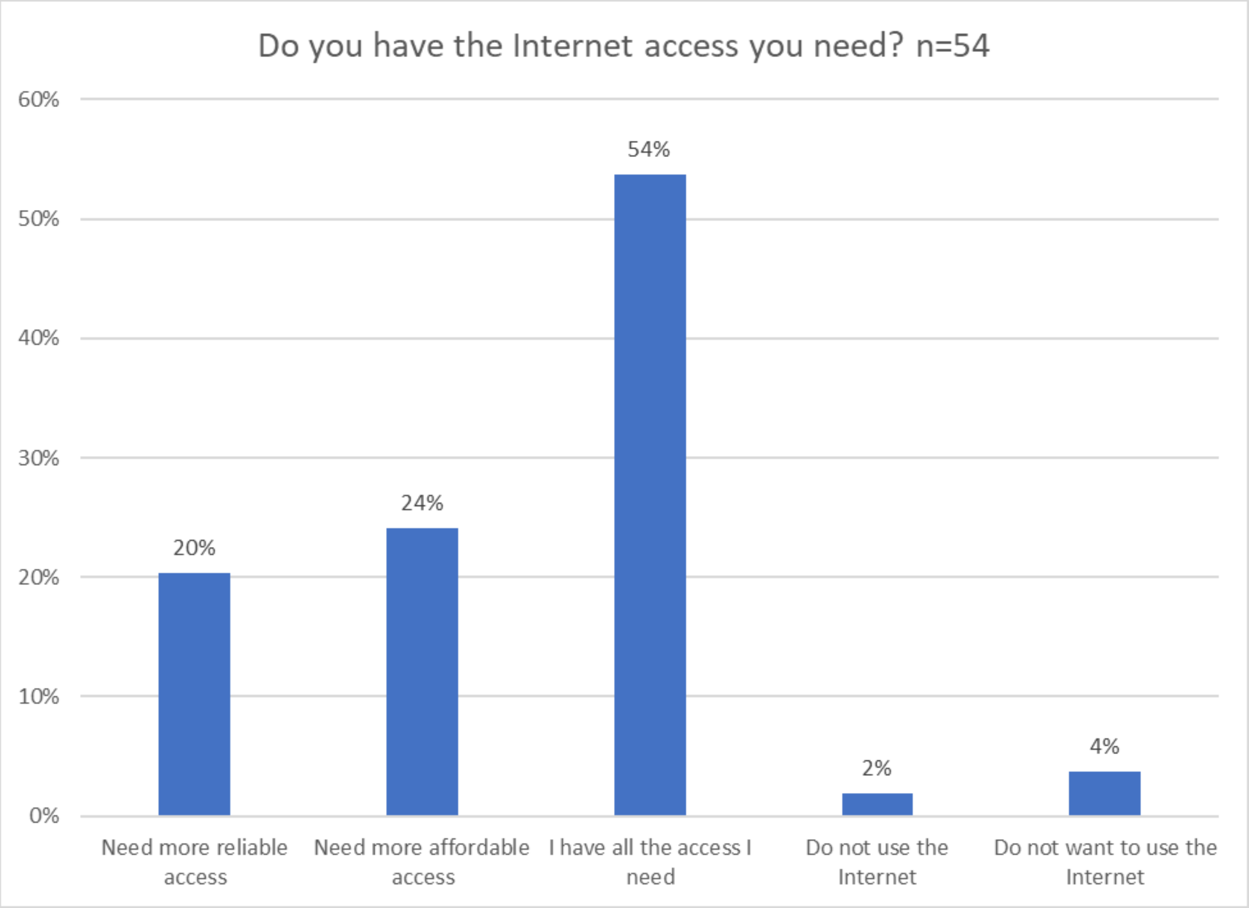
There was a narrative question about barriers that get in the way of accessing support services. Three respondents identified transportation as a barrier, two identified systemic issues (such as wait lists and paperwork), one indicated not knowing what was available or how to access, and one identified mental health issues (such as anxiety, panic, PTSD).

Internet access

Almost all FVHR respondents (91%) can access the Internet by phone, and 93% have some form of reliable Internet access (phone, computer, or both).



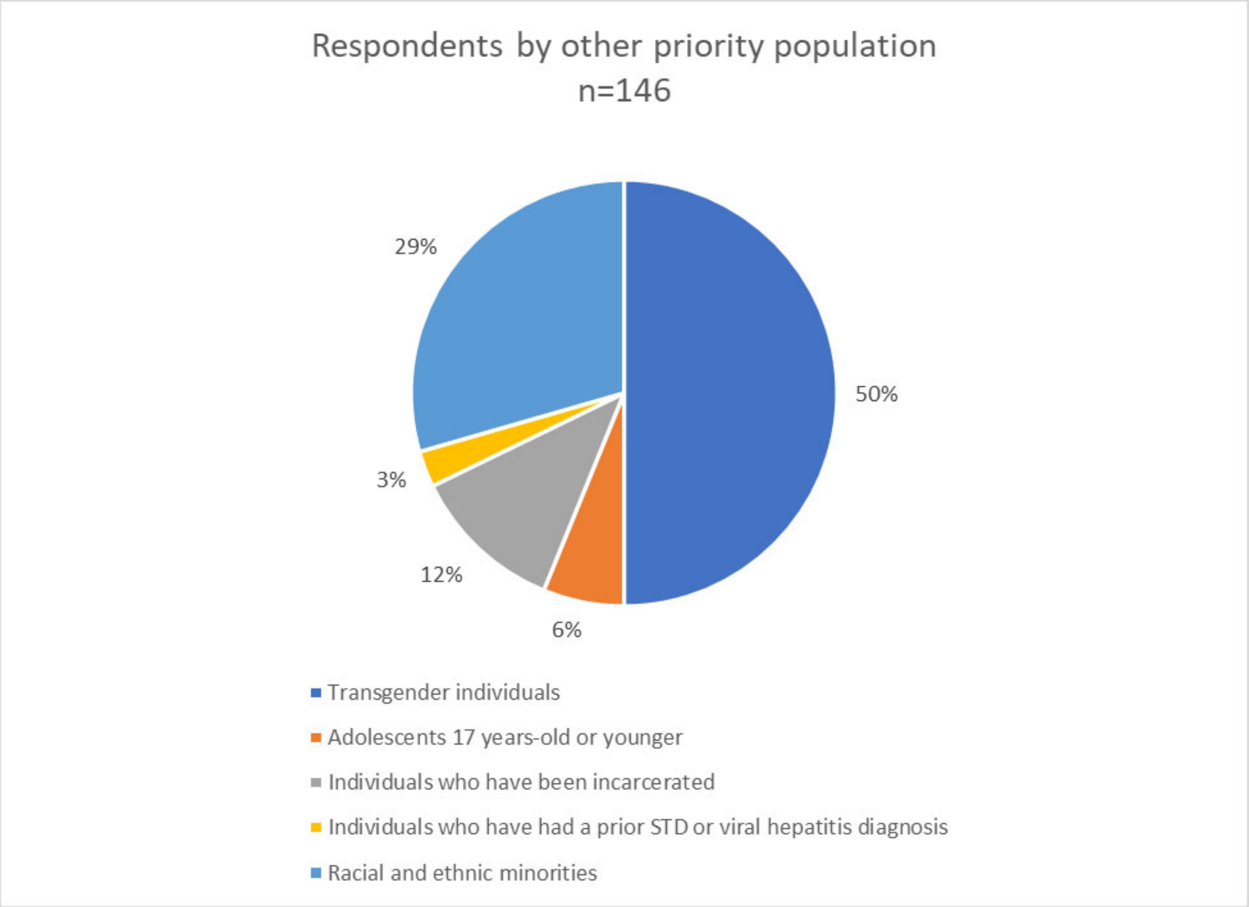
Most FVHR respondents (54%) indicated that they have all the Internet access they need. One respondent (2%) indicated that they needed more reliable and affordable Internet, 10 (19%) reported needing more reliable access only, and 12 (22%) reported needing more affordable access only.



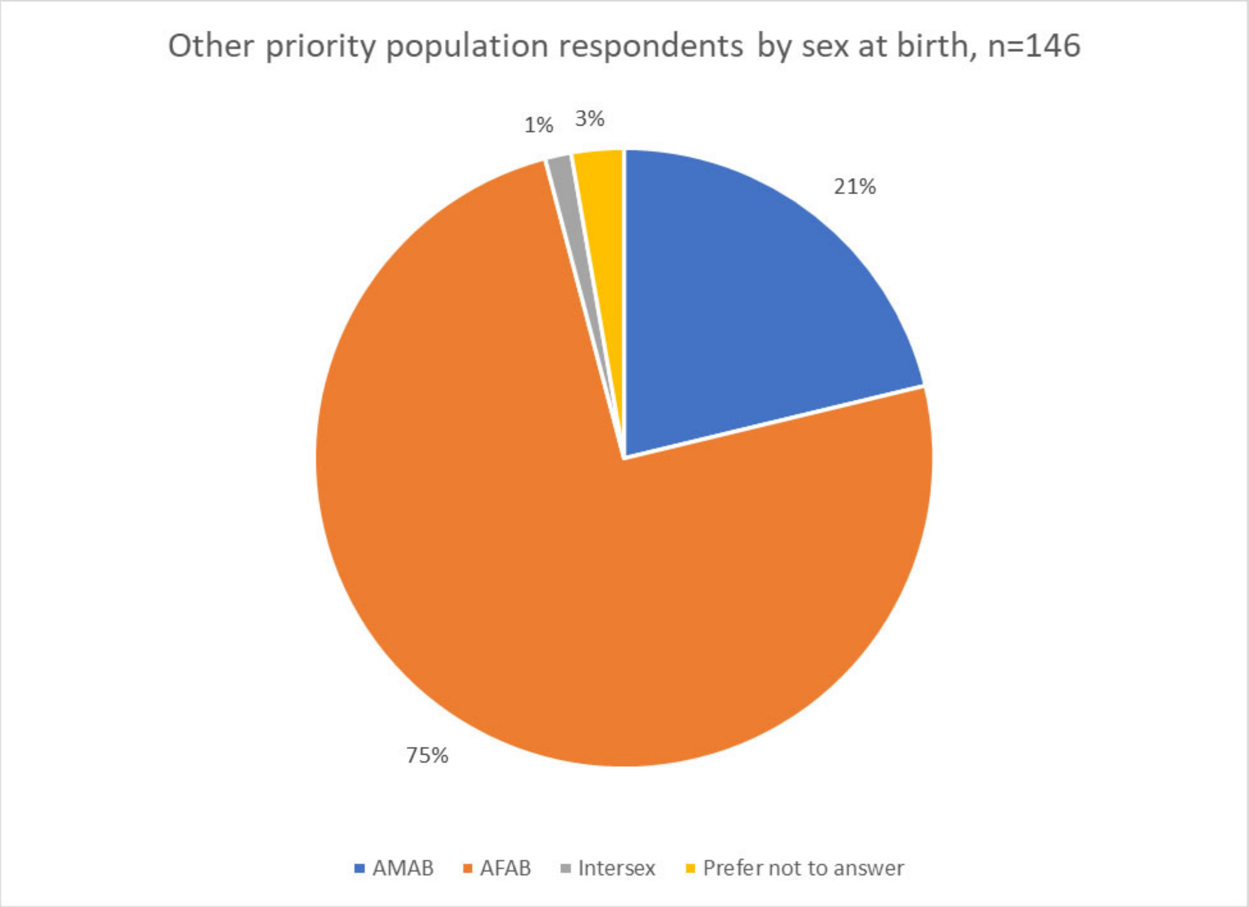
Other priority populations

There were 146 respondents (27%) who did not report behaviors that would classify them as MSM, PWID, or FVHR but would be included in a priority population identified in the most recent RFP for Community HIV Outreach and Testing Services. These include:

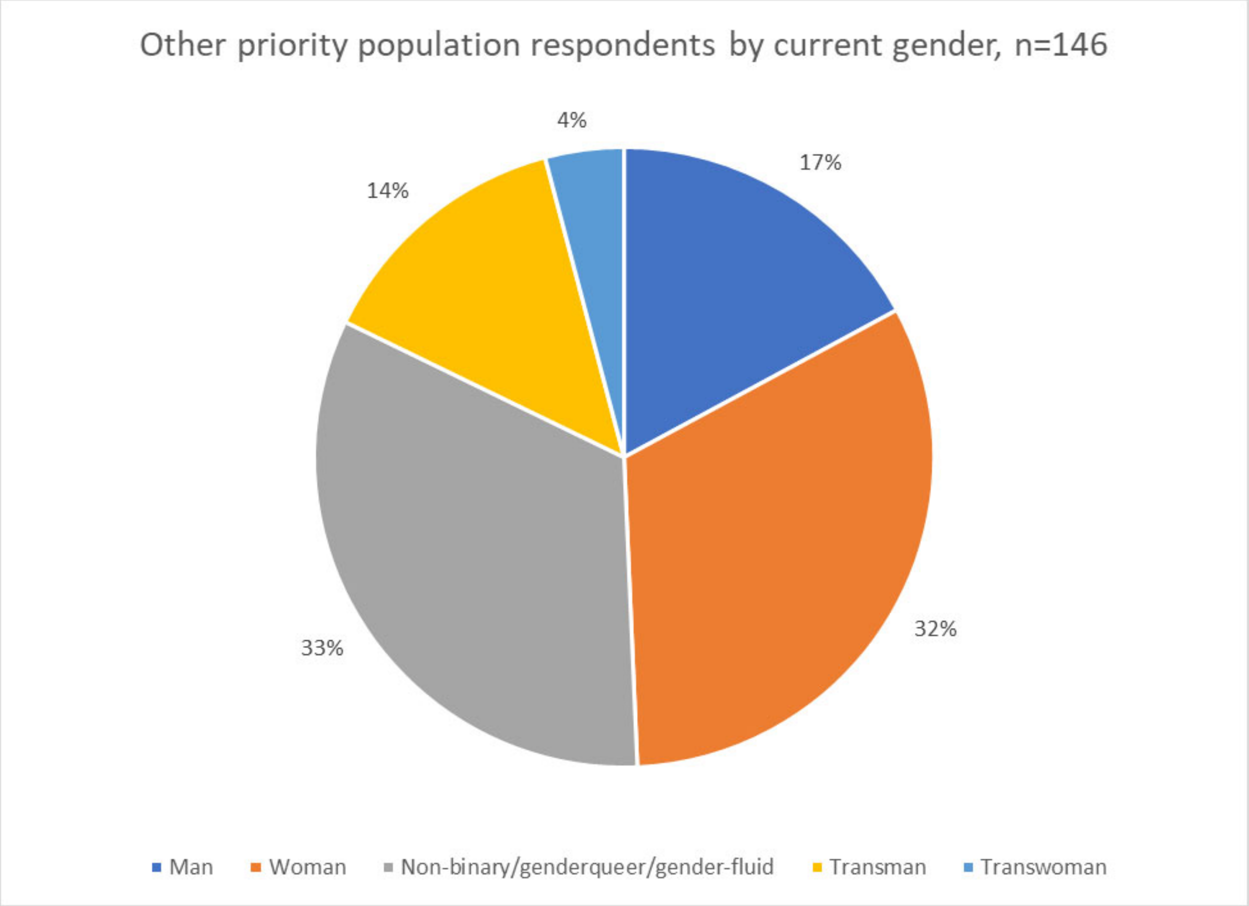
Population	**n**	**% of total respondents (n=546)**
Transgender individuals (includes non-binary/genderqueer/gender-fluid)	73	13%
Adolescents 17 years-old or younger	9	2%
Individuals who have been incarcerated	17	3%
Individuals who have had a prior STD or viral hepatitis diagnosis	4	1%
Racial and ethnic minorities	43	8%
Total	**146**	**27%**



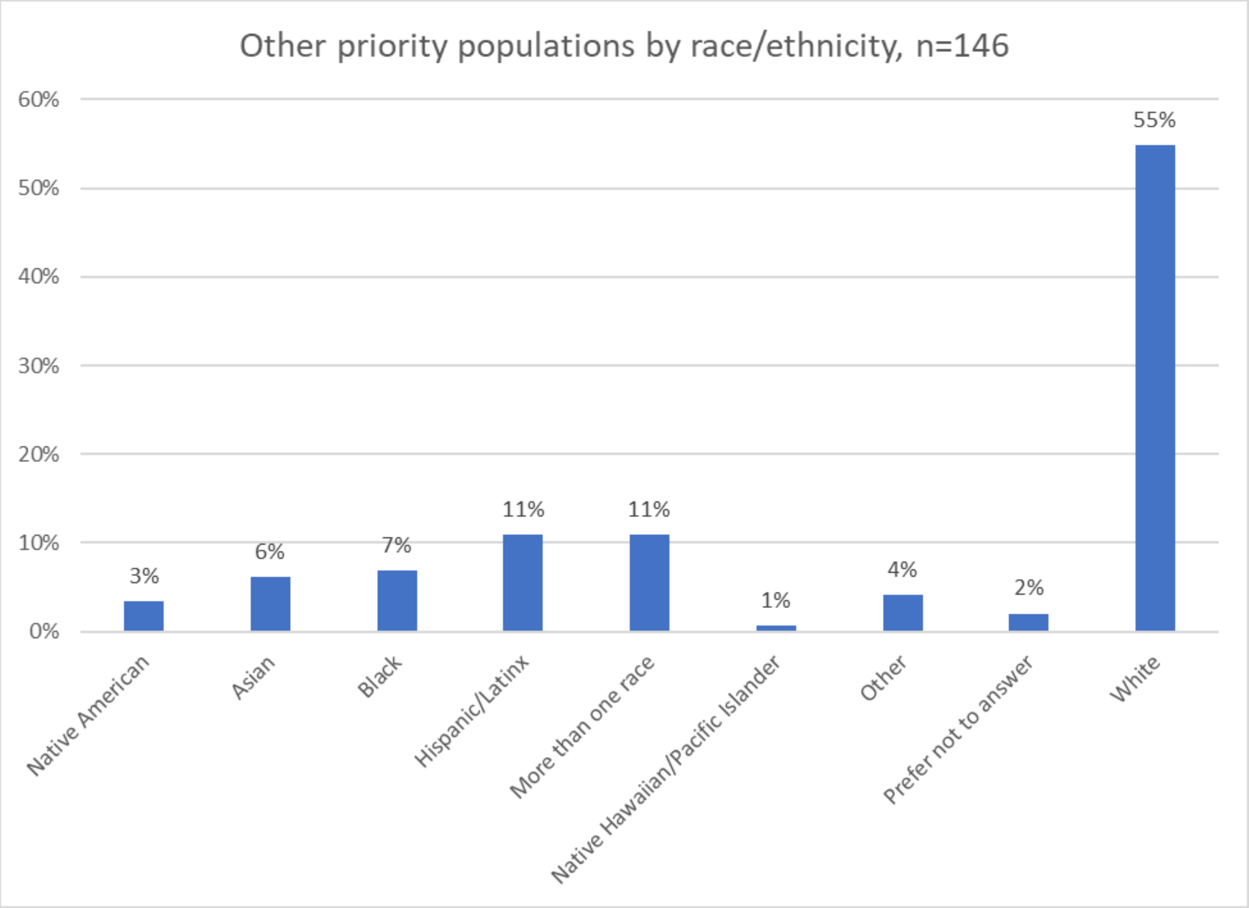
Three-quarters of these respondents were assigned female at birth.



One-third currently identify as non-binary/genderqueer/gender-fluid and about one-third identify as women.

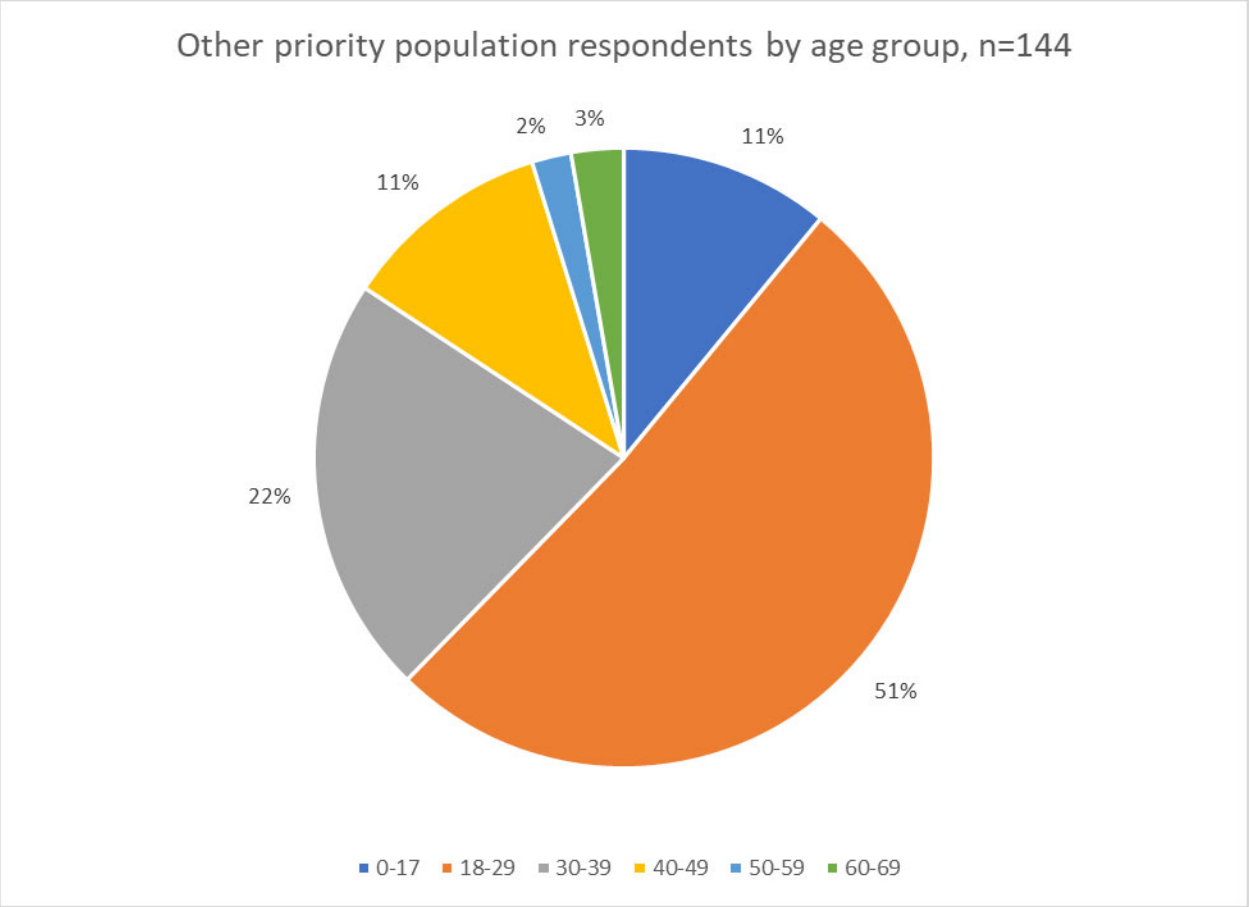


About 45% of respondents in other priority populations reported a race/ethnicity other than white/not-Hispanic.

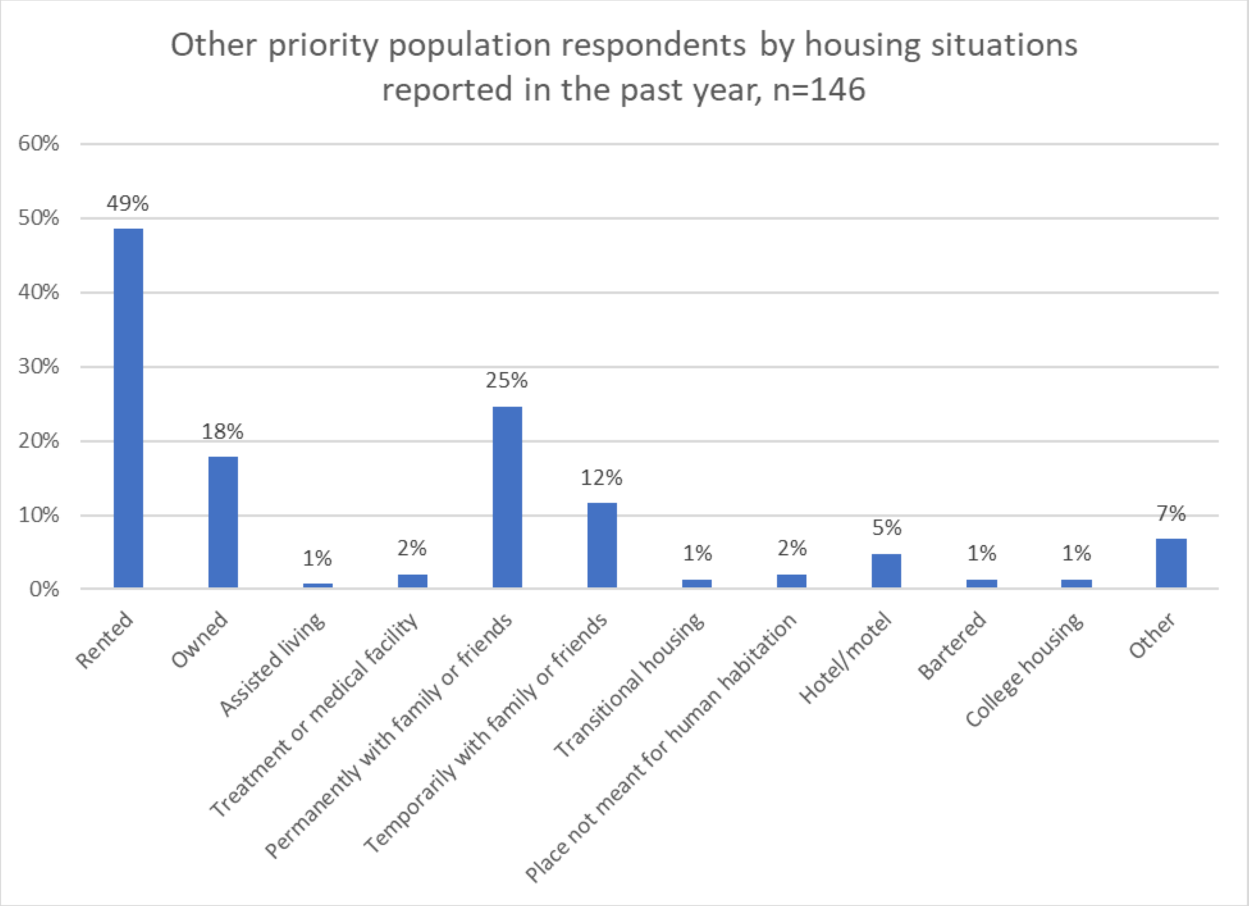


Most respondents in other priority populations (62%) were age 29 and younger.

More than half of respondents age 17 and younger (56%) identified as transgender/non-binary/genderqueer/gender-fluid.



A total of 2% of other priority population respondents (3 individuals) reported staying in a place not meant for human habitation at some point in the past year; 6% (9 individuals) reported three or more living situations in the past year; 2% reported staying in a treatment or medical facility in the past year.



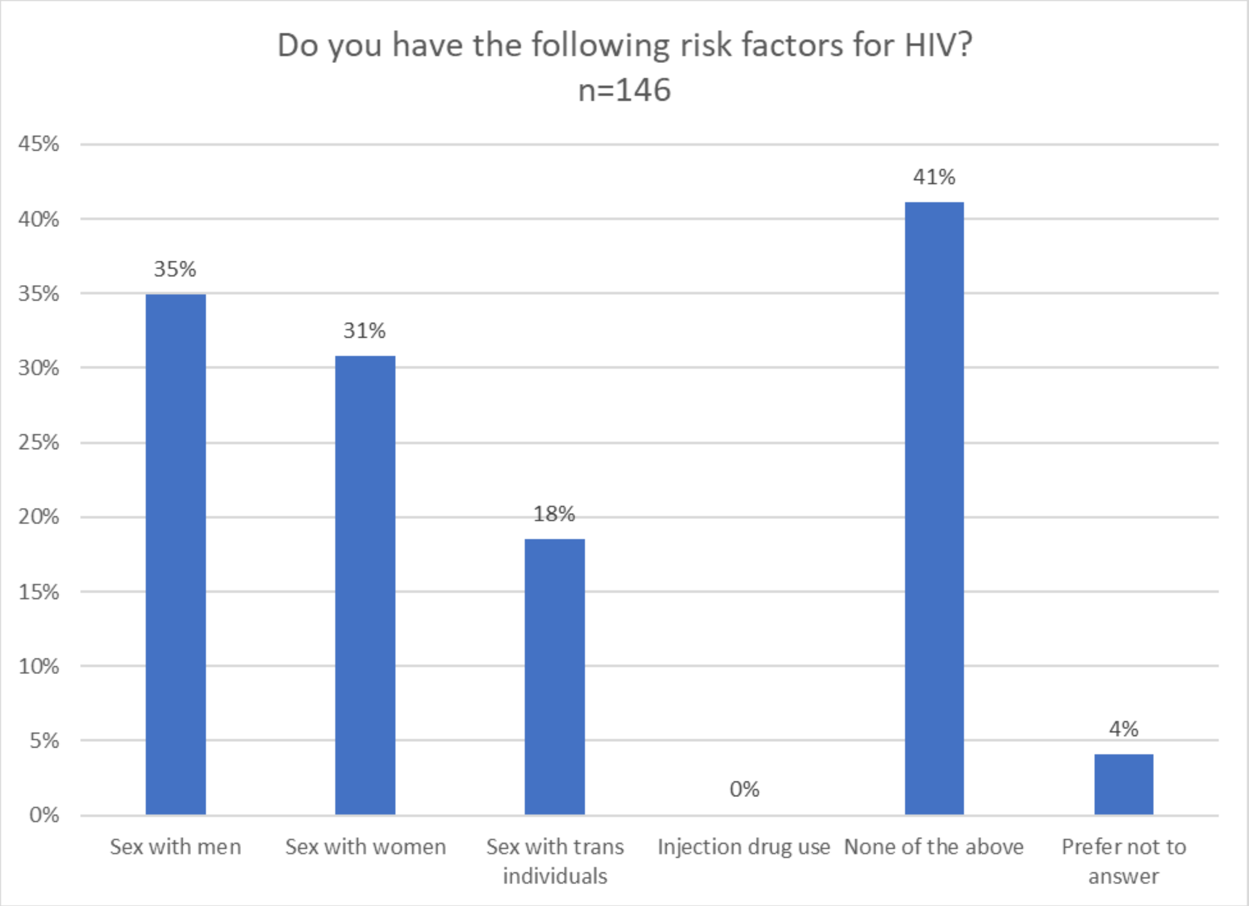
Twenty respondents (14%) reported being incarcerated; one-quarter of these reported being released in the past 12 months.

Other infections

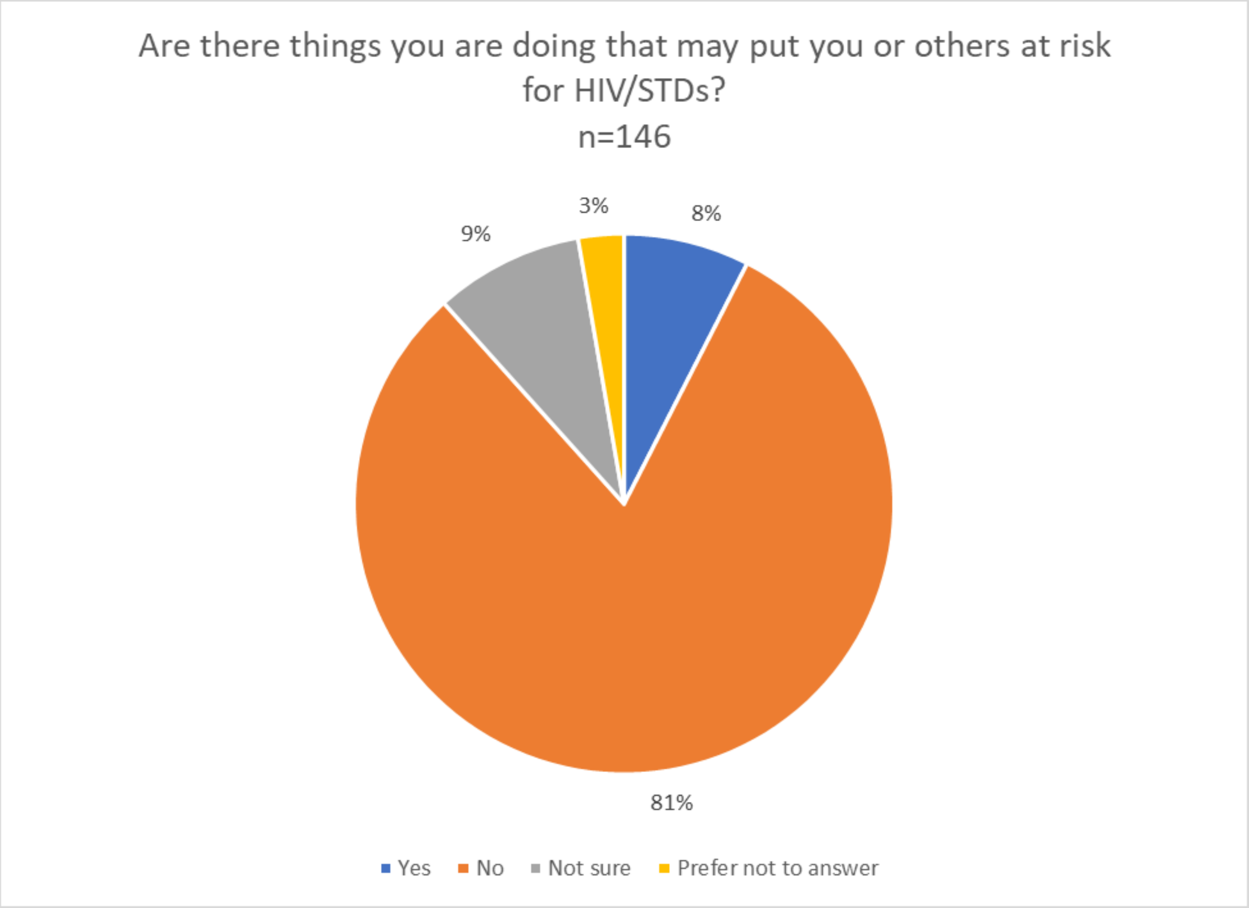
Four respondents were diagnosed with a reported STD or viral hepatitis in the past two years, one each with chlamydia, syphilis, Hepatitis A, and Hepatitis B.

Risk perception and HIV testing

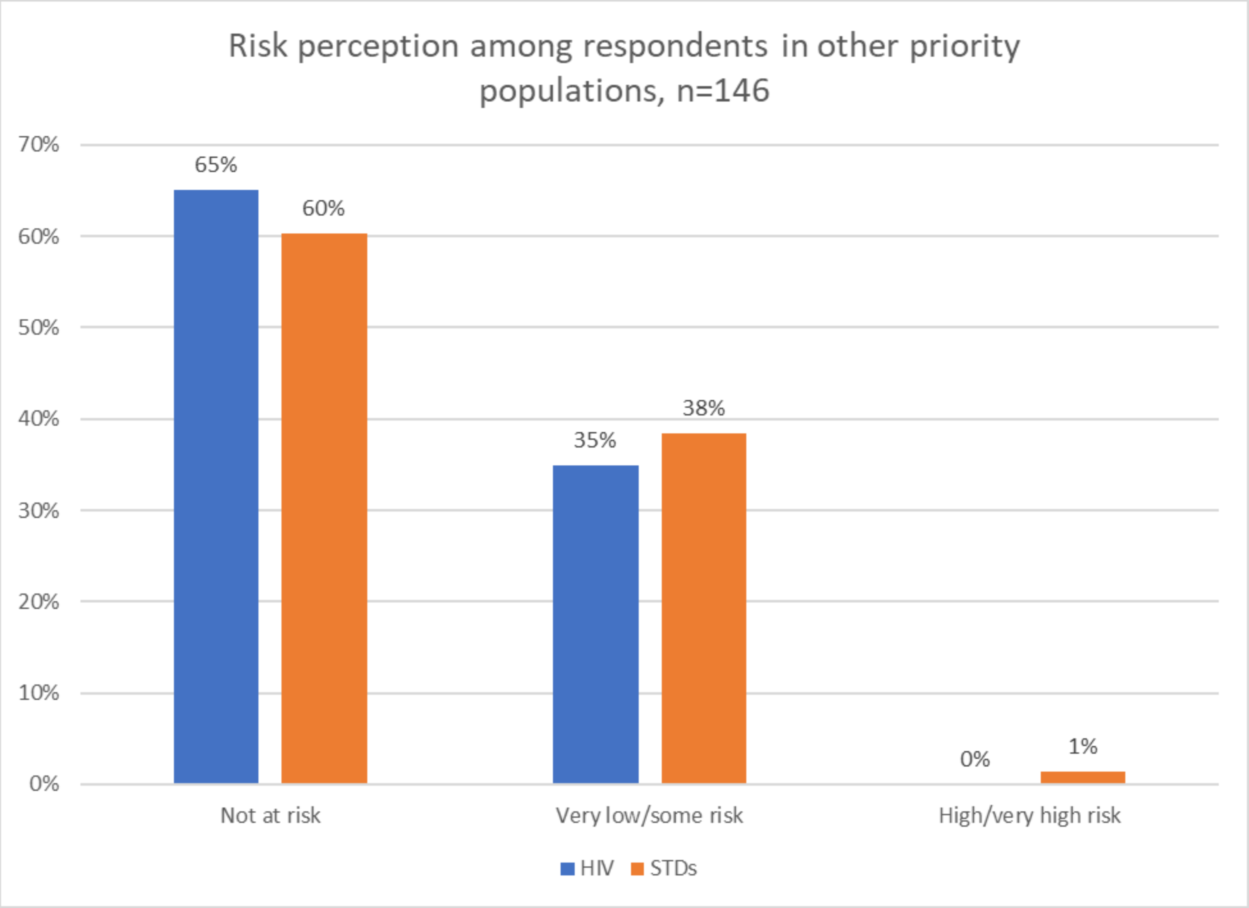
When asked to identify their risk factors for HIV, the most common response from respondents in other priority populations (41%) was “none of the above.”



Most respondents (81%) indicated that they are not doing things to put themselves or others at risk for HIV/STDs.

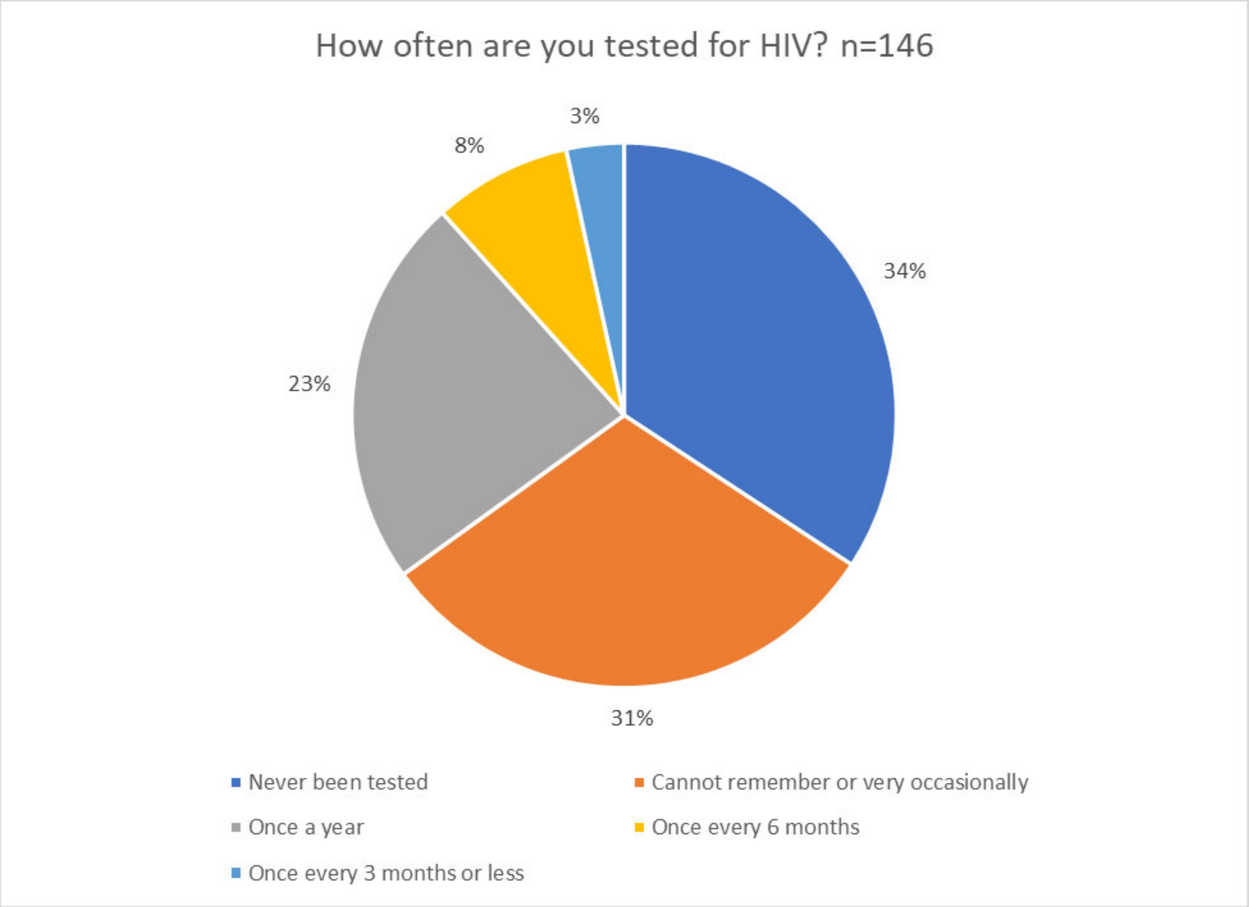


No respondents in other priority populations indicated that they were at high or very high risk for HIV infection, but two respondents (1%) indicated high risk for STDs. Of those two respondents, one indicated that they were not doing things that put themselves or others at risk for HIV/STDs and one did not answer.

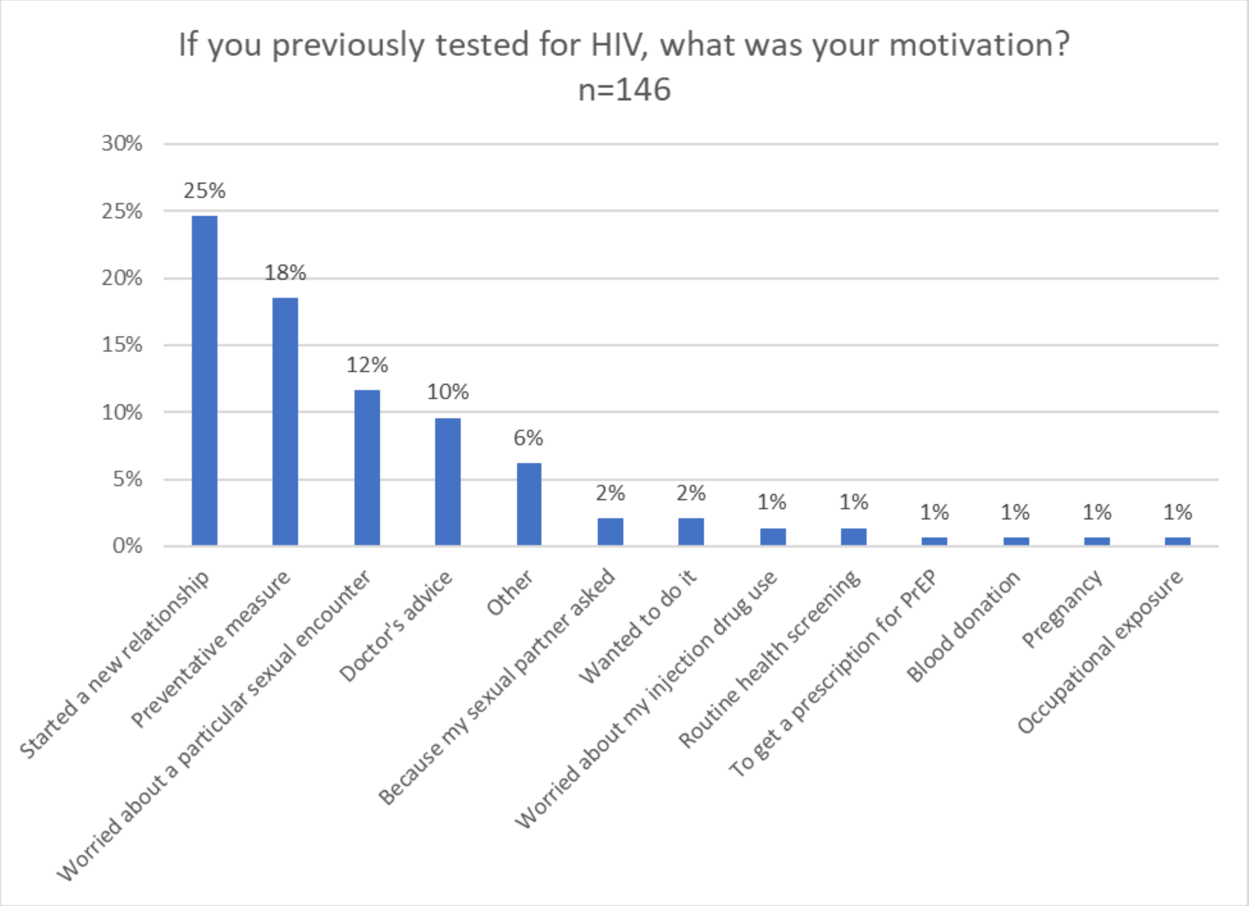


The survey included a narrative question, “Why do you believe you are not at risk for HIV?” Responses were aggregated by theme. The most common responses among respondents in other priority populations were that they were in a monogamous or committed relationship (29%) or that they were currently abstinent or asexual (21%). Eleven respondents (8%) reported knowing their partners’ status as the reason they were not at risk, and another 8% reported using “protection.”

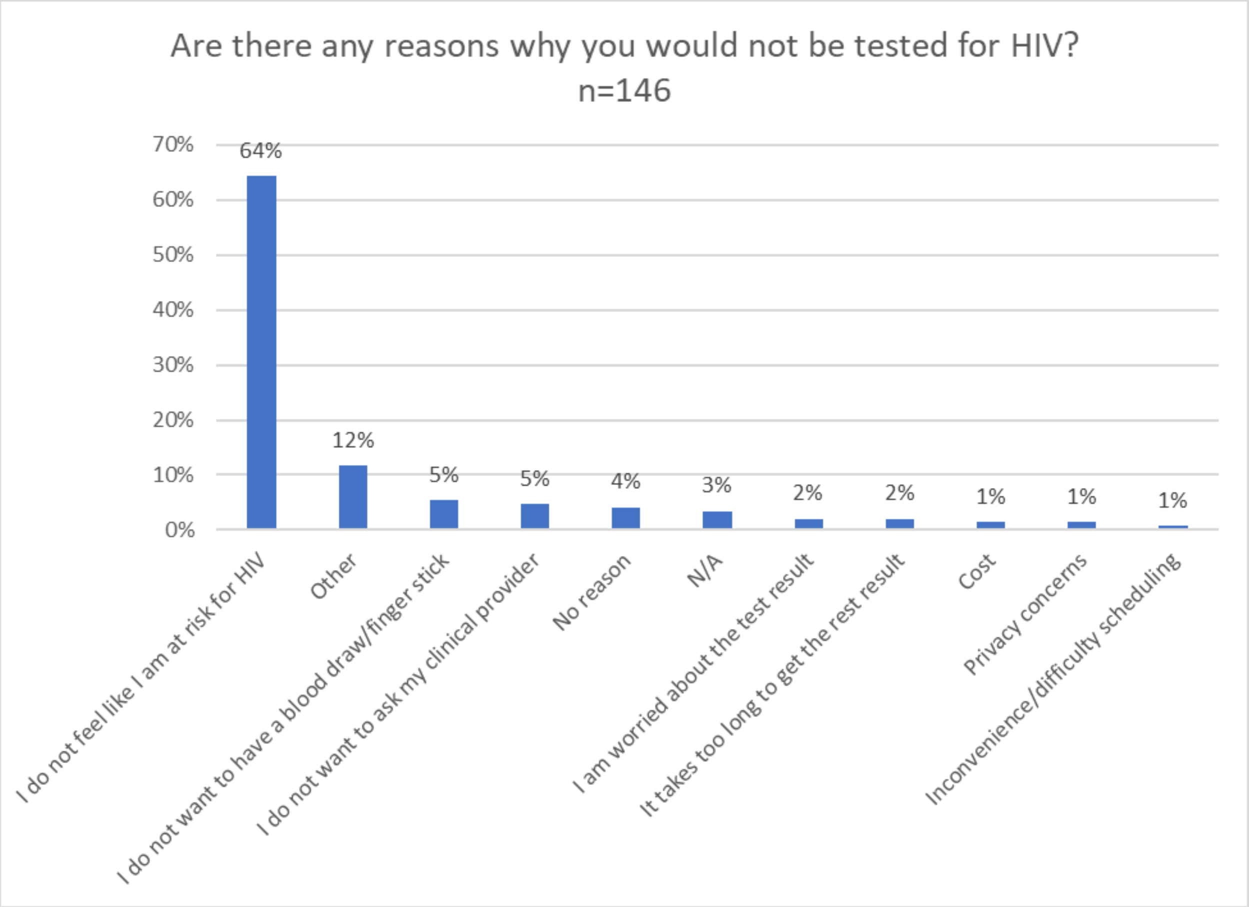
Two-thirds of respondents had never been tested for HIV, could not remember being tested, or tested very occasionally, while one-third tests at least once per year.



Respondents could select multiple options for the reason they have been previously tested for HIV. The most common response (25%) was that they had started a new relationship. Two respondents (1%) indicated that they were worried about their injection drug use, however these respondents did not indicated injection drug use anywhere else in the survey.



Respondents could select multiple options for any reasons they would not be tested for HIV. The most common response (64%) among respondents in other priority populations was "I do not feel like I am at risk for HIV."



Most respondents (54%) reported awareness of free HIV testing programs through Frannie Peabody Center, Portland Public Health, Maine Family Planning, or Health Equity Alliance, and 75% reported willingness to be tested for HIV at one of these sites.

Of the respondents who provided reasons why they would not be willing to test at one of the identified sites, nine reported not having transportation and eight reported needing more information about the test sites.

Ten respondents (7%) reported using an HIV home test; 84% would be willing to use one in the future.

Provider comfort

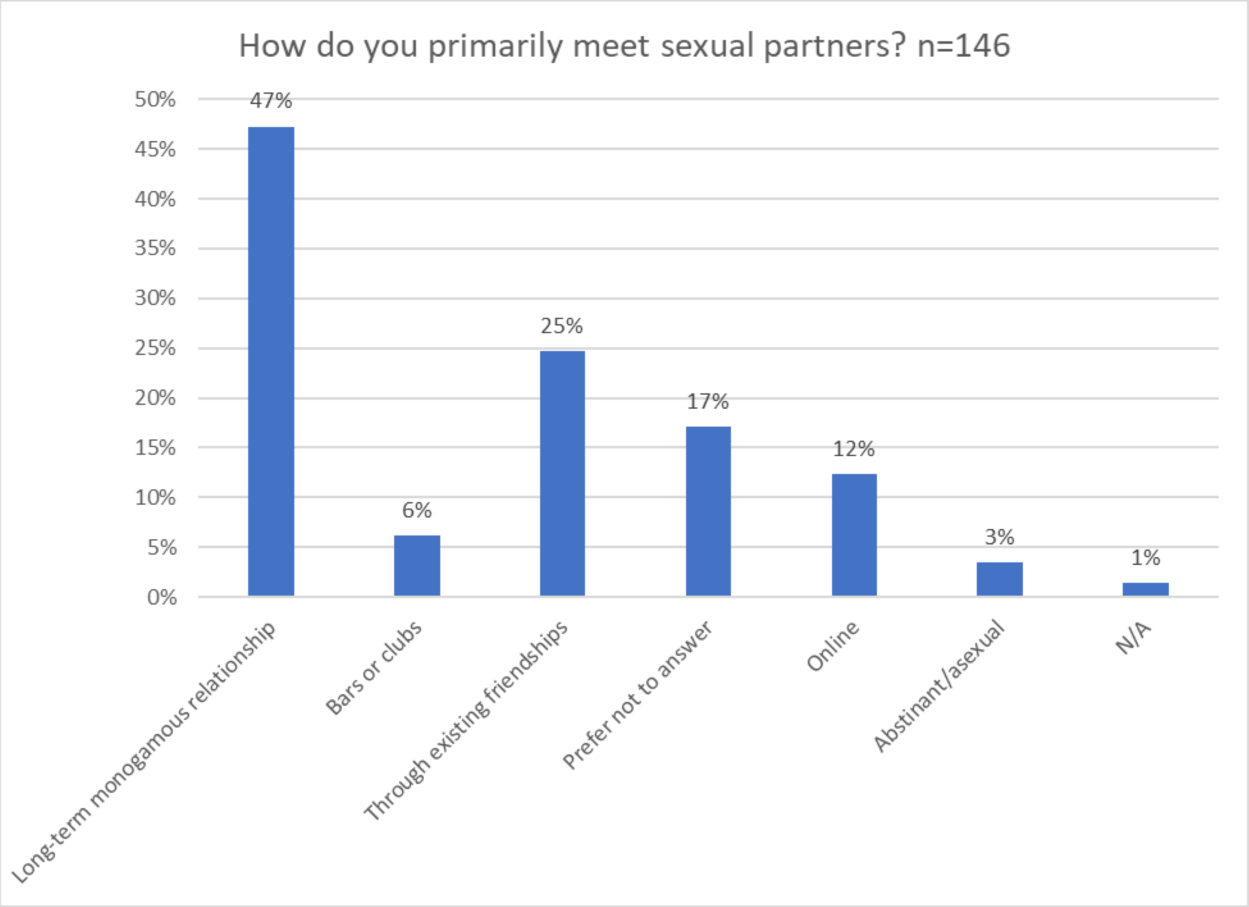
Most respondents in other priority populations (80%) indicated that they are comfortable speaking with their medical provider about their sexual history.

Less than one-quarter of respondents (21%) indicated that their medical provider had ever recommended HIV testing.

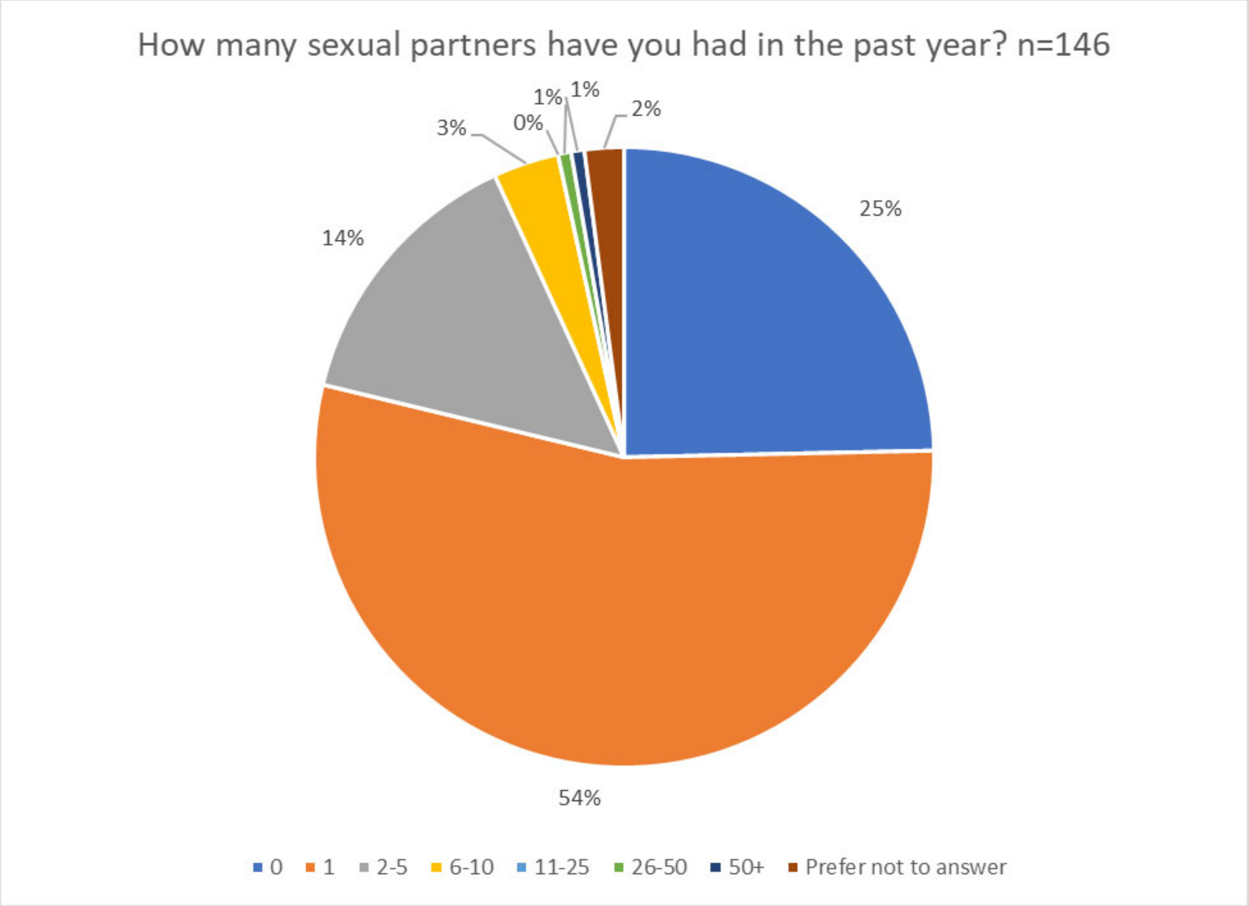
Nine respondents (6%) reported needing an interpreter at least sometimes to speak with their medical provider, but 23 respondents (16%) indicated that they had ever had difficulty communicating with their medical provider.

Sexual history

Respondents could select multiple choices to identify how they meet sexual partners. The most common response (47%) was that they were in a long-term monogamous relationship.



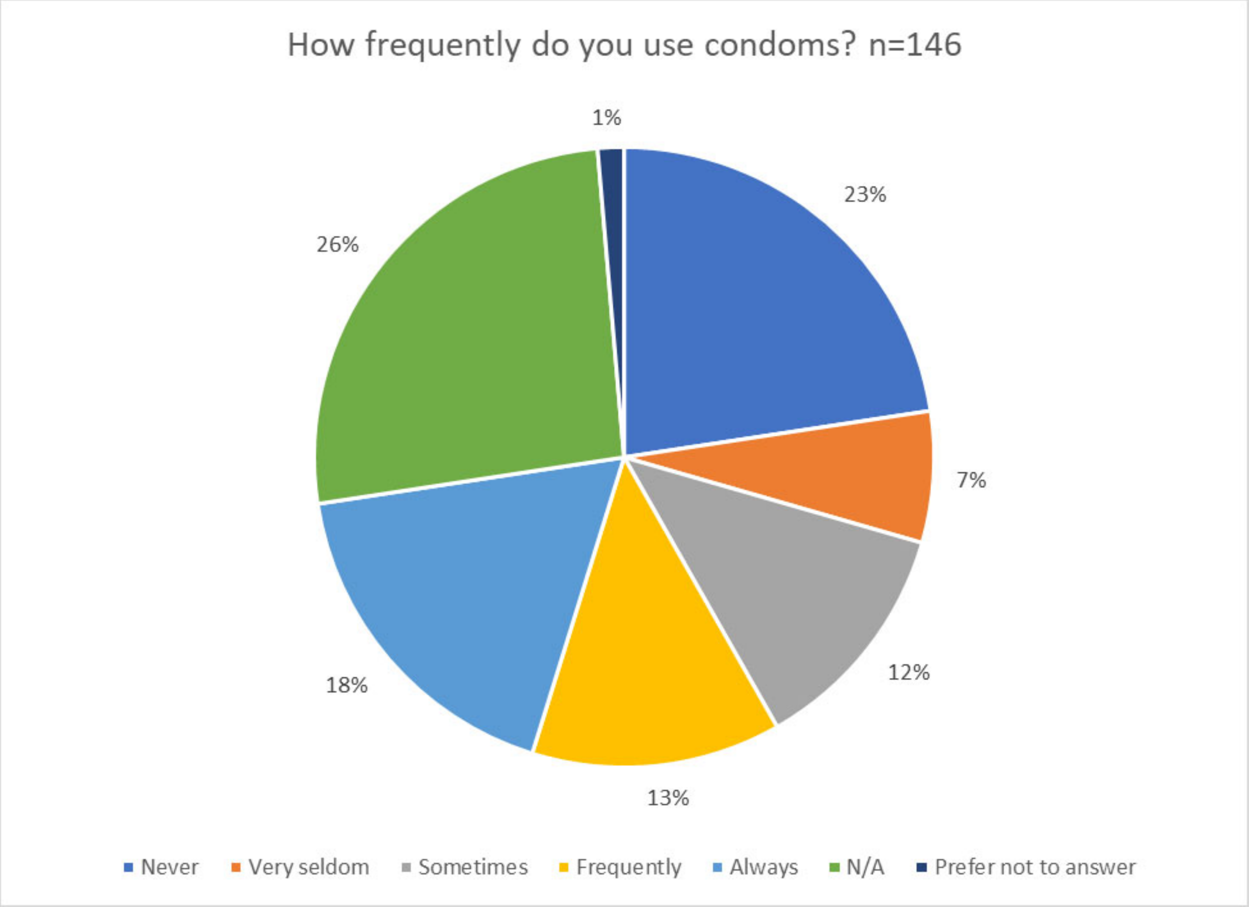
Six respondents (4%) identified the sites/apps they use to meet partners online. The most common response among these was Tinder (67%), followed by Grinder (50%), Scruff (33%). One respondent indicated that they use social media (Tumblr and Facebook).



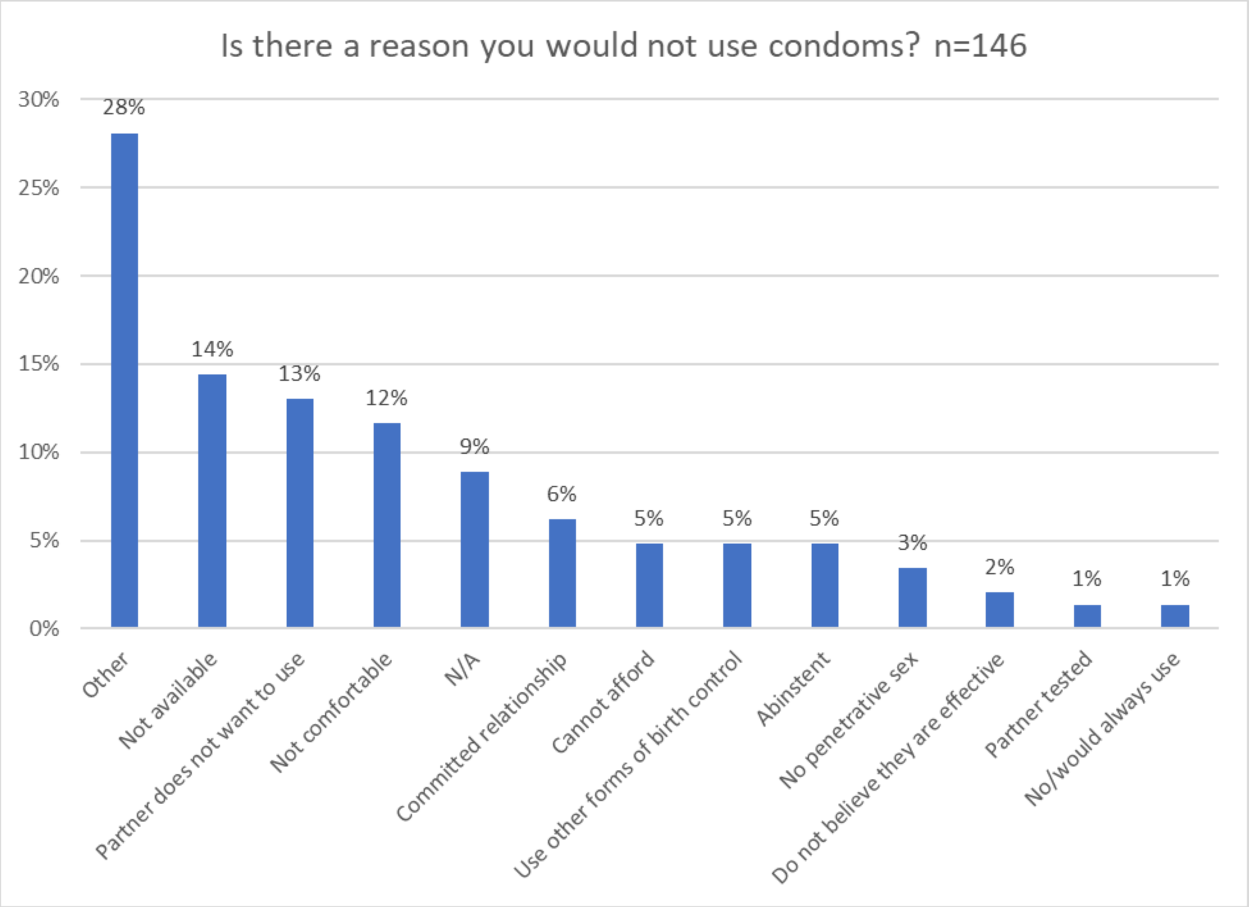
Seven respondents (5%) indicated that they had ever exchanged sex for money, substances, or goods.

Condom use

About 42% of respondents reported that they use condoms sometimes, very seldom, or never, compared to 31% who frequently or always use condoms.



Respondents could select multiple choices to indicate why they would not use condoms. The most common specified response (14%) was that they were not available.



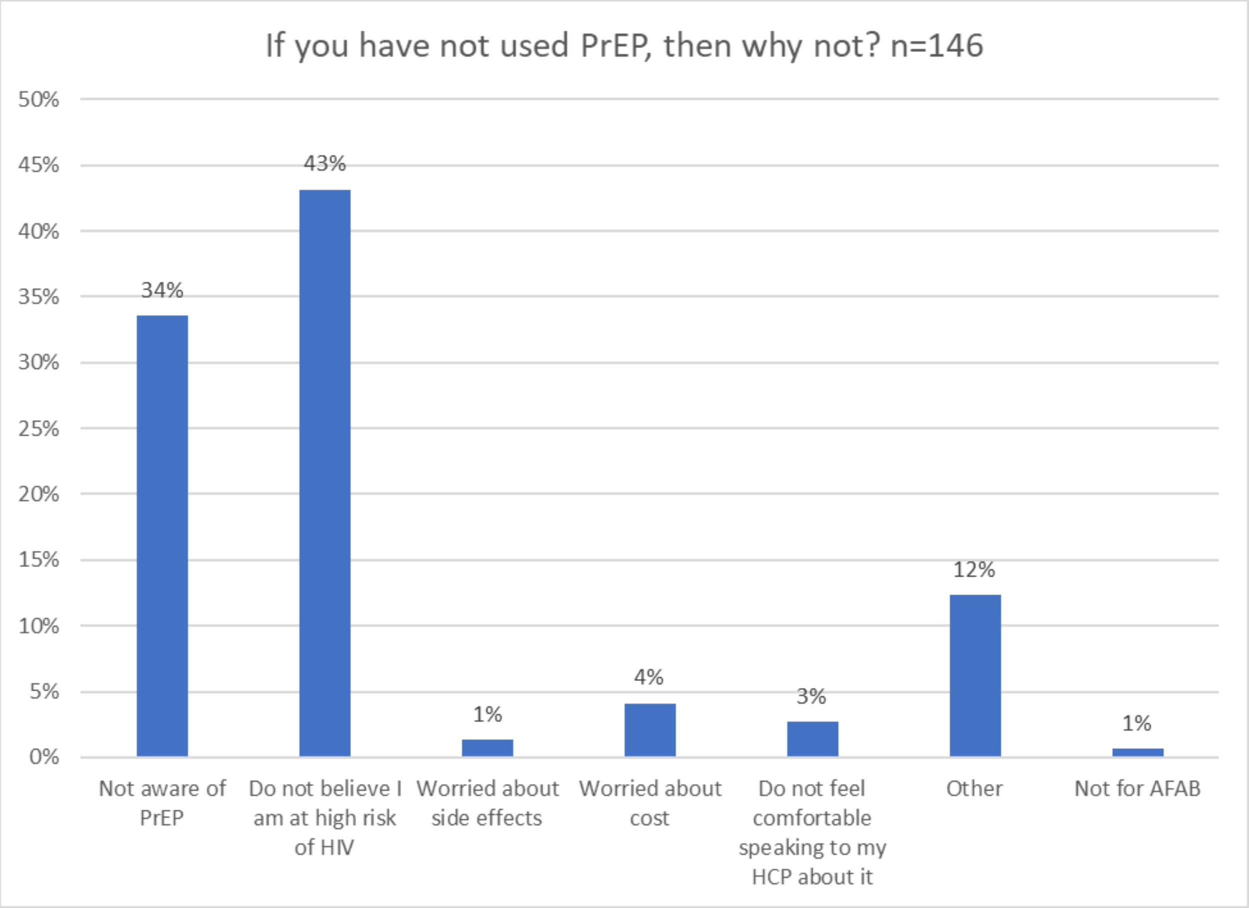
PrEP and PEP

A total of 65 respondents from other priority populations (45%) have heard of Pre-Exposure Prophylaxis (PrEP), but only 51 respondents (35%) have heard of Post-Exposure Prophylaxis (PEP).

Of those who have heard of PrEP, three individuals report currently taking PrEP and one reported taking PrEP in the past but not at the time of the survey.

Of those who have heard of PrEP, one individual who has never taken PrEP reported being refused PrEP by a health care provider.

Respondents could select multiple choices to indicate why they have not used PrEP. The most common response (43%) was, “I do not believe I am at high risk of HIV.”



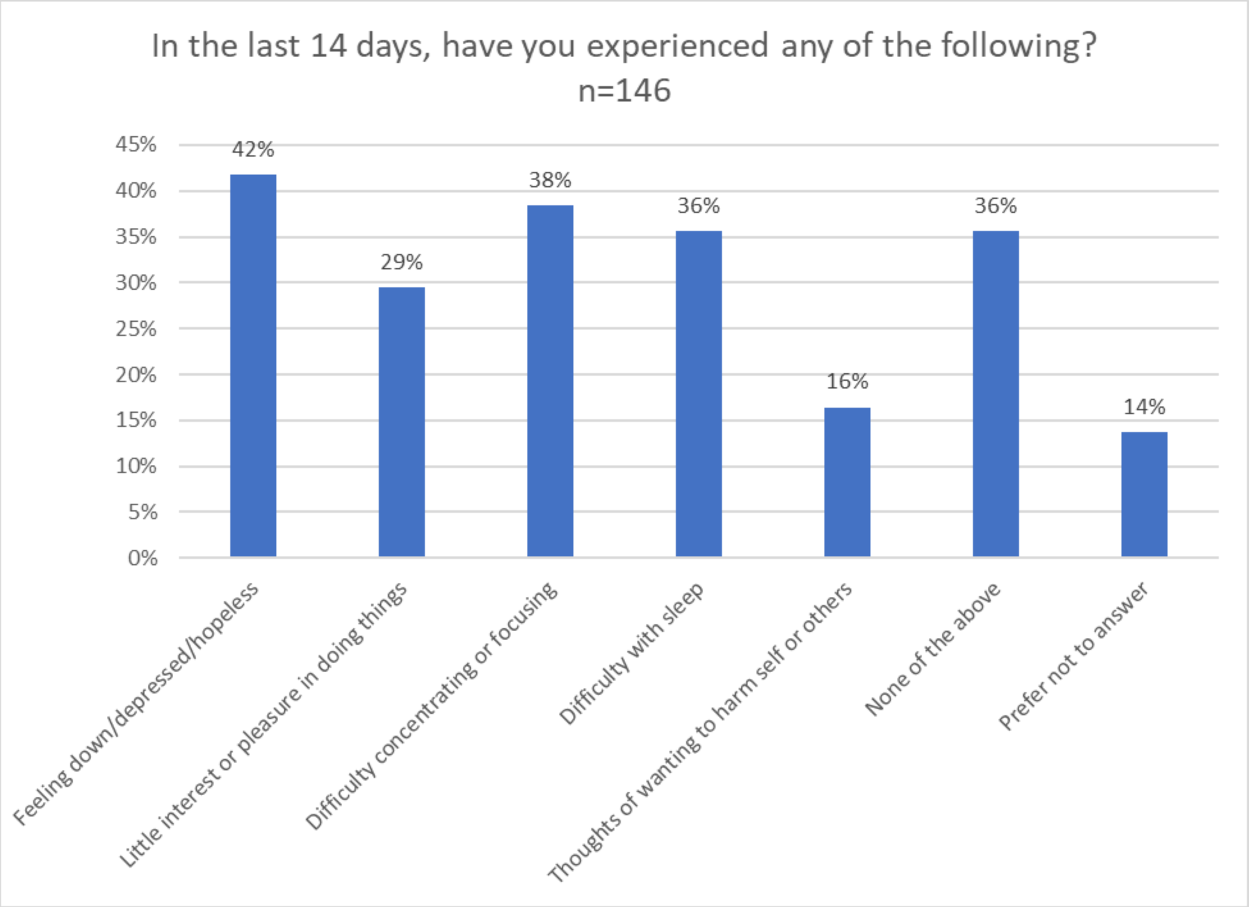
A total of 48% of respondents from other priority populations would be willing to take PrEP if it was available through a pharmacy without consulting a medical provider.

One respondent reported ever taking PEP and completed the full 28-day course.

Support services

Most respondents from other priority populations (71%) indicated that it takes an hour or less to travel one-way to most services they want (e.g. case management, support groups, etc.); 2% indicated that it takes one to two hours to get to such services.

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. About one-third (36%) of respondents indicated that they had not experienced any of symptoms on the list, but 42% reported feeling down/depressed/hopeless, 38% reported difficulty concentrating or focusing, and 36% reported difficulty with sleep. A total of 24 respondents (16%) reported thoughts of harming themselves or others.

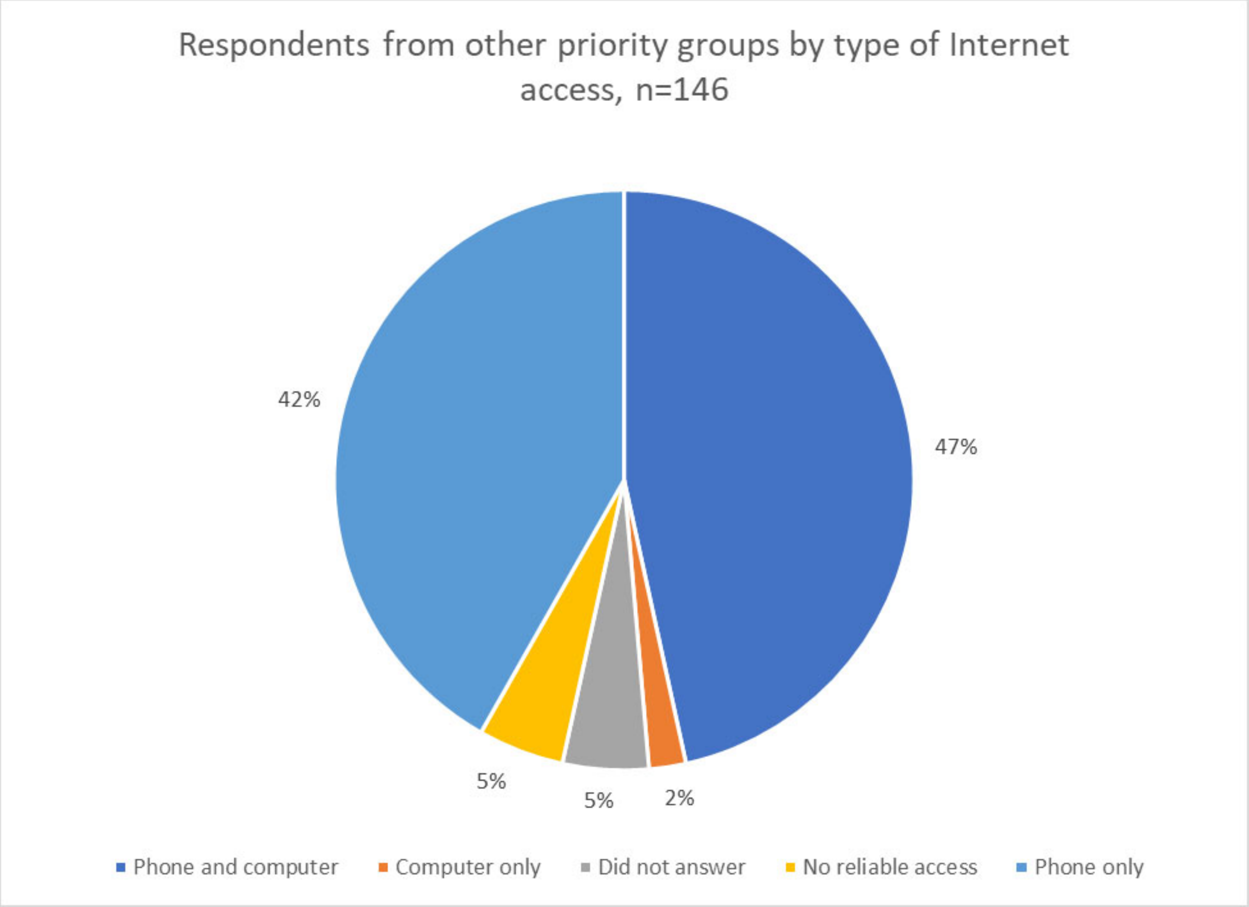


Respondents could select multiple choices to indicate if they needed more opportunities for social support. The most common response (62%) was "I don't need any opportunities," followed by peer supports (8%), weekly meetings (5%), community dinners (5%), and social retreats (5%).

There was a narrative question about barriers that get in the way of accessing support services. There were only six responses. Three reported mental health issues (anxiety, panic, PTSD), and two reported transportation issues.

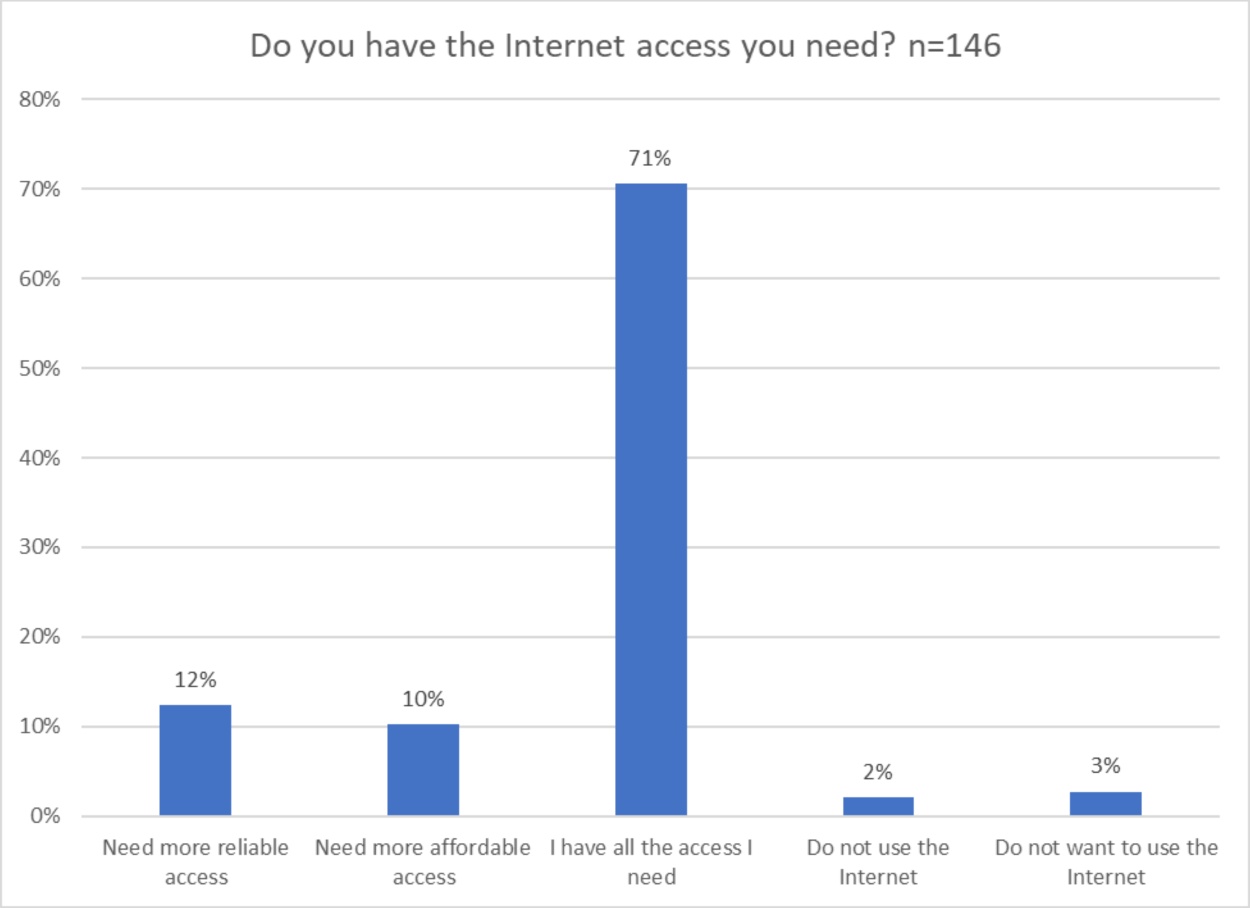
Internet access

Most respondents from other priority populations (88%) can access the Internet by phone, and 90% have some form of reliable Internet access (phone, computer, or both).



Most respondents (71%) indicated that they have all the Internet access they need. Two respondents (1%) indicated that they needed more reliable and affordable Internet, 16 (11%) reported needing more reliable access only, and 13 (9%) reported needing more affordable access only.

Four respondents selected “I do not want to use the Internet.”



Respondents not in priority populations

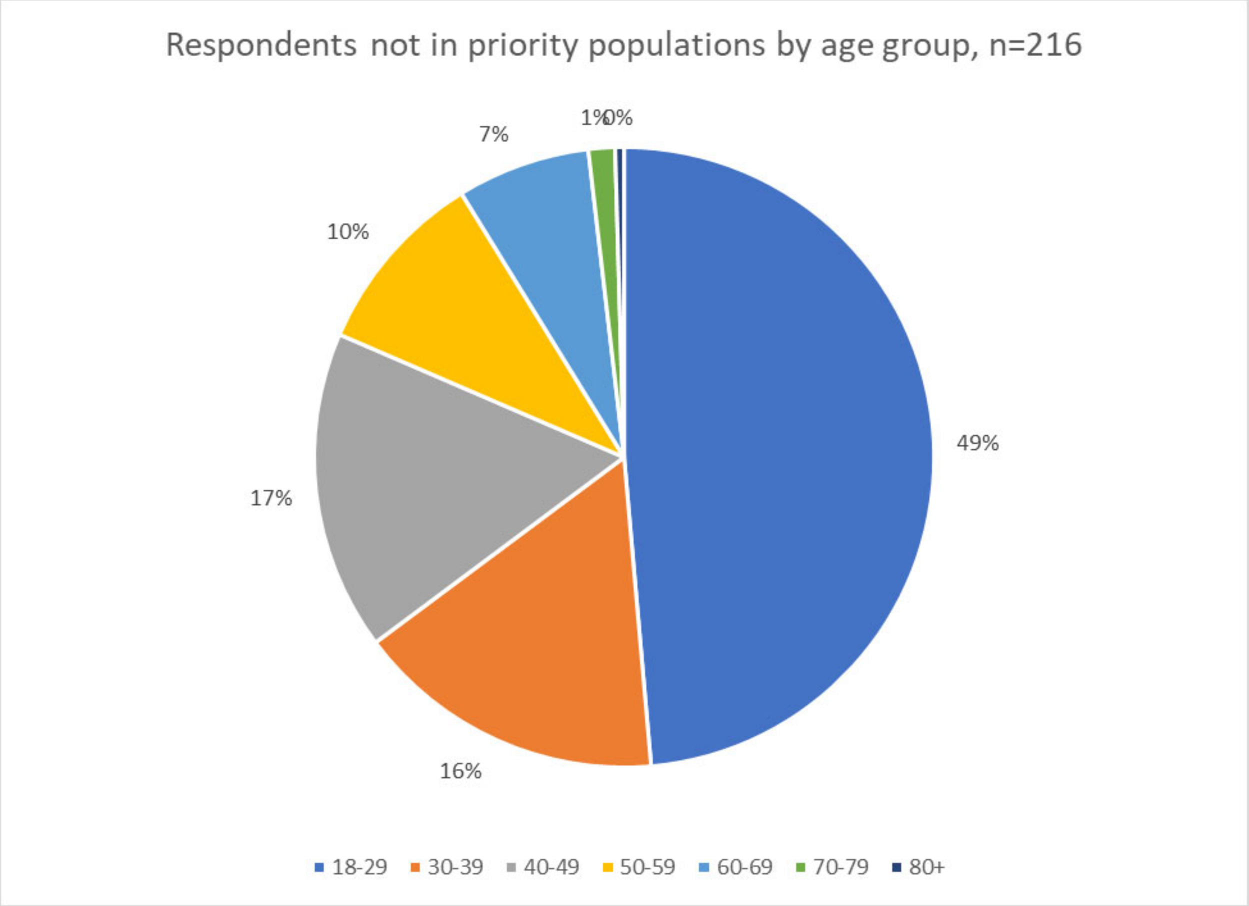
Note: It is possible that some of these respondents do fit into a priority group, but they did not report a demographic or risk that would identify them as such.

Asylum seekers, asylees, or refugees are considered a priority population. The survey did not ask any questions about immigration status, but seven respondents (3%) did identify a birth country other than the United States: three from Canada and one each from Germany, Lebanon, Norway, and the United Kingdom.

A total of 216 respondents (40%) did not report demographics or behaviors that would classify them to be included in any of the priority populations listed throughout this report.

About three-quarters (73%) of respondents identify as women, while 27% identify as men.

Almost half (49%) were between the ages of 18 and 29.



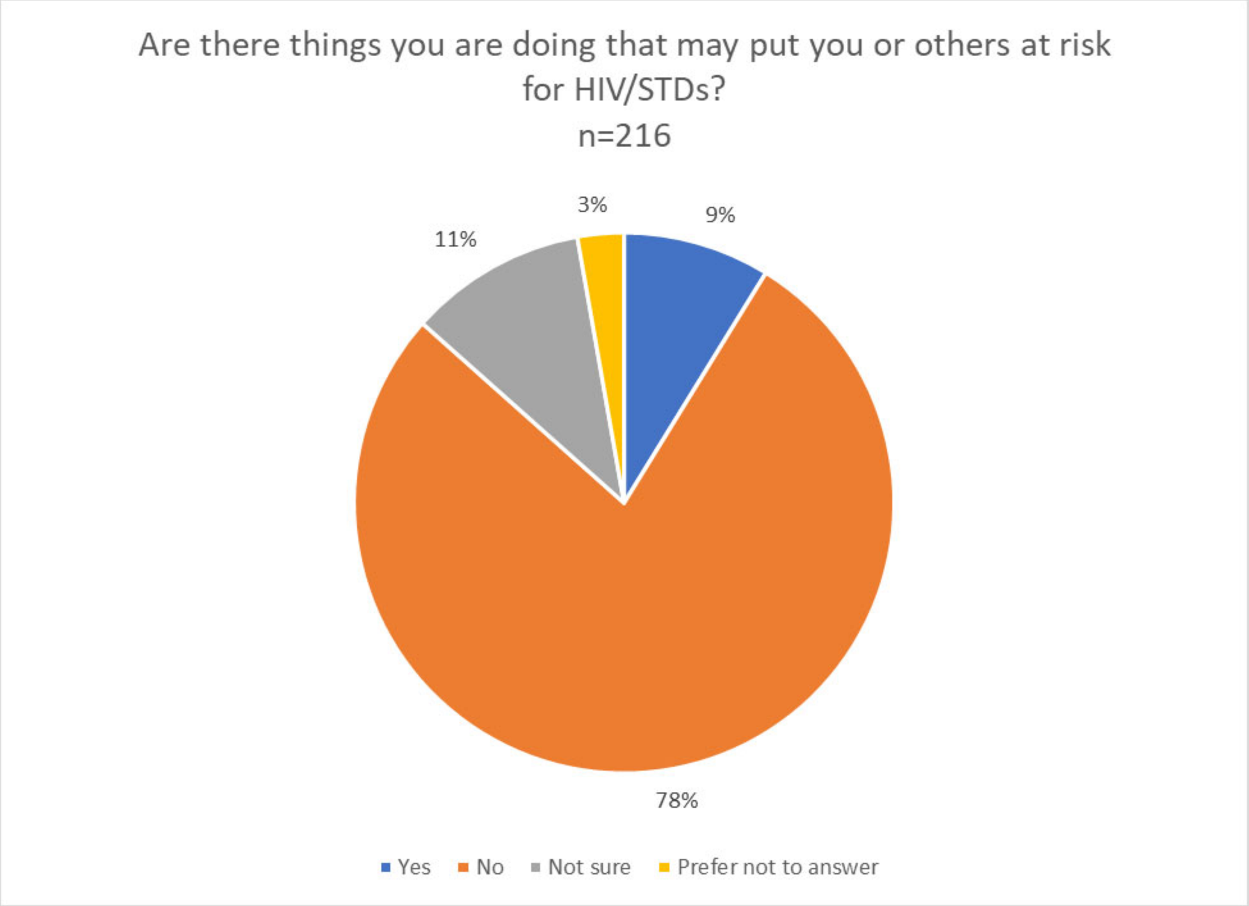
A total of 2% of respondents (4 individuals) reported staying in a place not meant for human habitation at some point in the past year; 2% (5 individuals) reported three or more living situations in the past year; 1% (2 individuals) reported staying in a treatment or medical facility in the past year.

A total of 26 respondents (12%) reported that they had not been tested for three reportable sexually transmitted infections or viral hepatitis in the past two years.

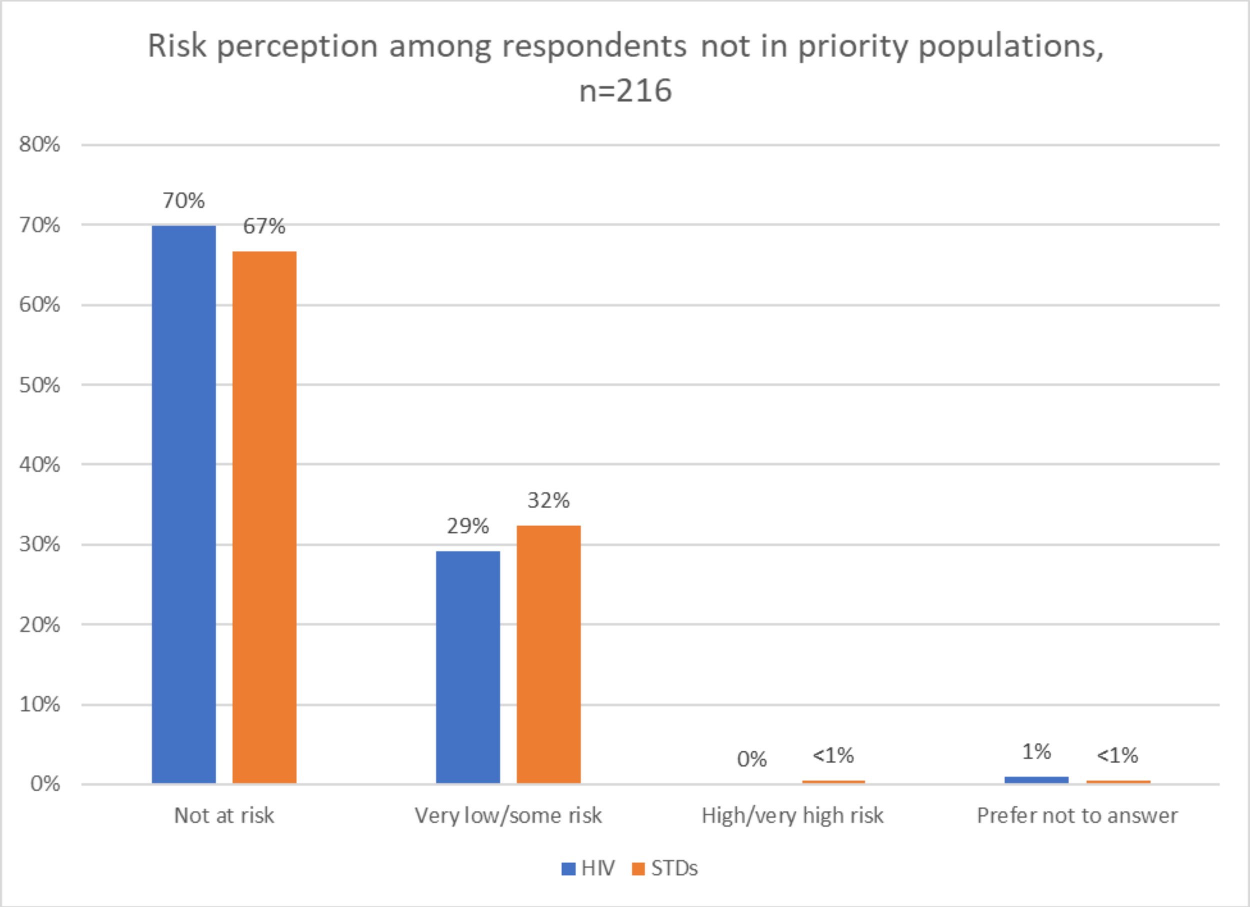
Risk perception and HIV testing

When asked to identify their risk factors for HIV, the most common response from respondents who are not members of priority populations (39%) was "none of the above."

Most respondents (77%) indicated that they are not doing things to put themselves or others at risk for HIV/STDs.

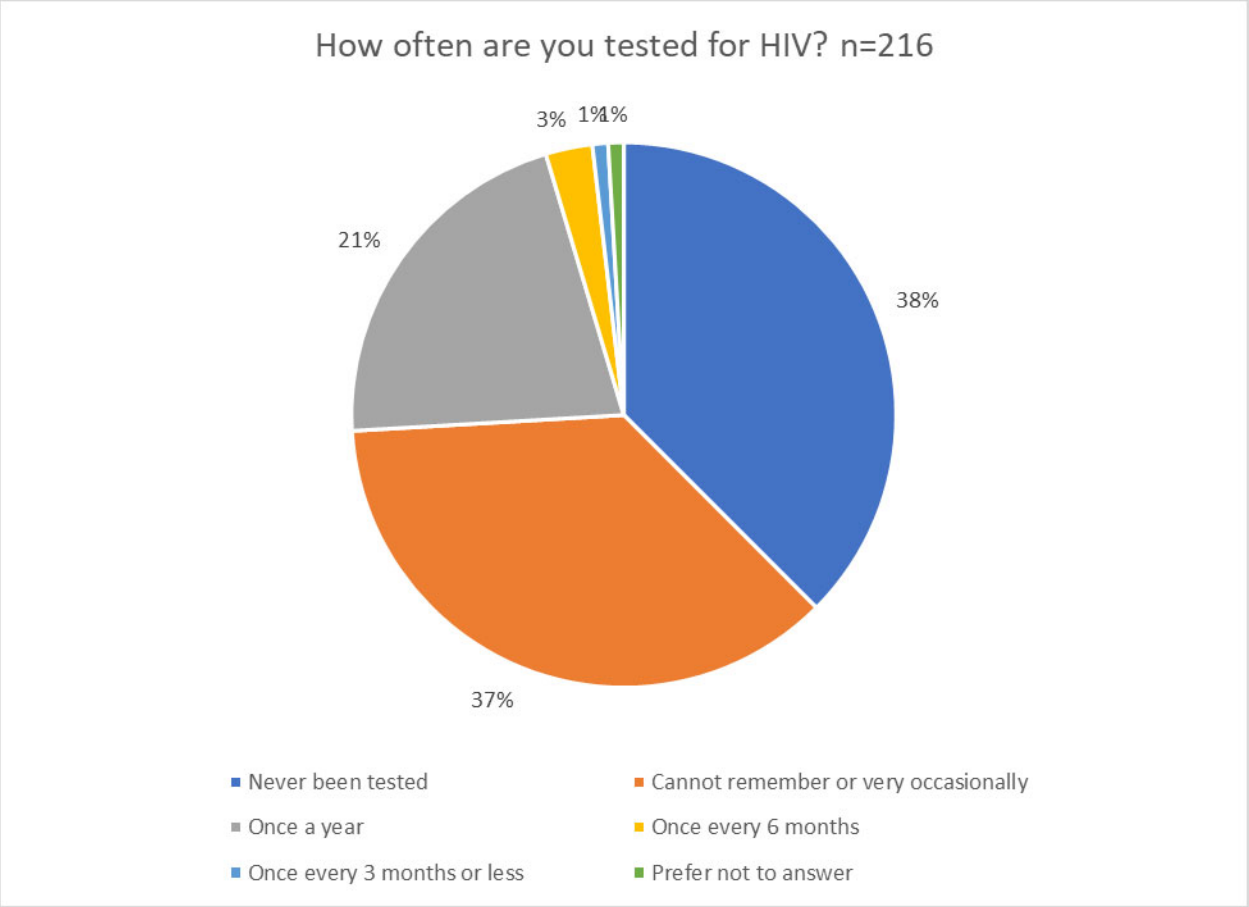


No respondents indicated that they were at high or very high risk for HIV infection, but one respondent (<1%) indicated high risk for STDs. That respondent indicated that they were not sure if they were doing things that put themselves or others at risk for HIV/STDs.



The survey included a narrative question, “Why do you believe you are not at risk for HIV?” Responses were aggregated by theme. One-third of respondents not in priority populations indicated that they were in monogamous/committed relationships. The next most common response was that the respondent was asexual or currently abstinent (13%).

Almost three-quarters of respondents (74%) reported never being tested for HIV, not remembering being tested for HIV, or very occasionally being tested for HIV. One-quarter test at least once per year.



Respondents could select multiple options for the reason they have been previously tested for HIV. The most common response (25%) was that they had started a new relationship. Two respondents (1%) indicated that they were worried about their injection drug use, however these respondents did not indicated injection drug use anywhere else in the survey.

Respondents could select multiple options for any reasons they would not be tested for HIV. The most common response (70%) among respondents not in priority populations was “I do not feel like I am at risk for HIV.”

About half of respondents (49%) reported awareness of free HIV testing programs through Frannie Peabody Center, Portland Public Health, Maine Family Planning, or Health Equity Alliance, and 70% reported willingness to be tested for HIV at one of these sites.

Of the respondents who provided reasons why they would not be willing to test at one of the identified sites, 17 (8%) reported needing more information about test sites.

Two respondents (1%) reported using an HIV home test; 70% would be willing to use one in the future.

Provider comfort

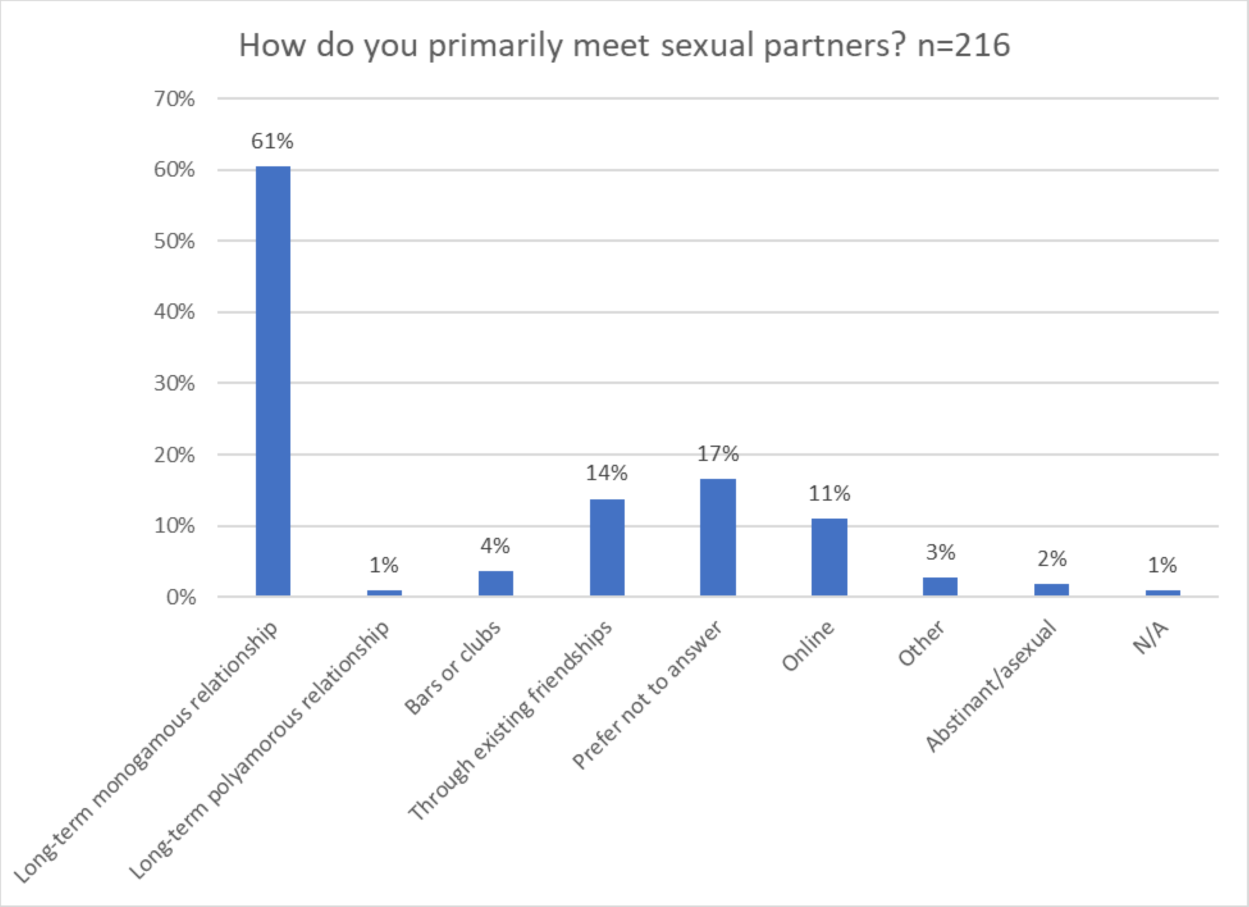
Most respondents not in priority populations (86%) indicated that they are comfortable speaking with their medical provider about their sexual history.

A total of 36 respondents (17%) indicated that their medical provider had ever recommended HIV testing.

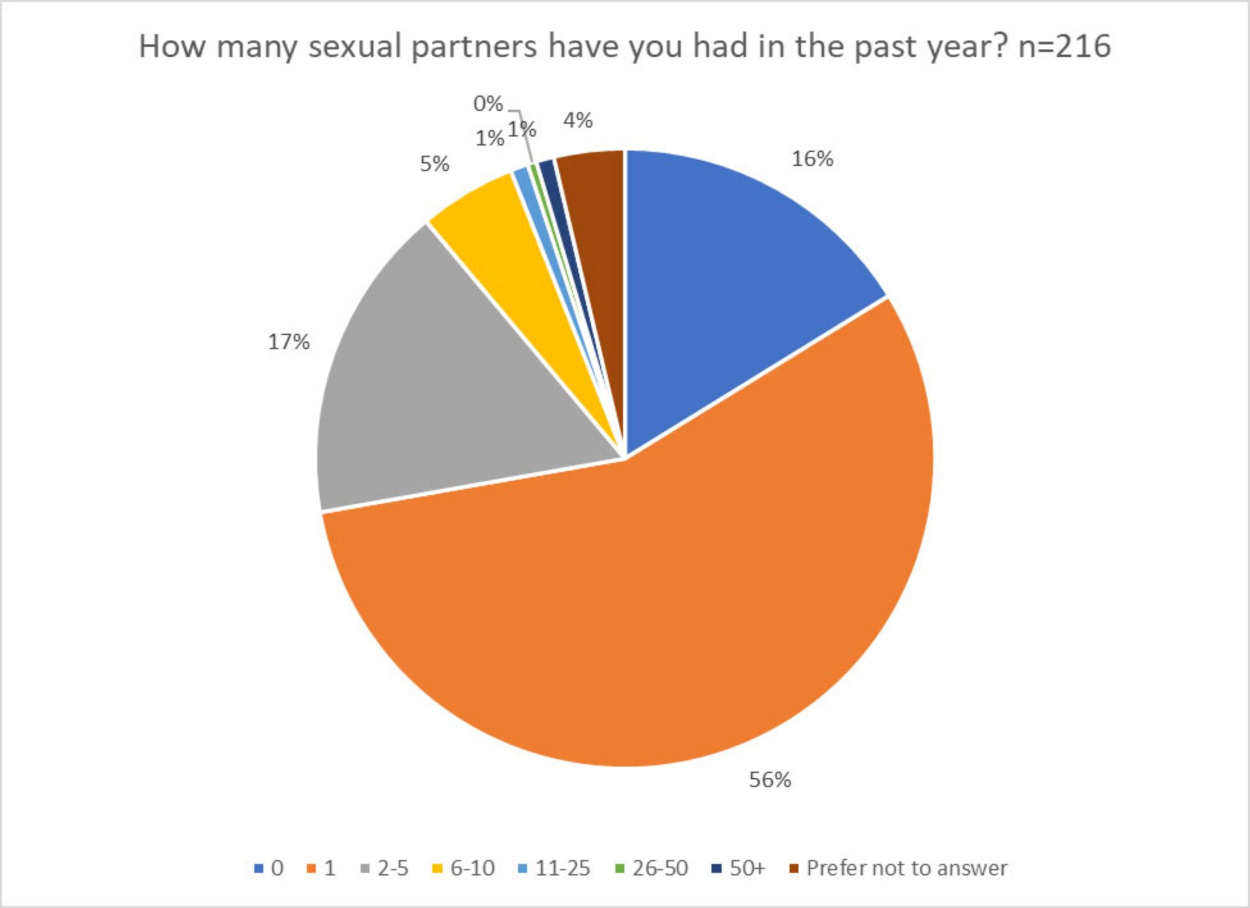
Five respondents (2%) reported needing an interpreter at least sometimes to speak with their medical provider, but 19 respondents (9%) indicated that they had ever had difficulty communicating with their medical provider.

Sexual history

Respondents could select multiple choices to identify how they meet sexual partners. The most common response (61%) was that they were in a long-term monogamous relationship.

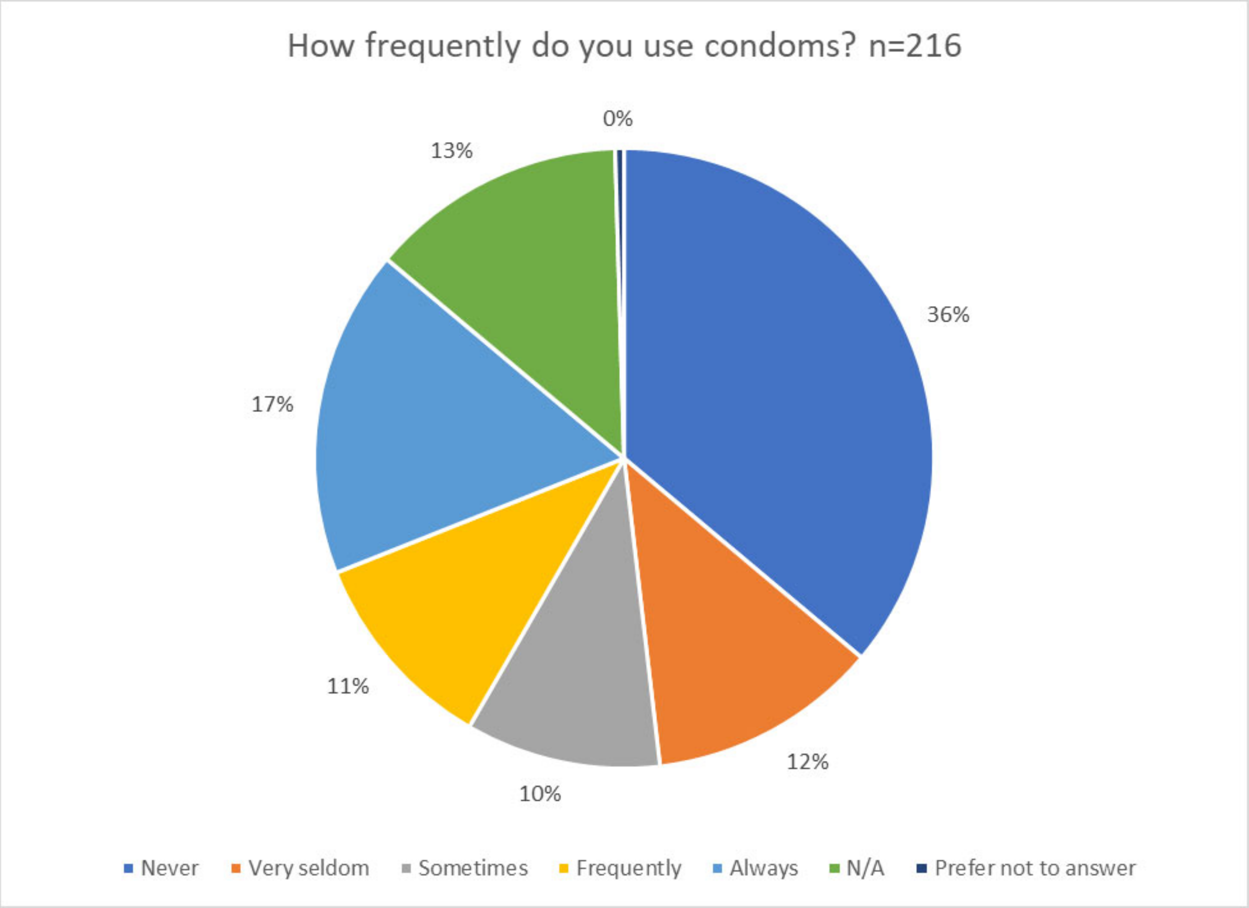


Eleven respondents (5%) identified the sites/apps they use to meet partners online. The most common response among these was Tinder (82%), followed by Hinge (45%), Bumble (27%), and OK Cupid (18%).

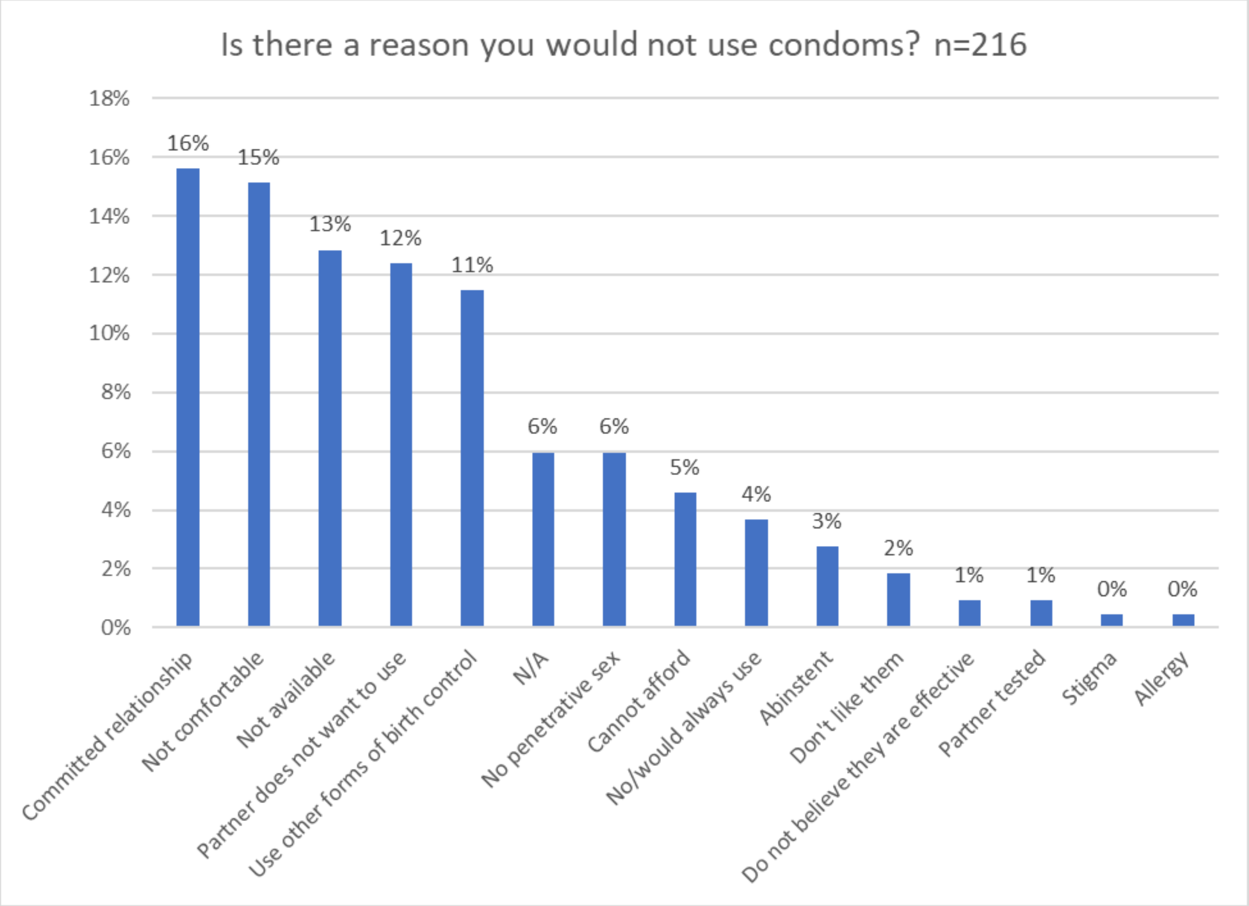


Condom use

A total of 58% of respondents reported that they use condoms sometimes, very seldom, or never, compared to 28% who frequently or always use condoms.



Respondents could select multiple choices to indicate why they would not use condoms. The most common specified response (17%) was that they were in a committed relationship.



PrEP and PEP

A total of 78 respondents who are not in priority populations (36%) have heard of Pre-Exposure Prophylaxis (PrEP), and 54 respondents (25%) have heard of Post-Exposure Prophylaxis (PEP).

Of those who have heard of PrEP, one individual reported currently taking PrEP. This respondent also indicated that they had been refused PrEP by a health care provider in the past.

Respondents could select multiple choices to indicate why they have not used PrEP. The most common response (50%) was, “I do not believe I am at high risk of HIV.” Three respondents (1%) indicated that they did not believe PrEP was for people assigned female at birth.

A total of 39% of respondents who are not in priority populations would be willing to take PrEP if it was available through a pharmacy without consulting a medical provider.

Two respondents reported ever taking PEP and one completed the full 28-day course.

Support services

Most respondents who are not in priority populations (76%) indicated that it takes an hour or less to travel one-way to most services they want (e.g. case management, support groups, etc.); 2% indicated that it takes more than an hour to get to such services.

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. A total of (38%) of respondents indicated that they had not experienced any of symptoms on the list, but 38% reported feeling down/depressed/hopeless, 33% reported difficulty concentrating or focusing, and 32% reported difficulty with sleep. A total of 18 respondents (8%) reported thoughts of harming themselves or others.

Respondents could select multiple choices to indicate if they needed more opportunities for social support. The most common response (77%) was "I don't need any opportunities."

Internet access

Most respondents not in priority populations (90%) can access the Internet by phone, and 94% have some form of reliable Internet access (phone, computer, or both).

Most respondents (69%) indicated that they have all the Internet access they need. One respondent indicated that they needed more reliable and affordable Internet, 21 (10%) reported needing more reliable access only, and 32 (14%) reported needing more affordable access only.

Ten respondents (5%) selected "I do not want to use the Internet."

Summary

In general, the population of respondents may not align with the population most at risk for HIV and STDs in Maine. About 60% of respondents met demographic or behavioral criteria to be included in a priority population. Of those respondents who would be considered members of a priority population, about one-quarter did not report any risk behaviors for HIV/STDs.

Data were stratified in a variety of ways to drill down into risk behaviors and needs for specifically for prioritized populations as well as those not included in prioritized populations, but gaps in representation may persist.

The most-frequently reported types of discrimination were based on gender identity and sexual practices. About 10% of respondents indicated fear of using HIV prevention services at least sometimes.

There are clear indications of risk perceptions that conflict with behaviors reported among all populations.

The prioritized population with the most STD diagnoses in the past two years was FVHR, with nearly one-third of FVHR respondents reporting a diagnosis with chlamydia. In addition, FVHR respondents report two cases of syphilis and one of gonorrhea.

Seven MSM respondents reported a chlamydia diagnosis, seven a gonorrhea diagnosis, and four a syphilis diagnosis.

Three different PWID respondents reported being diagnosed with one of the three-reportable STDs in the last two years, one each with chlamydia, gonorrhea, and syphilis.

No MSM reported being diagnosed with viral hepatitis in the past two years. Hepatitis C was the most commonly reported viral hepatitis diagnosis among respondents, reported by 12 PWID and four FVHR.

Monogamy was the main reason MSM, people in other priority populations, and people not included in priority populations cited for not being at risk for HIV, while abstinence was the primary reason reported by FVHR and PWID.

MSM were most likely to report being tested for HIV at least once per year (68% of MSM compared to 48% of FHVR, 46% of PWID, 33% of people in other priority groups, and 25% of people not included in priority populations).

The most common reason for getting an HIV test among MSM was testing as a preventative measure, while PWID most commonly reported being worried about their injection drug use. FVHR, other priority populations, and those not in a priority population all most commonly reported starting a new relationship as their motivation for testing.

The most common reason respondents of any group reported for not being tested for HIV was their perception that they were not at risk.

MSM were most likely to report being aware of free, community-based HIV testing (69%), followed by 63% of FVHR, 61% of PWID, 54% of people in other priority populations, and 49% of people not in priority populations.

Generally, respondents reported comfort with discussing their sexual history with their medical provider. MSM were least likely to report this and more likely to report experiencing discrimination from their medical provider related to their sexual practices.

More than 40% of FVHR reported experiencing discrimination by their medical provider based on their gender at least sometimes.

While 42% of MSM and 39% of FVHR reported that their medical provider had ever recommended HIV testing, only 27% of PWID, and 21% of people in other prioritized populations, and 17% of those not in prioritized populations reported this.

Respondents were more likely to report having had some difficulty communicating with their medical provider than needing an interpreter to speak with their medical provider.

MSM respondents most commonly reported meeting partners online while all other groups most commonly reported that they were in a long-term monogamous relationship.

A total of 67% of FVHR reported ever exchanging sex for money, substances, or goods, compared to 20% of MSM respondents, 18% of PWID respondents, and 5% of respondents in other priority populations.

About one-quarter of MSM, PWID, and FVHR respondents reported always or frequently using condoms. Closer to one-third of all other respondents reported using condoms always or frequently.

The most commonly reported reason for not using condoms among MSM was that their partner did not want to use them. PWID and FVHR respondents most commonly reported that they did not find condoms comfortable, while respondents in other priority populations were most likely to report that they did not have condoms available. Those who were not in any priority populations most commonly reported that they did not use condoms because they were in a committed relationship.

All groups were more likely to have heard of PrEP than PEP.

MSM respondents were the most likely to report having heard of, taken, or been refused PrEP.

A total of 83% of MSM respondents have heard of PrEP, with about one-third of these taking PrEP at the time of the survey.

MSM, respondents in other priority populations, and those not in any priority population were most likely to report no perception of risk as their reason for not taking PrEP while PWID and FVHR respondents were most likely to report not being aware of PrEP.

Very few respondents reported ever taking PEP. Of the ten who did, six reported completed the full course.

All groups had a high proportion of respondents who indicated that it takes an hour or less to travel to support services, although only 61% of MSM and 61% of PWID respondents made this report, compared to 78% of FVHR, 71% of people in other priority populations, and 76% of people in no priority populations.

All groups had high proportions of respondents who reported symptoms of depression and anxiety in the 14 days before the survey. Ratings were high for all questions among PWID respondents. FVHR respondents had more variation, but also generally reported more symptoms of anxiety and depression than MSM respondents, respondents in other priority populations, and respondents in no priority population.

Most respondents did not indicate a need for social opportunities. This was consistent across risk groups. For respondents who did identify social needs, the most common response that was reported by all risk populations was peer support. Other common selections included:

- Social retreats (MSM, people in other priority populations)
- Weekly meetings (MSM, FVHR, people in other priority populations)
- Community dinners (PWID, FVHR, people in other priority populations)
- Learning retreats (PWID)

Although barriers to accessing social supports were not often reported, the most common were cost, transportation, and mental health issues.

Internet access – particularly by phone – was common among most respondents, except PWID. All other populations had between 90% and 94% reporting that they had some form of reliable Internet access, while only 76% of PWID did. This may indicate needs for mobile-friendly Internet resources and to consider resources that are not online when outreaching to PWID.

About half or more of respondents in all groups reported that they had all the Internet access they needed, ranging from 51% among PWID to 71% among those in other priority populations.

Department of Health and Human Services

State of Maine
2022 Needs Assessment Survey Report: People Living with HIV/AIDS

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Ryan White Part B Program

Introduction

The 2022 Needs Assessment Survey was mailed to Ryan White Part B members in March 2022. The mailing included:

- A cover letter
- The survey instrument, which included a link to complete online if preferred, a label at the top with the member's ADAP ID, and option to receive a $10 Hannaford food card

In addition, a slightly modified survey instrument was made available for people living with HIV/AIDS who were not enrolled in the Ryan White Part B Program. This survey was available online and at community-based agencies (such as the Gilman Clinic at Maine Medical Center and the syringe exchange at the Horizon Program).

These surveys were anonymous, so there is no way to identify those who may in fact be currently enrolled in the Ryan White Part B Program. One of the responses included in this analysis was a Ryan White Part B member survey that was sent back with the client ID label removed.

A total of 21 surveys were returned that could not be linked to the Ryan White Part B membership.

All survey responses were entered into REDCap and analyzed using Excel.

Demographics

Gender

Almost all (90%) respondents identified as male, with one woman and one transwoman.

Race and ethnicity

Two respondents (10%) identified as Hispanic/Latinx ethnicity.

About 86% of respondents identified as white. There was one Black respondent, one person who did not respond, and one person who selected "other" for race but identified Hispanic/Latinx ethnicity.

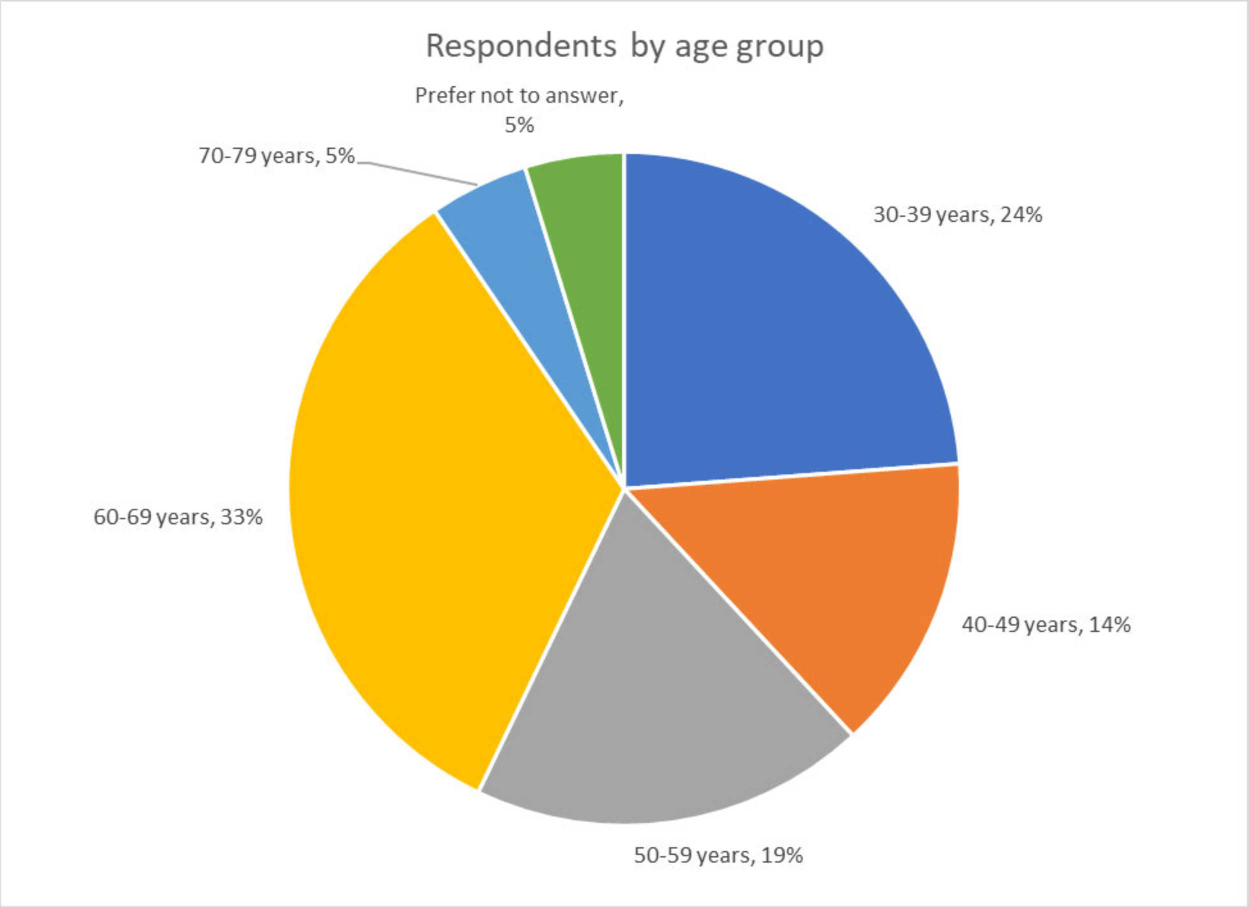
Country of birth and languages spoken at home

All respondents indicated that they were born in the United States.

One respondent did not answer the question about language. All respondents who answered the question indicated that they speak English at home. One reported speaking Spanish at home in addition to English.

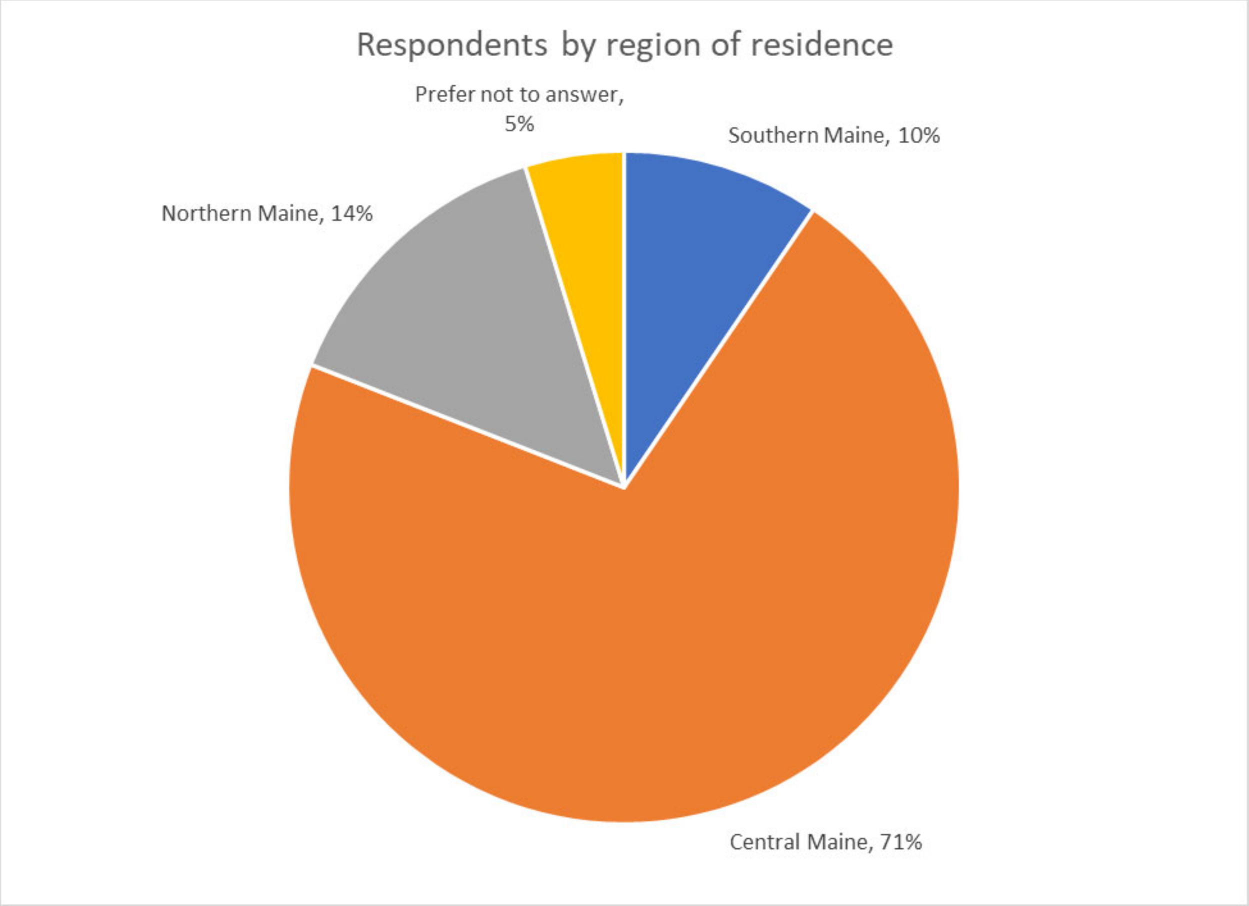
Age

Half of respondents were between age 50 and 69.


Respondents by age group
Prefer not to answer, 5%
70-79 years, 5%
30-39 years, 24%
60-69 years, 33%
40-49 years, 14%
50-59 years, 19%

Region of residence

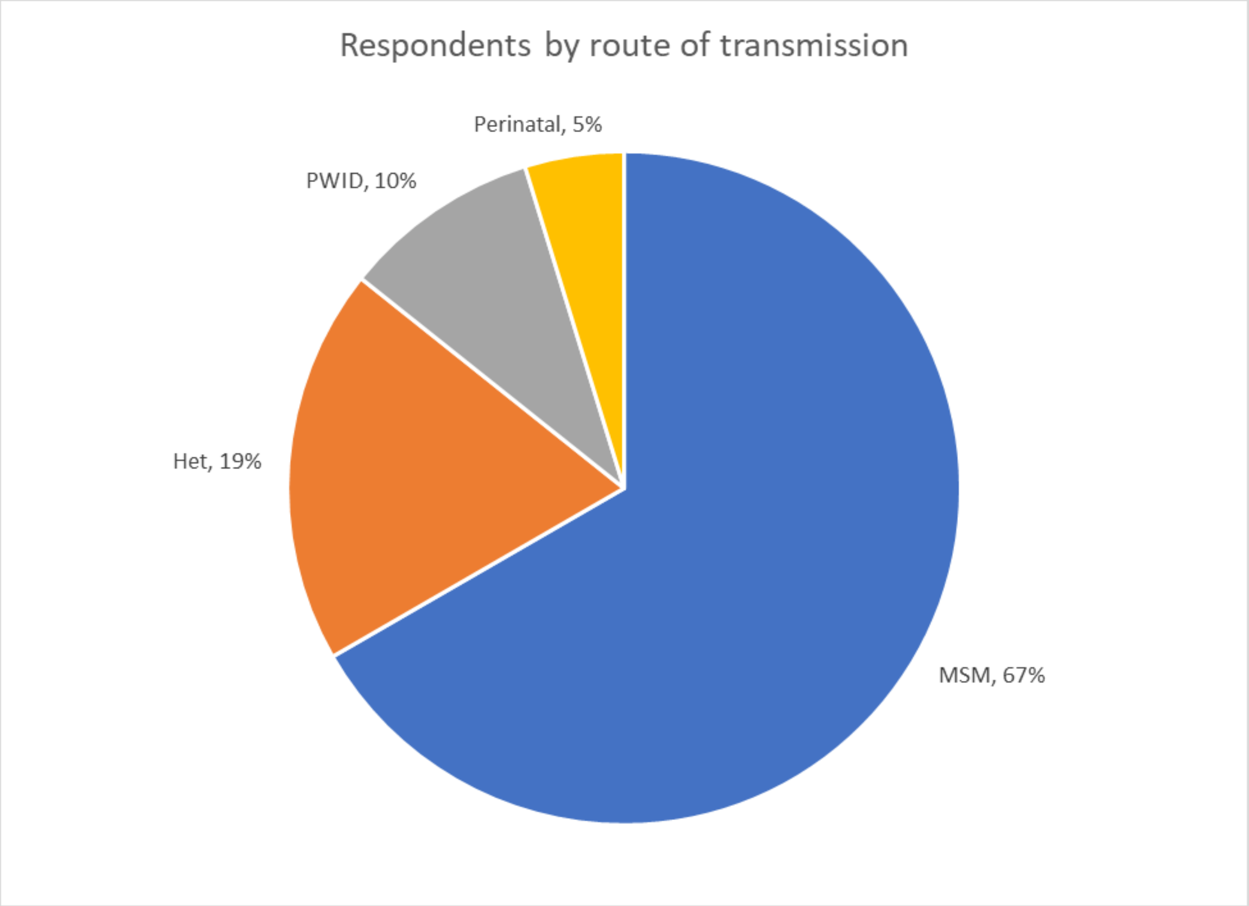
Most respondents (71%) reported living in Central Maine (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset, and Waldo counties). Three respondents were from Northern Maine (Aroostook, Hancock, Penobscot, Piscataquis, and Washington counties) and two were from Southern Maine (Cumberland and York counties).



Most respondents (78%) indicated that it takes an hour or less to travel one-way to most of the services they want (such as case management and supportive services). An additional 10% indicated that it takes between an hour and two hours and another 2% reported that it takes two or more hours to travel one-way to most services.

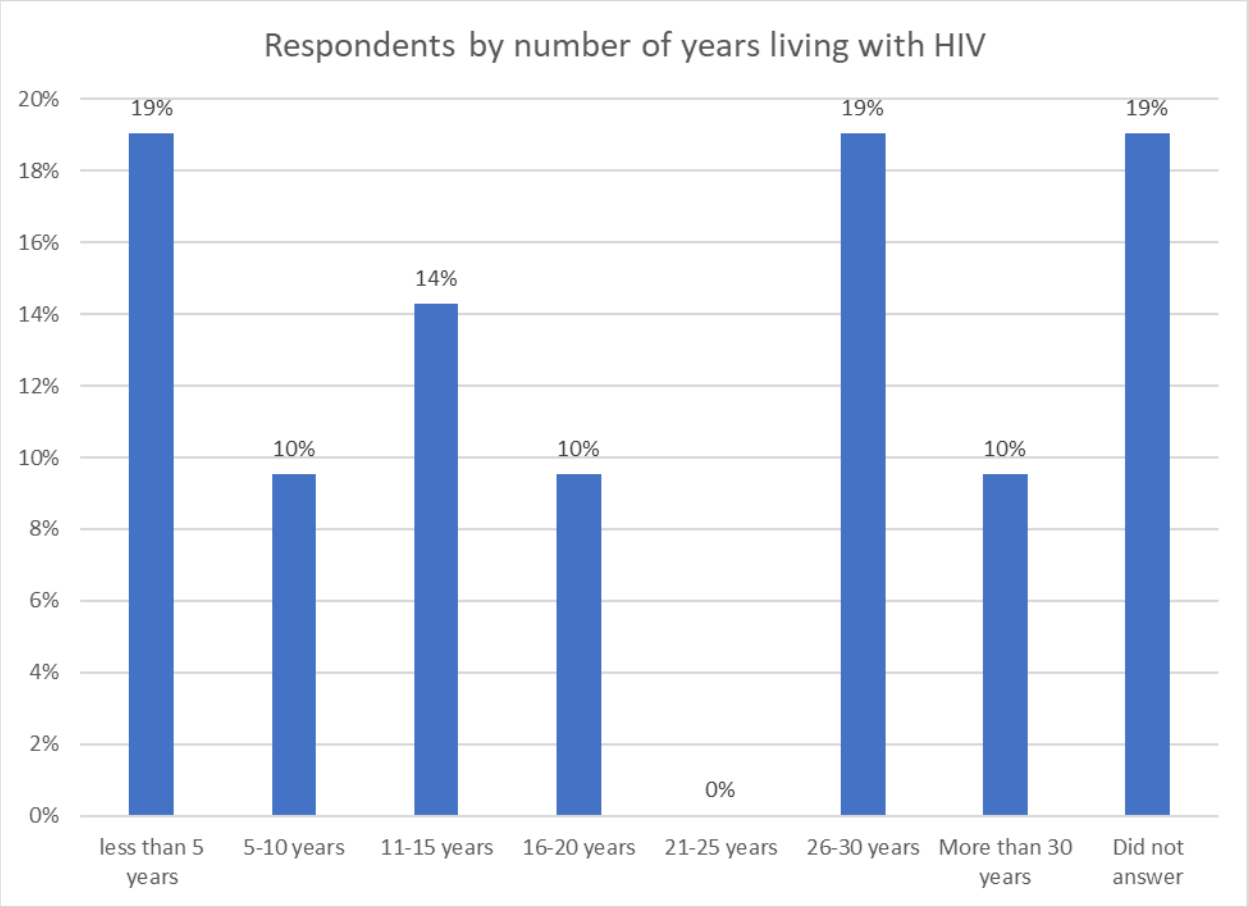
Route of transmission

Most respondents (67%) identified male-to-male sexual contact as their route of transmission.



Years living with HIV

Of those respondents who reported their year of diagnosis, about half have been living with HIV for 15 years or less and about half have been living with HIV for 16 years or more.



Housing status

Nearly all respondents (90%) reported a stable/permanent living situation. Two respondents reported staying temporarily with friends or family.

Incarceration

About 19% of respondents (4) indicated that they had been incarcerated at some point (three were released more than one year ago and one was released in the past year).

Injection drug use

Two respondents (10%) indicated that they had used injection drugs. One of these identified injection drug use as the likely source of their HIV infection (the other reported heterosexual contact).

Discrimination

In general, respondents did not indicate high frequency of discrimination in the areas identified below, but were more likely to identify discrimination than those who responded to the Ryan White Part B client survey.

How often do you experience the following?	Never	Very Seldom	Sometimes	Often	Always	N/A
Ill-treatment or discrimination by your medical provider due to your gender identity	71%	10%	5%	10%	5%	0%
Ill-treatment or discrimination by your medical provider due to your sexual practices	71%	14%	10%	5%	0%	0%
Ill-treatment or discrimination by your medical provider due to your racial or ethnic identity	76%	5%	0%	14%	5%	0%
Ill-treatment or discrimination by your medical provider due to your HIV status	76%	5%	0%	14%	5%	0%
Ill-treatment or discrimination by your landlord or prospective landlord because of your HIV status	76%	5%	10%	5%	0%	5%
Fear of using HIV prevention services (such as HIV testing, condoms, PrEP) because of how you feel you would be treated by family, friends, or community members	81%	0%	10%	10%	0%	0%

Of the four respondents who reported that they experience discrimination based on gender sometimes, often, or always, three identified as male and one as a transwoman.

Of the four respondents who reported that they experience discrimination based on race or ethnicity sometimes, often, or always, one identified as Hispanic/Latinx and the other three identified as white/not Hispanic/Latinx.

Prevention Services and Risk Behaviors

Infections and risk perception

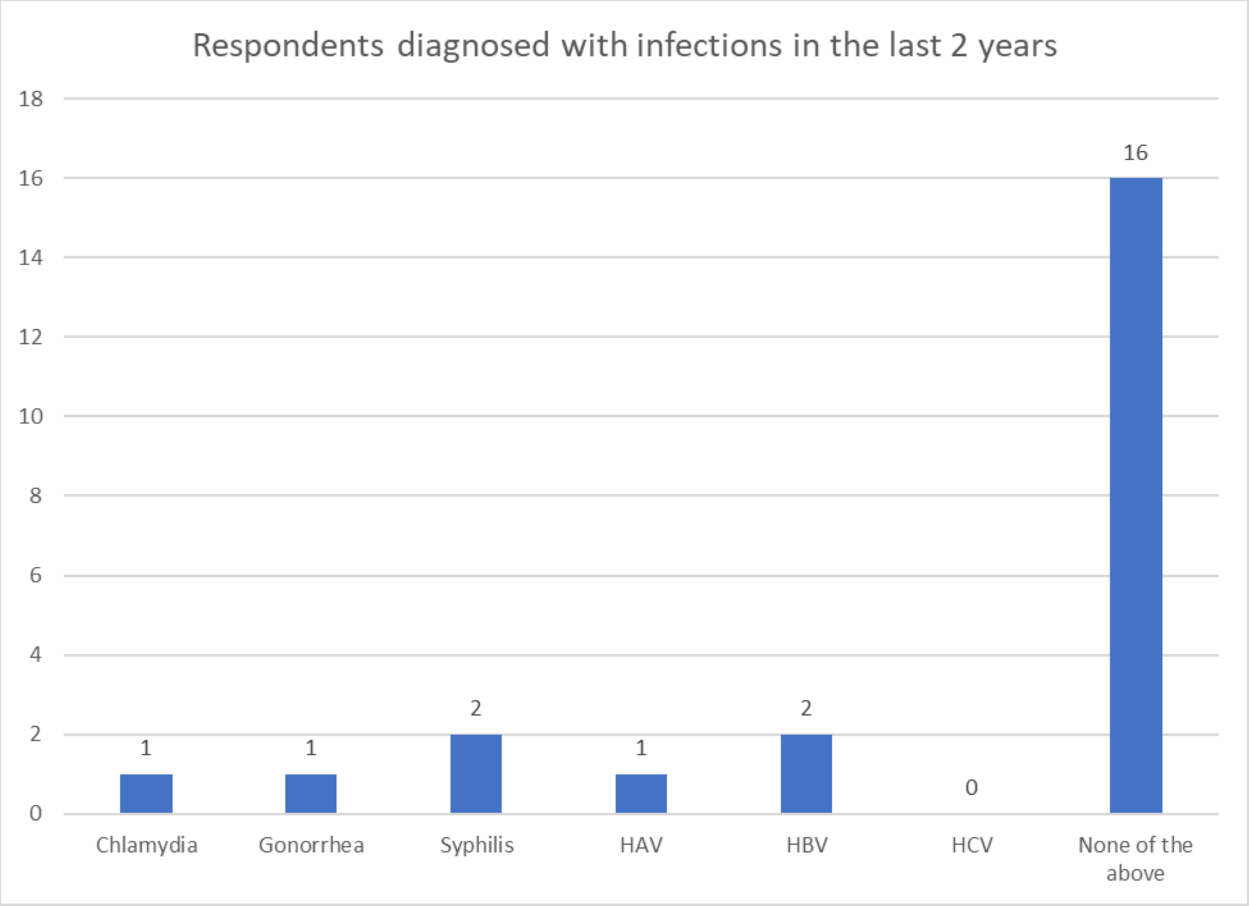
The survey asked the question, “Are there things you are doing that may put you or others at risk for HIV/STDs?”

Two respondents (10%) reported that there are things they are doing that may put themselves or others at risk for HIV/STDs.

One respondent who reported not engaging in risk behaviors reported being diagnosed with chlamydia, gonorrhea, and syphilis in the last two years.

A total of five respondents (23%) reported having been diagnosed with at least one sexually transmitted infection and/or Hepatitis in the last two years.

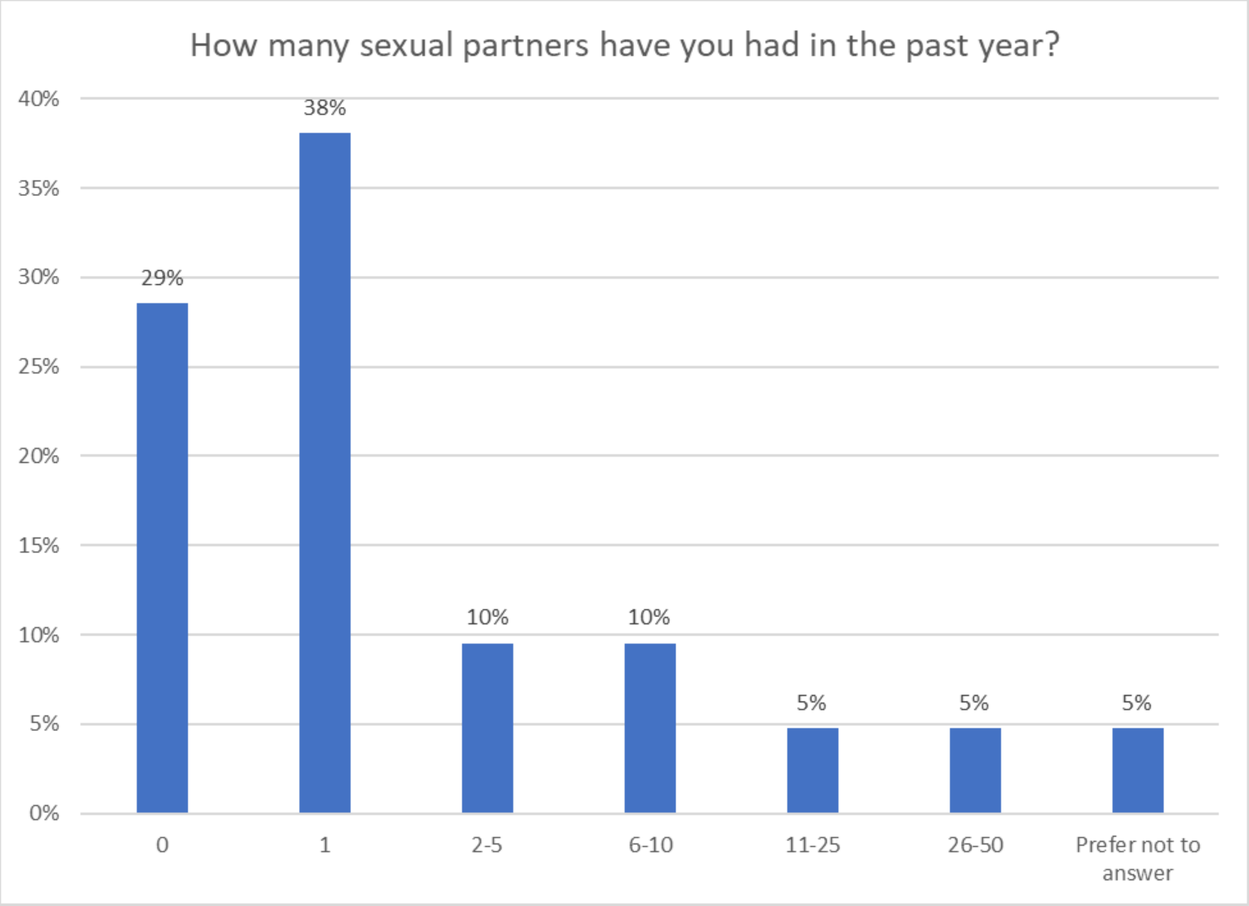
The chart below includes some duplication of individuals, as there were respondents who reported infections with multiple diseases:



Sexual history

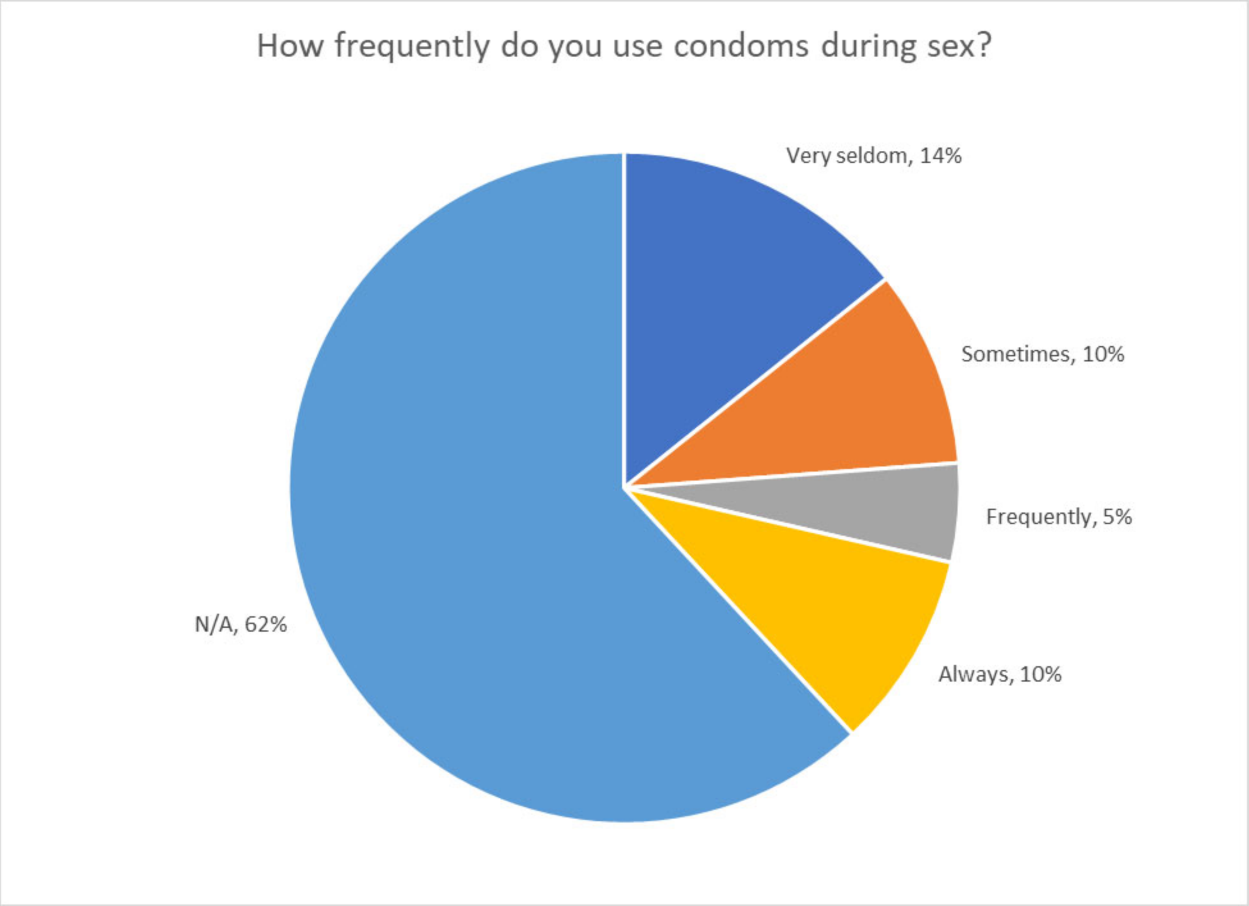
Most respondents (57%) indicated that they were in a long-term monogamous relationship. Of the nine respondents who were not in a long-term monogamous relationship, the most common ways to meet partners were through existing friendships or bars/clubs.

Most respondents (67%) indicated that they had had one or no sexual partners in the past year.

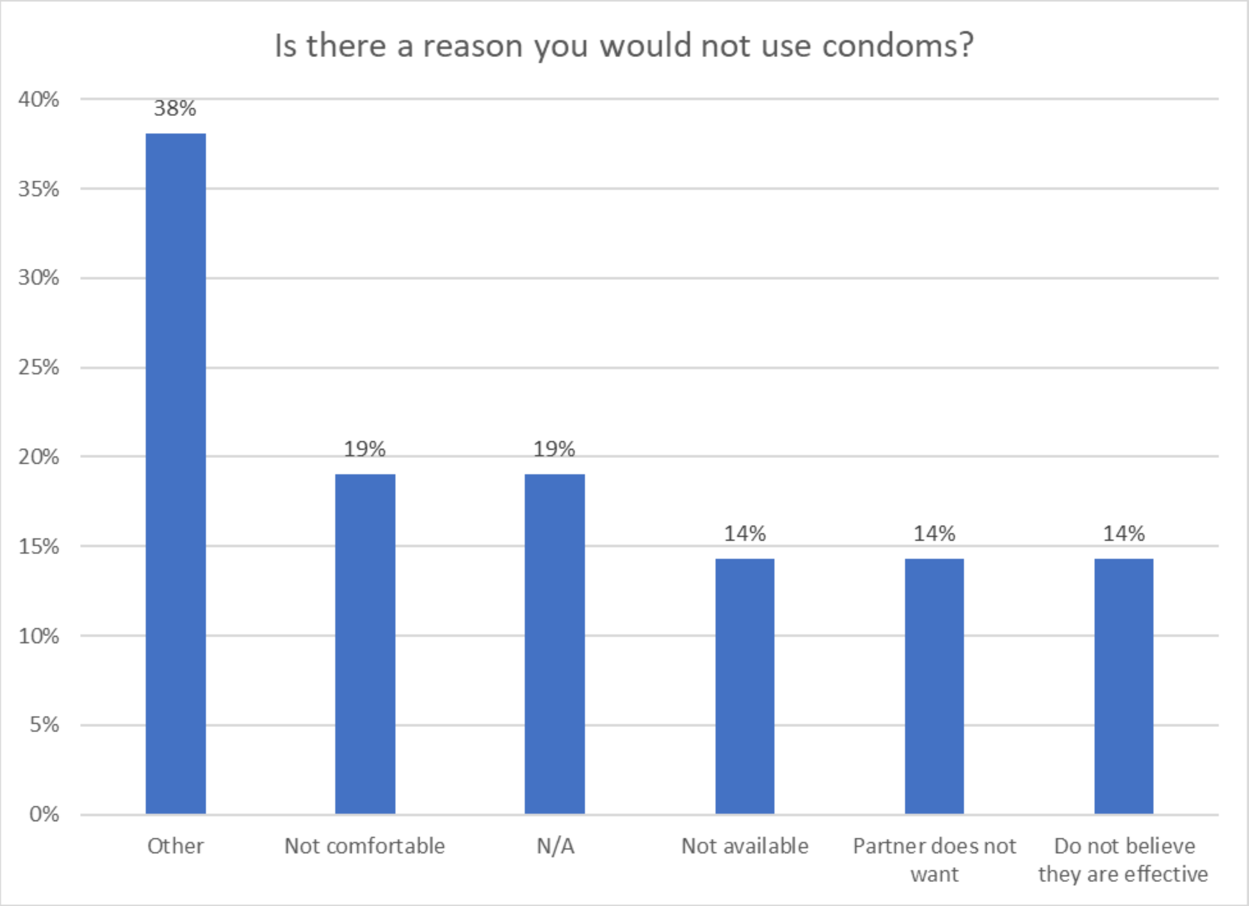


A total of 4 respondents (19%) indicated that they had ever exchanged sex for money, substances or goods.

Condom use



The survey asked if there was a reason the respondent would not use condoms with checkboxes for multiple answers. The most common response (written in under "other") was N/A. Other written in responses include: trying to conceive, undetectable/partner on PrEP, and loss of libido.



Pre-Exposure Prophylaxis (PrEP)

More than three-quarters (76%) of respondents have heard of PrEP.

Of the 16 respondents who indicated that they had heard of PrEP: 11 (69%) are very or pretty comfortable speaking about PrEP with partners while two (13%) selected N/A. Three (19%) were somewhat comfortable.

Two individuals reported that they had partners who requested PrEP from a medical provider and were refused.

Care Services and Unmet Needs

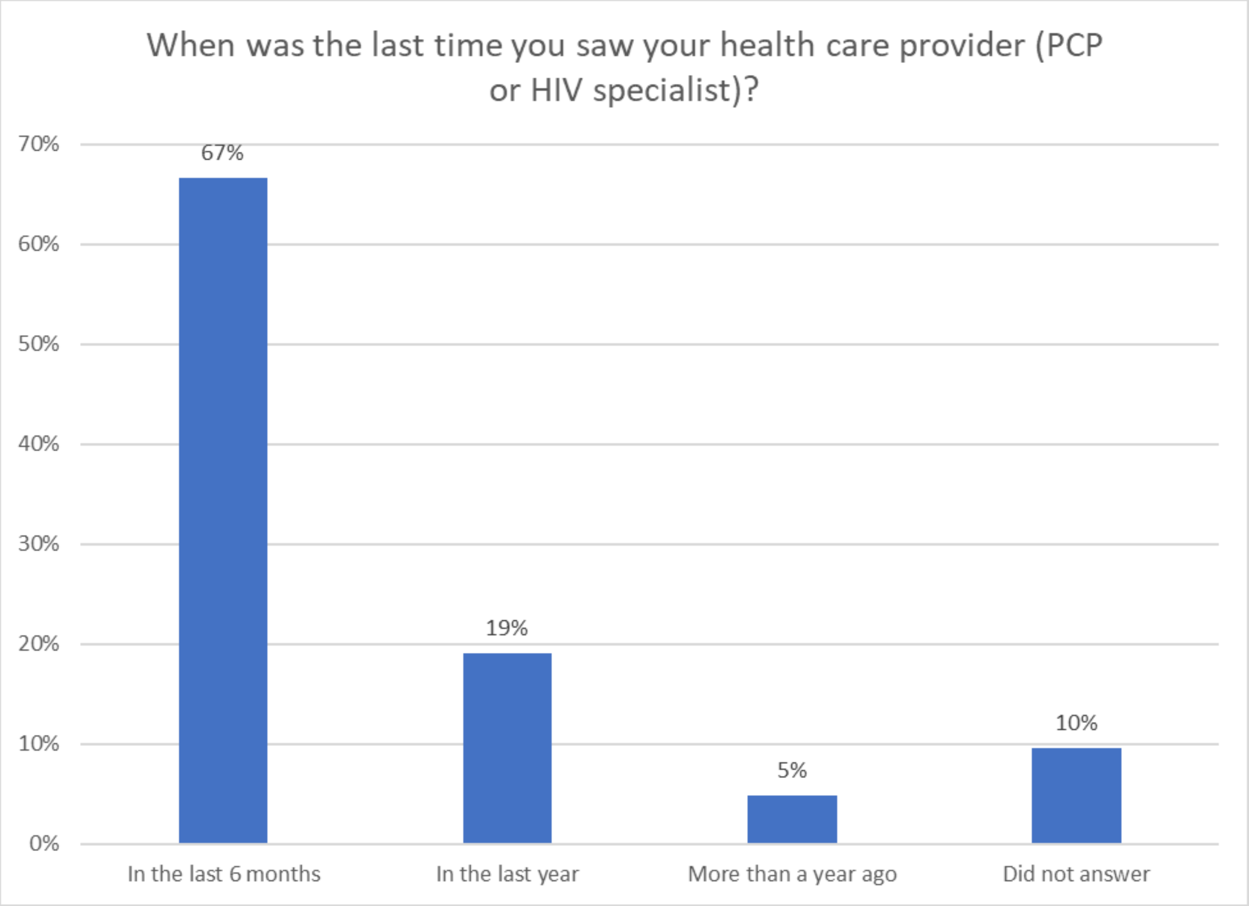
HIV medical care

Most (86%) respondents indicated that they are comfortable speaking with their medical provider about their sexual history.

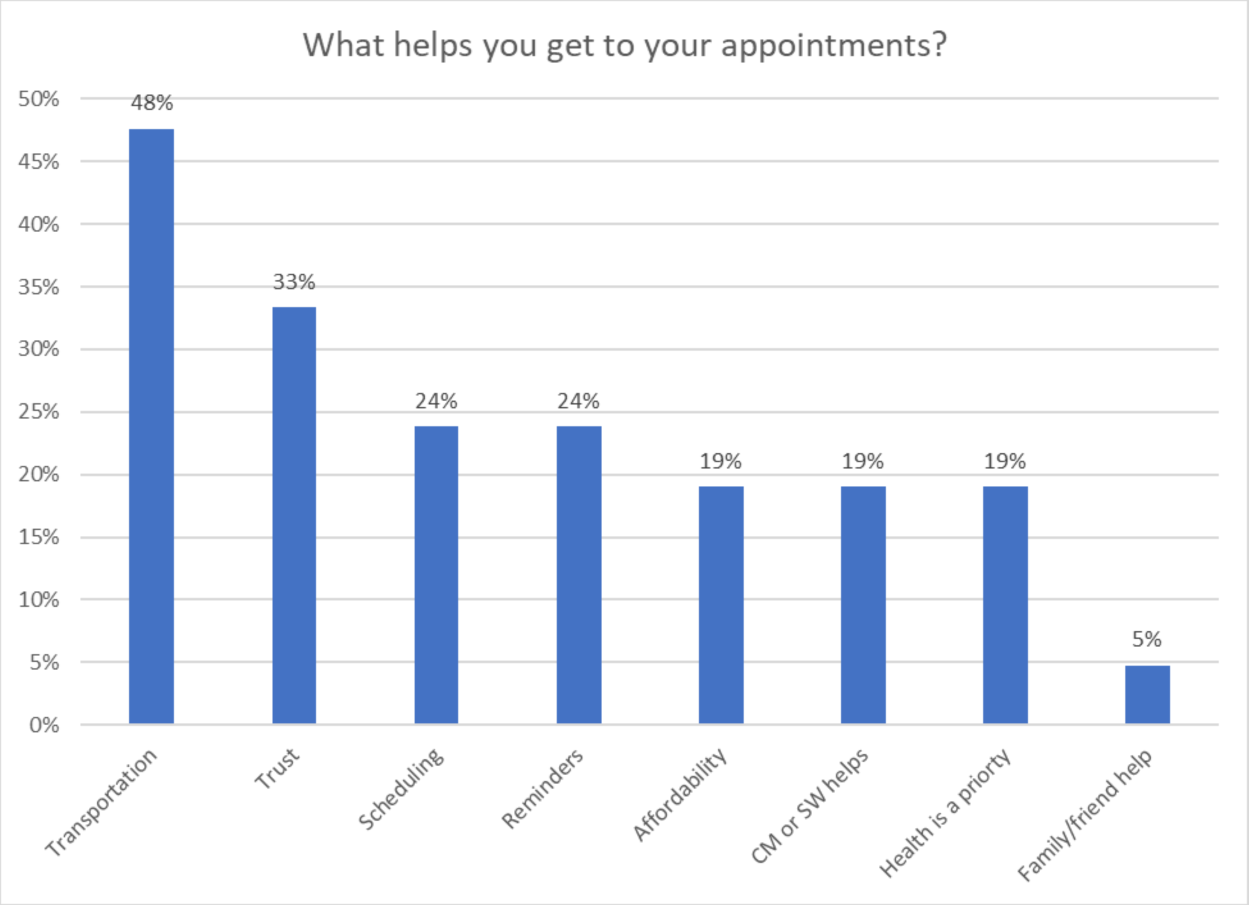
Three respondents (14%) indicated that they require an interpreter to speak with their medical provider. Two of these indicated that English was the only language spoken in their homes, while the third did not answer the language question.

Two respondents (10%) reported that they have difficulty communicating with their medical provider.

Most respondents (86%) have seen their health care provider (primary and/or HIV specialist) in the past year.



The survey asked what helps get the respondent to their appointments with checkboxes for multiple answers. As with Ryan White Part B clients, transportation was the most common response.



Most respondents (71%) indicated that it takes an hour or less to travel one-way to their HIV medical care. An additional 14% indicated that it takes between an hour and two hours and another 5% reported that it takes two or more hours to travel one-way to their HIV medical care.

One respondent (5%) was not sure when of the date or result of their last viral load test; two respondents (10%) did not answer.

Most respondents (81%) reported having their last viral load in the past year. Of these, 88% (15 respondents) reported a suppressed viral load.

One respondent reported a suppressed viral load last measured one to two years ago.

Vaccinations

Most respondents (67%) reported having all of their COVID-19 vaccinations (including boosters) with an additional 10% who had been vaccinated against COVID-19 but had not had all boosters available to them.

Most respondents (71%) reported having a flu vaccine, although the question did not ask if this was an annual practice.

About 43% reported being vaccinated against Hepatitis B and 38% reported being vaccinated against Hepatitis A.

One-third reported being vaccinated against HPV.

HIV treatment

About 90% of respondents (all but two individuals) reported that they had taken HIV medications in the past year.

Of the two who did not report taking HIV medications in the past year, one reported a suppressed viral load in the last six months to one year while the other reported not being sure of the date or result of their last viral load.

Four respondents (19%) reported ever having stopped taking their HIV medication without the advice of their doctor.

Fifteen respondents (71%) indicated that they understand how and when to take all of their HIV medications. An additional two respondents (10%) reported that they understood most things about their HIV medication or that they had a few questions about their HIV medications. The individual who had a few questions reported an unsuppressed viral load in the last six months to a year. The individual who understood most things about their HIV medications was not sure of their last viral load, which was drawn in the last six months to a year.

Dental care

Only 12 respondents (57%) reported having seen a dentist in the last 18 months.

Reasons for not seeing a dentist included anxiety, COVID-19 restrictions, and that the dentist office closed.

The two respondents who listed dental care as an unmet need later in the survey were among those who reported not having seen a dentist in the last 18 months.

HIV case management

Nine respondents (43%) reported getting HIV case management from the Horizon Program while an additional two (10%) reported case management from Frannie Peabody Center.

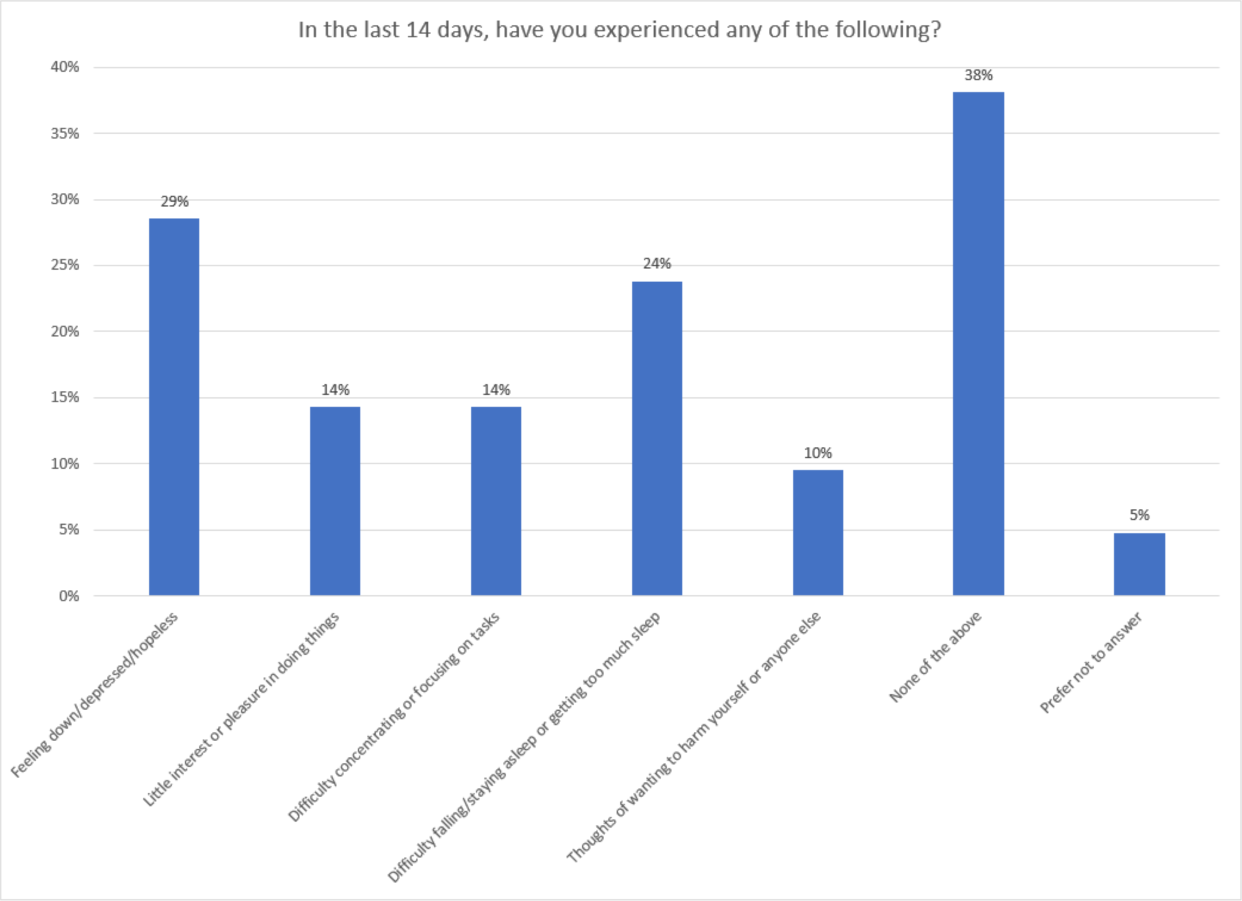
Almost one-quarter of respondents (5) reported not having or wanting case management.

One individual (5%) indicated that they did not have but wanted case management.

Two respondents selected HIV case management as an unmet need later in the survey. One of these was the individual who reported not having but wanting case management; one reported Horizon as their case management agency, which could indicate some confusion since Horizon provides both HIV medical care and case management.

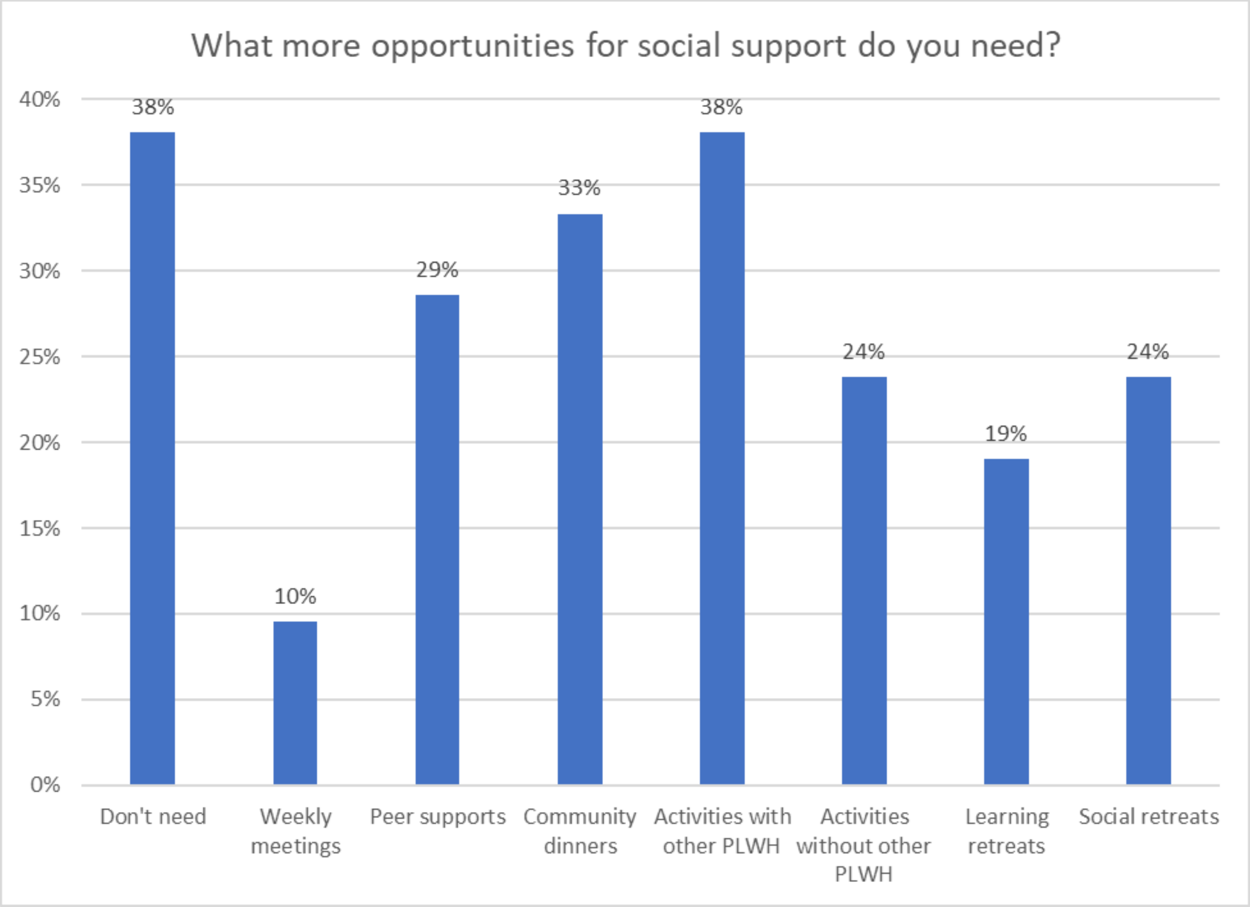
Mental health and social support

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. The most common response was “none of the above,” identified by 38%. However, more than one-quarter (29%) reported feeling down/depressed/hopeless and 24% reported having difficulty with sleep. Two individuals (10%) reported thought of wanting to harm themselves or others.



The most common responses to a question about needed social supports were none needed (38%), activities with other people living with HIV (38%), and community dinners (33%).

The chart below includes some duplication of individuals, as respondents could select multiple options:

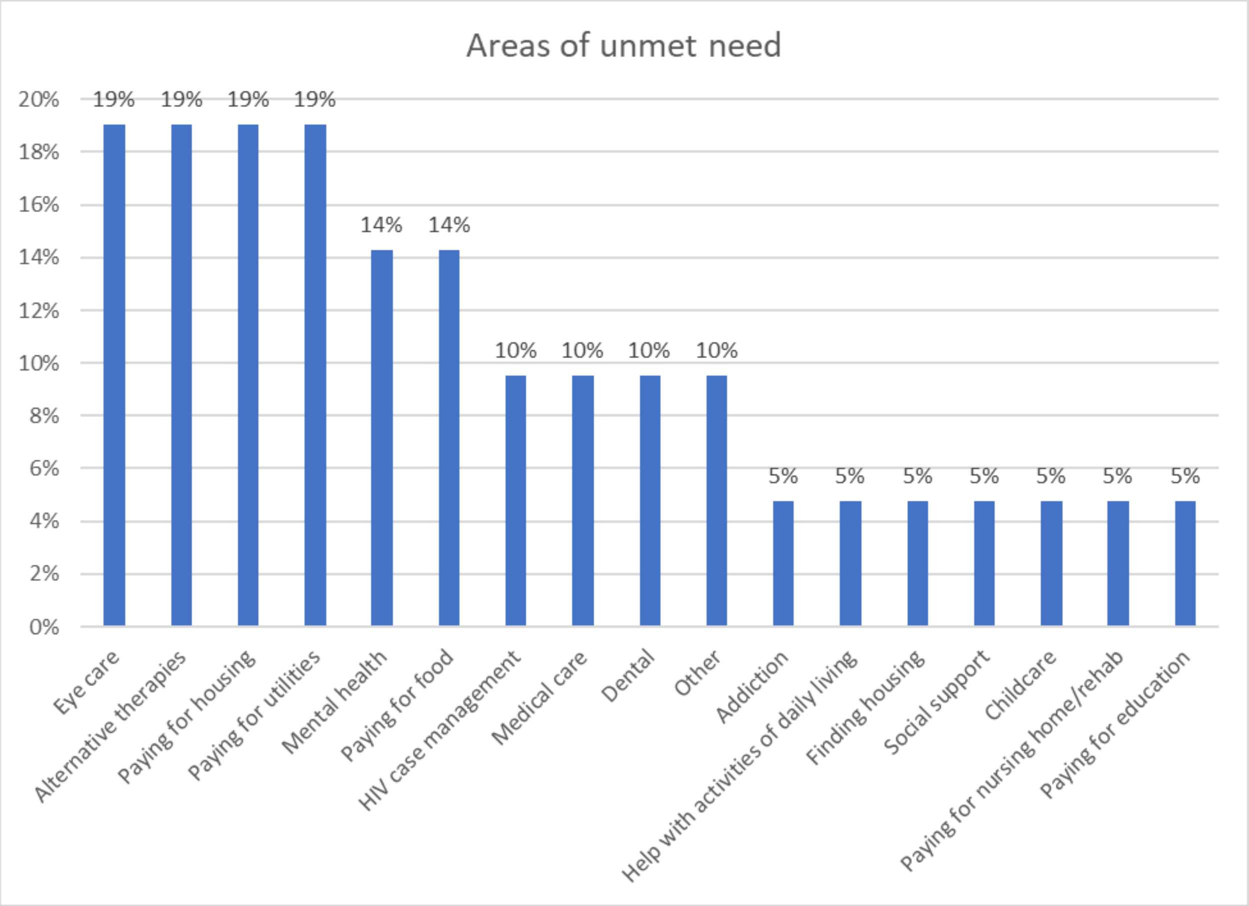


Unmet needs

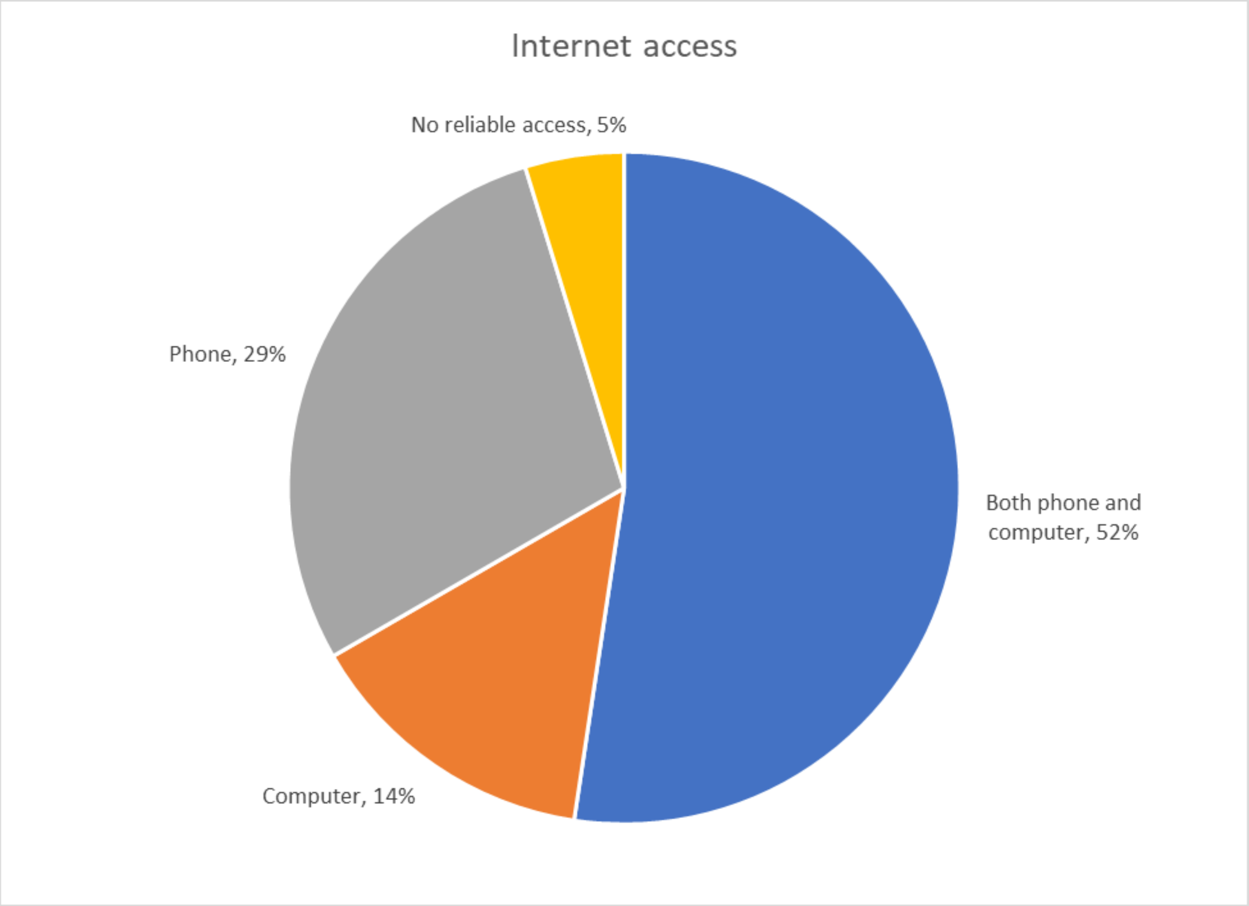
The survey asked respondents to identify the services they needed but did not have. The most-identified areas of unmet needs were: eye care, alternative therapies, paying for housing, and paying for utilities (each identified by 19% of respondents).

The following categories were not identified by any respondents: transportation, work or learning opportunities, help getting and taking medications on time, translation or interpretation, selecting or enrolling in insurance, quitting tobacco, paying for medical costs, finding a job/job training, legal assistance, and immigration assistance.

The chart below includes some duplication of individuals, as respondents could select multiple options:



All but one respondent (95%) indicated that they have reliable Internet access by phone and/or computer. No respondents indicated that they have no Internet access.



More than three-quarters of respondents (76%) indicated that they have all the Internet access they need, but 24% reported needing more affordable access. One respondent (5%) reported needing more reliable access.

No respondents selected the choices for "I do not use the Internet" or "I do not want to use the Internet."

Barriers

The survey included the open-ended question, "If you have trouble getting any services, please tell us more about what gets in your way." Only one respondent answered this question. The response was, "Being able to meet with case manager or service agency."

Summary

All results in this report should be contextualized by the small sample size (21 total respondents).

Data in this report are skewed toward residents of Central Maine (71% of respondents compared to 32% of Ryan White Part B enrollment), males (90% of respondents compared to 76% of Ryan White Part B enrollment), people of Hispanic/Latinx ethnicity (10% of respondents compared to 5% of Ryan White Part B enrollment), and white people (86% of respondents compared to 73% of Ryan White Part B enrollment). No respondents to this survey indicated that they were born outside of the United States, compared to about 20% of Ryan White Part B enrollment.

Generally, respondents did not report many (if any) risk behaviors and risk perception fell in line with behaviors.

Compared to the Ryan White Part B client survey:

- More respondents reported experiencing discrimination, however all discrimination was still generally infrequent.
- More respondents reported knowing about PrEP (76% compared to 66%).
- Fewer respondents reported seeing their health care provider in the last year (86% compared to 96%).
- Fewer respondents reported being virally suppressed at last test (88% compared to 91%).
- Fewer respondents were vaccinated against COVID-19, flu, Hepatitis A, and Hepatitis B, while more respondents reported being vaccinated against human papillomavirus.
- Fewer respondents indicated that they had taken HIV medications in the past year (90% compared to 97%).
- Fewer respondents reported seeing a dentist in the last 18 months (57% compared to 62%).
- More respondents reported symptoms of anxiety and depression in the last 14 days.
- More respondents indicated additional needs for social support. Activities with other people living with HIV was the most common response among both surveys.
- More respondents indicated that they had access to the Internet (95% compared to 80%).

The top six unmet needs were eye care, alternative therapies, paying for housing, paying for utilities, mental health, and paying for food. These (with the addition of dental care) are also among the most-identified unmet needs among Ryan White Part B clients.

Department of Health and Human Services

State of Maine
Ryan White Part B Program
2022 Needs Assessment Survey Report

Tara B. Thomas, MFA
Data & Quality Specialist
Ryan White Part B Program

Introduction

The 2022 Needs Assessment Survey was mailed in March 2022. The mailing included:

- A cover letter
- The survey instrument, which included a link to complete online if preferred, a label at the top with the member's ADAP ID, and option to receive a $10 Hannaford food card

These were mailed to all members enrolled in the Program who were active as of March 22, 2022, a total of 926 members.

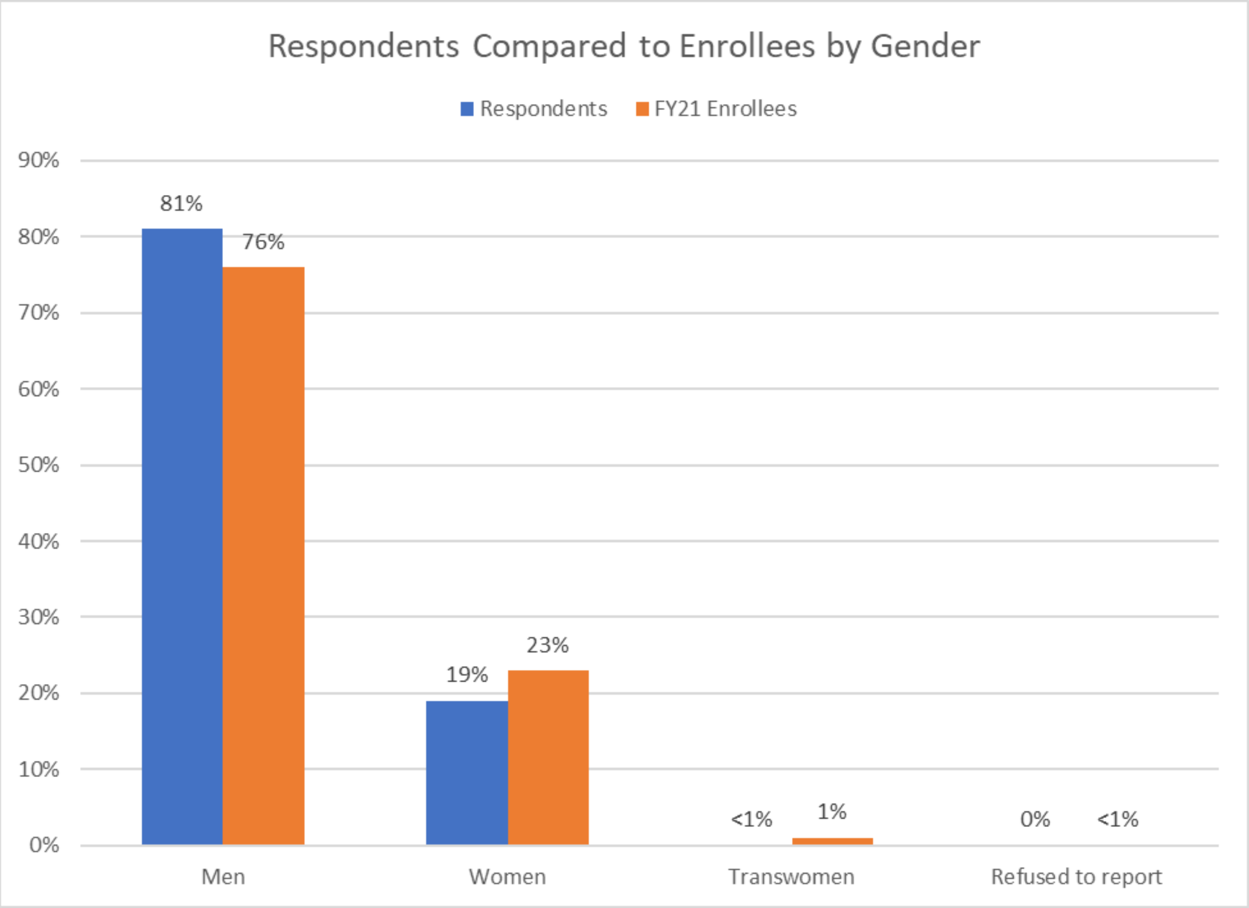
A total of 446 surveys were returned, for a response rate of 48%.

All survey responses were entered into REDCap. Because ADAP IDs were included in the mailing, response data were linked to demographic and utilization data from the Ryan White Part B Program database, CAREWare, as well as records from the HIV Surveillance database, eHARS.

Demographics

Gender

Men were over-represented among respondents, compared to Ryan White Part B Program (RWB) enrollees in FY21. About 81% of survey respondents identified as men, compared to 76% of enrollees.



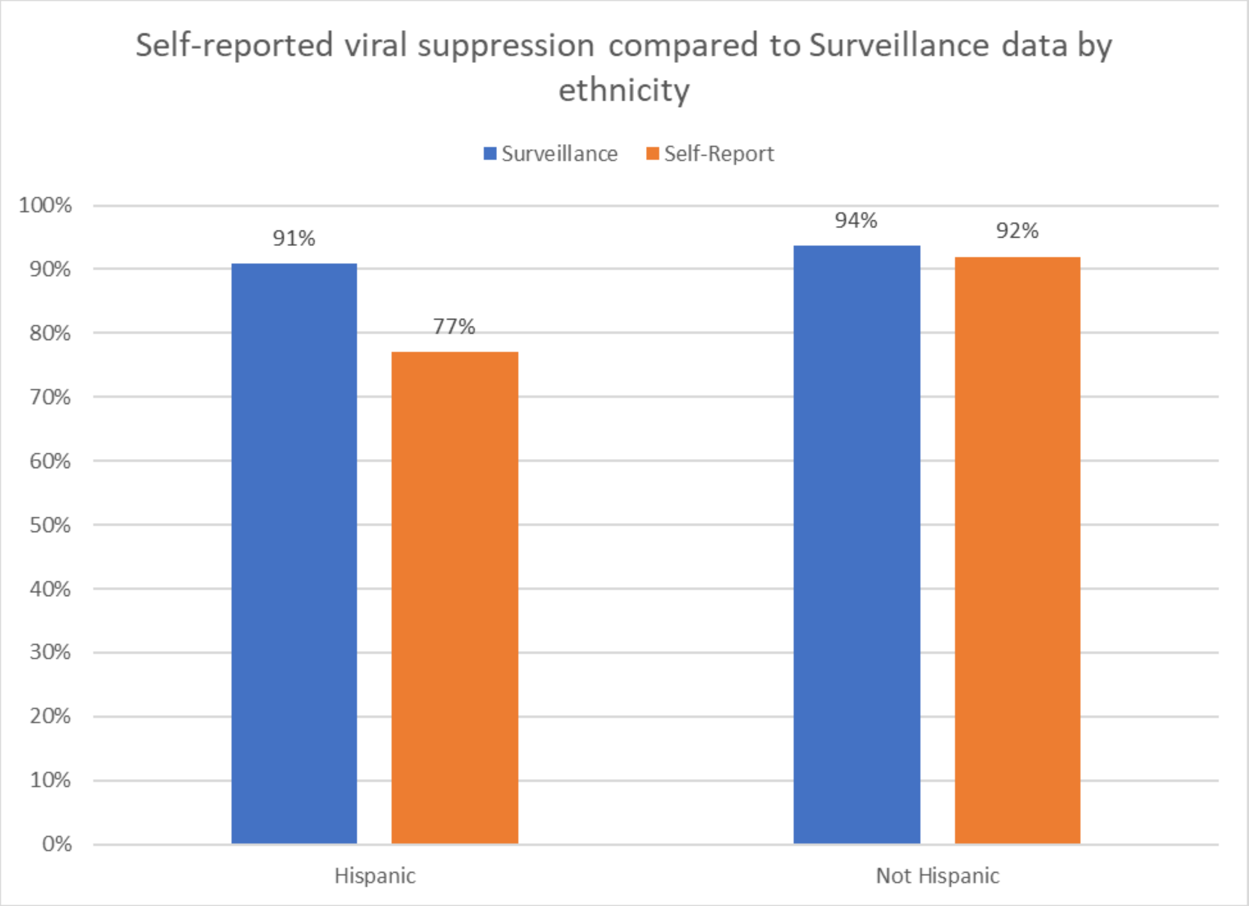
All three transwomen were virally suppressed at last test.

About 93% of men reported being virally suppressed at last test while about 82% of women reported being virally suppressed at last test. However, Surveillance data show that 94% of men and 93% of women were virally suppressed at last test.

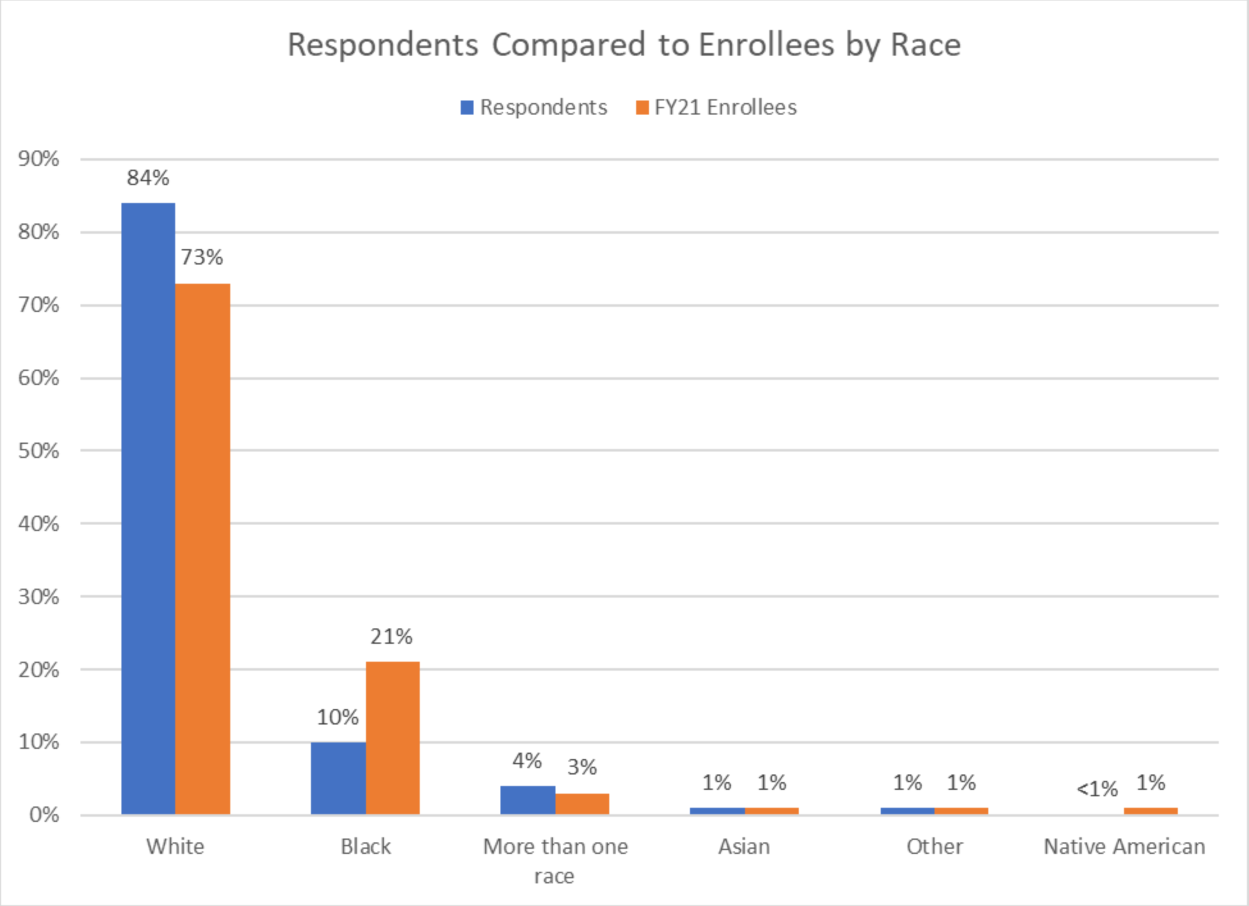
Race and ethnicity

Twenty-two respondents (5%) were of Hispanic/Latinx ethnicity. This is the same proportion of Hispanic/Latinx people identified among RWB enrollees in FY21.

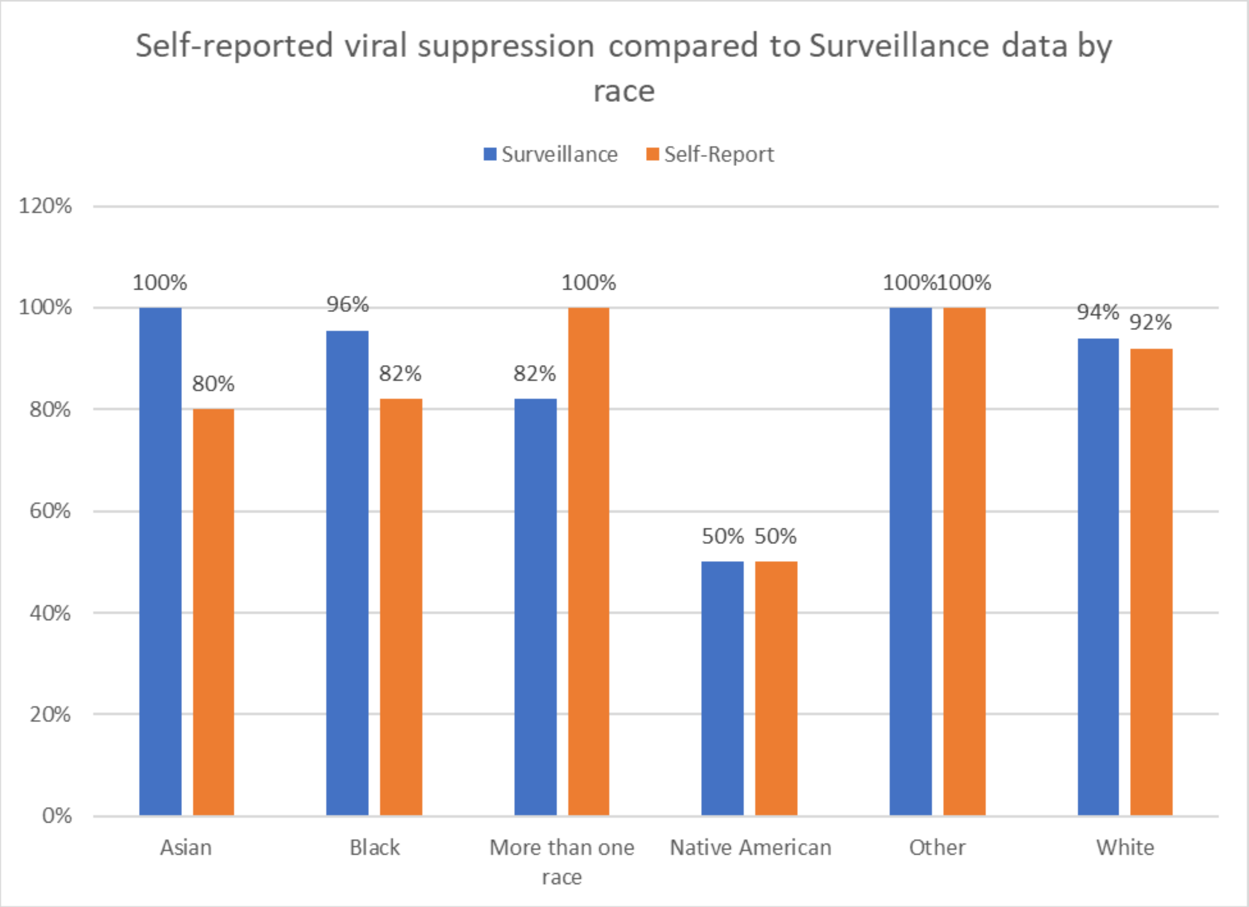
About 77% of Hispanic/Latinx respondents reported that they were virally suppressed. However, Surveillance data show that 91% of Hispanic/Latinx respondents were virally suppressed at last test.



White people are overly represented in survey responses, accounting for 84% of survey respondents, compared to 73% of RWB enrollment, while Black people are under-represented, accounting for 10% of respondents and 21% of enrollees, respectively.



About 82% of Black respondents and 80% of Asian respondents reported that they were virally suppressed. However, Surveillance data show that 96% of Black respondents and 100% of Asian respondents were virally suppressed at last test. Conversely, all multi-racial respondents reported being virally suppressed, but only 82% were virally suppressed at last test in Surveillance records.

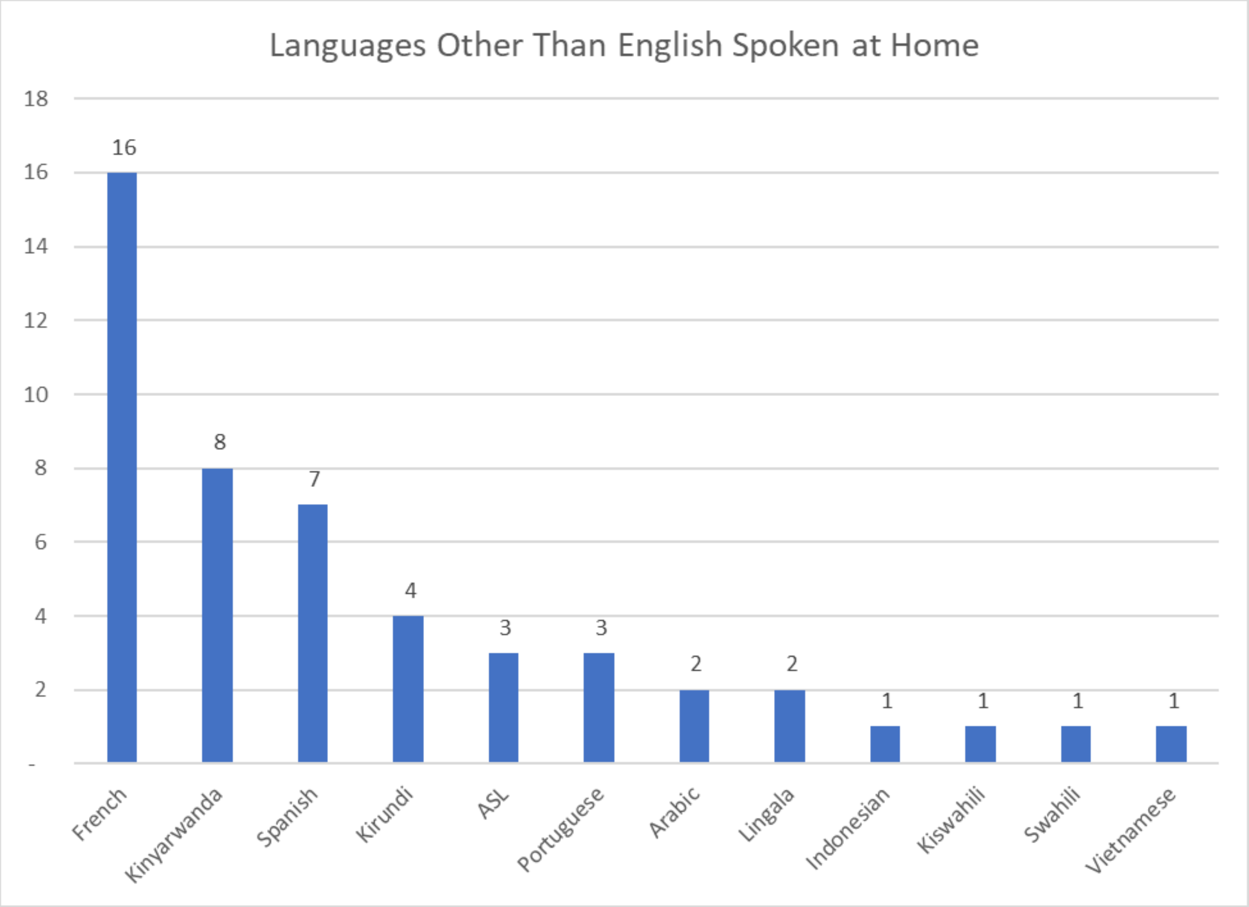


Note that there were only two respondents who reported being Native American and no other race.

Languages

Although the survey instrument was translated into French, Portuguese, and Kinyarwanda, no translated versions of the survey were returned. The survey asked respondents to identify the language(s) they speak at home. A total of 20 respondents (4%) indicated that they speak only languages other than English or American Sign Language (ASL) at home, while another 19 respondents (4%) indicated that they speak English in addition to at least one language that is not English or ASL at home.

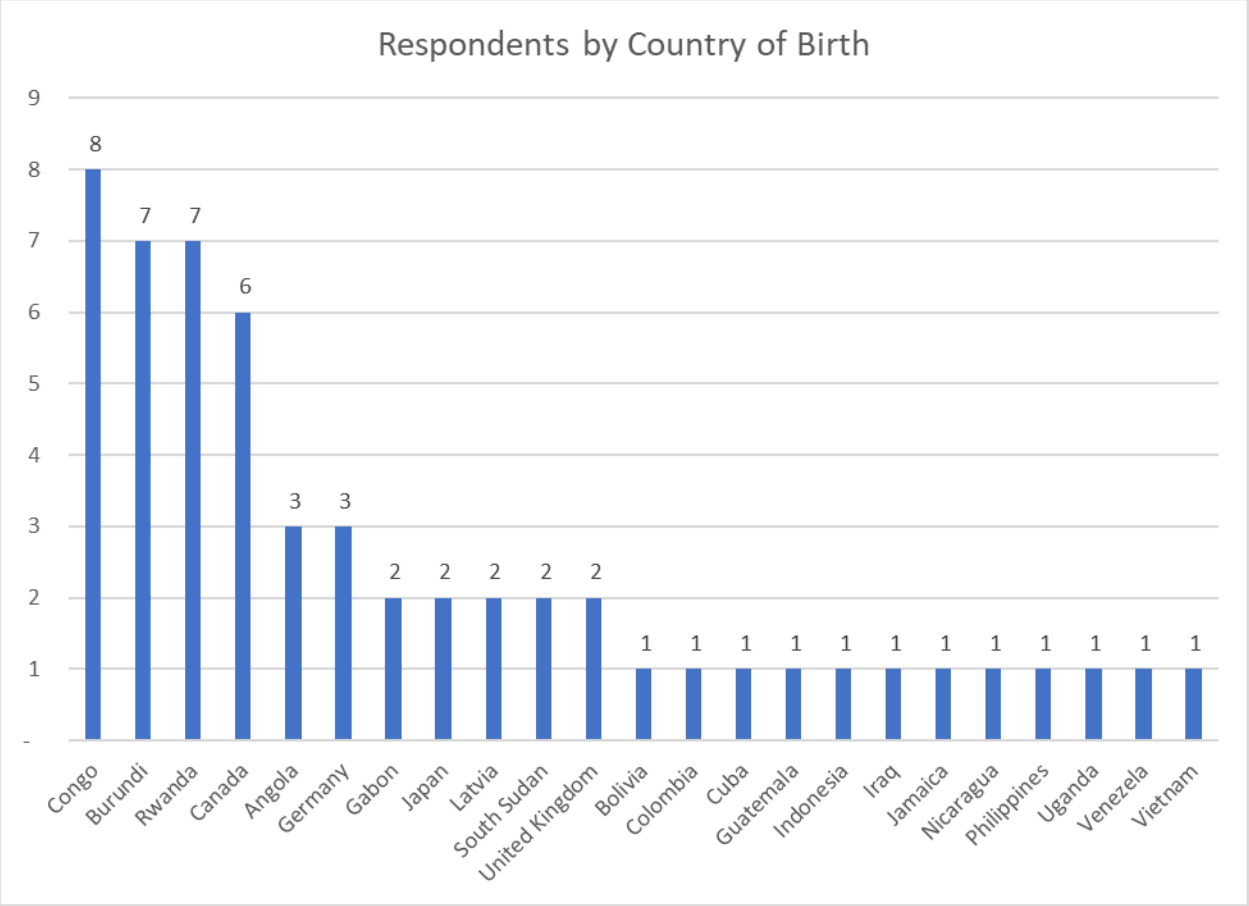
The count of languages identified includes duplication, because some respondents identified more than one language. A total of 429 respondents (96%) indicated that English was at least one of the languages spoken in their home.



Country of birth

According to the U.S. Census, about 4% of the population in Maine was born in another country.

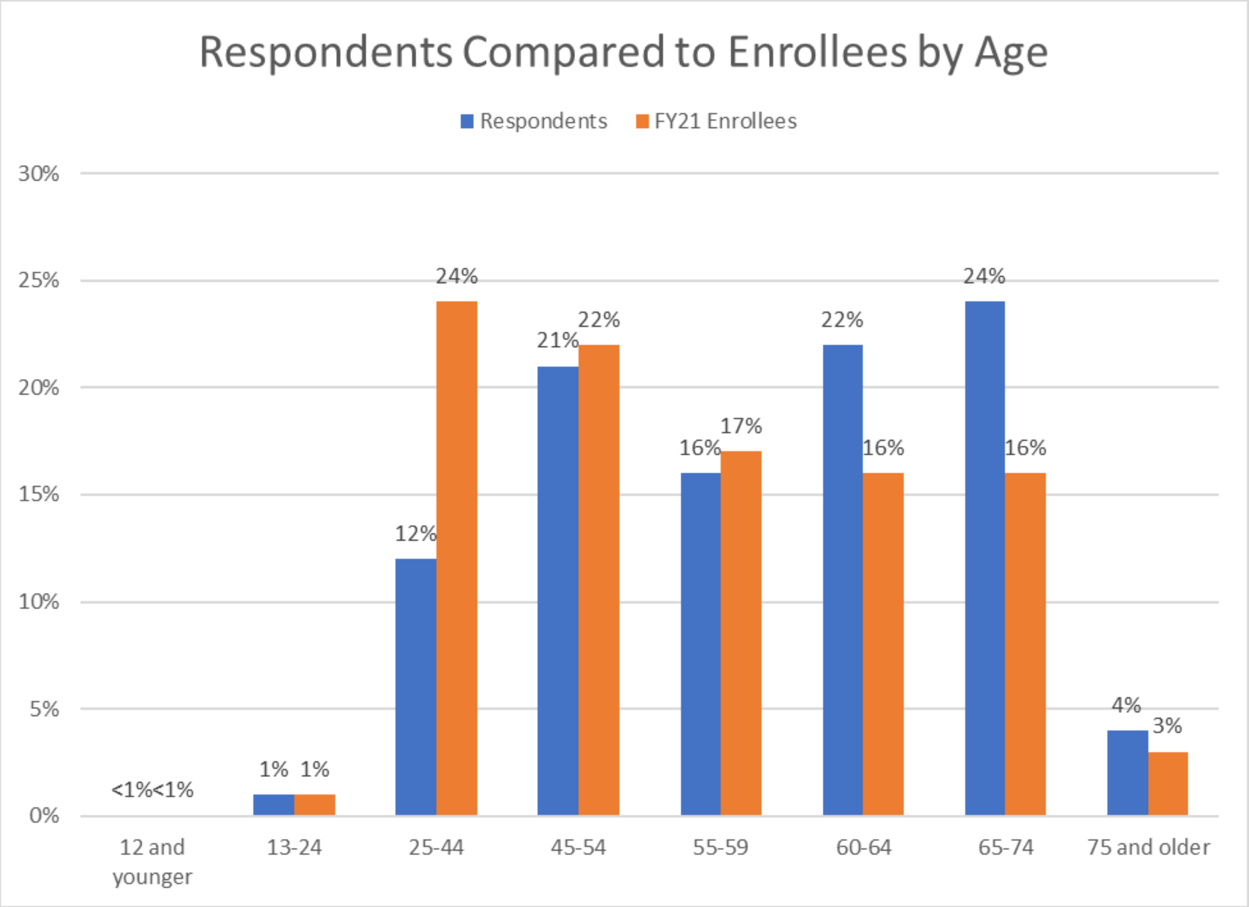
While about 20% of RWB enrollees are considered New Mainers, 13% of responses (56) were received from people born in countries other than the United States, including:

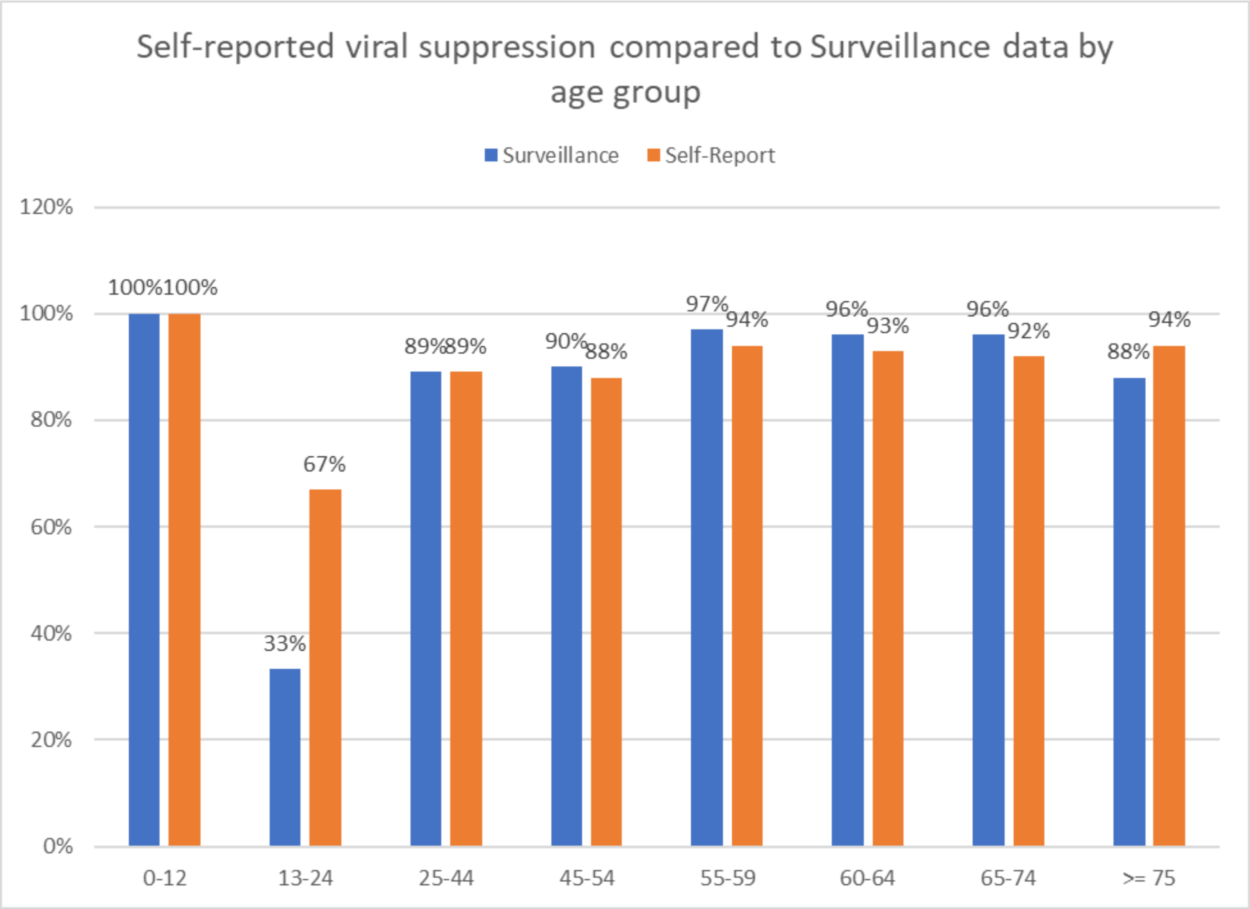


Those who reported being born in the United States were more likely to report being virally suppressed. About 92% of those born in the U.S. reported being virally suppressed at last result, compared to 84% of those born outside of the U.S.

Age

Clients age 25-44 are under-represented in responses, while those age 60 and older are over-represented. Half of respondents (50%) were age 60 and older, compared to 35% of enrollees.

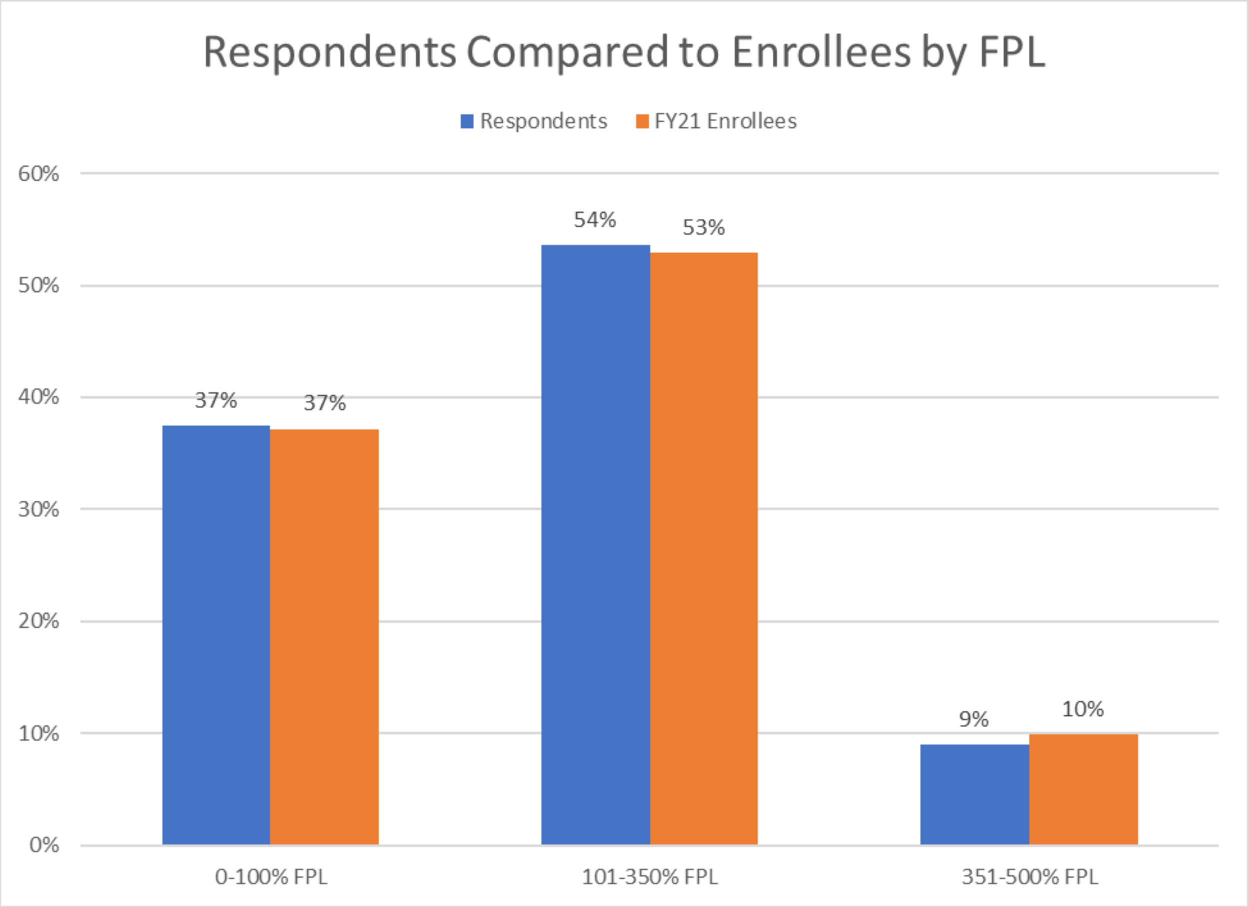




Note that there were three respondents who reported being in the 13-24 age group, but only one was virally suppressed at last result reported to Surveillance, which is statistically significant (and differs from what was self-reported by respondents).

Federal poverty level (FPL)

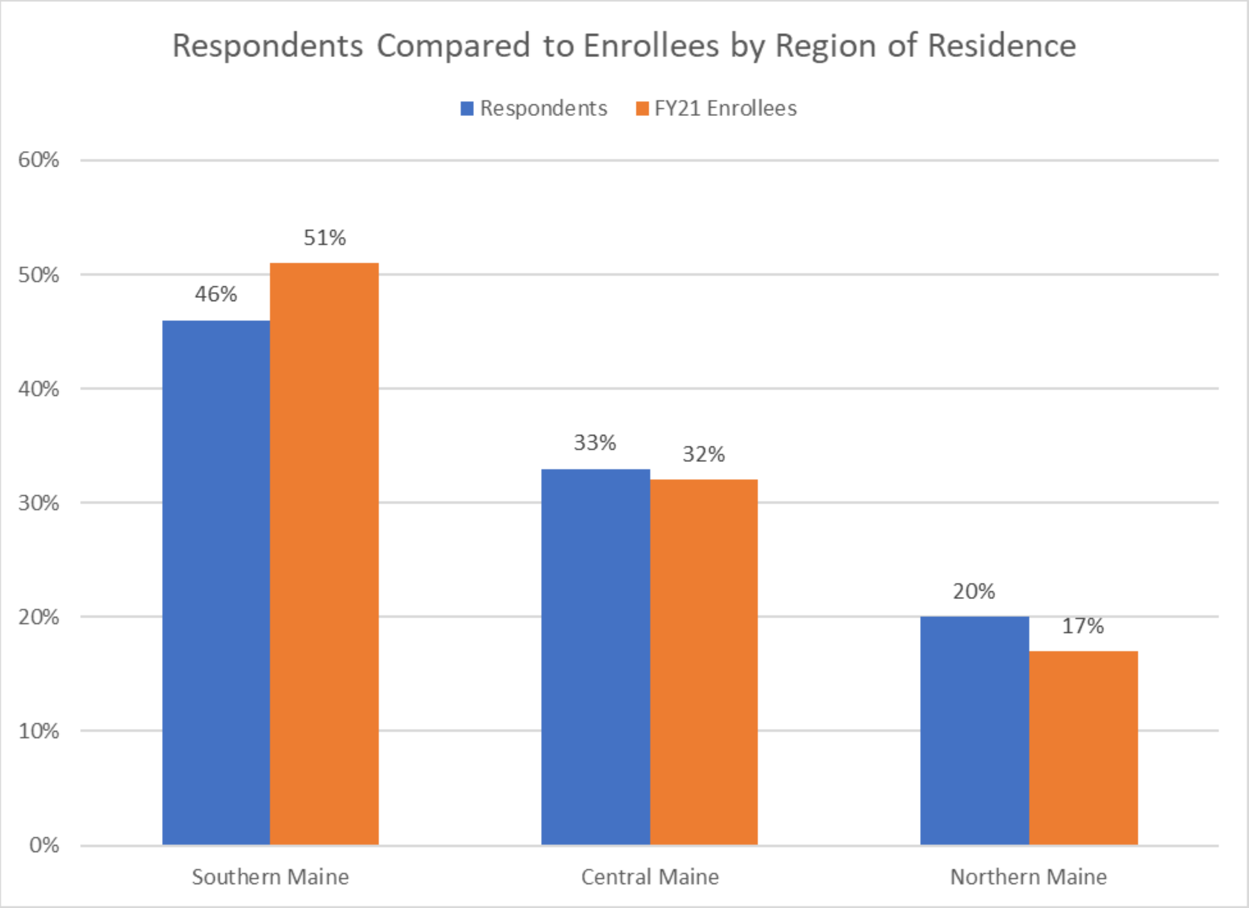
Almost all respondents (91%) have an income under the limit to qualify for RWB financial assistance (350% FPL).



Those with the lowest reported FPL were least likely to report being virally suppressed. While 95% of respondents over 100% FPL reported being virally suppressed at last test, only 85% of those with an FPL of 100% or lower reported same. According to the Surveillance data, about 91% of these respondents were actually suppressed at their last test.

Region of residence

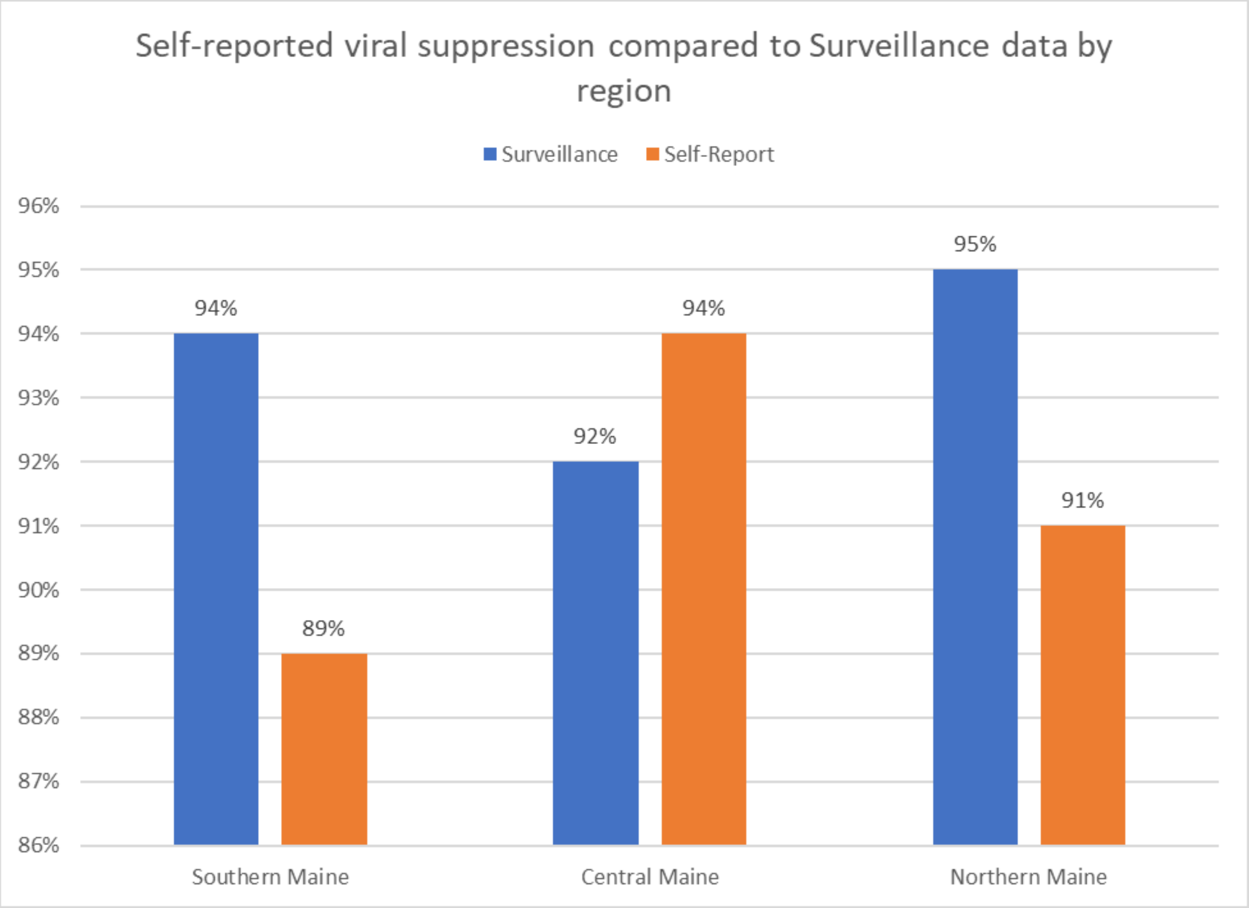
Northern Maine (Aroostook, Hancock, Penobscot, Piscataquis, and Washington counties) is over-represented in survey responses while Southern Maine (Cumberland and York counties) is under-represented. The distribution is about as expected for Central Maine (Androscoggin, Franklin, Kennebec, Knox, Lincoln, Oxford, Sagadahoc, Somerset, and Waldo counties).



Most respondents (78%) indicated that it takes an hour or less to travel one-way to most of the services they want (such as case management and supportive services). An additional 10% indicated that it takes between an hour and two hours and another 2% reported that it takes two or more hours to travel one-way to most services.

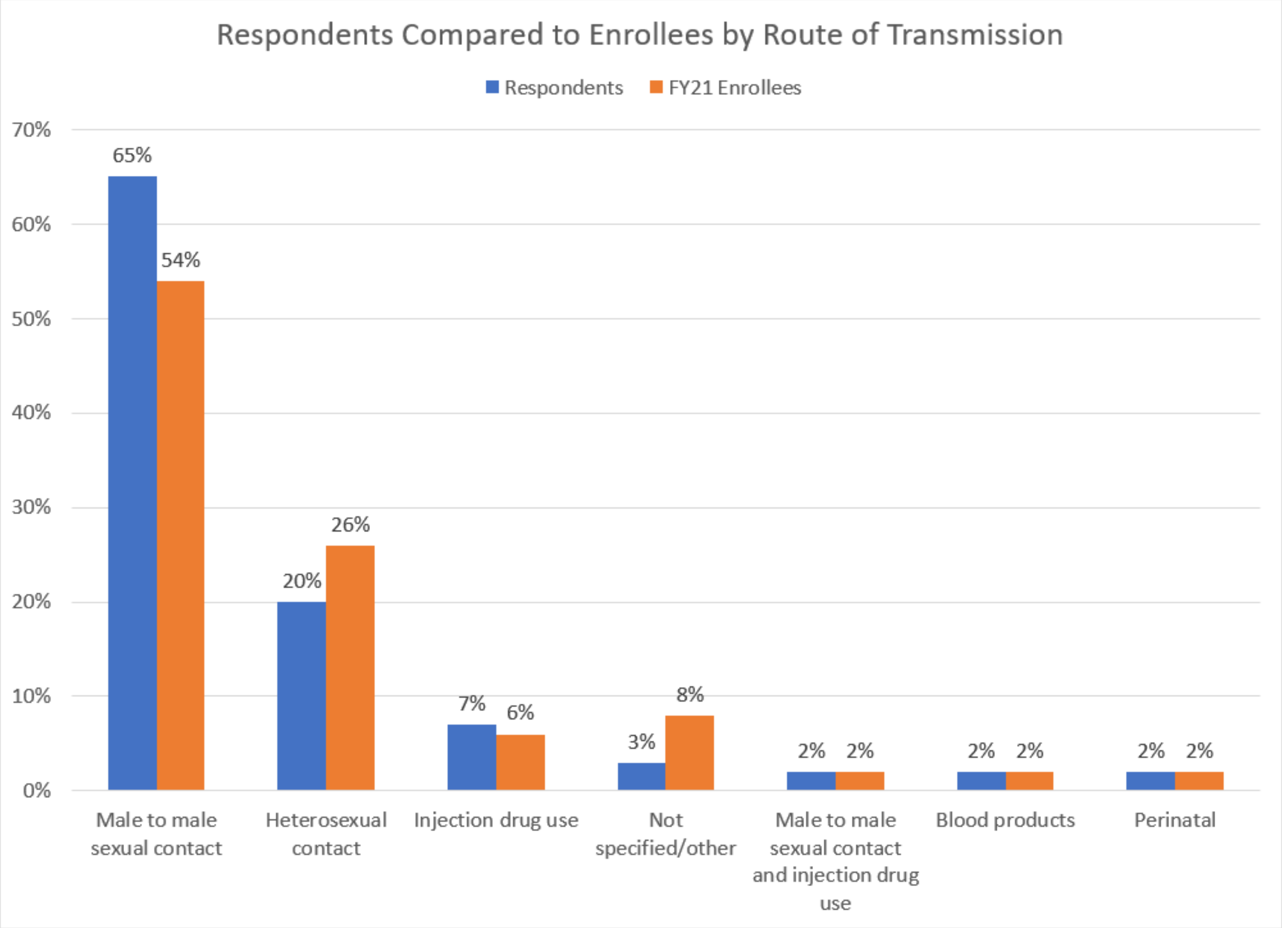
When comparing reported viral suppression to Surveillance data, residents of Southern Maine were most likely to report being unsure of their last result or a result that conflicted with Surveillance, with 89% of respondents self-reporting being suppressed compared to 94% with a suppressed result at last test. This was similar in the Northern Region, where 91% of respondents reported being suppressed compared to 95% who were suppressed at last result in eHARS.

In the Central Region, 94% reported being suppressed at last test, but only 92% were, according to Surveillance data.


Self-reported viral suppression compared to Surveillance data by region
Surveillance
Self-Report
96%
95%
94%
93%
92%
91%
90%
89%
88%
87%
86%
94%
89%
92%
94%
95%
91%
Southern Maine
Central Maine
Northern Maine

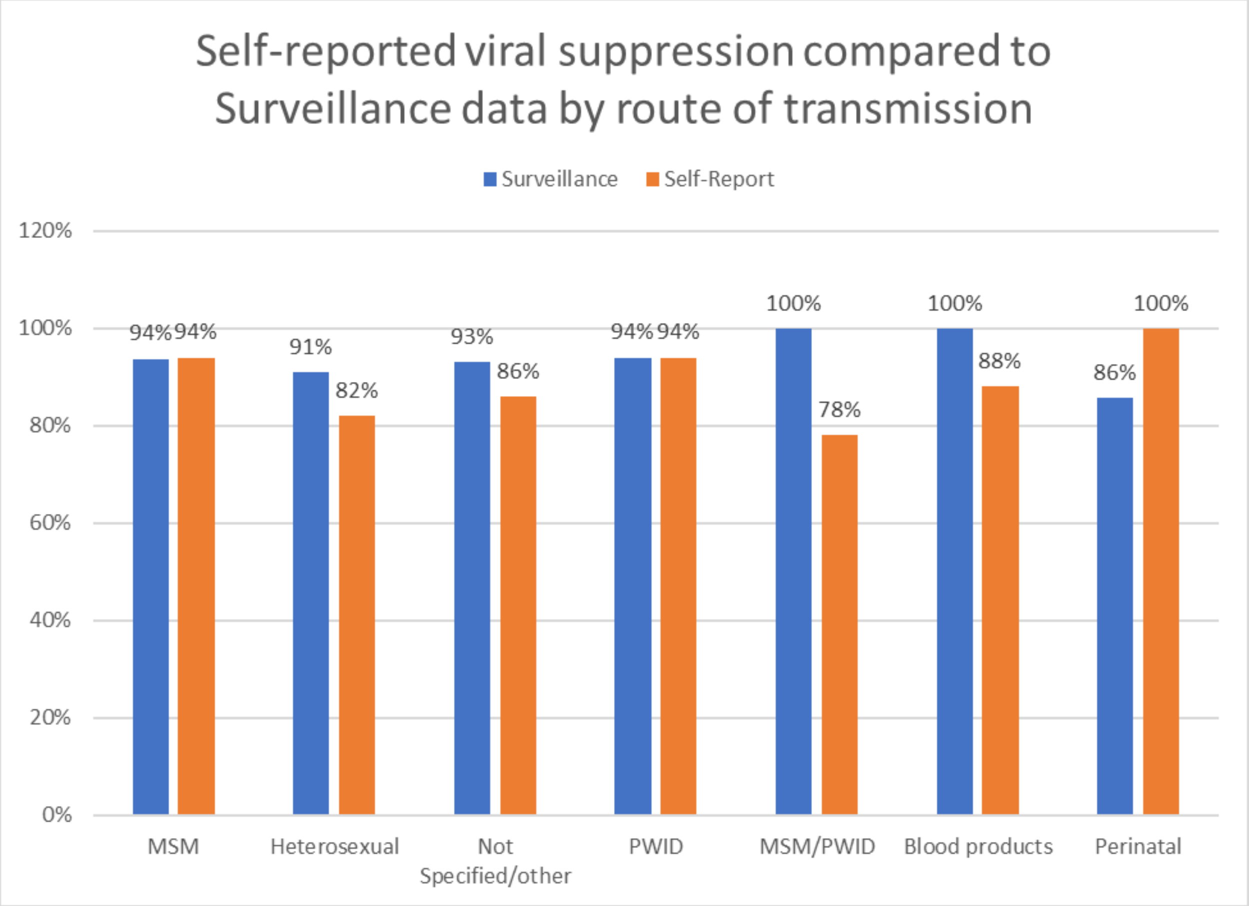
Route of transmission

There is an over-representation of people who acquired HIV through male-to-male sexual contact in survey responses, with under-representations of those who acquired HIV through heterosexual contact or through an unknown/unspecified route.



Although 82% of respondents who contracted HIV through heterosexual sex reported being virally suppressed at last test, Surveillance data show that 92% of these respondents were suppressed at last result.

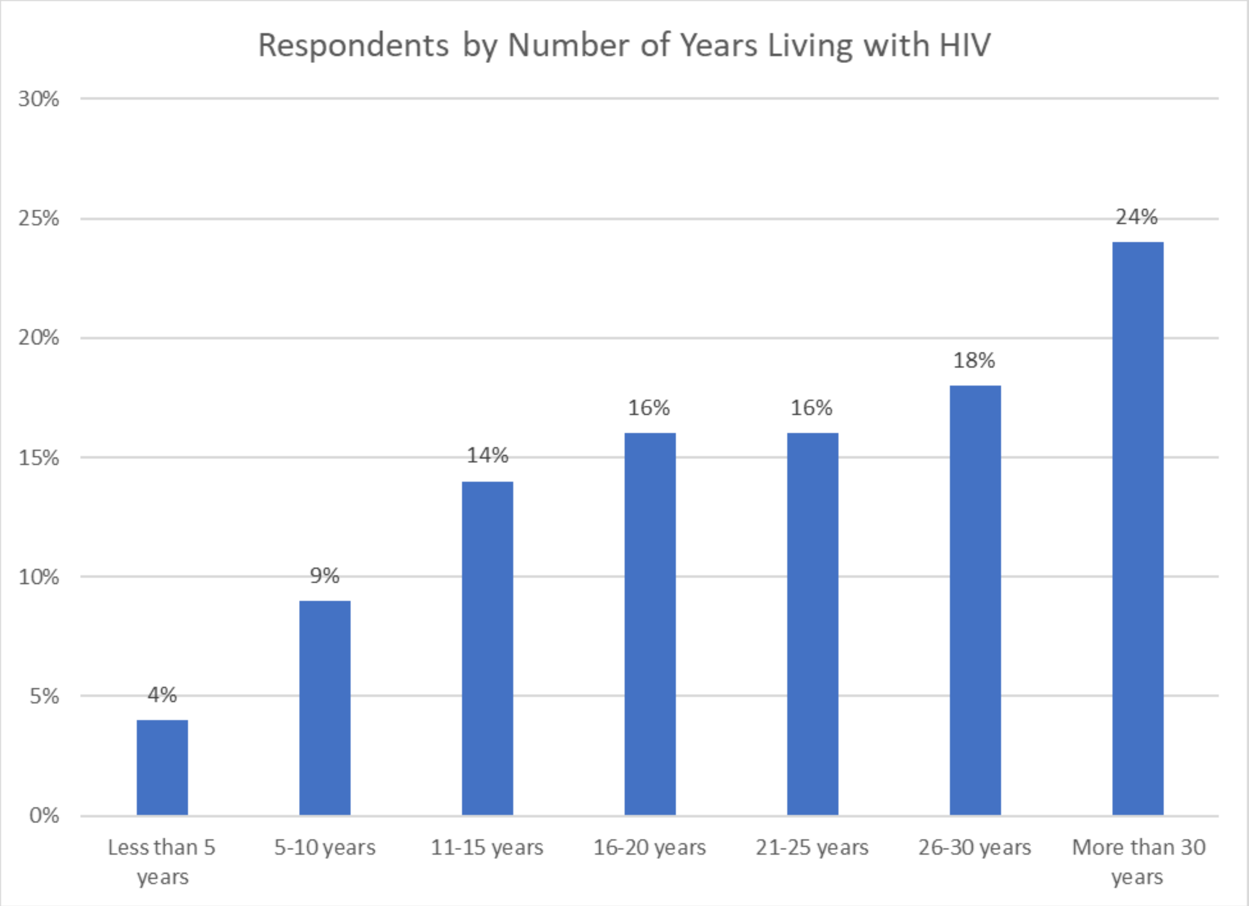
Similarly, 78% of those identified as MSM/PWID reported being virally suppressed at last test, but Surveillance data show that 100% of these respondents were suppressed at last test.



Years living with HIV

The survey included a space for respondents to identify the year they were first diagnosed with HIV. In some cases, the reported year of diagnosis varied from data reported in CAREWare (the RWB Program database) by as much as 20 years. In cases where the reported year of diagnosis was more than five years different from the value in CAREWare, data were compared to initial diagnosis date reported in eHARS (the Surveillance database). When eHARS matched a source, that value was used. CAREWare values were only updated if eHARS and the respondent-reported year matched.

The following breakdown is based on survey responses with updates from eHARS/CAREWare as appropriate:



While these data may not be completely accurate, they do clearly show that most respondents were what would be considered "long-term survivors."

Housing status

The majority of respondents indicated that they have stable housing, including 369 (83%) who own or rent or permanently live with friends or family.

Thirteen respondents (3%) reported three or more living situations during the past year. Of these, four individuals reported staying in a place not meant for human habitation and one reported staying in an emergency shelter.

A total of 31 (7%) respondents indicated that they had fewer changes in housing status but still reported temporary or unstable living situations in the past year. Of these, two individuals reported staying in a place not meant for human habitation and three reported staying in an emergency shelter.

Of those who reported temporary or unstable living situations and/or three or more living situations, about 84% reported being virally suppressed at last result, compared to 91% of all respondents. Of the remaining eight individuals, six reported being unsure of their last result (Surveillance data show that five of these were virally suppressed at last test and one was not) and two reported not being virally suppressed.

Incarceration

More than 15% of respondents (69) indicated that they had been incarcerated at some point. Only three of these indicated that they had been released from a correctional facility in the last 12 months.

Those who reported having been incarcerated account for 29% of those with an unstable living situation in the past year, 69% of those who had three or more living situations in the past year, 50% of those who lived in a place not meant for human habitation, and 50% of those who had stayed in an emergency shelter in the past year.

About 91% of those who reported being incarcerated at some point also reported being virally suppressed at last result, compared to 91% of all respondents.

Injection drug use

Based on certain answers received and feedback from people completing the survey in person, it is possible that respondents were answering about any injectable drugs (including hormones and insulin).

A total of 17 (4%) respondents indicated that they had used injection drugs, although one commented that they had not engaged in this behavior in more than 30 years. Of these:

- Only three were identified as having injection drug use as the likely source of their HIV infection.
- All (100%) indicated that they never shared syringes or works.
- Most (13 or 76%) indicated that they never used Syringe Service Programs (SSPs).
    - Of those remaining: one indicated that they always used SSPs, one indicated that they often did, and two reported that they very seldom use SSPs.
- About three-quarters (76%) reported being virally suppressed at last viral load, compared to 91% of all respondents.
    - Of those who did not report being virally suppressed at last result, one individual reported not being virally suppressed and three reported not being sure of their results. (Surveillance data show that those three individuals had suppressed viral loads at last test.)

Discrimination

In general, respondents did not indicate high frequency of discrimination in the areas identified below.

How often do you experience the following?	Never	Very Seldom	Sometimes	Often	Always	N/A
Ill-treatment or discrimination by your medical provider due to your gender identity	87%	4%	1%	0%	0%	8%
Ill-treatment or discrimination by your medical provider due to your sexual practices	87%	5%	2%	<1%	0%	6%
Ill-treatment or discrimination by your medical provider due to your racial or ethnic identity	89%	2%	<1%	<1%	<1%	7%
Ill-treatment or discrimination by your medical provider due to your HIV status	84%	7%	3%	1%	<1%	5%
Ill-treatment or discrimination by your landlord or prospective landlord because of your HIV status	80%	2%	2%	0%	0%	16%
Fear of using HIV prevention services (such as HIV testing, condoms, PrEP) because of how you feel you would be treated by family, friends, or community members	83%	5%	2%	1%	1%	9%

Of those who reported they experienced discrimination based on gender sometimes, two are female and four are male.

Of those who reported they experienced discrimination based on race or ethnicity sometimes, often, or always, four were Black, one was Native American, and one was multi-racial.

Prevention Services and Risk Behaviors

Infections and risk perception

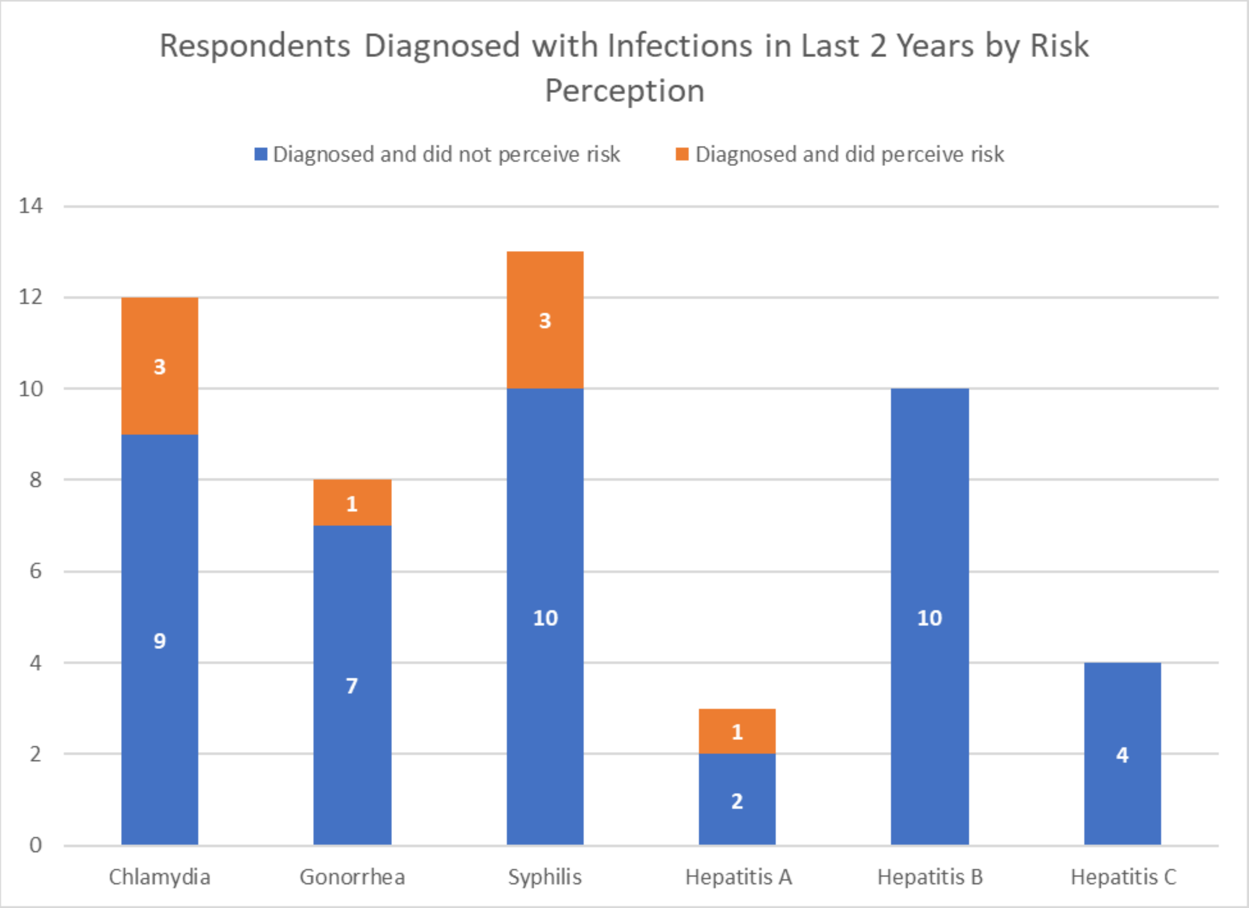
The survey asked the question, “Are there things you are doing that may put you or others at risk for HIV/STDs?”

A total of 18 respondents (4%) reported that there are things they are doing that may put themselves or others at risk for HIV/STDs, but some data are conflicting due to a lack of comparable timeframes in related questions. Of these, 83% reported being virally suppressed at last result.

A total of 40 respondents (9%) reported having been diagnosed with at least one sexually transmitted infection and/or viral hepatitis in the last two years. Of these:

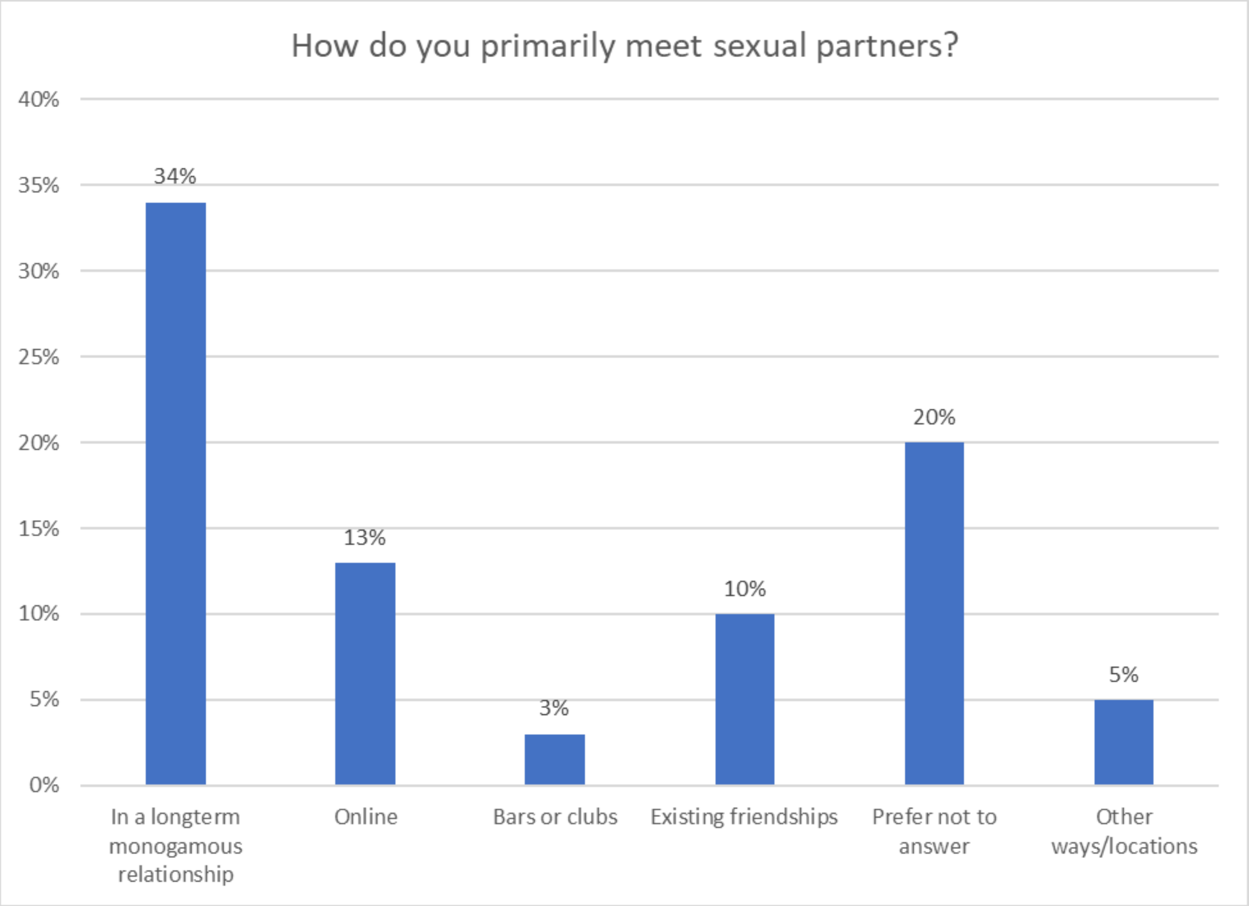
- Thirty (75%) indicated that they were not engaging in behaviors that put themselves or others at risk for HIV/STDs.
    - Ten of these (one-third) indicated that they had not had any sexual partners in the past year.
- Three of these respondents were not virally suppressed at last viral load test. One of the three self-reported being undetectable at last result.

The chart below includes some duplication of individuals, as there were respondents who reported infections with multiple diseases:


Respondents Diagnosed with Infections in Last 2 Years by Risk Perception
Diagnosed and did not perceive risk
Diagnosed and did perceive risk
14
12
10
8
6
4
2
0
3
9
1
7
3
10
1
2
10
4
Chlamydia
Gonorrhea
Syphilis
Hepatitis A
Hepatitis B
Hepatitis C

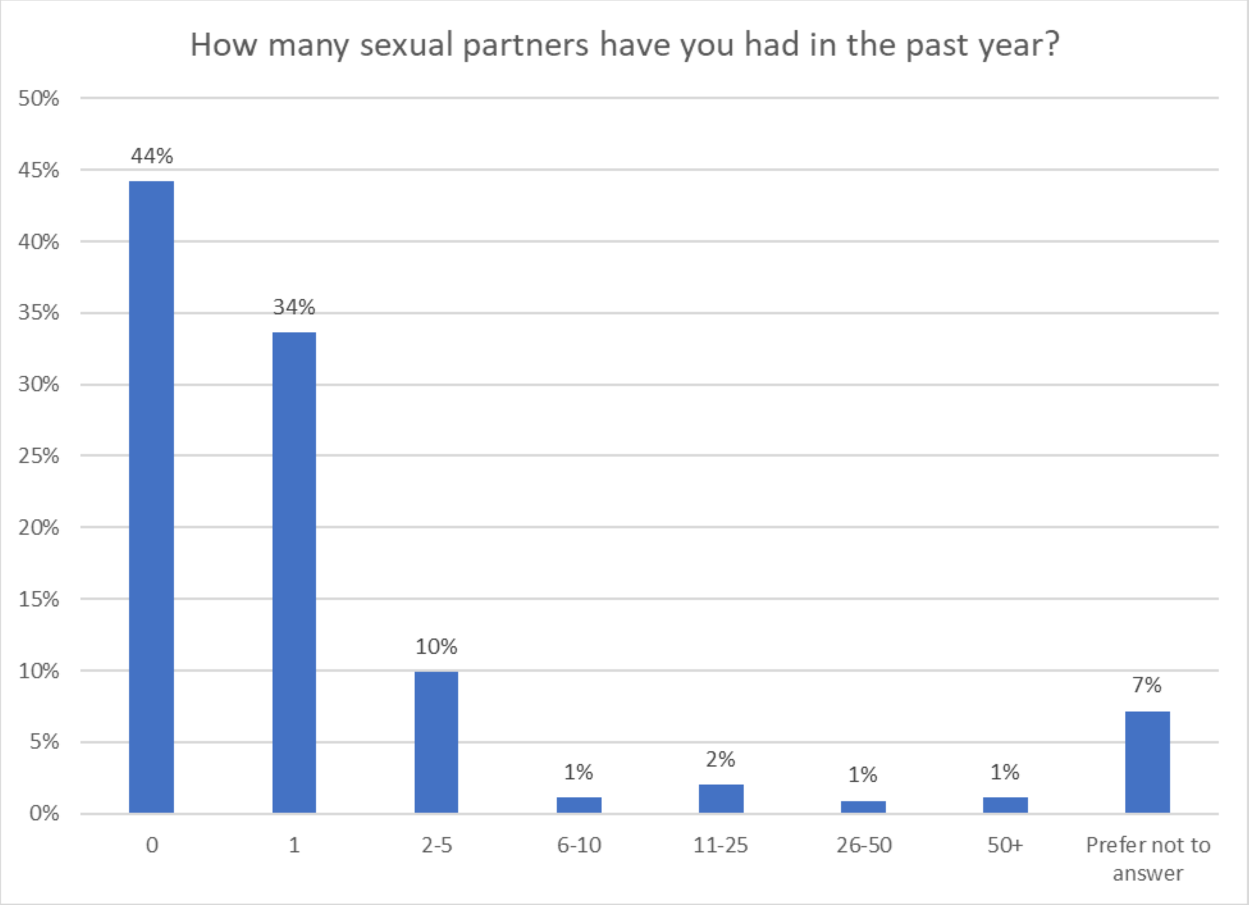
Sexual history

About 58% of respondents selected at least one answer about how they primarily meet sexual partners. The most common response was that they were already in a long-term monogamous relationship.



Only 14 respondents (out of 59 who identified meeting partners online) identified the apps or websites they use. All 14 (100%) listed Grindr. Four (29%) also listed Scruff while three (21%) also listed Manhunt.

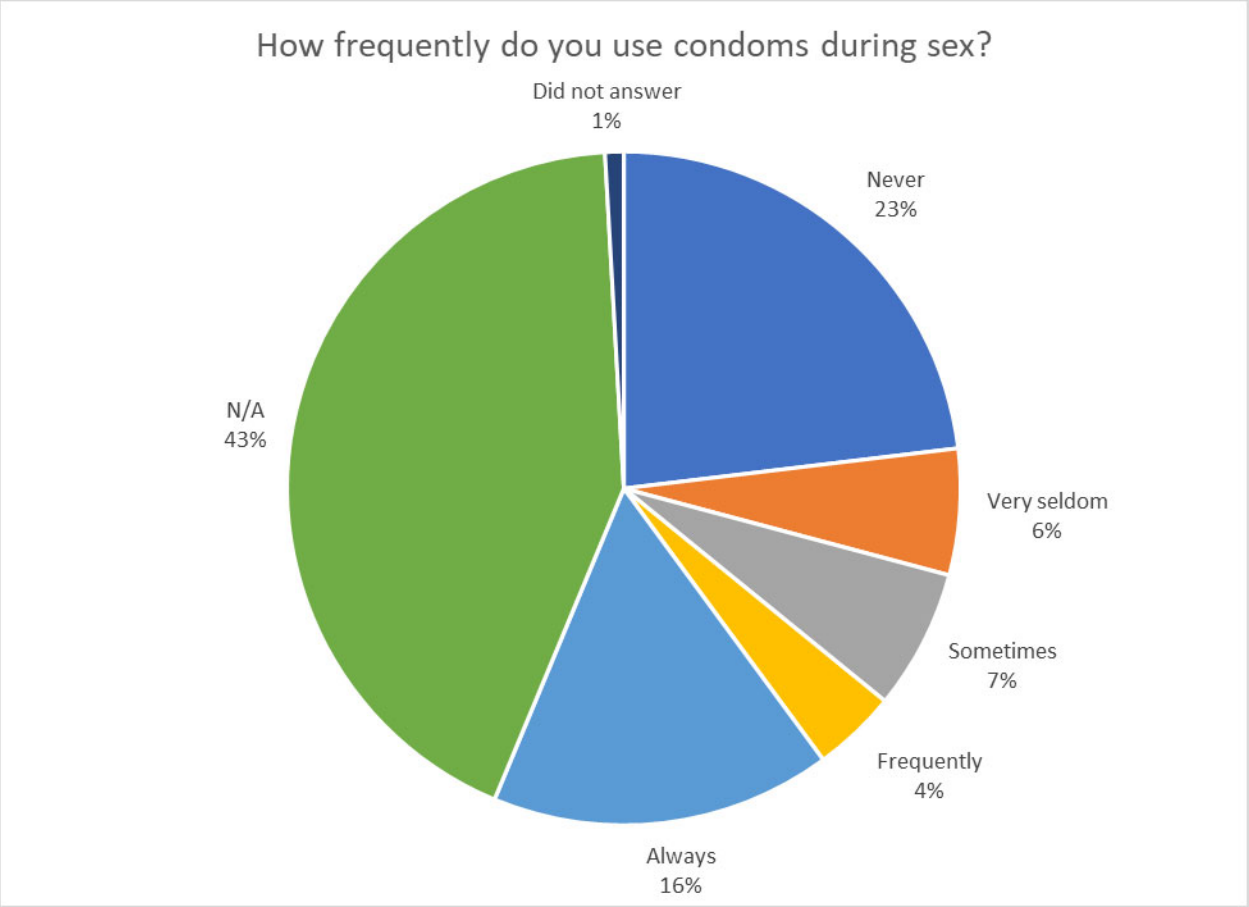
Most respondents (78%) indicated that they had had one or no sexual partners in the past year.



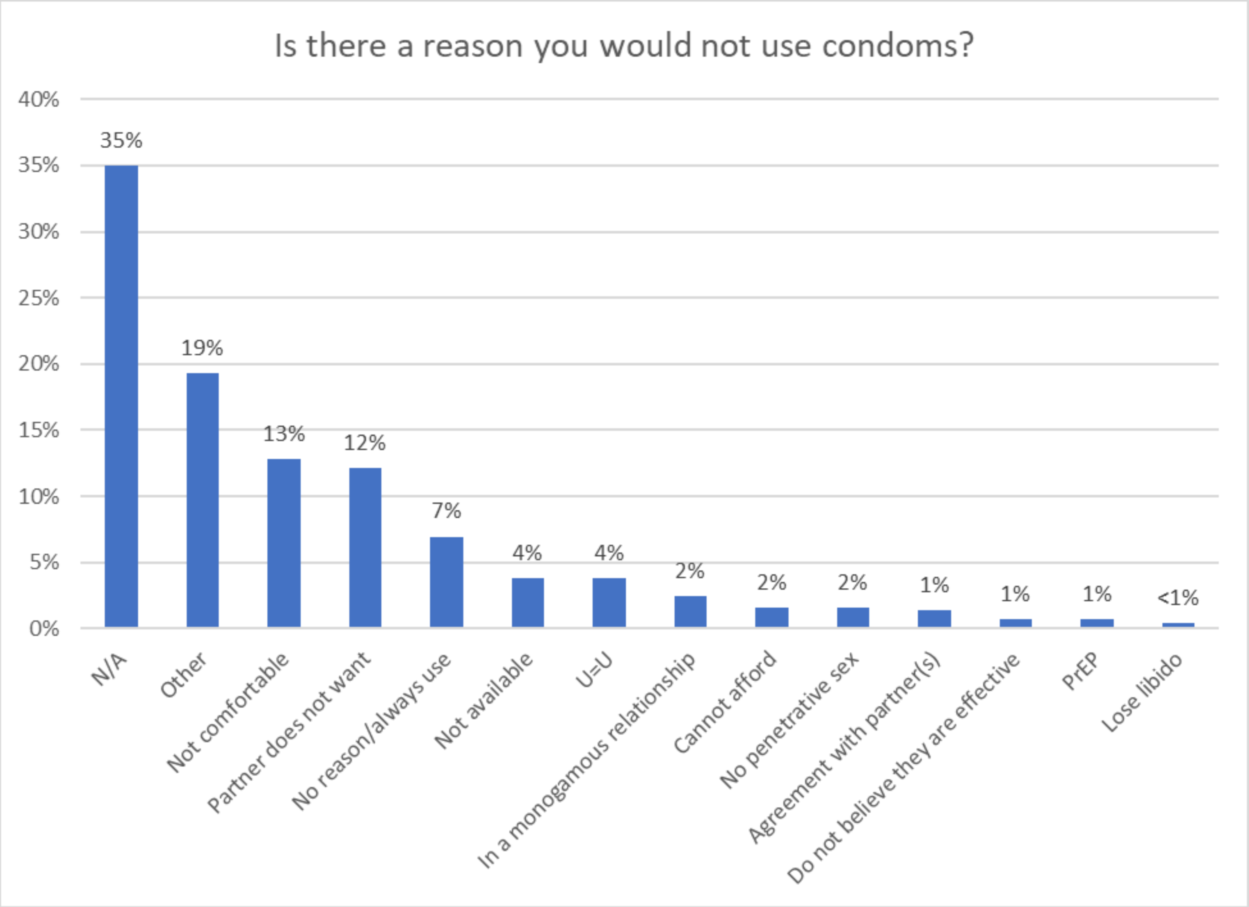
A total of 45 respondents (10%) indicated that they had ever exchanged sex for money, substances, or goods.

Condom use

About 59% of respondents indicated that they use condoms always or that it is not applicable to them.



The survey asked if there was a reason the respondent would not use condoms with checkboxes for multiple answers. The most common response (written in under "other") was N/A.



Pre-Exposure Prophylaxis (PrEP)

About two-thirds of respondents (66%, 295 individuals) have heard of PrEP. Of these:
- 64% are very or pretty comfortable speaking about PrEP with partners
- 18% selected N/A
- 10% are not very or not at all comfortable speaking about PrEP with partners
- 7% were somewhat comfortable speaking about PrEP with partners

Care Services and Unmet Needs

HIV medical care

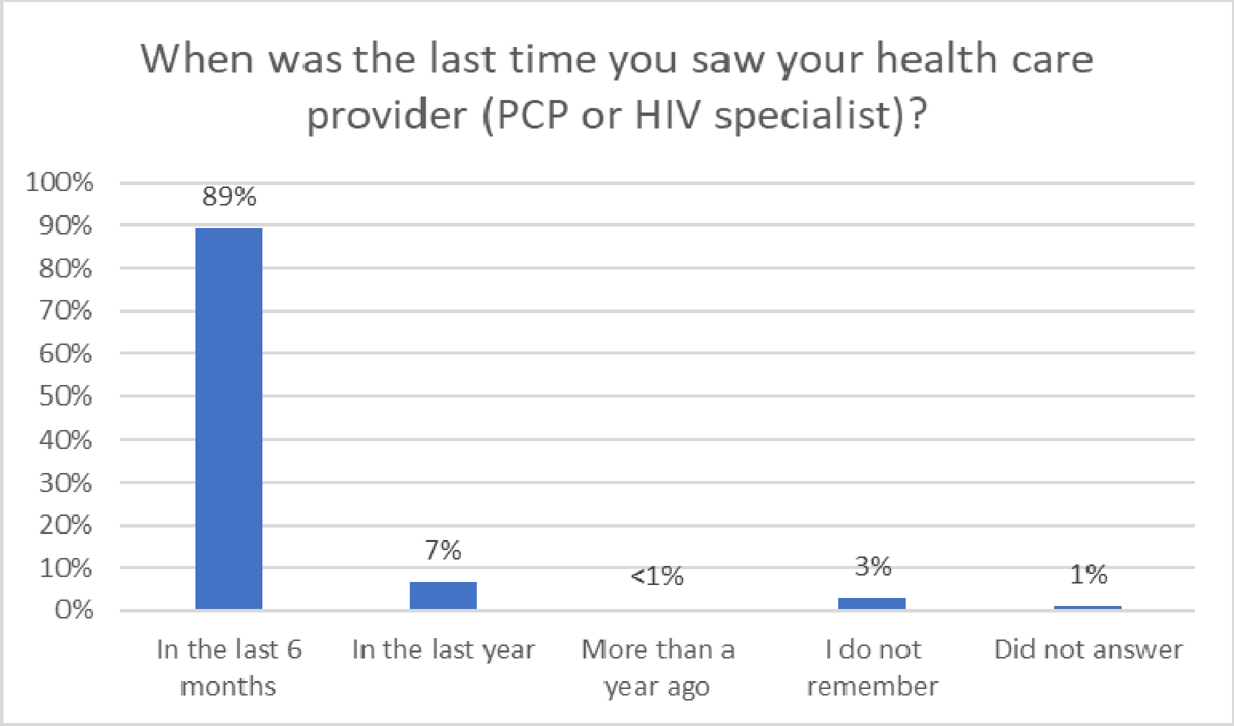
Most respondents (87%) indicated that they are comfortable speaking with their medical provider about their sexual history.

Nineteen respondents (4%) indicated that they require an interpreter to speak with their medical provider all of the time or sometimes. The languages they speak at home are:

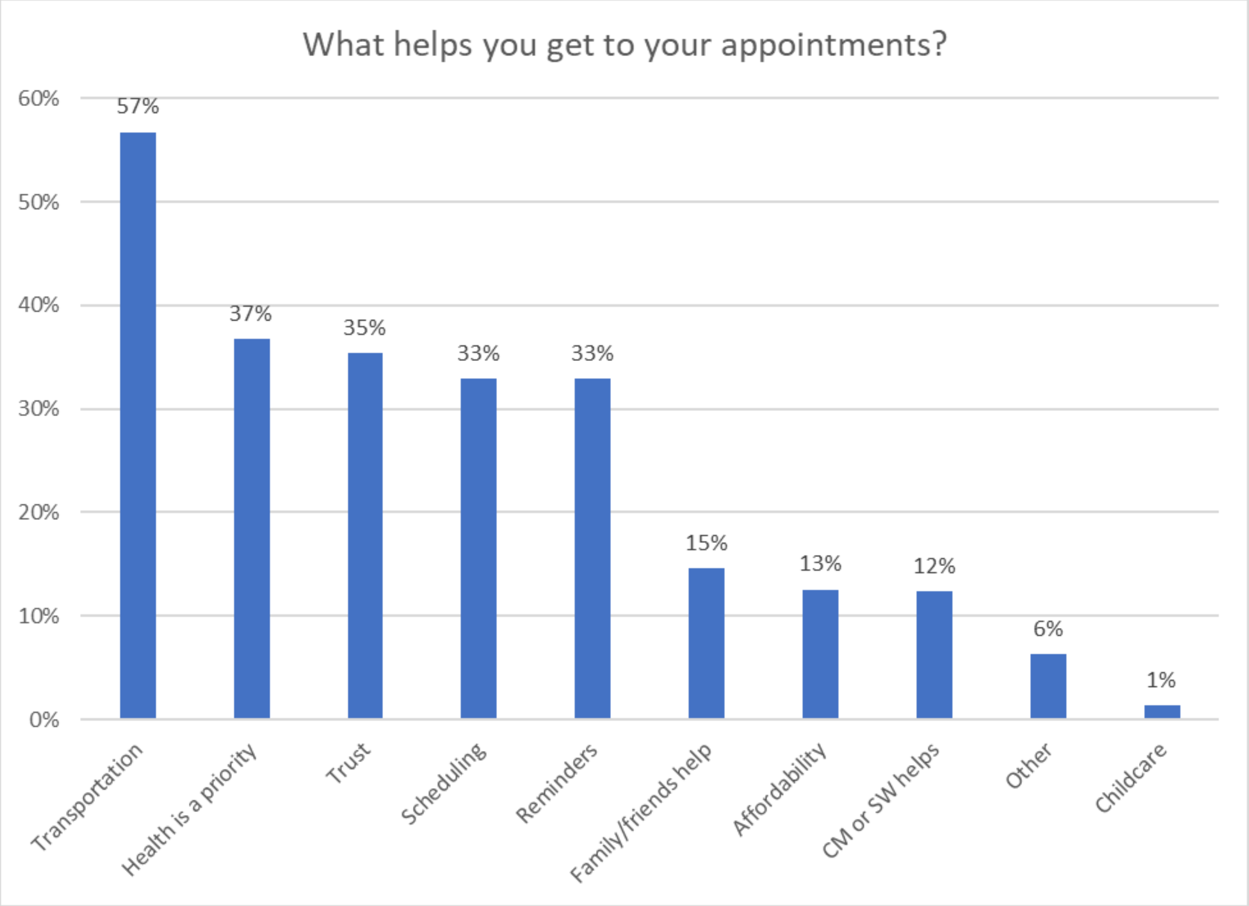
- English only (4)
- French (4)
- ASL (3)
- Spanish (2)
- Arabic (2)
- Kirundi (2)
- Kinyarwanda (1)
- Lingala (1)
- Portuguese (1)
- Vietnamese (1)

A total of 29 respondents (7%) indicated that they at least sometimes have difficulty communicating with their medical provider.

Most respondents (96%) have seen their health care provider (primary and/or HIV specialist) in the past year.



The survey asked what helps get the respondent to their appointments with checkboxes for multiple answers. Transportation was the most common response.



Most respondents (79%) indicated that it takes an hour or less to travel one-way to their HIV medical care. An additional 12% indicated that it takes between an hour and two hours and another 4% reported that it takes two or more hours to travel one-way to their HIV medical care.

As of March 31, 2022, Maine has more designated Primary Care Health Professional Shortage Areas than any other state in Region 1, with a total of 76 (11 more than Massachusetts with the next-highest number of designations). However, Maine only needs 21 practitioners to remove the designations, which is less than Connecticut (61) and Massachusetts (104). [1]

Health outcomes

About 91% of respondents indicated that they were virally suppressed at last test, compared to 93% based on labs reported in eHARS.

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[1] Source: Designated Health Professional Shortage Areas Statistics, Second Quarter of Fiscal Year 2022 Designated HPSA Quarterly Summary, as of March 31, 2022.

As has been noted elsewhere in this report, there are instances where respondents' self-report of their last viral load does not match Surveillance. This could be related to timing of the survey in comparison to Surveillance records reported by healthcare providers, but it may indicate an area of confusion for clients.

About 7% of respondents (31 individuals) reported not being sure of their last viral load at the time of the survey. Of these, one had not had a viral load reported in the past year and three had unsuppressed viral loads at last test.

There were three individuals (<1% of respondents) who reported that their last viral load was suppressed or undetectable while the last result in eHARS indicates the result was not suppressed (more than 200 copies/mL).

Disparities

The following data were prepared using a tool developed by the Ryan White Part A Phoenix EMA to calculate disparities related to viral suppression utilizing test results from eHARS. The only statistically significant disparity noted was among people age 13-24, as previously noted.

Ryan White Part B Needs Assessment Respondents

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
All Clients	**446**	**9**	**20**	**417**	**93%**		
Male	359	7	16	336	94%	0.1%	Not Sig
Female	83	2	4	77	93%	-0.7%	Not Sig
Transwomen	4	0	0	4	100%	6.5%	Not Sig

Race and ethnicity

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
White	374	6	17	351	94%	0.4%	Not Sig
Black	45	1	1	43	96%	2.1%	Not Sig
More than one race	17	1	2	14	82%	-11.1%	Not Sig
Asian	5	0	0	5	100%	6.5%	Not Sig
Other	3	0	0	3	100%	6.5%	Not Sig
Native American	2	1	0	1	50%	-43.5%	Not Sig
Not Hispanic/Latinx	424	7	20	397	94%	0.1%	Not Sig
Hispanic/Latinx	22	2	0	20	91%	-2.6%	Not Sig

Age groups

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
0-12	1	0	0	1	100%	6.5%	Not Sig
13-24	3	2	0	1	33%	-60.2%	Sig
25-44	56	2	4	50	89%	-4.2%	Not Sig
45-54	93	3	6	84	90%	-3.2%	Not Sig
55-59	77	1	1	75	97%	3.9%	Not Sig
60-64	93	0	4	89	96%	2.2%	Not Sig
65-74	106	1	3	102	96%	2.7%	Not Sig
>= 75	17	0	2	15	88%	-5.3%	Not Sig

Last FPL reported in FY21

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
0-100%	164	8	6	150	91%	-2.0%	Not Sig
101-350%	246	1	12	233	95%	1.2%	Not Sig
351-500%	36	0	2	34	94%	0.9%	Not Sig

Route of transmission

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
MSM	288	4	13	271	94%	0.6%	Not Sig
Heterosexual	87	4	4	79	91%	-2.7%	Not Sig
PWID	33	0	2	31	94%	0.4%	Not Sig
Not Specified/other	14	0	1	13	93%	-0.6%	Not Sig
MSM/PWID	9	0	0	9	100%	6.5%	Not Sig
Blood products	8	0	0	8	100%	6.5%	Not Sig
Perinatal	7	1	0	6	86%	-7.8%	Not Sig

Housing stability

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
Stable/permanent	378	5	16	357	94%	0.9%	Not Sig
Temporary/unstable	44	3	4	37	84%	-9.4%	Not Sig
Other	24	1	0	23	96%	2.3%	Not Sig

Incarceration

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
Not formerly incarcerated	334	5	16	313	94%	0.2%	Not Sig
Formerly incarcerated	69	3	2	64	93%	-0.7%	Not Sig
Prefer not to answer	43	1	2	40	93%	-0.5%	Not Sig

Injection drug use

Populations/Subpopulations	Total	Unsuppressed	Not reported	Suppressed	% Suppressed	Disparity	Sig Disparity
Did not report injection drug use	415	9	17	389	94%	0.2%	Not Sig
Reported injection drug use	18	0	2	16	89%	-4.6%	Not Sig
Prefer not to answer	13	0	1	12	92%	-1.2%	Not Sig

Vaccinations

Most respondents (83%) reported having all of their COVID-19 vaccinations (including boosters) with an additional 8% who had been vaccinated against COVID-19 but had not had all boosters available to them.

Most respondents (78%) reported having a flu vaccine, although the question did not ask if this was an annual practice.

About 60% reported being vaccinated against Hepatitis B and 57% reported being vaccinated against Hepatitis A.

About one-quarter of respondents (24%) reported being vaccinated against human papillomavirus.

A total of 22 respondents (5%) indicated that they had not had any of the above-mentioned vaccines.

HIV treatment

All but 15 respondents (97%) reported that they had taken HIV medications in the past year. Of the 15 who reported not taking HIV medications in the past year:

- Three had an unsuppressed viral load at last result reported in eHARS. Two of these respondents indicated that they their last viral load was unsuppressed, while the third reported that their last result was undetectable, which may indicate a need for education.
- About three-quarters (73%) indicated that they have seen their medical provider in the past year.

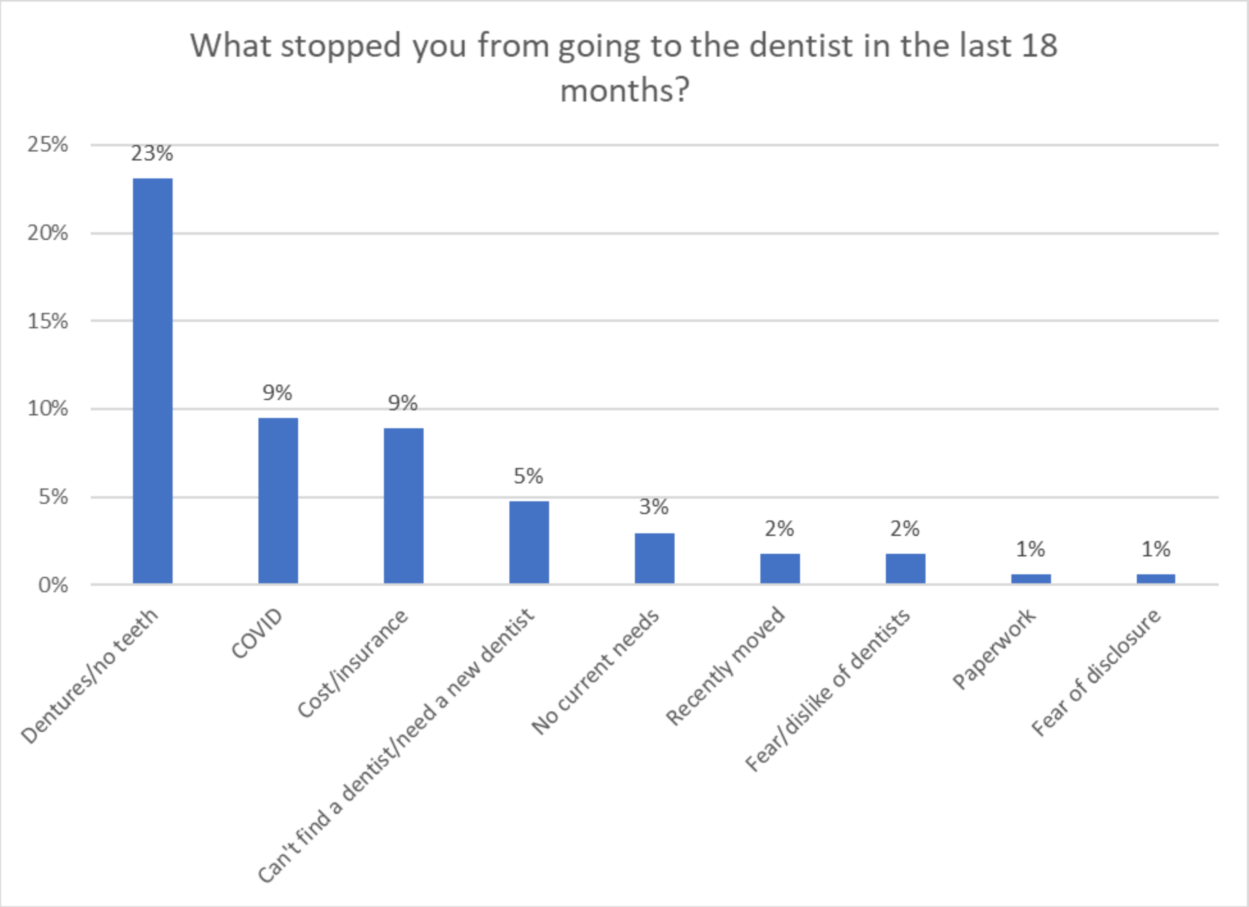
About 12% of respondents (53 individuals) reported ever having stopped taking their HIV medication without the advice of their doctor.

Most respondents (93%) indicated that they understand how and when to take all of their HIV medications. One individual reported being pretty confused about their HIV medications and another reported that they did not understand their medications at all. Both individuals have case managers, saw their health care provider in the last six months, and had an undetectable viral load at last result.

Dental care

Only 277 respondents (62%) reported having seen a dentist in the last 18 months.

Of those who identified a reason why they did not see a dentist in that timeframe, the most common response was that they had dentures or no teeth (23%).



All but one of the respondents who indicated that cost was the reason for not going to the dentist meet the income limit for RWB dental assistance.

Dental care was the fourth-most identified unmet need reported later in the survey by 19% of respondents.

As of March 31, 2022, Maine has more designated Dental Health Professional Shortage Areas than any other state in Region 1, with a total of 92 (33 more than Massachusetts with the next-highest number of designations). Maine needs 58 practitioners to remove the designations, which is only less than Connecticut (101). [2]

HIV case management

The survey asked respondents to identify which, if any, agency provided their HIV case management. Data in CAREWare are real-time, so it is possible that some changes have

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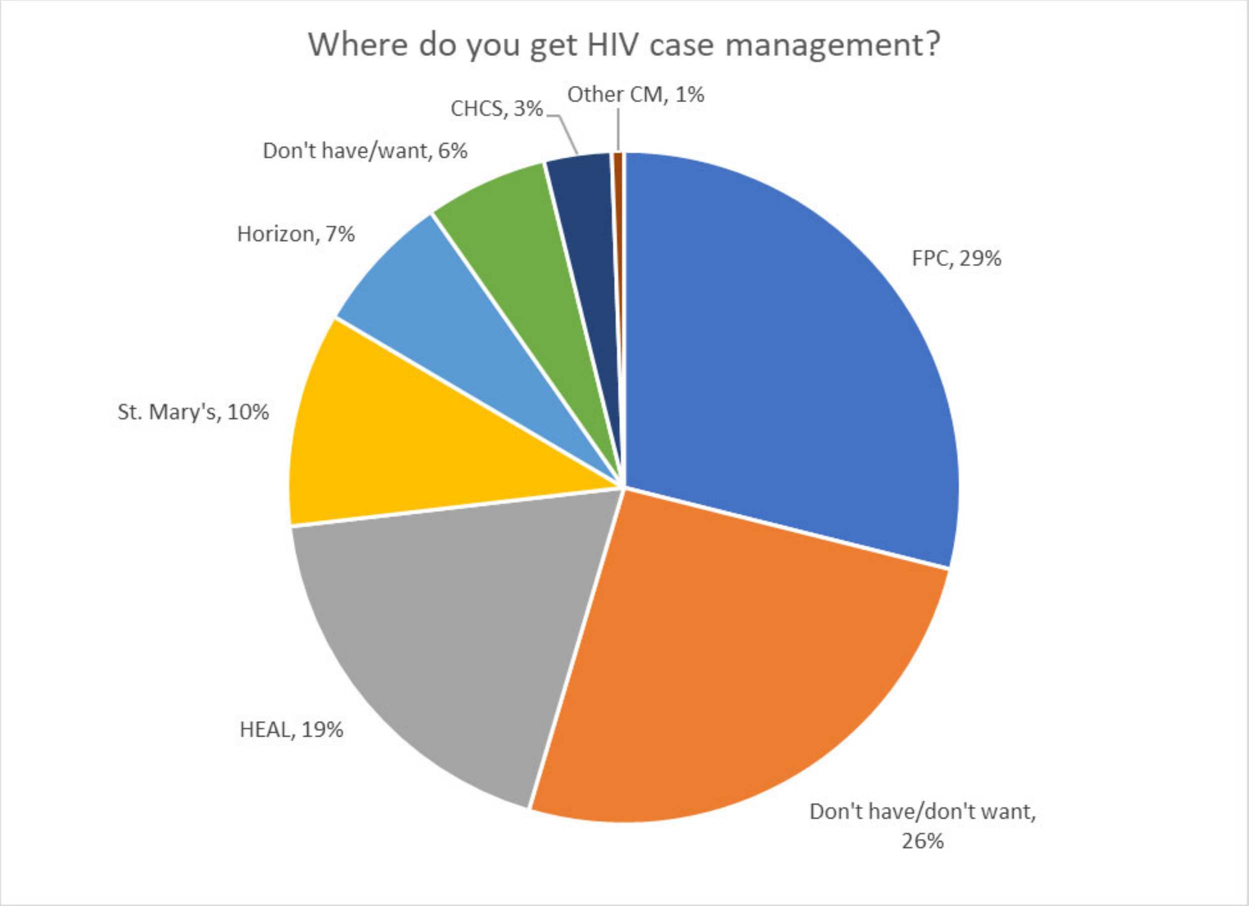
[2] Source: Designated Health Professional Shortage Areas Statistics, Second Quarter of Fiscal Year 2022 Designated HPSA Quarterly Summary, as of March 31, 2022.

occurred for respondents in between when they submitted their surveys and when data were analyzed.

However, comparing responses to current CAREWare data showed discrepancies for 48 respondents. Of those, 25 individuals indicated they had a case manager at the time of the survey, but current CAREWare data show that they do not. Another eight respondents indicated that they didn't have or want case management but currently have a case manager assigned in CAREWare.

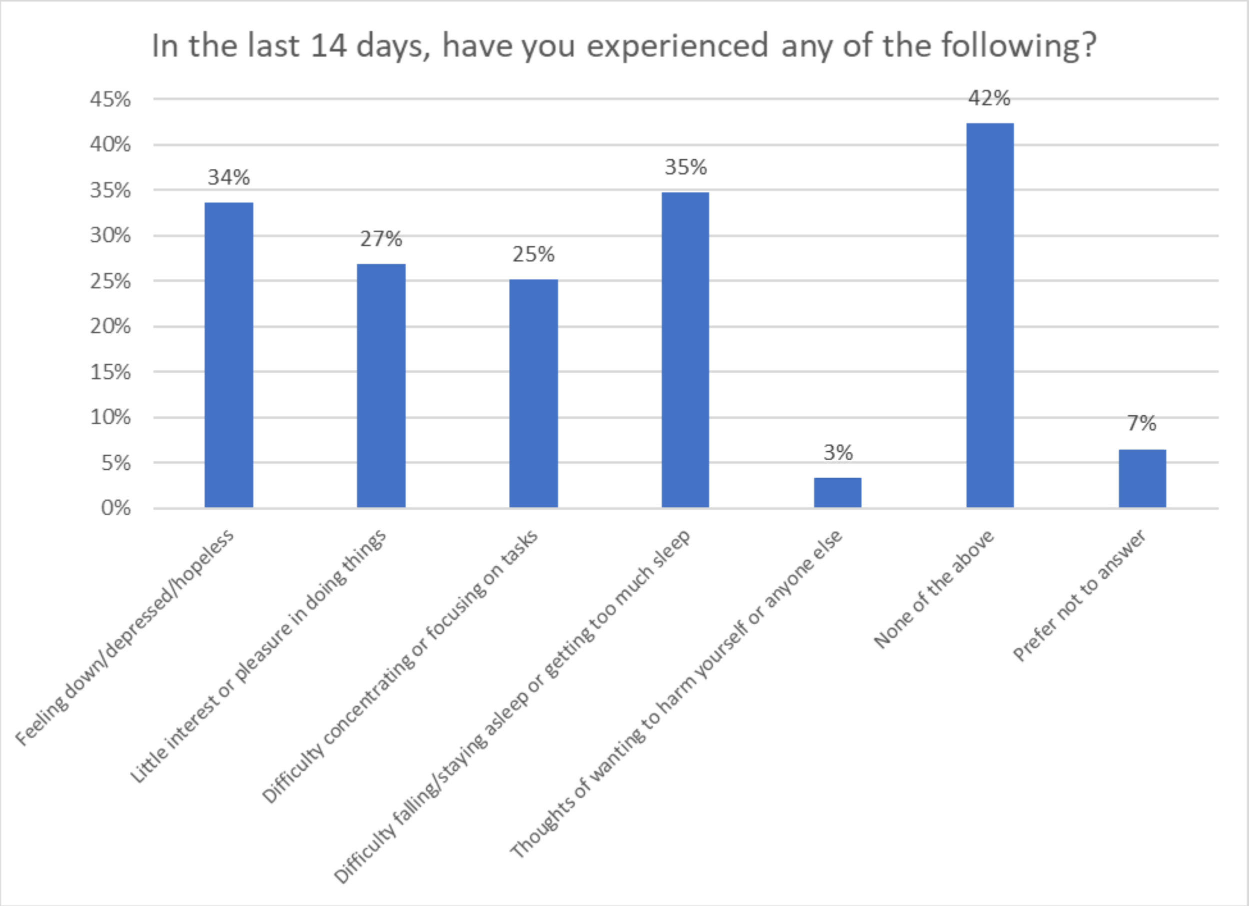
About three-quarters (76%) of respondents identified a case management agency that matches current CAREWare data. The chart below shows the breakdown of their responses:



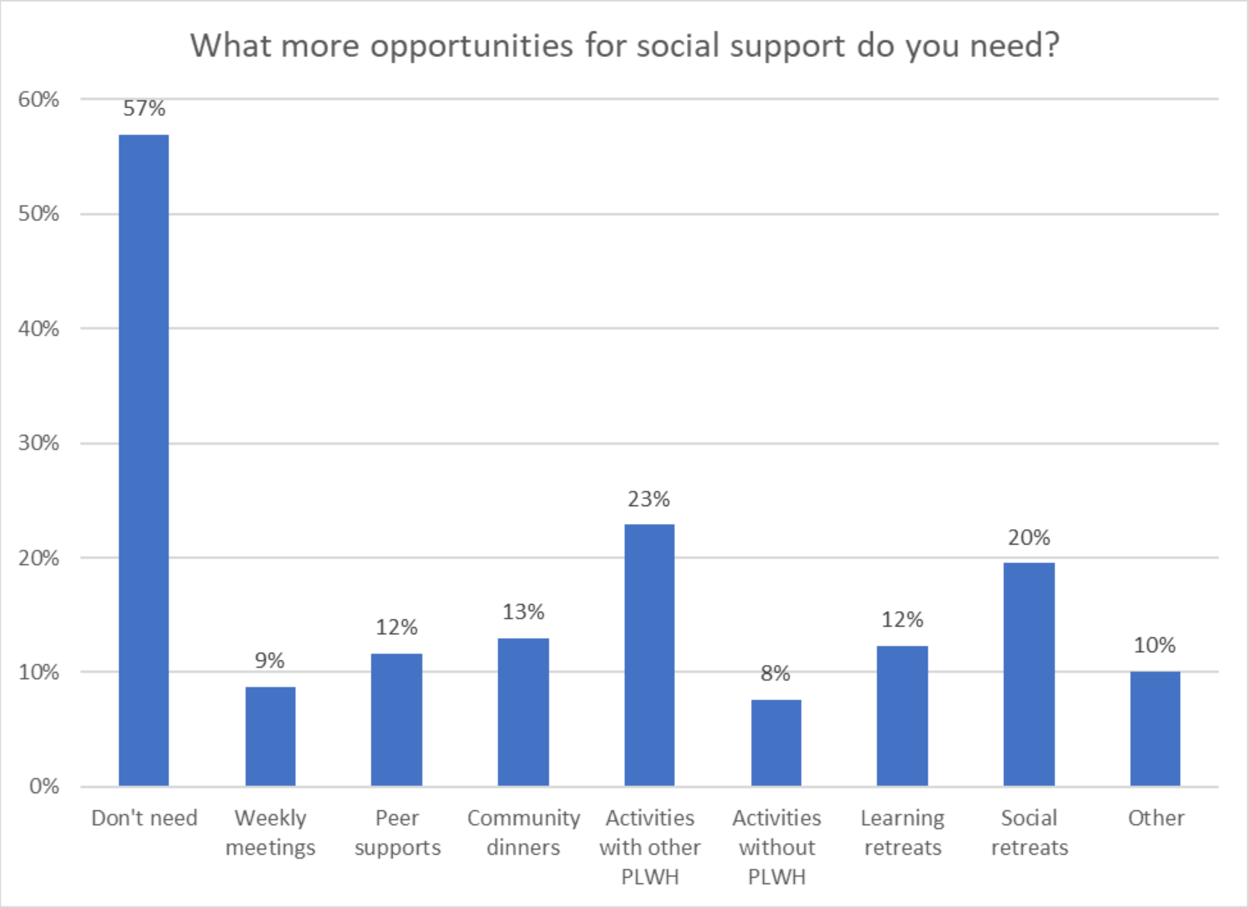
Of the 28 respondents (6%) who identified HIV case management as an unmet need later in the survey, nearly half reported that they either had case management or did not have and did not want case management.

Mental health and social support

The survey included a question with multiple choices where respondents were asked to identify if they had experienced certain symptoms of depression and anxiety in the last 14 days. The most common response was "none of the above," identified by 42%. However, about one-quarter of respondents indicated that they had little interest or pleasure in doing things (27%) and difficulty concentrating or focusing on tasks (25%). In addition, more than one-third of respondents indicated feeling down/depressed or hopeless (34%) and having difficulty with sleep (35%). Fifteen individuals (3%) reported thoughts of wanting to harm themselves or others.



More than half of all respondents (57%) indicated that they did not need additional social supports. The chart below includes some duplication of individuals, as respondents could select multiple options:



As of March 31, 2022, Maine has more designated Mental Health Care Health Professional Shortage Areas than any other state in Region 1, with a total of 66 (9 more than Massachusetts with the next-highest number of designations). Maine needs 29 practitioners to remove the designations, which is only less than Connecticut (83). [3]

Unmet needs

The survey asked respondents to identify the services they needed but did not have. The most-identified areas of unmet needs were:

- Food (21%)
- Alternative therapies (20%)
- Paying for utilities (19%)
- Dental care (19%)
- Eye care (17%)
- Paying for housing (15%)

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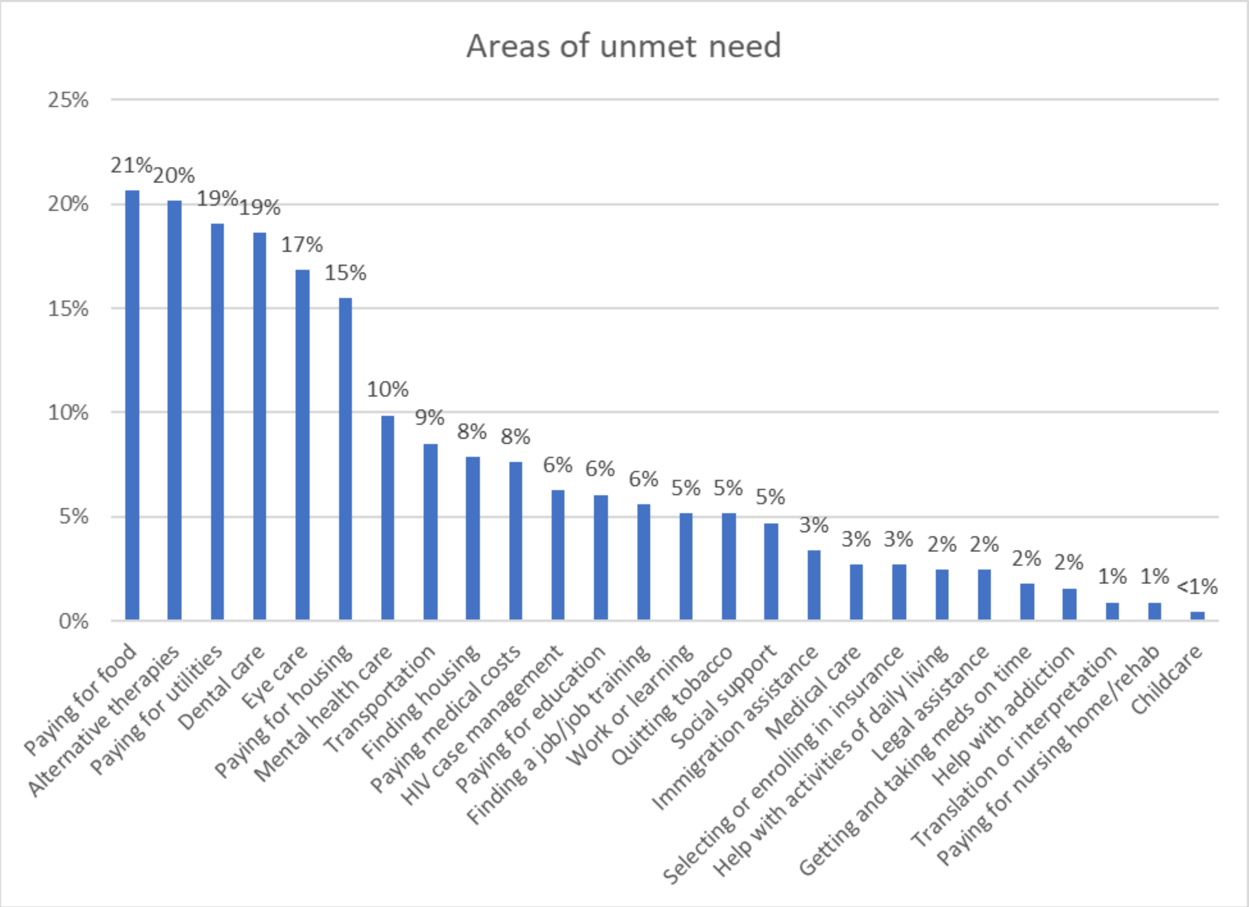
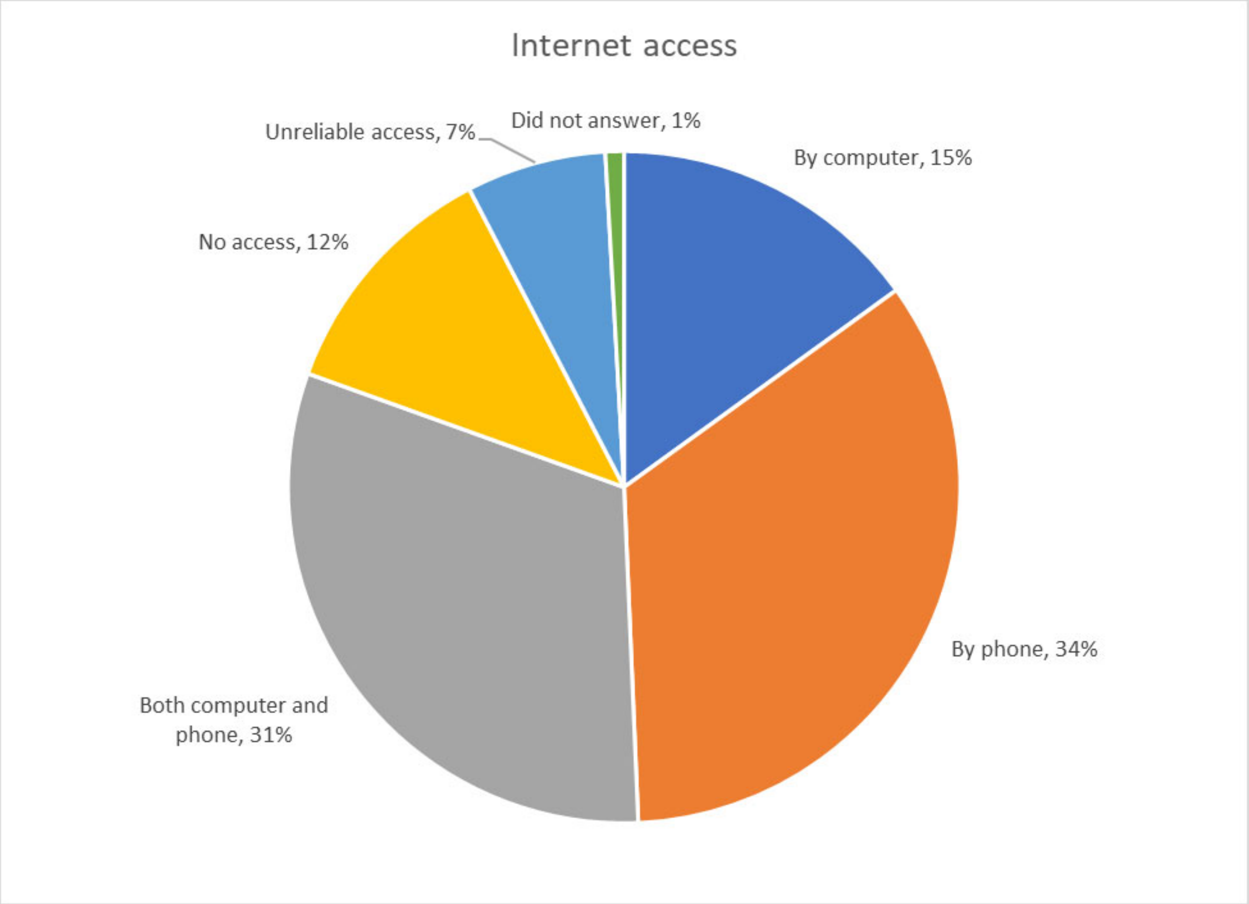
[3] Source: Designated Health Professional Shortage Areas Statistics, Second Quarter of Fiscal Year 2022 Designated HPSA Quarterly Summary, as of March 31, 2022.

The chart below includes some duplication of individuals, as respondents could select multiple options:



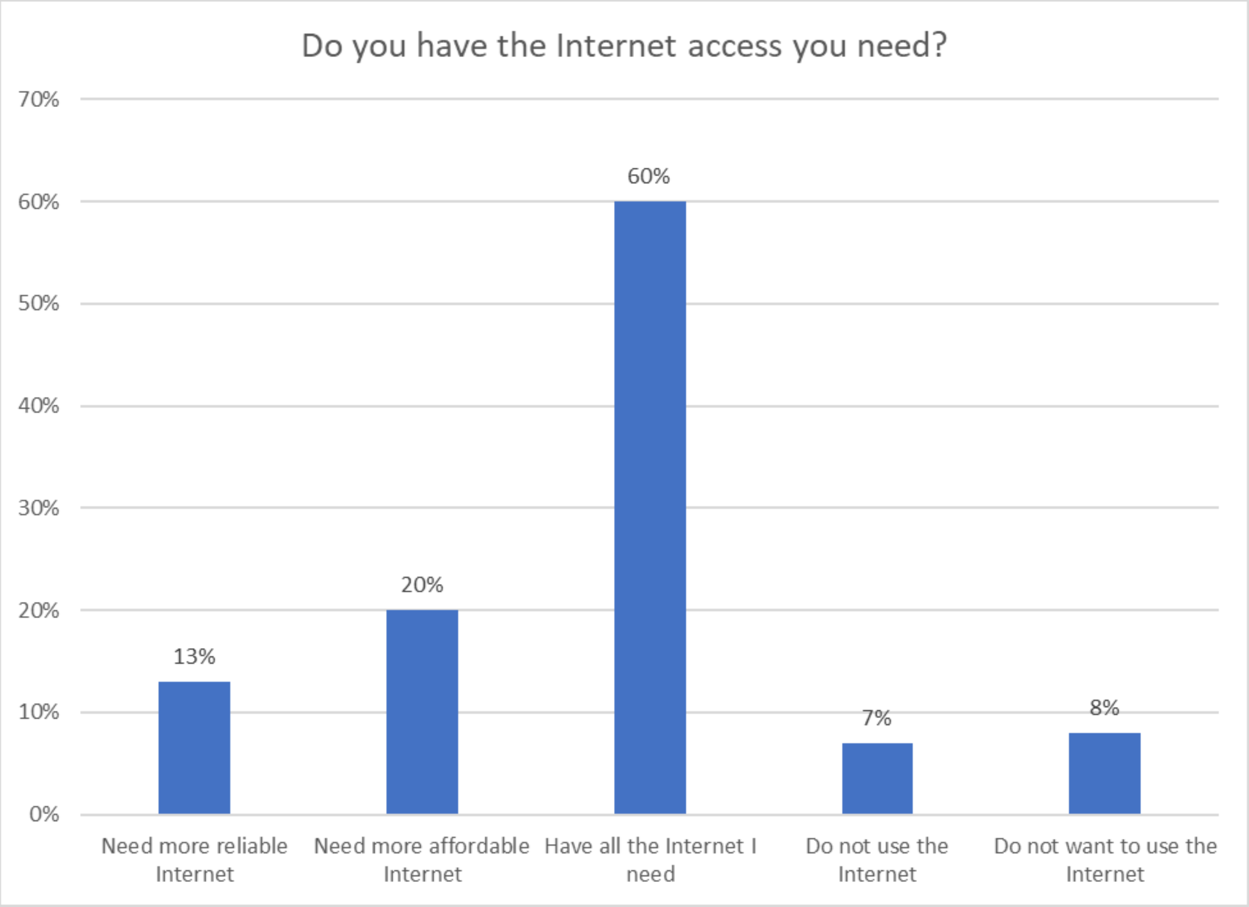
Most respondents (65%) access the Internet by phone while about 20% have little or no access to the Internet.



Most respondents (60%) indicated that they have all the Internet access they need, but more than one-quarter of respondents (26%) identified unmet needs related to Internet access.

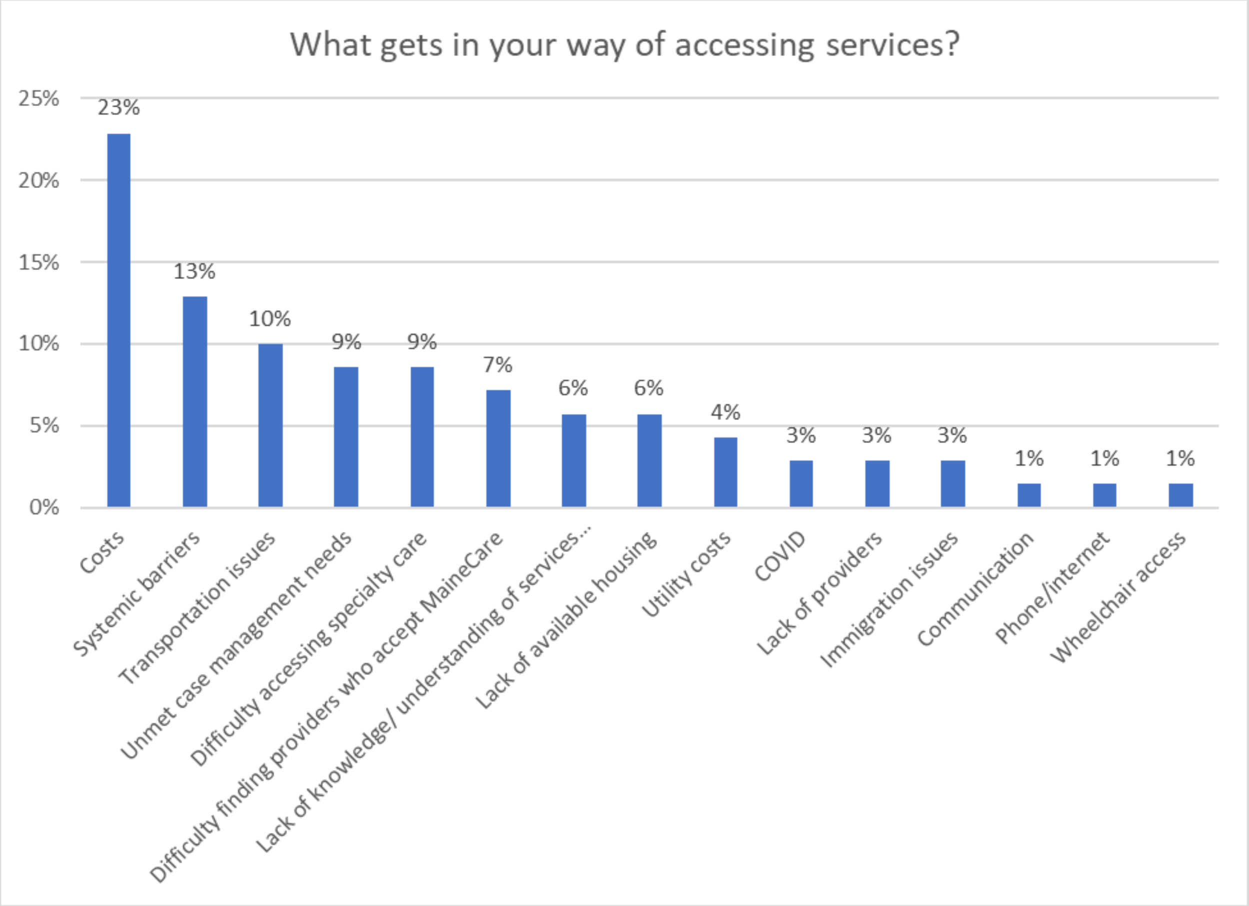
A total of 118 individuals reported that they needed more reliable and/or affordable access, did not have all the access they needed, and did not report that they did not want to use the Internet.

The chart below includes some duplication of individuals, as respondents could select multiple options:



Barriers

The survey included the open-ended question, “If you have trouble getting any services, please tell us more about what gets in your way.” A total of 70 respondents wrote in answers that were aggregated by theme. The most common theme (23%) was costs, followed by systemic barriers (13%), such as wait lists and bureaucracy.



Summary

The pool of respondents represents a little less than half of Ryan White Part B enrollees. Respondents were roughly representative of RWB enrollment, although they were more likely to be older, white, MSM, born in the United States, and living in Northern Maine.

Most respondents were long-term survivors.

The majority of respondents (83%) indicated that they had stable housing. About 82% of those reporting unstable housing reported being virally suppressed at last test, compared to about 91% of all respondents. Surveillance data actually show even higher proportions of viral suppression (84% of those in unstable housing situations and 93% of all respondents).

More than 15% of respondents reported a history of incarceration. Those with a history of incarceration account for nearly one-third of those with an unstable living situation in the past year. They are more likely to report three or more living situations in the past year, and account for half of those who stayed in places not meant for human habitation and half of those staying in emergency shelters.

About 90% of those who reported being incarcerated at some point reported being virally suppressed at last viral load. Surveillance records show that 93% of those who reported being incarcerated were virally suppressed at last test.

Data related to injection drug use may be skewed. About 4% of respondents indicated that they had used injection drugs. About three-quarters of these respondents reported being virally suppressed at last test while Surveillance data show that 89% of these individuals were virally suppressed at last result.

In general, respondents did not indicate high frequency of discrimination from their medical provider due to their gender identity, sexual practices, racial or ethnic identity, or HIV status. Most respondents did not indicate a high frequency of discrimination from their landlord based on their HIV status or a fear of using HIV prevention services because of how others might perceive them.

While only 4% of respondents indicated that they were engaging in behaviors that might put themselves or others at risk for HIV/STDs, 9% of respondents reported being diagnosed with at least one STI or Hepatitis in the last two years.

More than three-quarters of respondents indicated that they had had no sexual partners in the past year, while another third of respondents reported having one partner.

About two-thirds of respondents have heard of PrEP, with about two-thirds of those being comfortable speaking about PrEP with partners.

Generally, respondents indicated that they were comfortable speaking with their health care providers. Nearly all (96%) of respondents reported seeing their primary care provider and/or HIV specialist in the past year.

When asked what helped get respondents to their medical appointments, transportation was the most common response. Most (79%) of respondents live within an hour of their medical care.

In general, self-reported rates of viral suppression were lower than what is documented in Surveillance records.

When comparing reported viral suppression to Surveillance data, residents of Southern Maine were most likely to report being unsure of their last result or a result that conflicted with Surveillance, with 89% of respondents self-reporting being suppressed compared to 94% with a suppressed result at last test. This was similar in the Northern Region, where 91% of respondents reported being suppressed compared to 95% who were suppressed at last result in eHARS.

In the Central Region, 94% reported being suppressed at last test, but only 92% were, according to Surveillance data.

Most respondents (91%) have been at least partially vaccinated against COVID-19. Most respondents (78%) reported having a flu vaccine, although the question did not ask if this was an annual practice. About 60% reported being vaccinated against Hepatitis B and 57% reported being vaccinated against Hepatitis A. About one-quarter of respondents have been vaccinated against HPV.

Nearly all (97%) reported that they had taken HIV medications in the past year. Some of those who reported not taking medications in the past year were virally suppressed at last test.

Most respondents (93%) indicated that they understand how and when to take all of their HIV medications.

Only 62% reported having seen a dentist in the last 18 months, but 23% of respondents indicated that they have dentures or no teeth. Dental care was the fourth-most identified unmet need reported later in the survey by 19% of respondents.

About one-quarter of respondents indicated that in the last 14 days they had little interest or pleasure in doing things and difficulty concentrating or focusing on tasks. In addition, more than one-third of respondents indicated feeling down/depressed or hopeless and having difficulty with sleep in the last 14 days. Fifteen individuals (3%) reported thoughts of wanting to harm themselves or others in the last 14 days.

More than half of all respondents indicated that they did not need additional social supports while about one-quarter of respondents indicated a need for activities with other people living with HIV.

The most-identified areas of unmet needs were:

- Food (21%)
- Alternative therapies (20%)
- Paying for utilities (19%)
- Dental care (19%)
- Eye care (17%)
- Paying for housing (15%)

Most respondents (65%) access the Internet by phone while about 20% have little or no access to the Internet. Most respondents (60%) indicated that they have all the Internet access they need, but more than one-quarter of respondents (26%) identified unmet needs related to Internet access.

The most common barriers identified by respondents included costs and systemic barriers (such as wait lists and bureaucracy).

MaineCare Services
HIV/AIDS Waiver- Member Survey Analysis 2020

Background, Objective, and Survey Process

The Office of MaineCare Services 1115 demonstration waiver titled “Maine Medicaid Section 1115 Health Care Reform Demonstration for Individuals with HIV/AIDS” has been operational since July 1, 2002. This waiver provides a defined set of MaineCare services to individuals living with HIV/AIDS who have an individual income equal to or less than 250% of the Federal Poverty Level (FPL) and are not otherwise eligible for MaineCare. The waiver aims to improve the health status of individuals living with HIV/AIDS in Maine by:

- Improving access to continuous healthcare services
- Arresting progression of HIV/AIDS status by providing early and optimal care coupled with high quality and cost-efficiency
- Using the savings generated from disease prevention and the delayed onset of AIDS to expand coverage to additional low-income individuals living with HIV

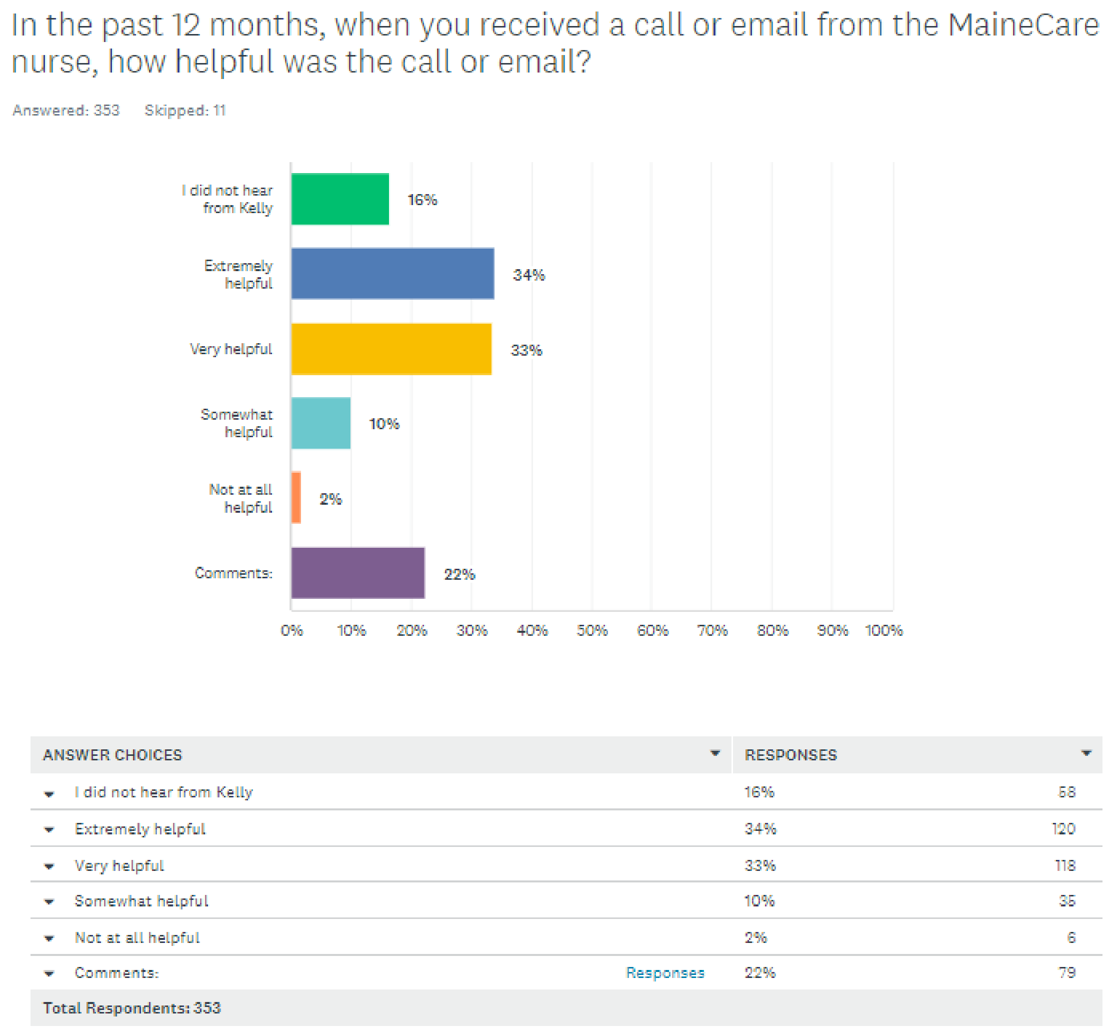
Annually, MaineCare sends a survey to all MaineCare members living with HIV/AIDS and to the 1115 waiver enrollees. The 2020 survey was administered in September 2021, and responses may reflect the members’ 2020 and 2021 experiences. This survey aims to gain feedback on our members’ ability to obtain services, their experiences with MaineCare and other service providers, and their satisfaction with OMS HIV waiver program staff. The surveys are coded to identify survey participants who need follow-up phone calls to address concerns, remove barriers, and offer referrals to needed services. The survey is in English, but includes an enclosure with text in five languages, offering a phone number to call to have the survey translated into another language. To encourage responses from younger members, the 2020 survey included a QR code and website URL to SurveyMonkey. SurveyMonkey analysis tools were used to summarize the responses.

This document contains data from the 2020-member survey as well as year-to-year comparisons with past surveys. The questions on the 2020 survey were slightly changed to gather new data from participants to help guide internal care management efforts for the HIV waiver staff and to use in the waiver’s evaluation plan. Because of these changes, some questions do not have year-to-year comparable results.

Survey Results

The 2020 HIV/AIDS MaineCare member survey was sent to 748 members, and we received 364 responses. This shows a 49% response rate, compared to 53% the previous year (2019). OMS is interested in learning if waiver participants find the outreach from the Nurse Coordinator helpful to them. We asked members who reported speaking with our Nurse Coordinator how helpful they found the call. We received a response from 353 out of 364 survey respondents (97%). Figure 1 shows that out of 353 responses, 69% of survey participants reported speaking with the MaineCare Nurse Coordinator about their health and MaineCare benefits (compared to 67% of survey participants last year). Sixteen percent of survey participants reported having no contact with the Nurse Coordinator (compared to 33% last year). Of the members that reported speaking with the Nurse Coordinator, 98% found the call at least somewhat helpful. Some members included additional comments about the Nurse Coordinator reporting that the Nurse is “pleasant, available, compassionate, a good listener, and always able to get answers”.

Figure 1



In the past 12 months, when you received a call or email from the MaineCare nurse, how helpful was the call or email?

Answered: 353   Skipped: 11

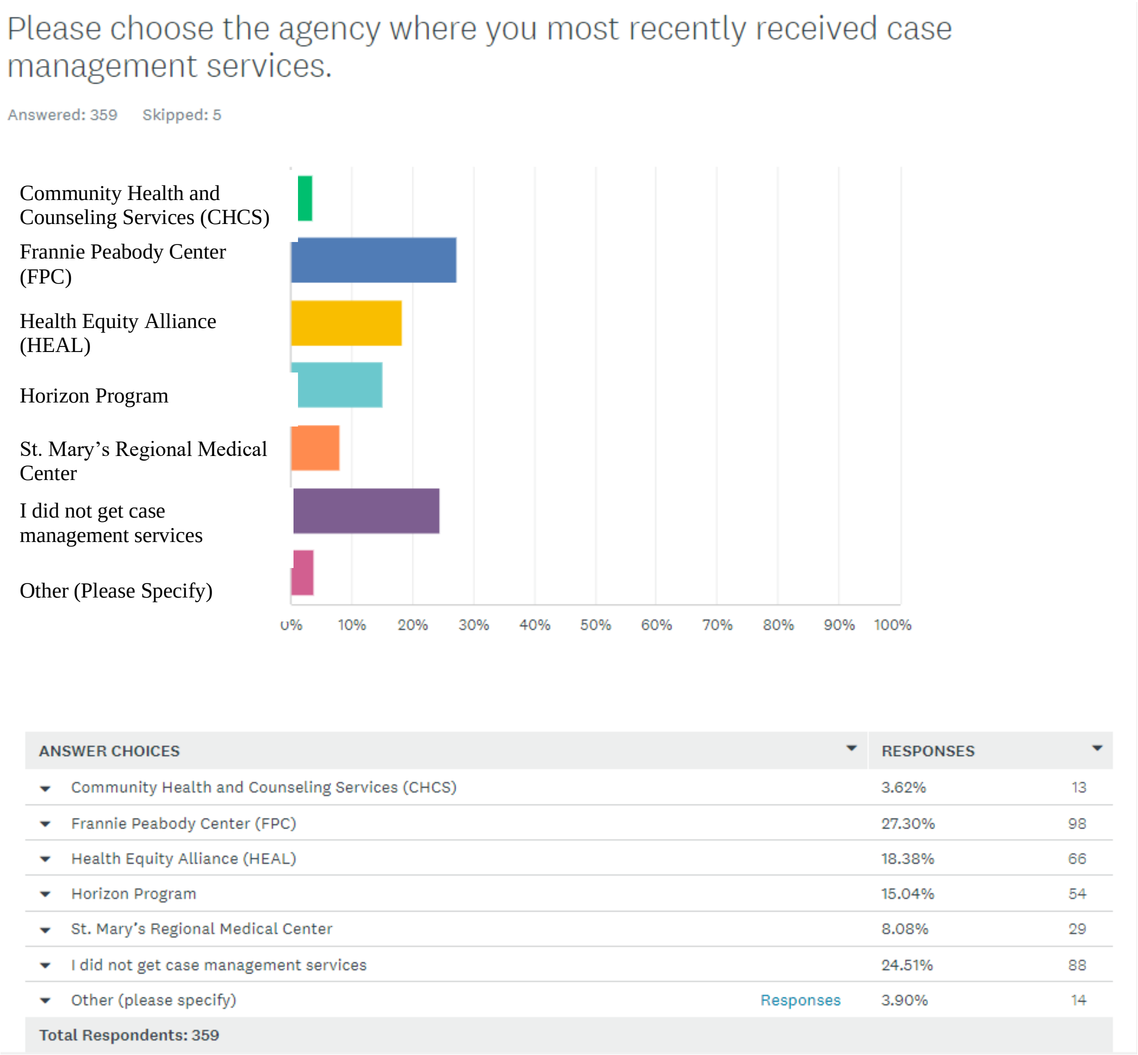
ANSWER CHOICES		RESPONSES	
I did not hear from Kelly		16%	58
Extremely helpful		34%	120
Very helpful		33%	118
Somewhat helpful		10%	35
Not at all helpful		2%	6
Comments:	Responses	22%	79
Total Respondents: 353			

In addition to the care management services provided by our Nurse Coordinator, both MaineCare members and waiver enrollees are eligible for Targeted Case Management (TCM) services under their MaineCare benefit. Most individuals with HIV choose to get TCM services, specifically through an HIV TCM agency. In Maine, five agencies provide these services. MaineCare asks on the survey from which agency the member received services so we can track and share data at the agency level. We received a response from 359 out of 364 survey participants (99%). Figure 2 shows that of the 359 survey participants:

- 25% did not get TCM services
- 27% indicated they received TCM services from Frannie Peabody Center (FPC)
- 18% indicated they received TCM services from Health Equity Alliance (HEAL)
- 15% indicated they received TCM services from the Horizon Program

- 8% indicated they received TCM services from St. Mary's
- 4% indicated they received TCM services from Community Health and Counseling Services (CHCS) and "other" various agencies

Figure 2



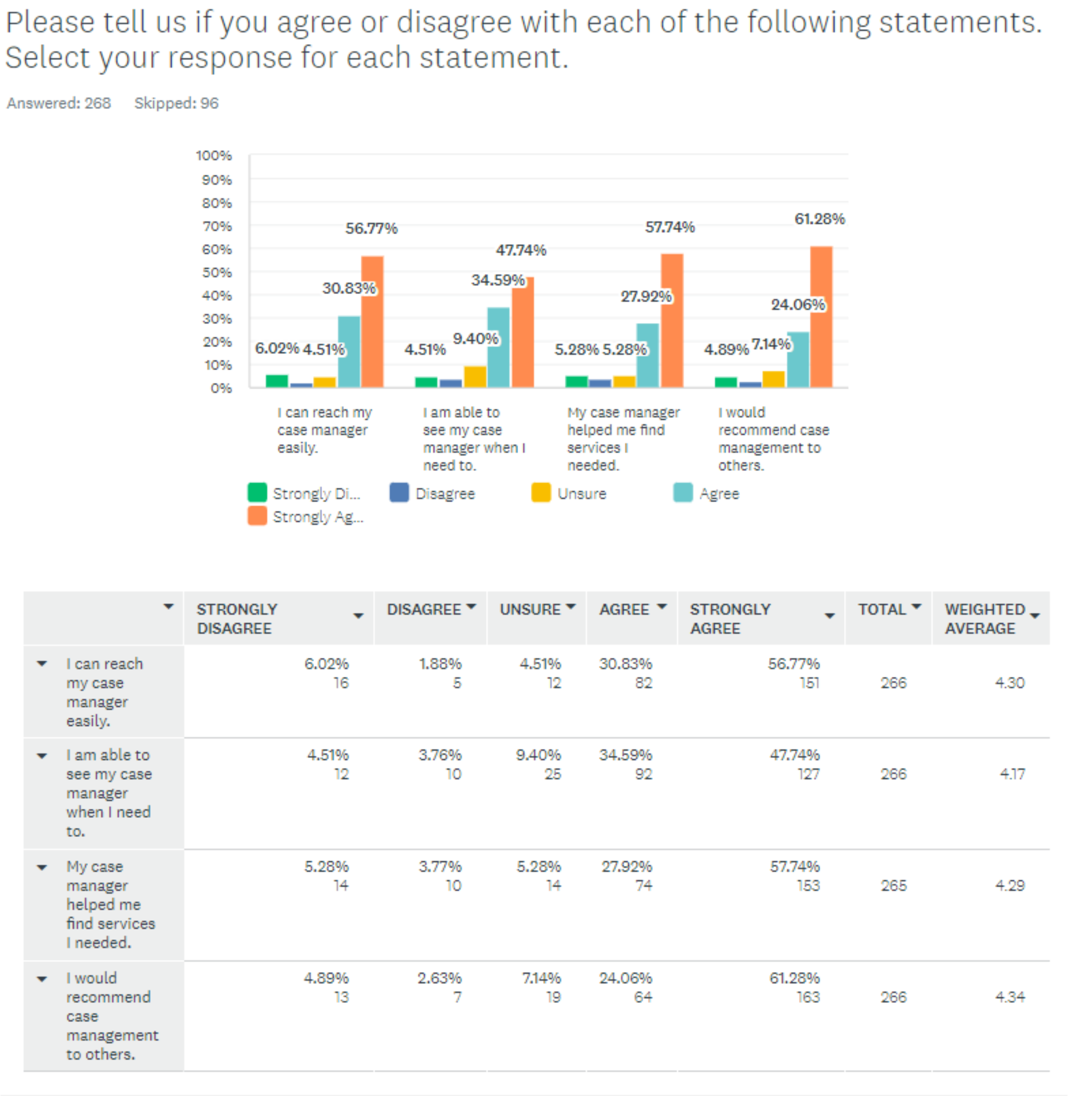
Please choose the agency where you most recently received case management services.

Answered: 359 Skipped: 5

ANSWER CHOICES		RESPONSES	
Community Health and Counseling Services (CHCS)		3.62%	13
Frannie Peabody Center (FPC)		27.30%	98
Health Equity Alliance (HEAL)		18.38%	66
Horizon Program		15.04%	54
St. Mary's Regional Medical Center		8.08%	29
I did not get case management services		24.51%	88
Other (please specify)	Responses	3.90%	14
Total Respondents: 359			

When asked if members could reach their case manager easily, 57% strongly agreed and 31% agreed, accounting for 88% of survey participants (compared to 62% and 29% in 2019). When asked if they felt they were able to see their case manager when they needed to, 48% strongly agreed and 35% agreed (54% and 30% in 2019), representing 83% of survey participants. Members were also asked if their case manager helped them find the services they needed. Fifty-seven percent strongly agreed and 28% agreed, accounting for 85% of survey participants (66% and 24% respectively in 2019). Lastly, we asked members if they would recommend case management to others. Sixty-one percent strongly agree they would recommend the services and 24% agreed, representing 85% of survey participants (68% and 21% respectively in 2019). The responses indicate that those members/enrollees who are receiving TCM largely feel that the services are addressing their needs. This data is shown below in Figure 3.

Figure 3



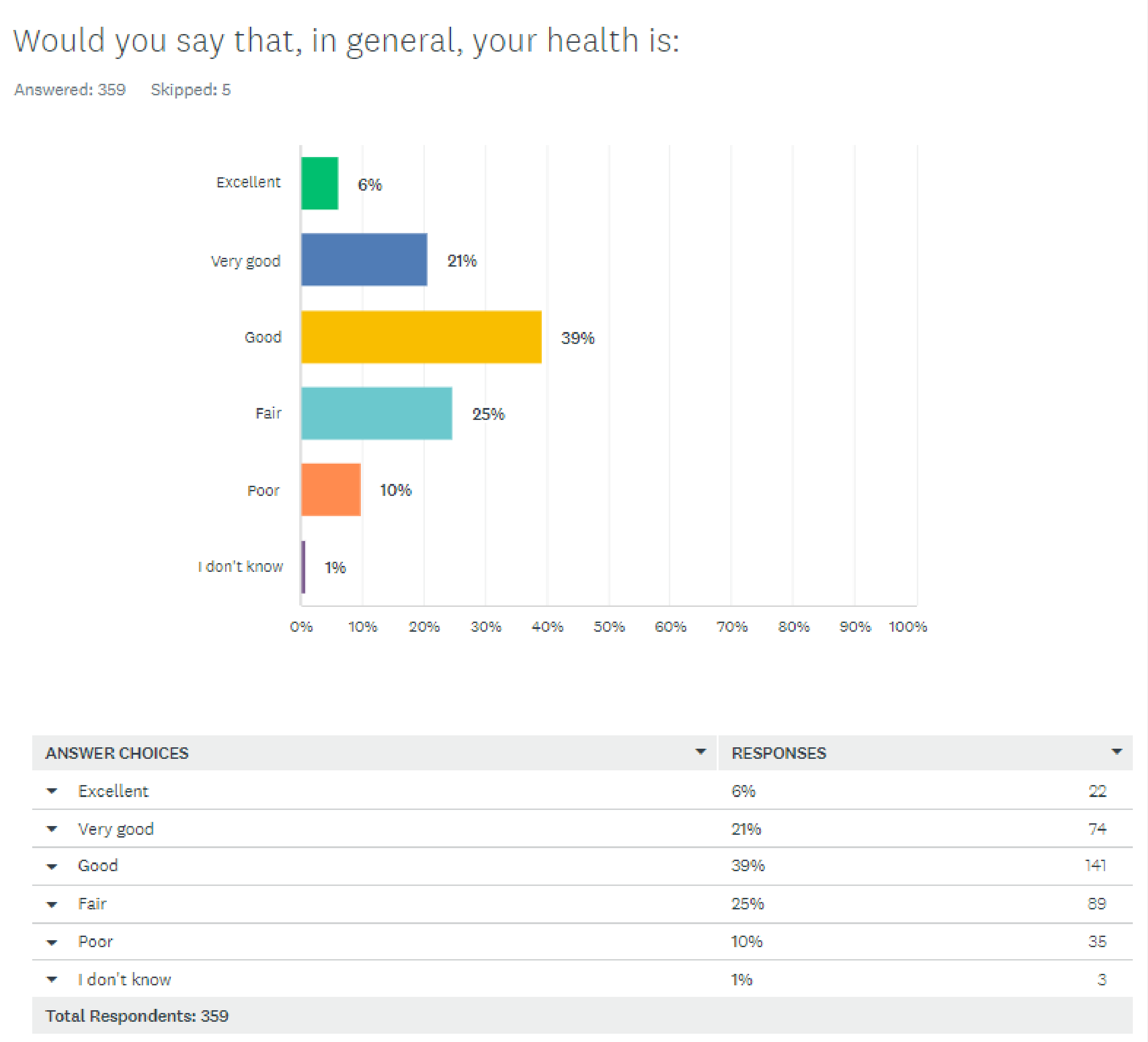
Please tell us if you agree or disagree with each of the following statements. Select your response for each statement.

Answered: 268 Skipped: 96

	STRONGLY DISAGREE	DISAGREE	UNSURE	AGREE	STRONGLY AGREE	TOTAL	WEIGHTED AVERAGE
I can reach my case manager easily.	6.02% 16	1.88% 5	4.51% 12	30.83% 82	56.77% 151	266	4.30
I am able to see my case manager when I need to.	4.51% 12	3.76% 10	9.40% 25	34.59% 92	47.74% 127	266	4.17
My case manager helped me find services I needed.	5.28% 14	3.77% 10	5.28% 14	27.92% 74	57.74% 153	265	4.29
I would recommend case management to others.	4.89% 13	2.63% 7	7.14% 19	24.06% 64	61.28% 163	266	4.34

We asked members to indicate their general health status. We received 359 responses of the 364 returned surveys (99%). Thirty-nine percent of survey participants rated their general health as “good.” The second highest response was “fair” at 25%, followed by “very good” at 21%, “poor” at ten percent, and “excellent” at six percent. Overall, survey participants’ self-perceived health status indicates that 66% feel that their general health is “good” or better; this is significantly below what the general population of adults in Maine report. In 2020, 87% of Maine adults reported their health to be “good” or better[i]. See Figure 4.

Figure 4



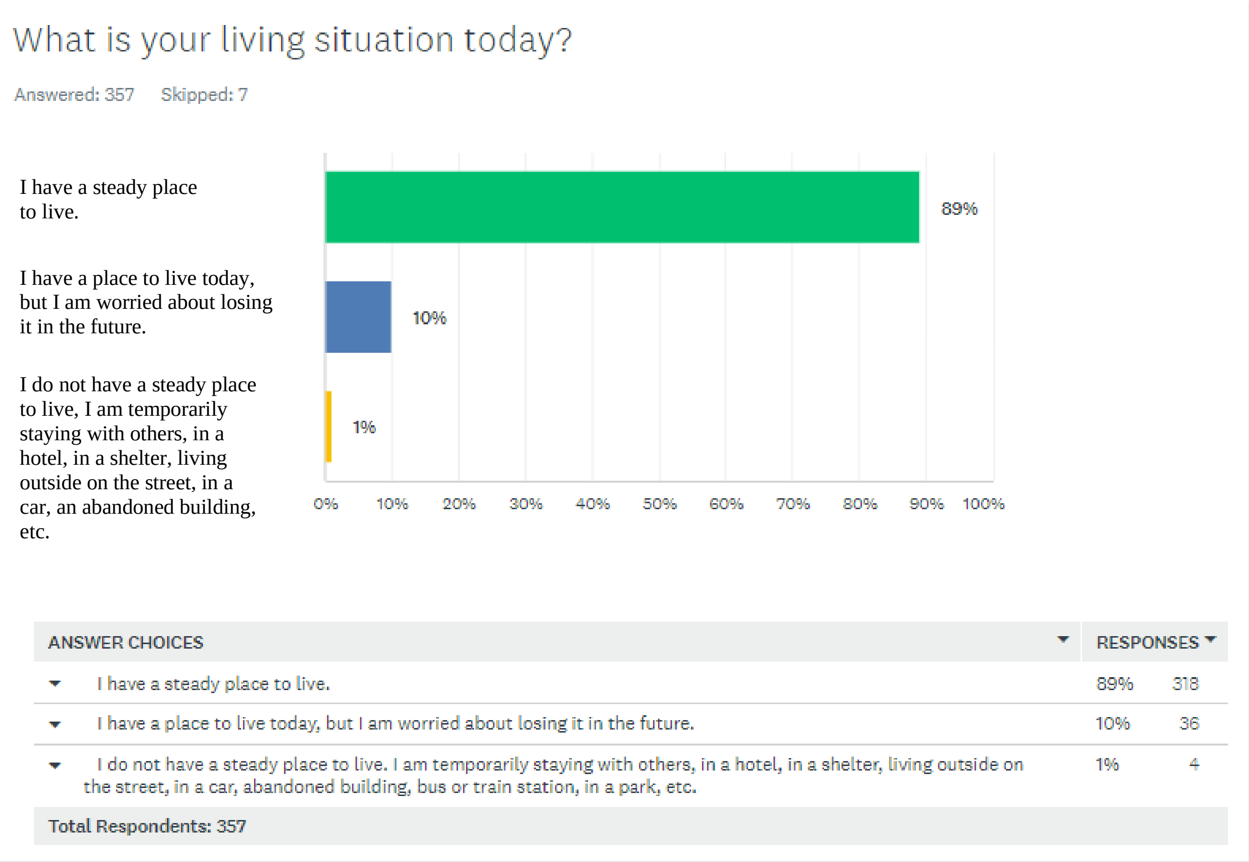
Would you say that, in general, your health is:

Answered: 359   Skipped: 5

ANSWER CHOICES	RESPONSES	
Excellent	6%	22
Very good	21%	74
Good	39%	141
Fair	25%	89
Poor	10%	35
I don't know	1%	3
Total Respondents: 359		

We asked members about their living situation (see Figure 5). We received 357 responses out of 364 returned surveys (98%). Eighty-nine percent of survey participants responded that they have a steady place to live (the same percentage as 2019), while 10% of survey participants said they have a place currently but are worried about losing it in the future. Only one percent of survey participants said they do not have a steady place to live, and are staying with others, in a hotel, car, shelter, etc. While it is encouraging that most members and enrollees r report having stable housing, particularly since there is a shortage of housing across the State for low-income residents, members who do not have a steady place to live may be less likely to respond to the survey.

Figure 5



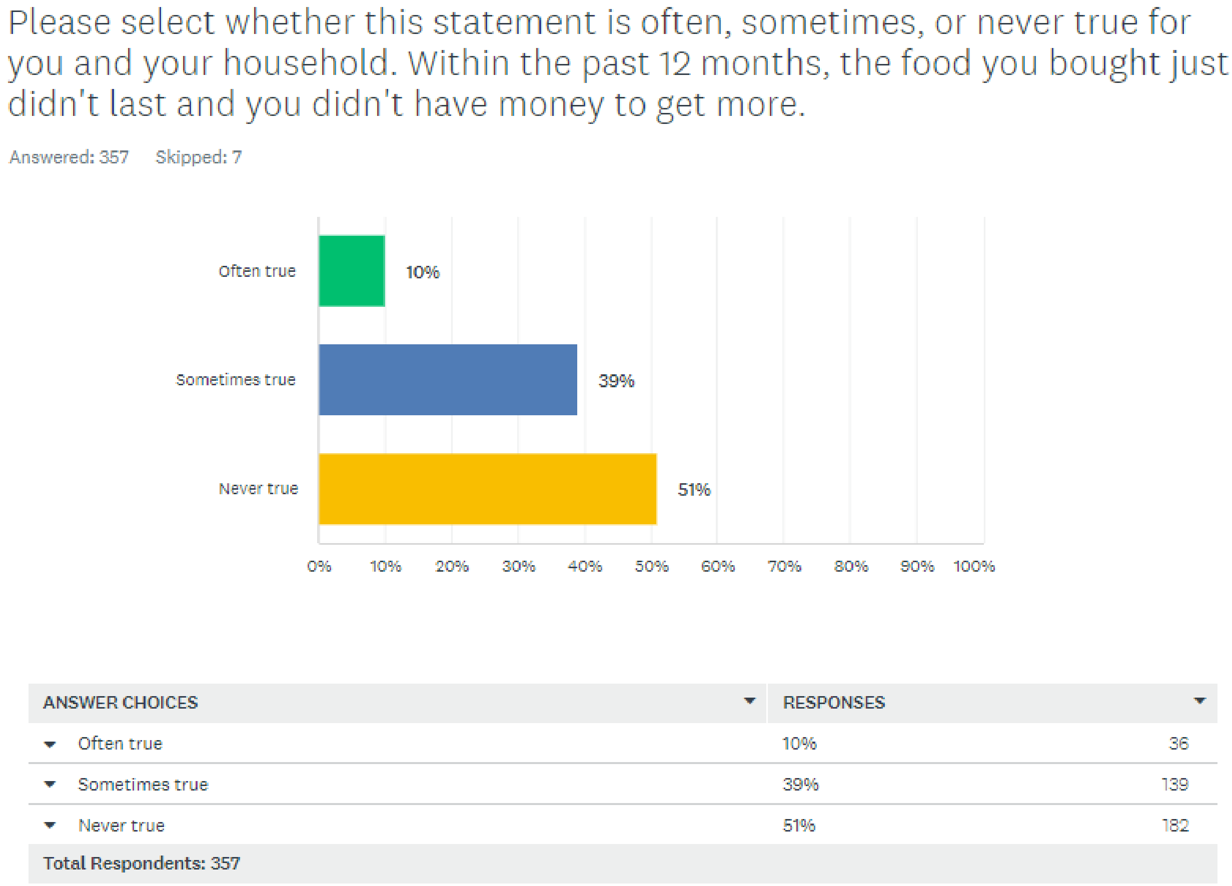
What is your living situation today?

Answered: 357 Skipped: 7

ANSWER CHOICES	RESPONSES	
I have a steady place to live.	89%	318
I have a place to live today, but I am worried about losing it in the future.	10%	36
I do not have a steady place to live. I am temporarily staying with others, in a hotel, in a shelter, living outside on the street, in a car, abandoned building, bus or train station, in a park, etc.	1%	4
Total Respondents: 357		

We asked the members to indicate if the statement “Within the past 12 months, the food you bought just didn't last and you didn't have money to get more” is often, sometimes, or never true for them and their household. Food security is recognized as a social determinant of health; people who do not have steady access to food will likely have difficulty following treatment plans and therefore will have poorer health outcomes. The results indicated that 357 survey participants responded to the question out of 364 survey participants that returned the survey (98%). Fifty-one percent of survey participants indicated that this statement is never true. Thirty-nine percent answered it is sometimes true (same percent as last year), with 10% responding it is often true (15% last year). The results for this question are shown in Figure 6. However, since the 2020 survey had a lower response rate which may have been related to various challenges brought on by the pandemic, further research may be warranted to determine whether food security actually improved for members from 2019 to 2020. See Figure 6a for year-to-year comparisons.

Figure 6

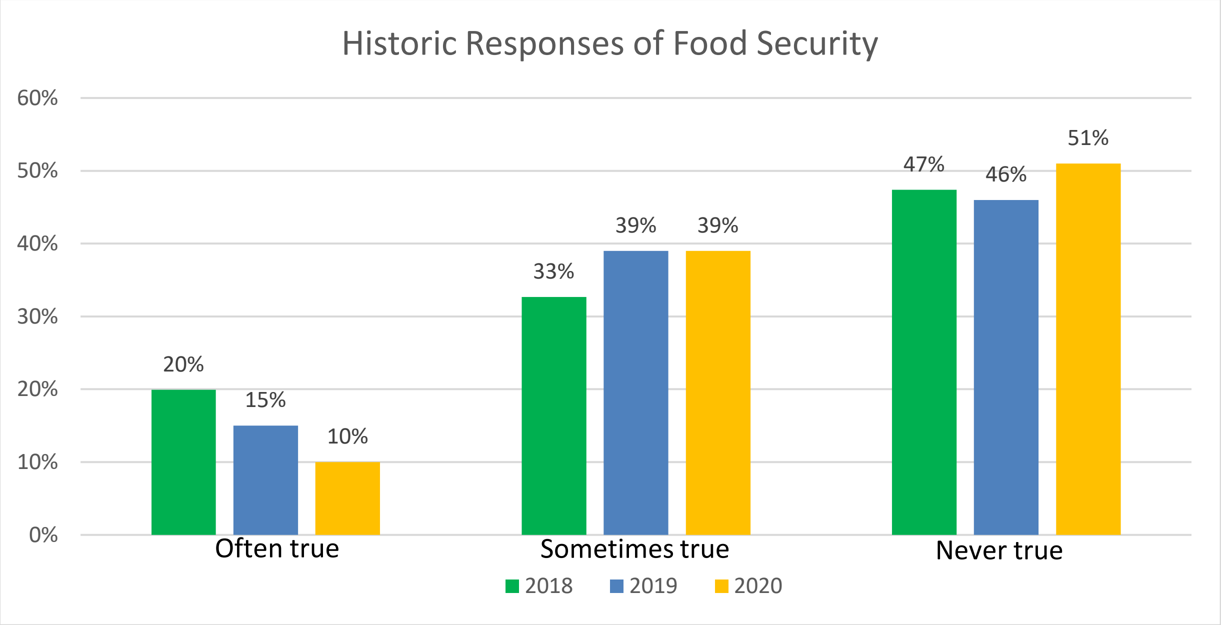


Please select whether this statement is often, sometimes, or never true for you and your household. Within the past 12 months, the food you bought just didn't last and you didn't have money to get more.

Answered: 357 Skipped: 7

ANSWER CHOICES	RESPONSES	
Often true	10%	36
Sometimes true	39%	139
Never true	51%	182
Total Respondents: 357		

Figure 6a

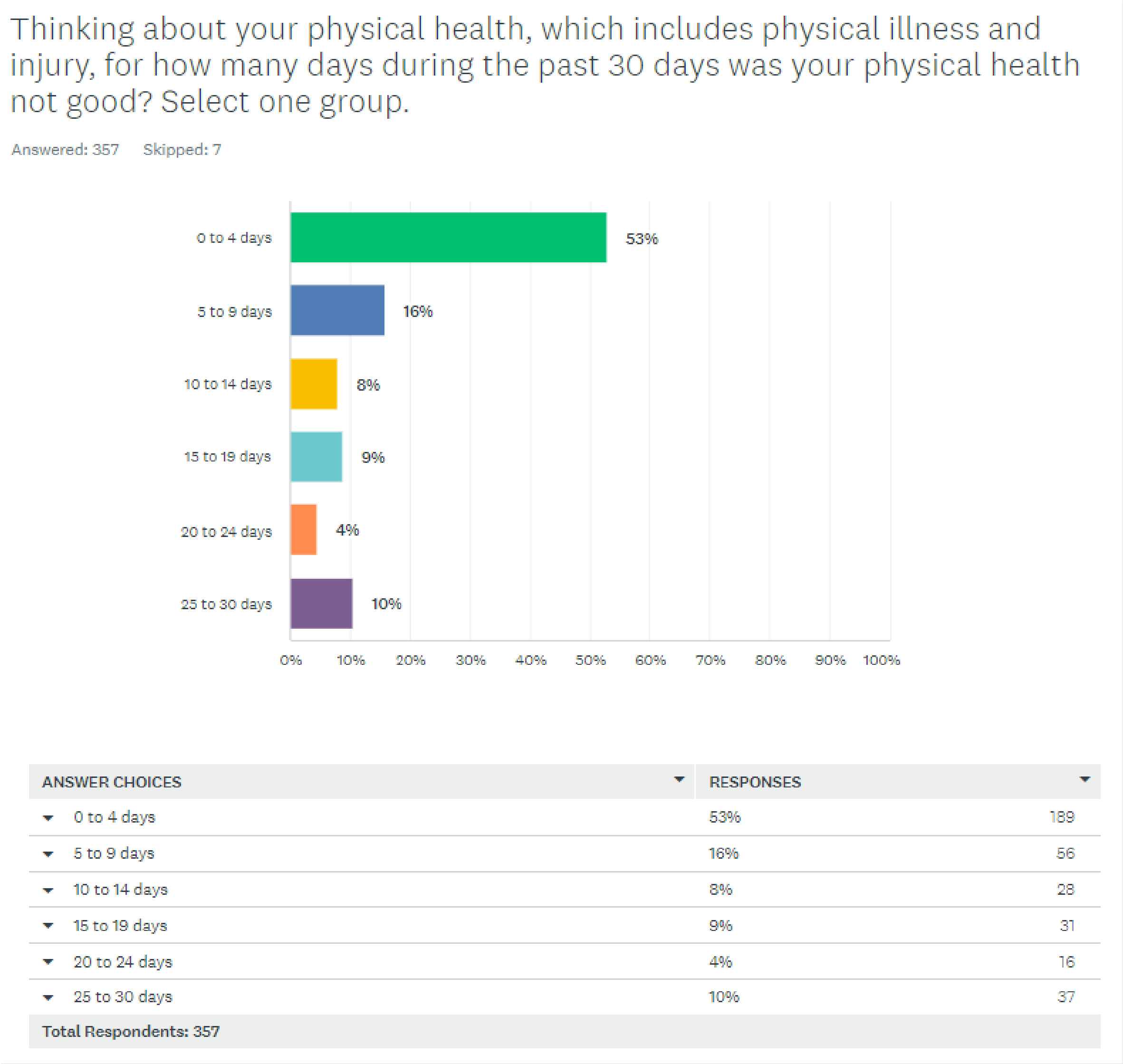


We asked about the physical health of our members. We asked, “for how many days during the past 30 days was your physical health not good?” Participants most commonly responded with “0 to 4 days”. The results were as follows:

- “0 to 4 days” at 53%
- “5 to 9 days” at 16%
- “25 to 30 days” at 10%
- “15 to 19 days” at 9%
- “10 to 14 days” at 8%
- “20 to 24 days” at approximately 4%

Thus, it appears from the responses that the majority of survey participants who reported poor physical health felt this way for a limited period. Twenty-three percent of respondents reported having physical health problems more than half of the days in a 30-day period (28% last year). In 2020, Maine adults experienced on average 3.9 days of poor physical health during the past 30 days.[ii] With more than half of respondents choosing four or fewer days on this question, our respondents are similar to the general population in experiencing poor physical health.

Figure 7



Thinking about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good? Select one group.

Answered: 357 Skipped: 7

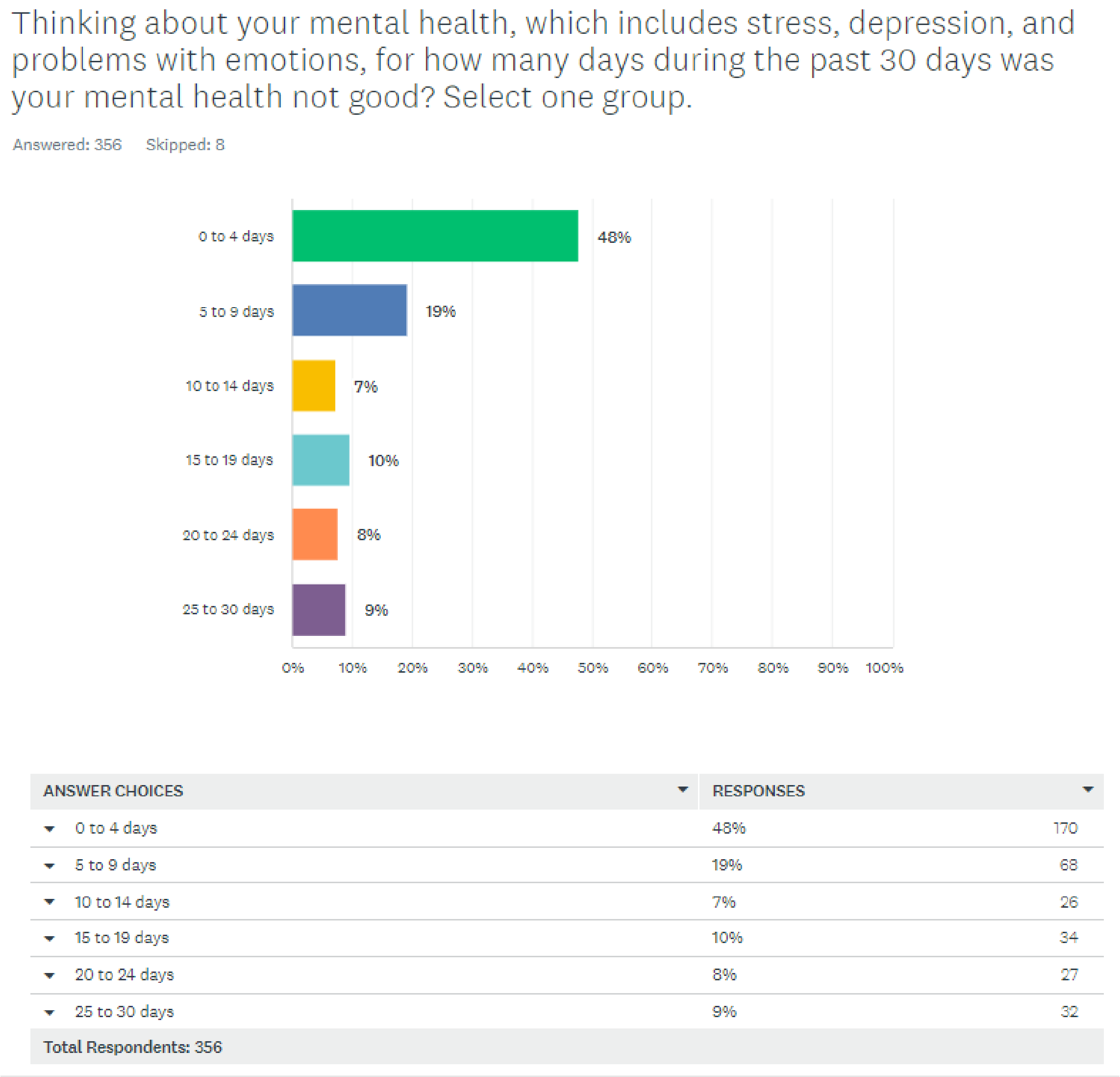
ANSWER CHOICES	RESPONSES	
0 to 4 days	53%	189
5 to 9 days	16%	56
10 to 14 days	8%	28
15 to 19 days	9%	31
20 to 24 days	4%	16
25 to 30 days	10%	37
Total Respondents: 357		

We then asked members a similar question about their mental health. We asked, “for how many days during the past 30 days was your mental health not good?” A large portion of survey participants reported “0 to 4” such days, which accounted for 48% of respondents (49% last year). The rest of the responses were as follows:

- “5 to 9 days” at 19%
- “10 to 14 days” at 7%
- “15 to 19 days” at 10%
- “20 to 24 days” at 8%
- “25 to 30 days” at 9%

Additionally, 24% of survey participants reported experiencing poor mental health for greater than half of the days in a 30-day period (this was also 24% in 2019). According to The State Health Access Data Center, Maine adults reported an average of 4.3 days of poor mental health in 2020. Fifty-three percent of our survey respondents reported experiencing poor mental health four or fewer days in a 30-day period; this is similar to the general population. See Figure 8.

Figure 8



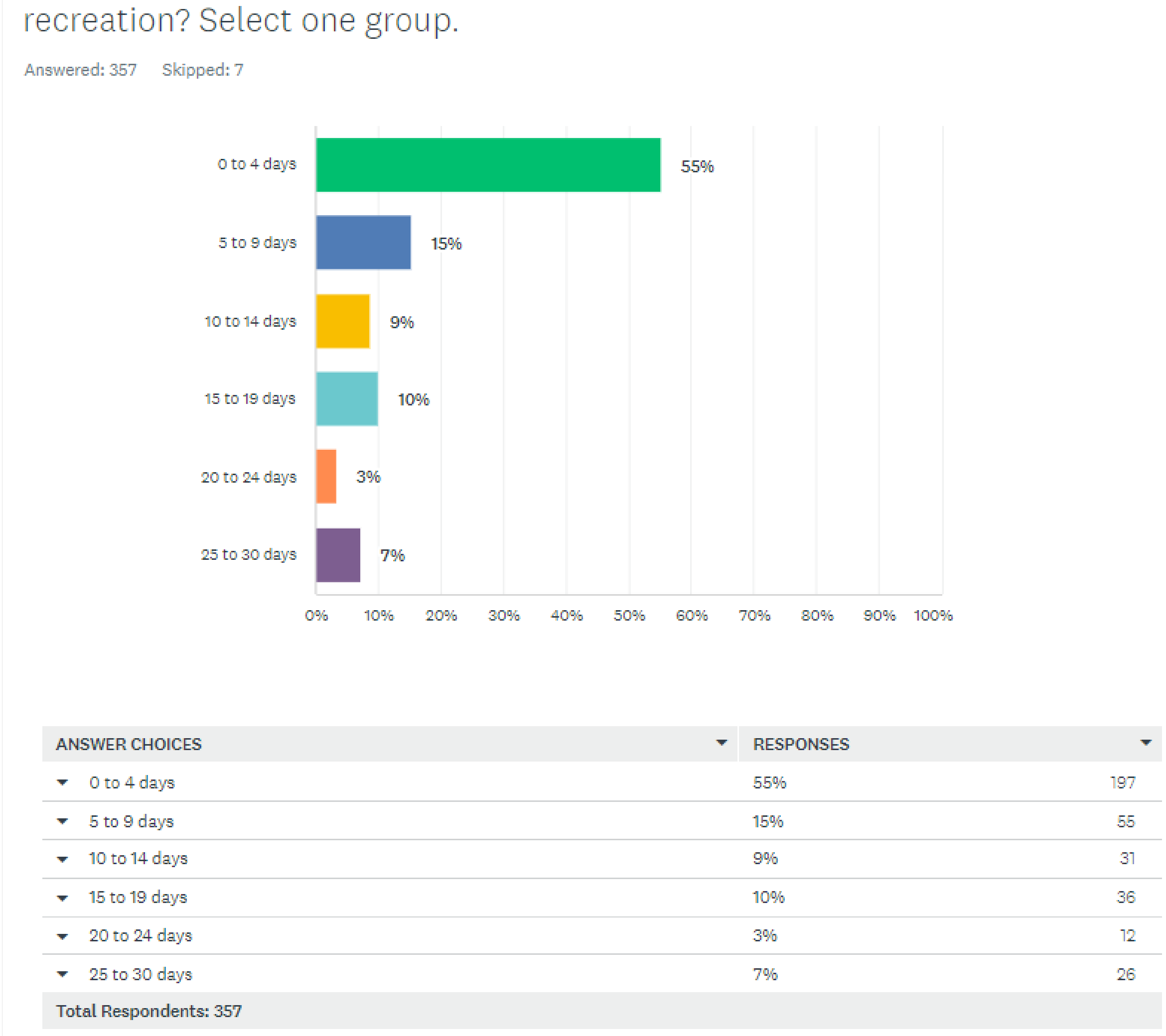
Thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good? Select one group.

Answered: 356 Skipped: 8

ANSWER CHOICES	RESPONSES	
0 to 4 days	48%	170
5 to 9 days	19%	68
10 to 14 days	7%	26
15 to 19 days	10%	34
20 to 24 days	8%	27
25 to 30 days	9%	32
Total Respondents: 356		

The survey asks, “how many days of the past 30 days did physical or mental health interfere with normal activities?” The most common response shows a limited impact of health issues on general activities in a 30-day period, with “0 to 4 days” being the highest selected answer at 55% (51% last year). Next was “5 to 9 days” with 15% of survey participants selecting the answer, followed by “10 to 14 days,” “15 to 19 days,” and “20 to 24 days” representing nine, ten, and three percent, respectively. Seven percent of survey participants indicated they experience “25 to 30 days” in a 30-day period with either mental or physical health problems (six percent last year).

Figure 9



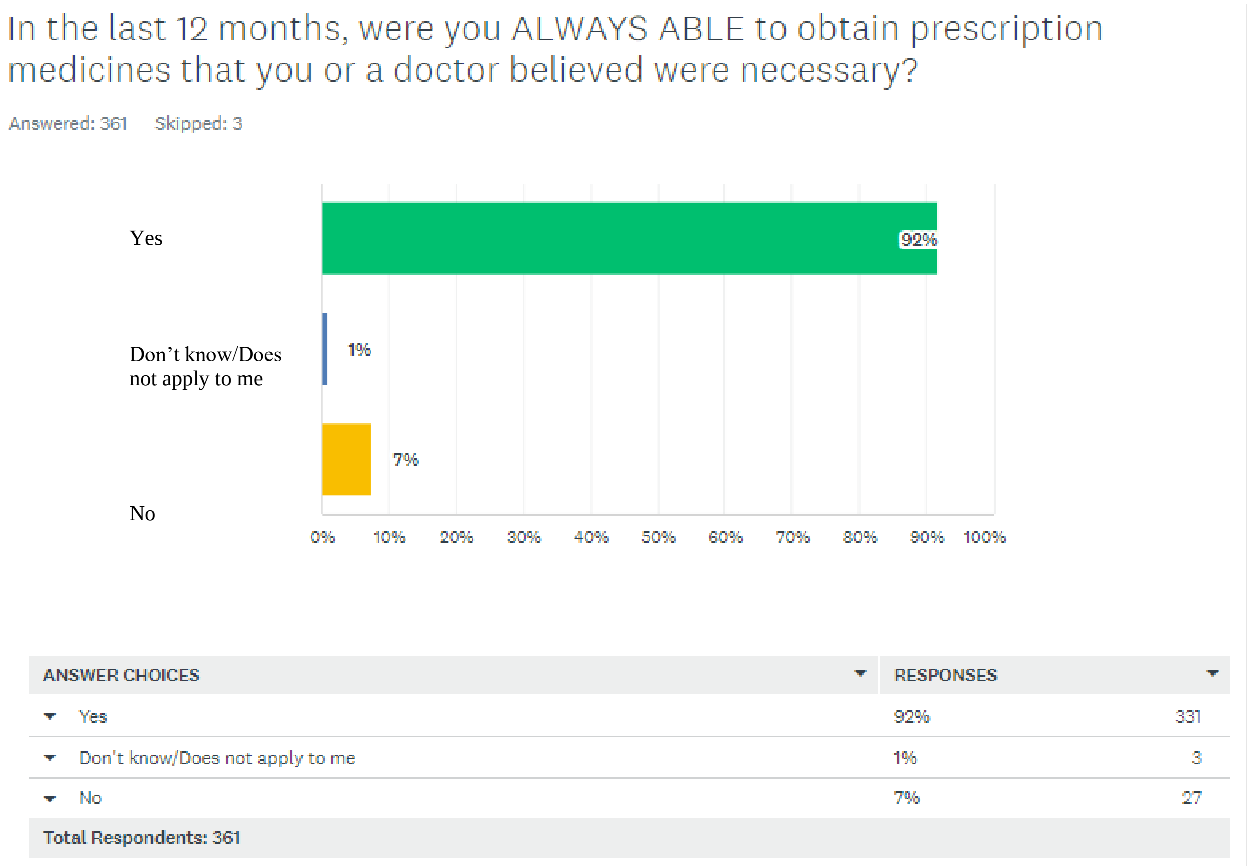
During the past 30 days, how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation? Select one group.

Answered: 357 Skipped: 7

ANSWER CHOICES	RESPONSES	
0 to 4 days	55%	197
5 to 9 days	15%	55
10 to 14 days	9%	31
15 to 19 days	10%	36
20 to 24 days	3%	12
25 to 30 days	7%	26
Total Respondents: 357		

We asked members if they were always able to obtain prescription medicines that they or a doctor believed were necessary, with the results shown in Figure 10 below. Ninety-nine percent of survey participants responded to this question with 92% selecting “yes,” that they are always able to get these prescription medicines (90% last year). Less than one percent of survey participants said they didn’t know, or it did not apply to them. Seven percent of survey participants (27 members) selected “no,” indicating they were not always able to obtain prescription medicines that they or their doctor believed were necessary. Nine members cited issues with their insurance company and three members indicated there were transportation issues. Some members reported that their pharmacies didn’t have the medicine or there were issues on the provider’s end (e.g. prior authorizations weren’t completed timely). In addition to their MaineCare coverage, some respondents have Medicare, private plans through an employer, or the Marketplace and the reported insurance issues could be related to their other coverages. Of this seven percent, 80% had this issue once or twice in the 30-day period. Only a few respondents cited issues “3 to 5” (4 of 27 members) or “6 or more” (1 of 27 members) times in a 30-day period.

Figure 10

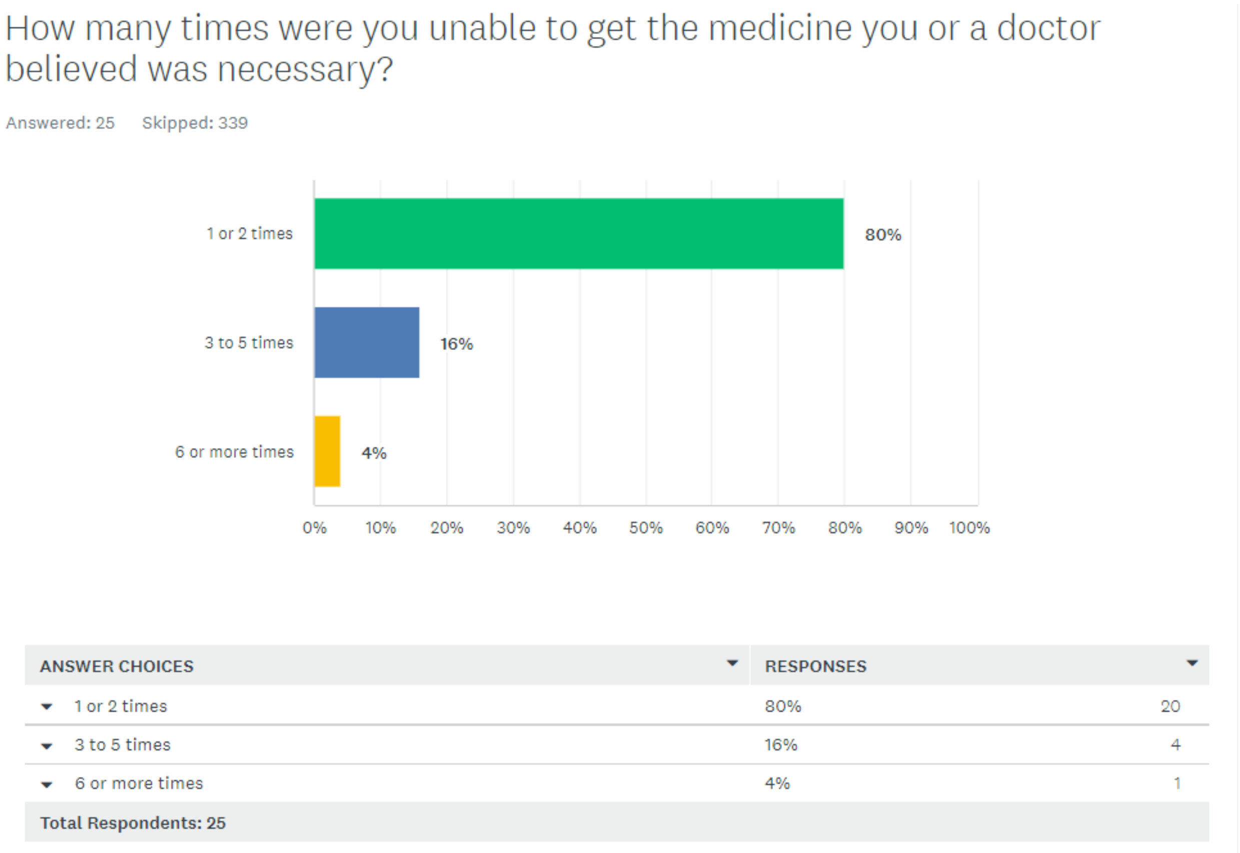


In the last 12 months, were you ALWAYS ABLE to obtain prescription medicines that you or a doctor believed were necessary?

Answered: 361 Skipped: 3

ANSWER CHOICES	RESPONSES	
Yes	92%	331
Don’t know/Does not apply to me	1%	3
No	7%	27
Total Respondents: 361		

Figure 10a



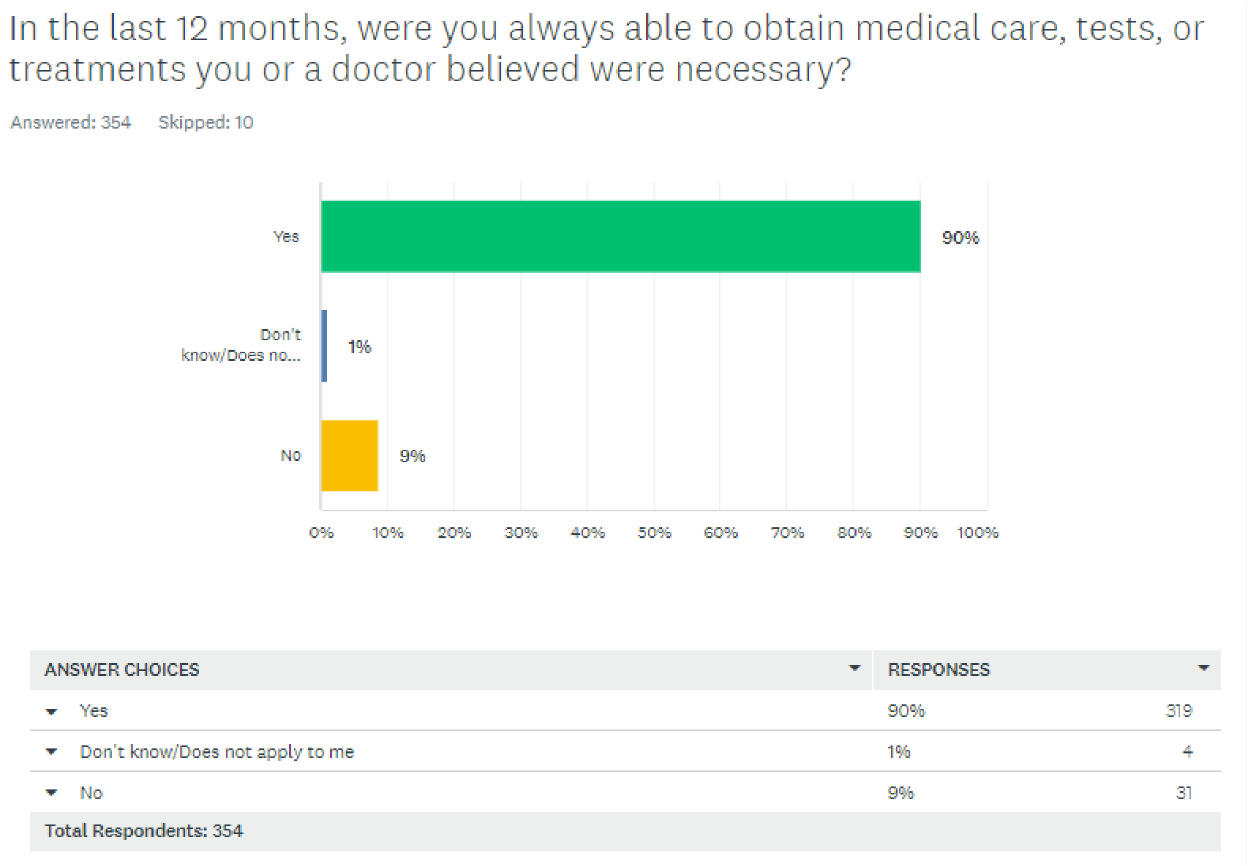
How many times were you unable to get the medicine you or a doctor believed was necessary?

Answered: 25 Skipped: 339

ANSWER CHOICES	RESPONSES	
1 or 2 times	80%	20
3 to 5 times	16%	4
6 or more times	4%	1
Total Respondents: 25		

We asked members if they were always able to obtain medical care, tests, or treatments that they or their doctor believed were necessary. Ninety percent of respondents to this question indicated that they were always able to obtain the services they needed (89% last year). One percent selected that they "don't know/does not apply," and the other nine percent indicated they were not always able to obtain these services, noting transportation, insurance company issues, and the coronavirus pandemic as barriers. See Figure 11.

Figure 11

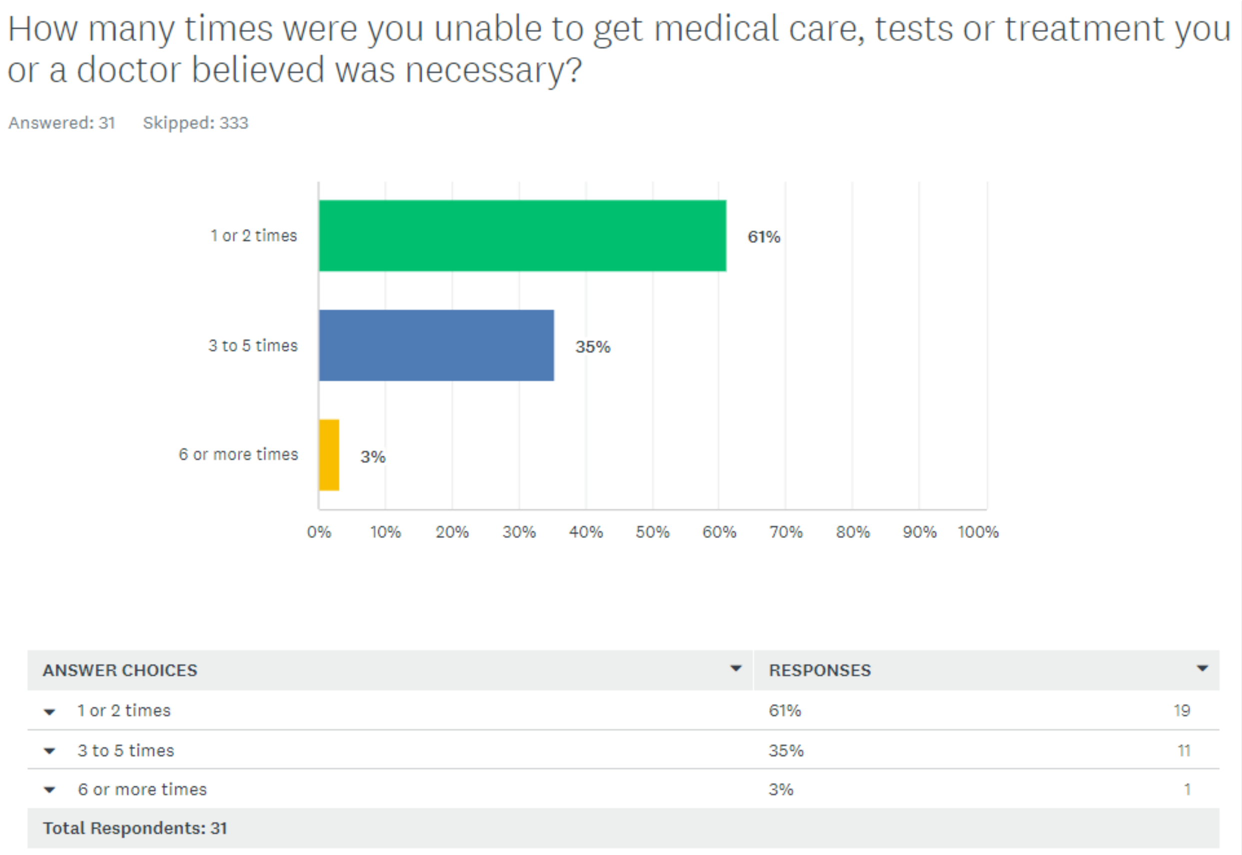


In the last 12 months, were you always able to obtain medical care, tests, or treatments you or a doctor believed were necessary?

Answered: 354 Skipped: 10

ANSWER CHOICES	RESPONSES	
Yes	90%	319
Don't know/Does not apply to me	1%	4
No	9%	31
Total Respondents: 354		

Figure 11a



How many times were you unable to get medical care, tests or treatment you or a doctor believed was necessary?

Answered: 31 Skipped: 333

ANSWER CHOICES	RESPONSES	
1 or 2 times	61%	19
3 to 5 times	35%	11
6 or more times	3%	1
Total Respondents: 31		

We asked members to indicate their confidence in their medication use on a 1 to 5 scale. Medication adherence is crucial to successful management of HIV: when antiretroviral therapy adherence is 90% or higher, virologic failure and resistance are prevented and the patient's health status is preserved.[iii] Knowing whether members are confident about following their medication plan helps the program focus its efforts. We asked survey participants to rate the following:

a. I can follow directions when my doctor changes my medications.
b. I can take my medication when there is a change in my usual day or unexpected things happen.
c. I can manage my medication without help.
d. I can list my medications, including the doses and schedule.

Eighty percent of survey participants are very confident in their ability to follow directions when their doctor changes their medications, while 17% are quite confident. One percent of survey participants feel somewhat confident, leaving only one percent that are not at all confident in their ability to follow their doctor's directions.

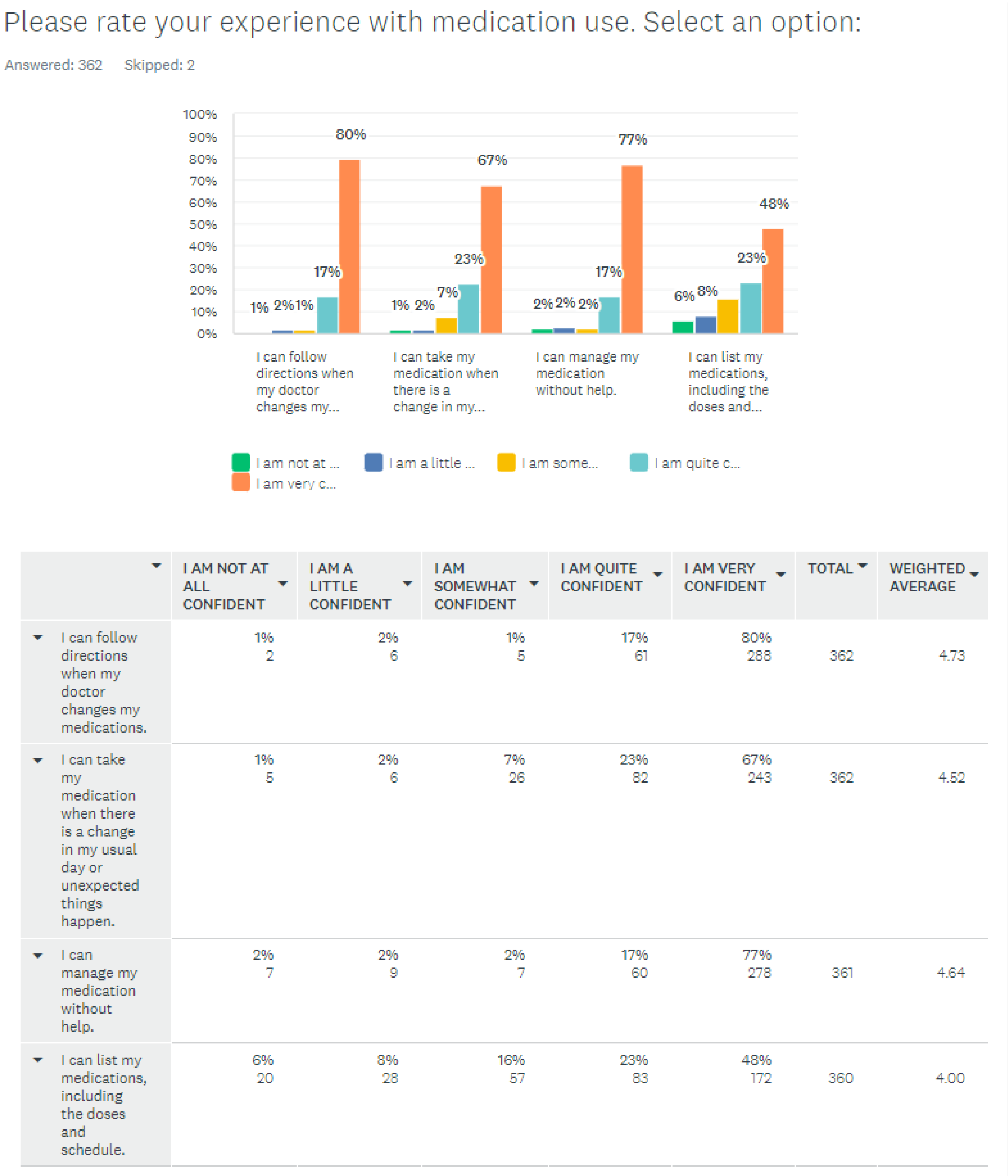
Sixty-seven percent of survey participants indicated they are very confident in their ability to take their medications when there is a change in their usual day or something unexpected happens. Twenty-three percent indicate they are quite confident, while seven percent report they are somewhat confident. Three percent of survey participants reported being either a little confident or not confident at all.

Seventy-seven percent of survey participants indicated that they are very confident and 17% indicate they are quite confident in their ability to manage their medication. Two percent feel somewhat confident in their ability to manage their medication, while two percent of survey participants responded they are a little confident, and two percent have no confidence in their ability to take medication.

Only 48% of survey participants are very confident in their ability to list their medications, including the doses and schedule. Twenty-three percent feel quite confident in their ability, 16% are somewhat confident, eight percent are a little confident, and six percent are not at all confident in their ability to list their medications with the dose. The Nurse Care Coordinator will make medication management a regular part of calls with members, even when medication was not otherwise planned to be the major focus of the outreach. Staff will also explore other ways to support medication adherence.

Member responses are shown in Figure 12. The weighted average for all four questions was 4.0 or higher, indicating that overall respondents are “quite confident” about medication management and changes.

Figure 12



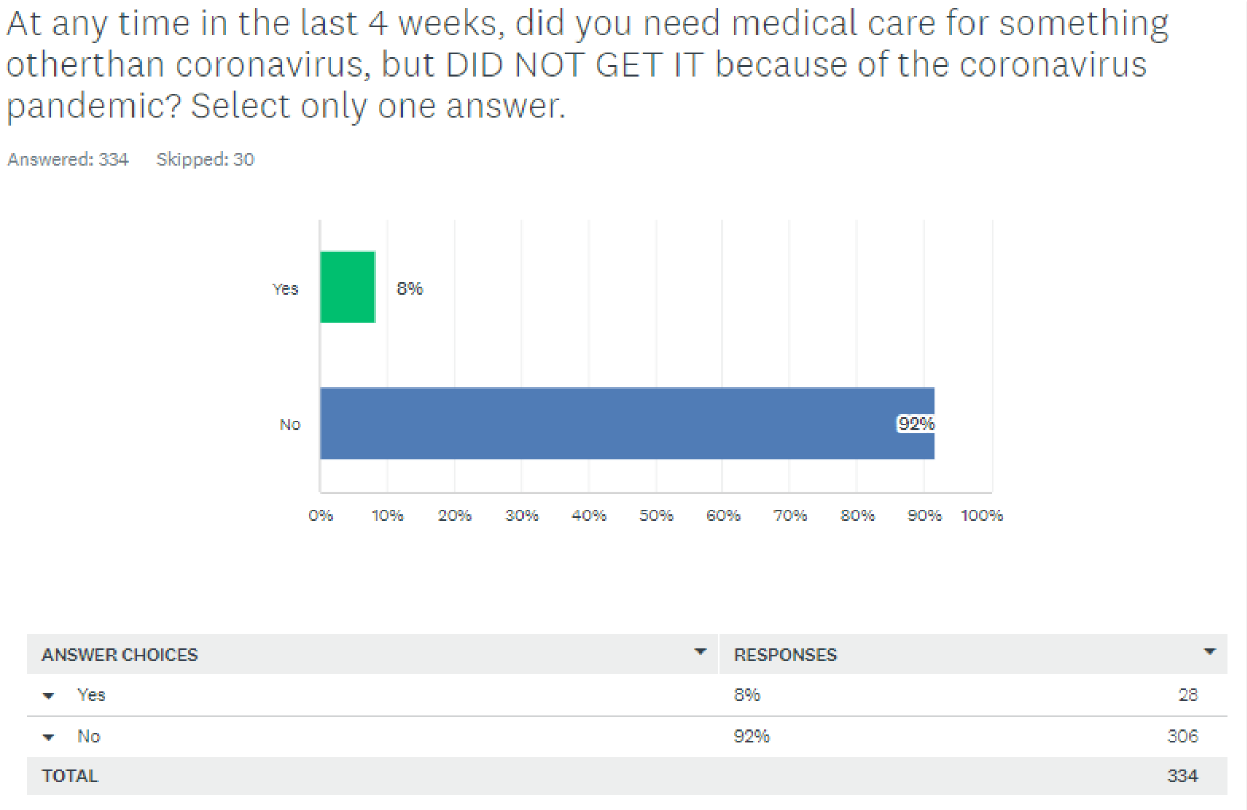
Please rate your experience with medication use. Select an option:

Answered: 362 Skipped: 2

	I AM NOT AT ALL CONFIDENT	I AM A LITTLE CONFIDENT	I AM SOMEWHAT CONFIDENT	I AM QUITE CONFIDENT	I AM VERY CONFIDENT	TOTAL	WEIGHTED AVERAGE
I can follow directions when my doctor changes my medications.	1% 2	2% 6	1% 5	17% 61	80% 288	362	4.73
I can take my medication when there is a change in my usual day or unexpected things happen.	1% 5	2% 6	7% 26	23% 82	67% 243	362	4.52
I can manage my medication without help.	2% 7	2% 9	2% 7	17% 60	77% 278	361	4.64
I can list my medications, including the doses and schedule.	6% 20	8% 28	16% 57	23% 83	48% 172	360	4.00

To assess whether COVID-19 has affected access medical care, we asked members: “At any time in the last 4 weeks, did you need medical care for something other than coronavirus, but DID NOT GET IT because of the coronavirus pandemic?” eight percent of members indicated that they did not get care at least once because of the coronavirus pandemic (13% last year). This finding suggests that respondents were less hindered by the pandemic in getting medical care than in 2020.

Figure 13



At any time in the last 4 weeks, did you need medical care for something otherthan coronavirus, but DID NOT GET IT because of the coronavirus pandemic? Select only one answer.

Answered: 334 Skipped: 30

ANSWER CHOICES	RESPONSES	
Yes	8%	28
No	92%	306
TOTAL		334

Health Equity and Respondent Demographics & Identity

The HIV program staff seek to support all members in managing their health. To determine whether members' experience of the care they receive differs by race, ethnicity or sexual orientation, and whether any difference may be related to differential treatment by providers, we added new questions to this year's survey. In addition, how a patient perceives communication with a provider can influence the care outcomes and their willingness to follow treatment plans. Thus, improving health equity is central to the program's overall success.

We asked members about their race, ethnicity, gender, primary spoken language, and sexual orientation. We also asked a series of questions about how providers treated them (e.g., with courtesy, respect, etc.) so staff can segment the responses by race, gender, language, and sexual orientation to see whether a particular group experienced their care differently.

Results of this analysis are as follows: 96% of Black/African American members reported never being treated with less courtesy than other patients, compared to 79% of White members. Similarly, 83% of gay and lesbian members reported that the doctor or nurse never acted as if the patient were not smart; compared to 79% of straight/ heterosexual members and 81% of bisexual members. The analysis highlighted that the straight/heterosexual respondents reported receiving less courtesy more often than gay or lesbian respondents, identified at a 95% confidence level (11 out of 95 straight/heterosexual members and 8 out of 208 gay or lesbian members). Interestingly, the minority group reported the same or better treatment by providers than the group that makes up the majority of respondents. In addition, the small size of subgroups (such as Bisexual members) means that only a few members' responses can influence the result.

Though very little inequitable treatment was reported, we cannot assume that non-respondents are receiving equitable treatment. Boosting response rates would help inform where and whether health equity issues need to be addressed.

Race and Ethnicity Reported by Survey Respondents

Three hundred thirty-three members responded to "What is your race?" Ninety percent of survey respondents selected White or Caucasian, seven percent selected Black or African American, three percent indicated they are American Indian or Alaskan Native, one percent selected "another race," while "Native Hawaiian or Pacific Islander" and "Asian or Asian American" both represented less than one percent of respondents. See Figure 14 below.

MaineCare enrollment and claims data indicate 78% of MaineCare members living with HIV/AIDS are white/Caucasian; Maine Center for Disease Control and Prevention (CDC) data (2019 Enhanced HIV/AIDS Reporting System) shows 72% of people living with HIV in Maine are white/non-Hispanic. As noted above, survey respondents in the white/Caucasian category are over-represented at 90%. Black and African American people are under-represented in survey respondents. They were seven percent of respondents, compared to 12% of MaineCare members living with HIV/AIDS (MaineCare data), and 18%.[1] (CDC: 2019 Enhanced HIV/AIDS Reporting System).

Staff will research this over-representation and determine what further and/or different outreach strategies may improve this. Staff is considering calling all non-respondents and strengthening relationships with all BIPOC members through our care management activities. Staff will also explore community-based organizations and publications as a way to reach these groups. Regardless of each race group's size, the program will work on responding to and lessening health disparities. For example, with the respondents' race data, staff can segment responses to questions about providers by race. We can use this data to examine variations in patient experience between White and African American respondents.

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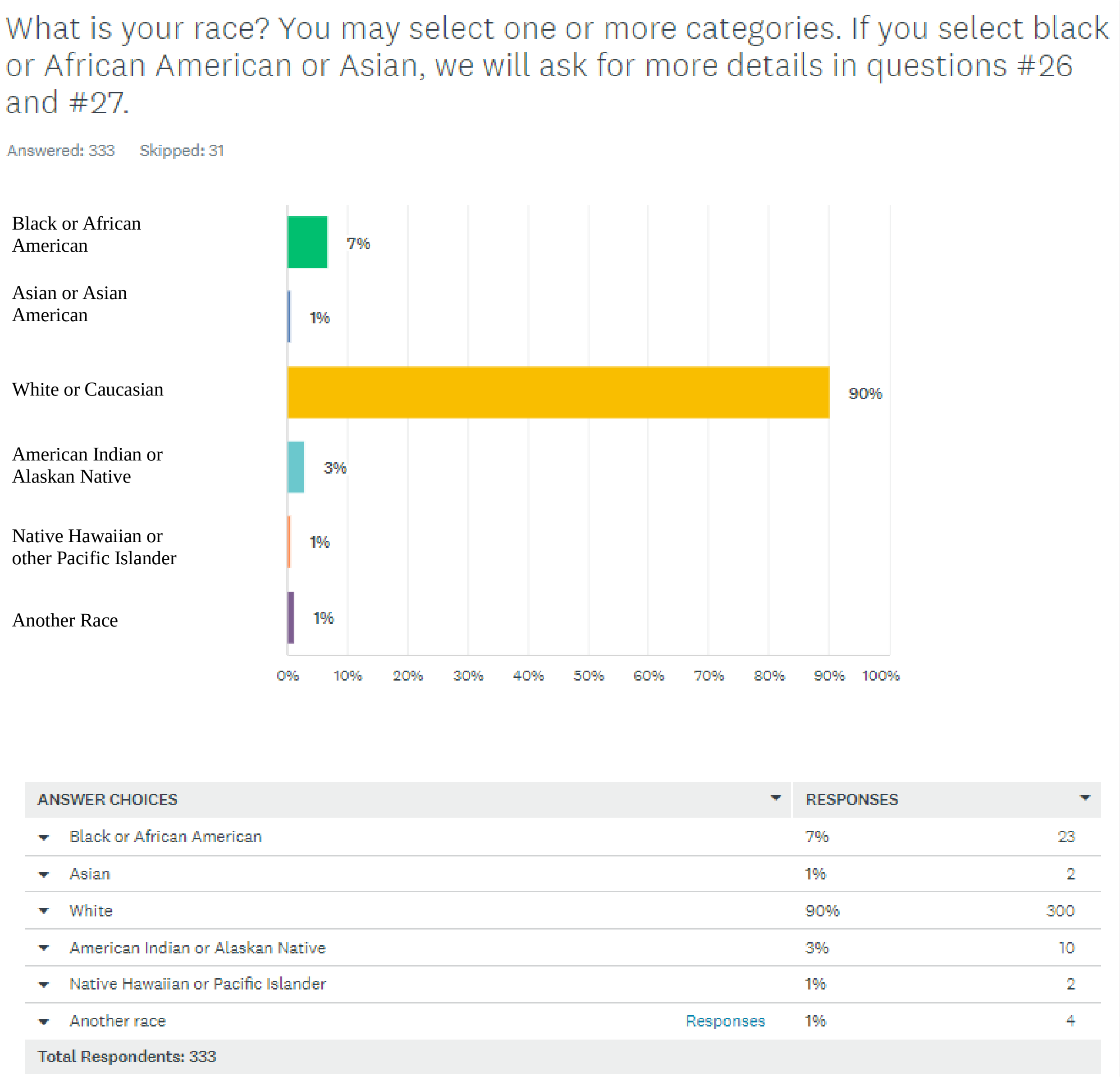
[1] It should be noted that when comparing race data between MaineCare and CDC, a discrepancy between the number of Native Hawaiian/Pacific Islanders living with HIV in Maine and our survey respondents was identified. Two survey respondents self-identified as Native Hawaiian/Pacific Islanders, while CDC reports there are none living in Maine. This data highlights the inconsistencies with self-reported data and comparing two different data sets.

Figure 14



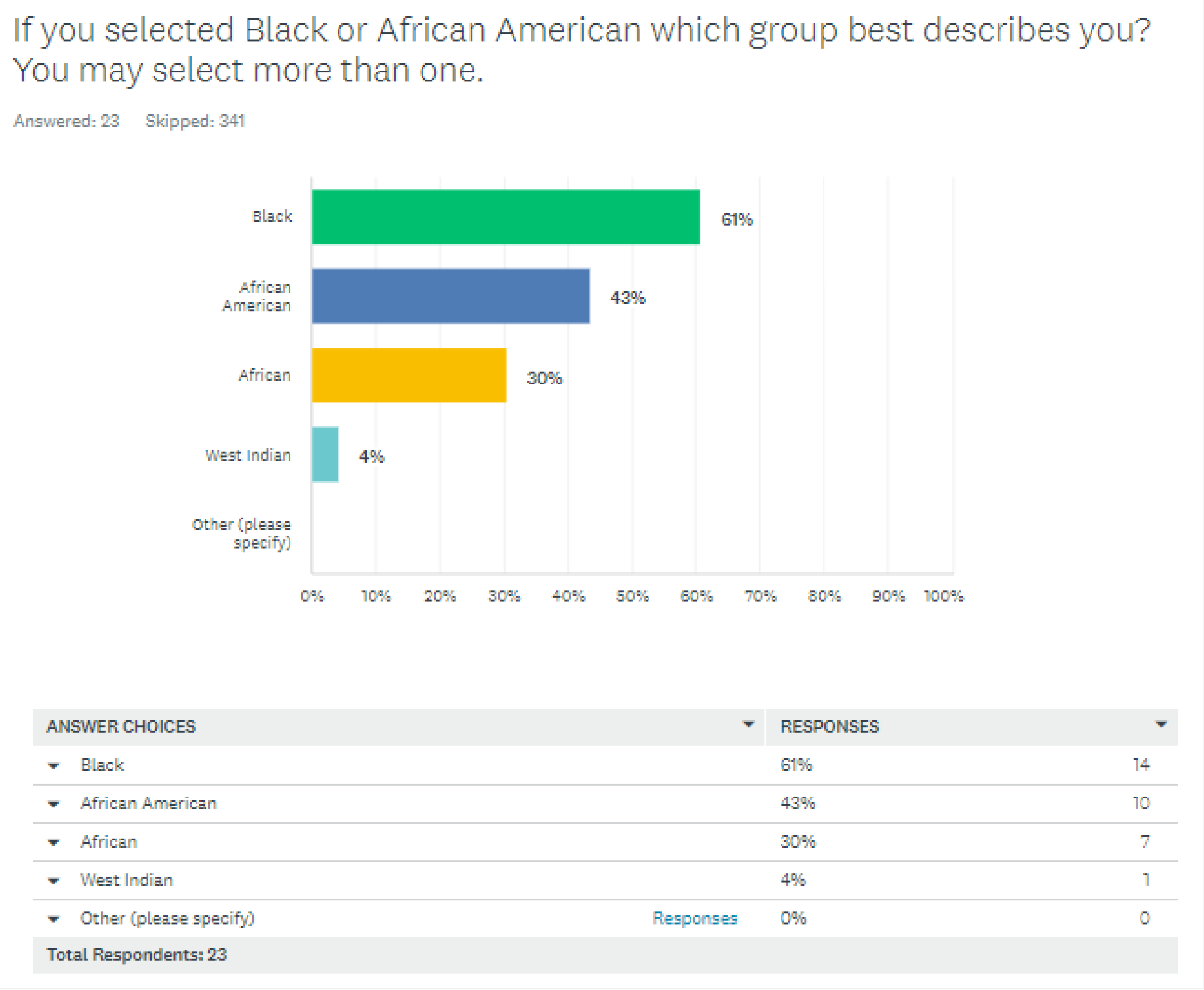
What is your race? You may select one or more categories. If you select black or African American or Asian, we will ask for more details in questions #26 and #27.

Answered: 333 Skipped: 31

ANSWER CHOICES		RESPONSES	
Black or African American		7%	23
Asian		1%	2
White		90%	300
American Indian or Alaskan Native		3%	10
Native Hawaiian or Pacific Islander		1%	2
Another race	Responses	1%	4
Total Respondents: 333			

Out of the 23 respondents, 14 indicated they are best described as “Black,” and 10 indicated they are best described as “African American.” Additionally, 7 members are best described as “African,” and no members selected “Other” and did not specify. See Figure 15.

Figure 15



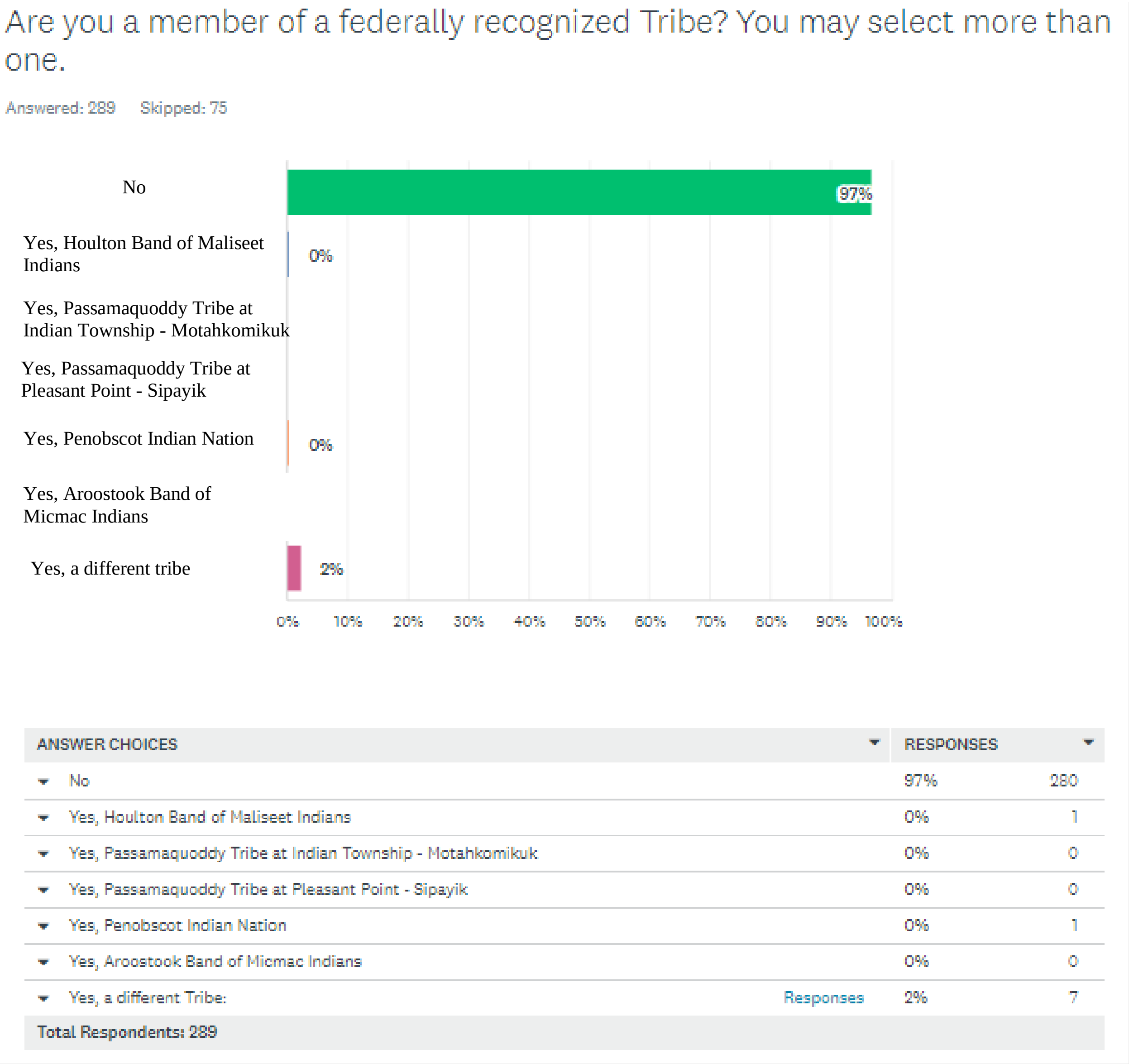
If you selected Black or African American which group best describes you? You may select more than one.

Answered: 23 Skipped: 341

ANSWER CHOICES		RESPONSES	
Black		61%	14
African American		43%	10
African		30%	7
West Indian		4%	1
Other (please specify)	Responses	0%	0
Total Respondents: 23			

We asked participants, “Are you a member of a federally recognized Tribe?” Ninety-seven percent of respondents selected “No,” while two percent of respondents selected “Yes, a different tribe” (Cherokee and Canadian were specified). Blank response options included two “Passamaquoddy Tribes” and the “Aroostook Band of Micmac Indians.” Two groups received one response each “Houlton Band of Maliseet Indians” and “Penobscot Indian Nation.” See Figure 16.

Figure 16



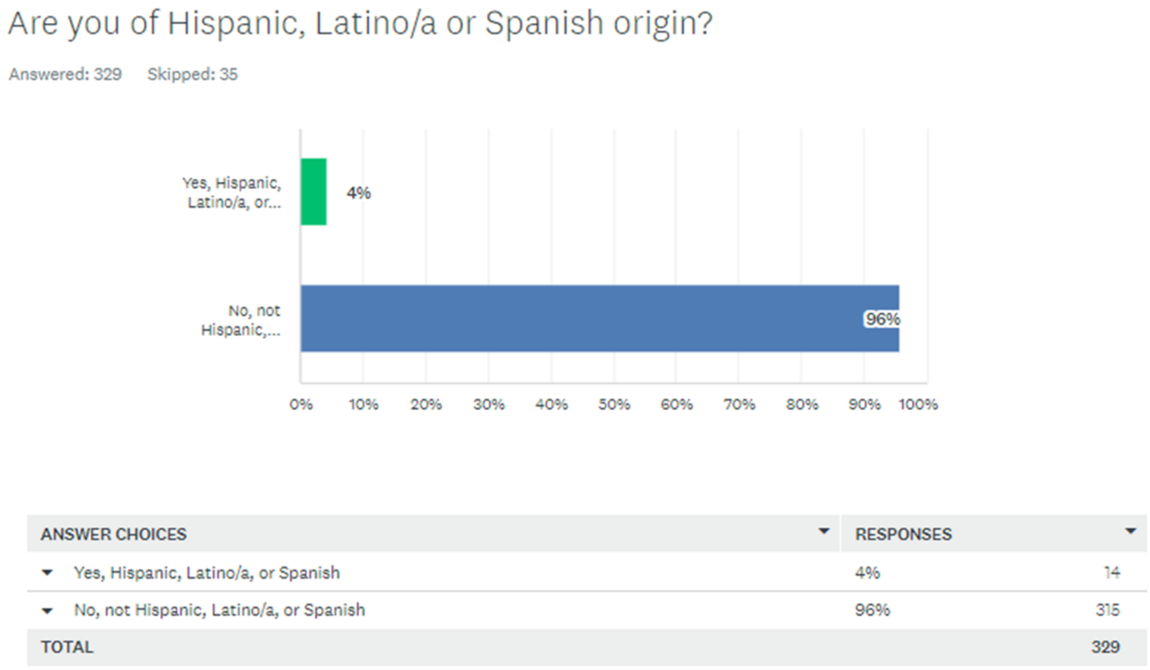
Are you a member of a federally recognized Tribe? You may select more than one.

Answered: 289 Skipped: 75

ANSWER CHOICES		RESPONSES	
No		97%	280
Yes, Houlton Band of Maliseet Indians		0%	1
Yes, Passamaquoddy Tribe at Indian Township - Motahkomikuk		0%	0
Yes, Passamaquoddy Tribe at Pleasant Point - Sipayik		0%	0
Yes, Penobscot Indian Nation		0%	1
Yes, Aroostook Band of Micmac Indians		0%	0
Yes, a different Tribe:	Responses	2%	7
Total Respondents: 289			

We then asked: “Are you of Hispanic, Latino/a, or Spanish origin?” There were 329 responses to this question, with 96% of members selecting “No” and four percent selecting “Yes.” Of the 14 members who selected yes, eight are “Puerto Rican,” two are another “Hispanic, Latino/a, or Spanish origin,” three are “Cuban,” and one is “Mexican, Mexican American, or Chicano.” See Figure 17 and Figure 18.

Figure 17

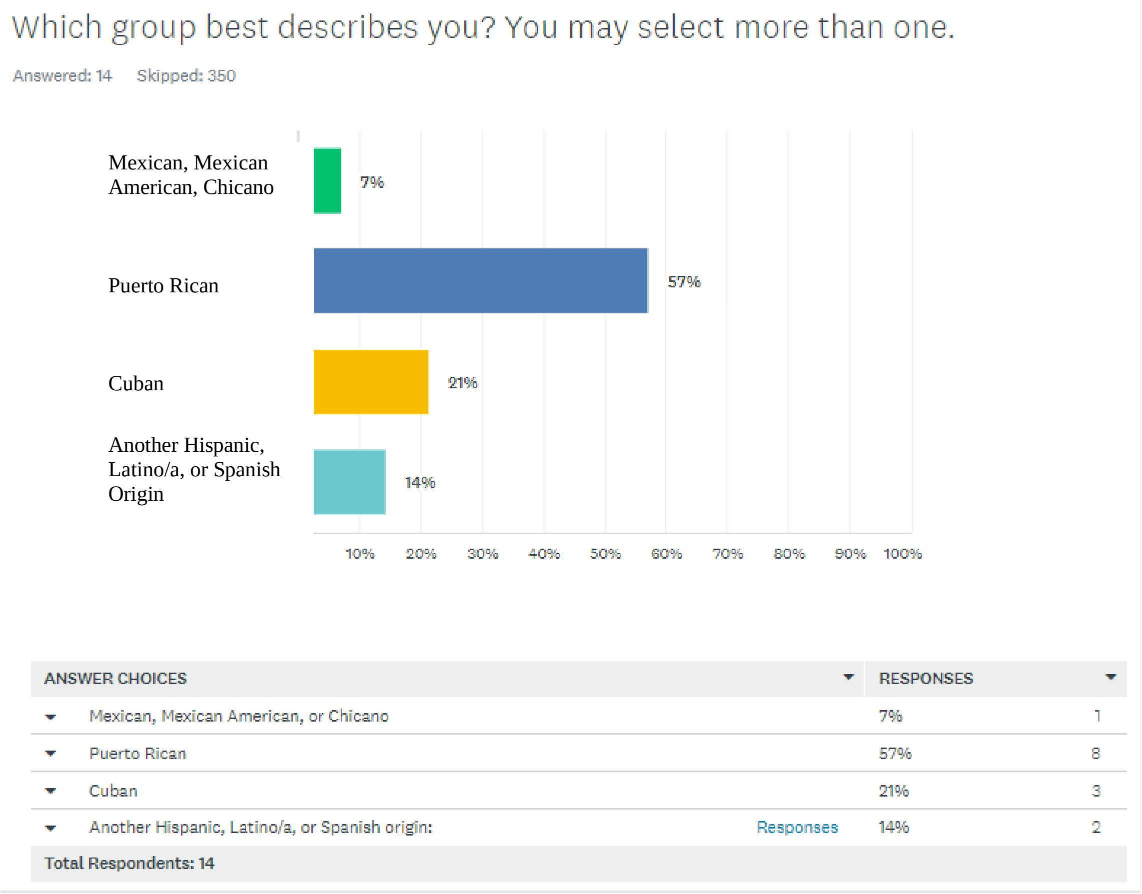


Are you of Hispanic, Latino/a or Spanish origin?

Answered: 329 Skipped: 35

ANSWER CHOICES	RESPONSES	
Yes, Hispanic, Latino/a, or Spanish	4%	14
No, not Hispanic, Latino/a, or Spanish	96%	315
TOTAL		329

Figure 18



Which group best describes you? You may select more than one.

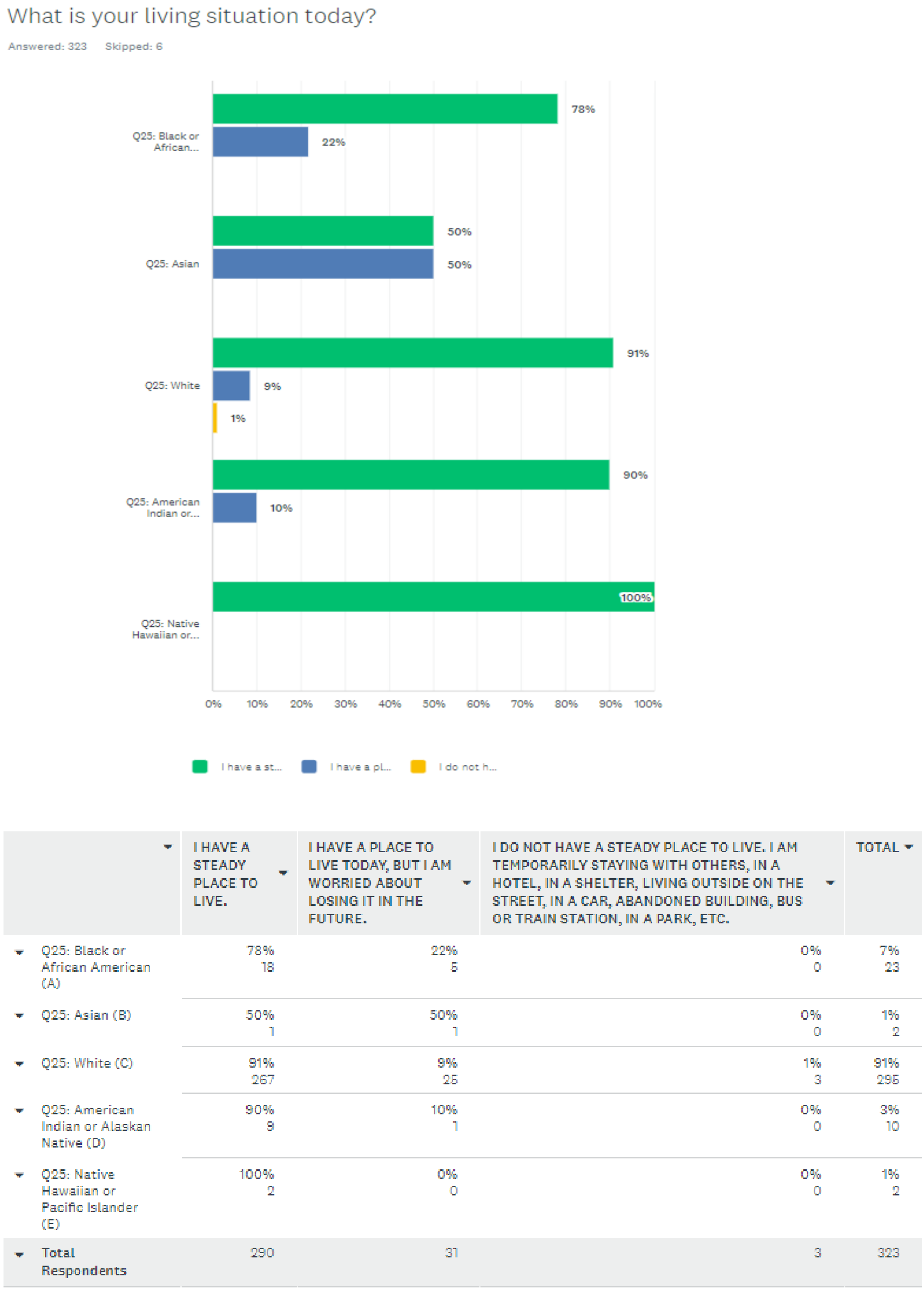
Answered: 14 Skipped: 350

ANSWER CHOICES		RESPONSES	
Mexican, Mexican American, or Chicano		7%	1
Puerto Rican		57%	8
Cuban		21%	3
Another Hispanic, Latino/a, or Spanish origin:	Responses	14%	2
Total Respondents: 14			

Member Experience Responses Segmented by Race

We are interested in knowing if all populations are being cared for in an equitable manner. The next several figures stratify responses to certain questions by race. Figure 19 below graphs responses to “What is your living situation today?” by race. Black or African American respondents reported being fearful of losing their steady place to live at a higher rate (5 out of 23 respondents, or 22%) than White or Caucasian respondents (25 out of 296 respondents, or 8%). This appears to occur at a disproportionate rate, although the difference between the two groups was not statistically significant, due to the small sample size for Black/ African American respondents. The data is shown below, nonetheless.

Figure 19



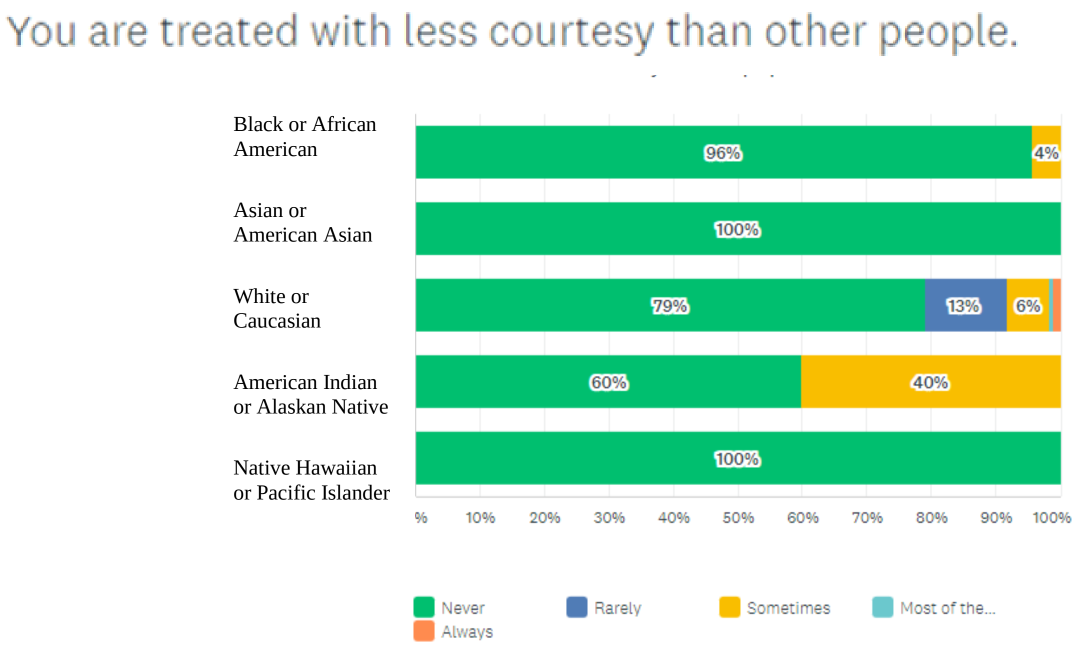
What is your living situation today?

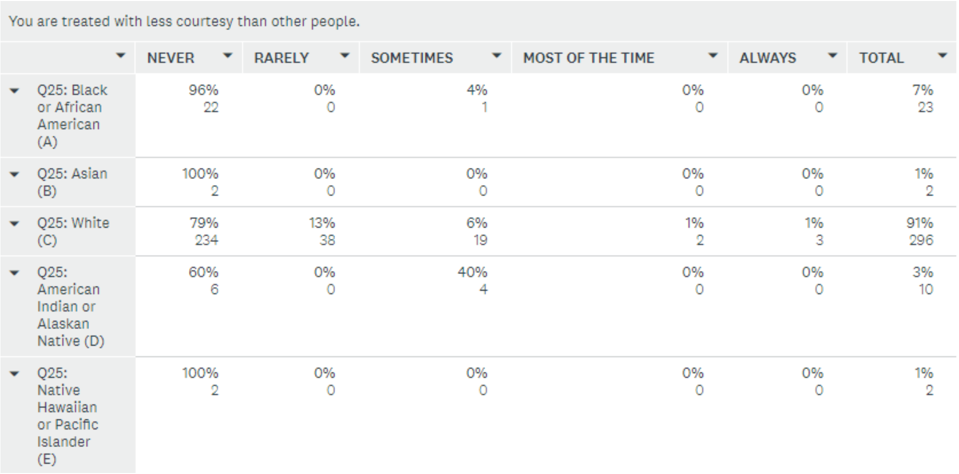
Answered: 323   Skipped: 6

	I HAVE A STEADY PLACE TO LIVE.	I HAVE A PLACE TO LIVE TODAY, BUT I AM WORRIED ABOUT LOSING IT IN THE FUTURE.	I DO NOT HAVE A STEADY PLACE TO LIVE. I AM TEMPORARILY STAYING WITH OTHERS, IN A HOTEL, IN A SHELTER, LIVING OUTSIDE ON THE STREET, IN A CAR, ABANDONED BUILDING, BUS OR TRAIN STATION, IN A PARK, ETC.	TOTAL
Q25: Black or African American (A)	78% 18	22% 5	0% 0	7% 23
Q25: Asian (B)	50% 1	50% 1	0% 0	1% 2
Q25: White (C)	91% 267	9% 25	1% 3	91% 295
Q25: American Indian or Alaskan Native (D)	90% 9	10% 1	0% 0	3% 10
Q25: Native Hawaiian or Pacific Islander (E)	100% 2	0% 0	0% 0	1% 2
Total Respondents	290	31	3	323

Figure 20 below compares the question “What is your race?” with the Likert scale responses to the statement “You are treated with less courtesy than other people.” The analysis did not highlight any data differences below as statistically significant.

Figure 20



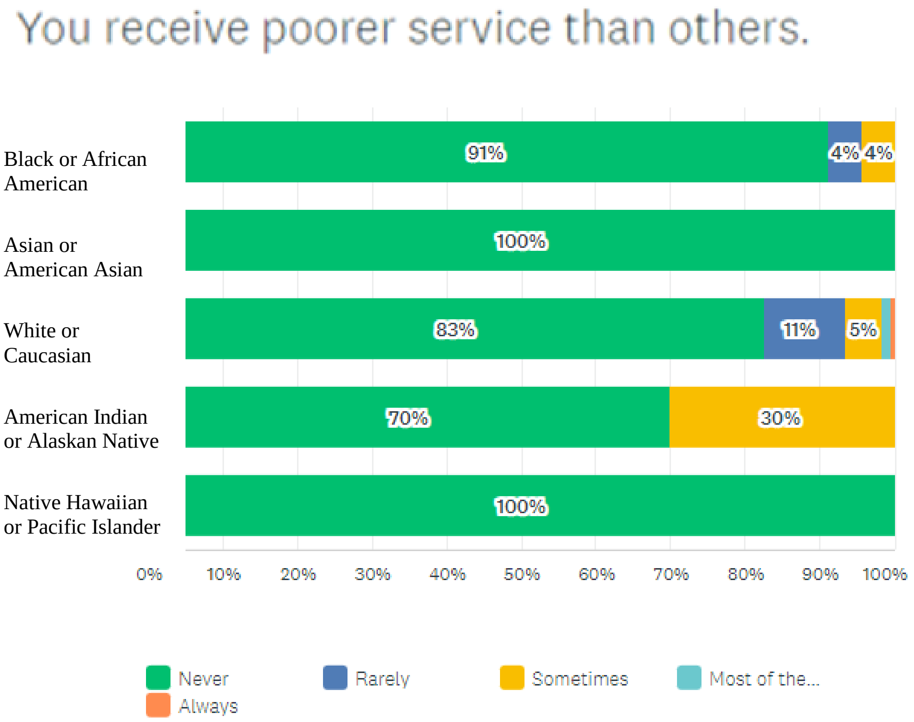


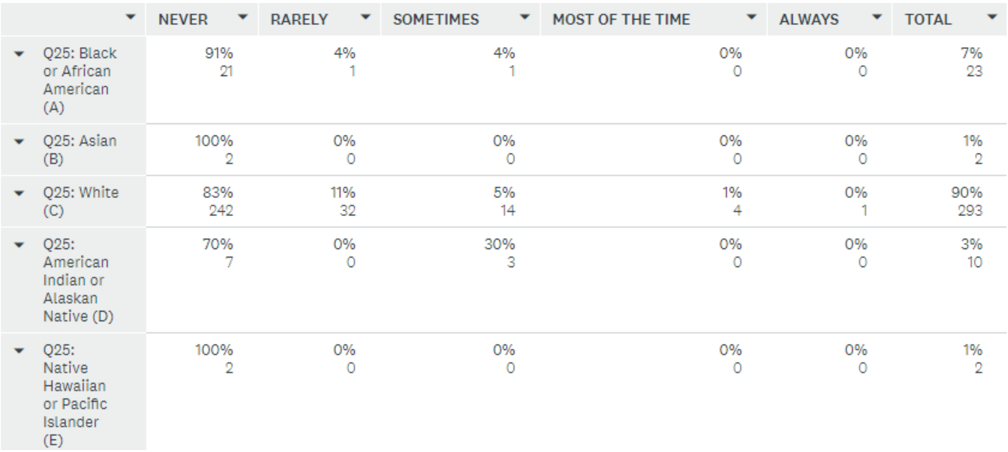
You are treated with less courtesy than other people.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q25: Black or African American (A)	96% 22	0% 0	4% 1	0% 0	0% 0	7% 23
Q25: Asian (B)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2
Q25: White (C)	79% 234	13% 38	6% 19	1% 2	1% 3	91% 296
Q25: American Indian or Alaskan Native (D)	60% 6	0% 0	40% 4	0% 0	0% 0	3% 10
Q25: Native Hawaiian or Pacific Islander (E)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2

Figure 21 below compares the question “What is your race?” with the Likert scale responses to the statement “You receive poorer service than others.” White or Caucasian respondents reported receiving poorer service “most of the time” and “always” more often than other race groups. Members who indicated they receive poorer service than others “Most of the time” can be broken down as follows: 4 out of 293 White or Caucasian; 0 out of 32 Black or African American. Members who indicated “Always” can be broken down as follows: 1 out of 293 White or Caucasian; 0 out of 32 Black or African American.

Figure 21

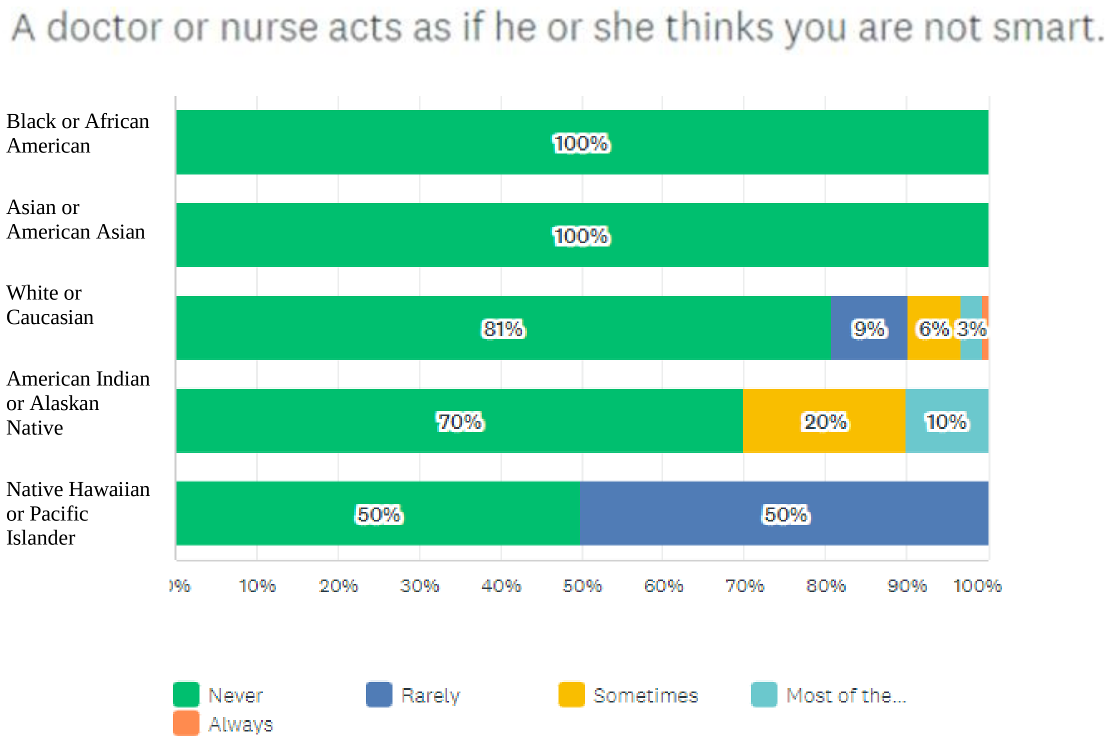

You receive poorer service than others.

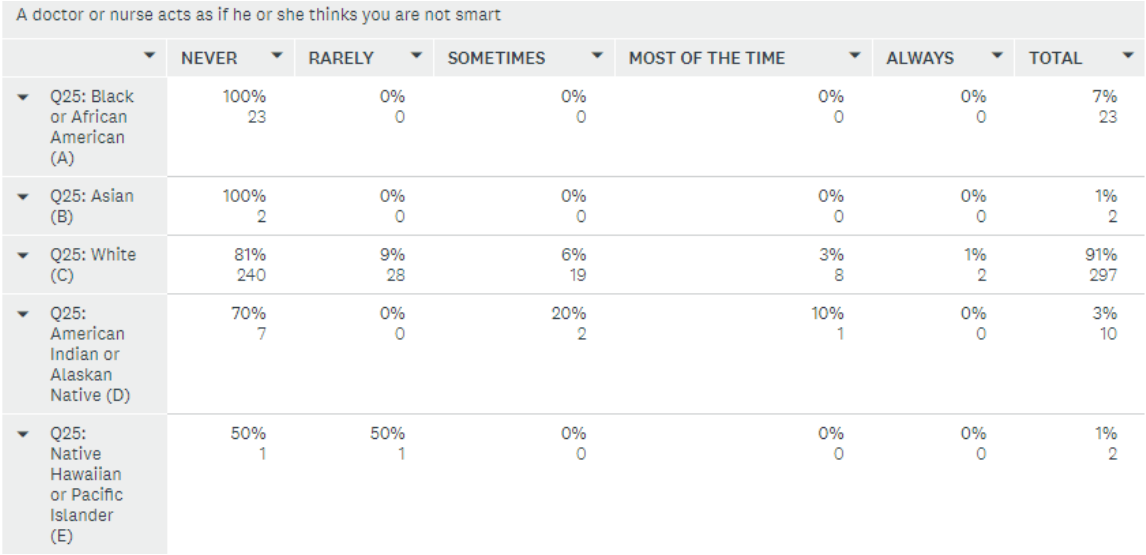


	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q25: Black or African American (A)	91% 21	4% 1	4% 1	0% 0	0% 0	7% 23
Q25: Asian (B)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2
Q25: White (C)	83% 242	11% 32	5% 14	1% 4	0% 1	90% 293
Q25: American Indian or Alaskan Native (D)	70% 7	0% 0	30% 3	0% 0	0% 0	3% 10
Q25: Native Hawaiian or Pacific Islander (E)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2

Figure 22 below compares the question “What is your race?” with the Likert scale responses to the statement “A doctor or nurse acts as if he or she thinks you are not smart.” The analysis did not highlight any differences in the data below as statistically significant.

Figure 22



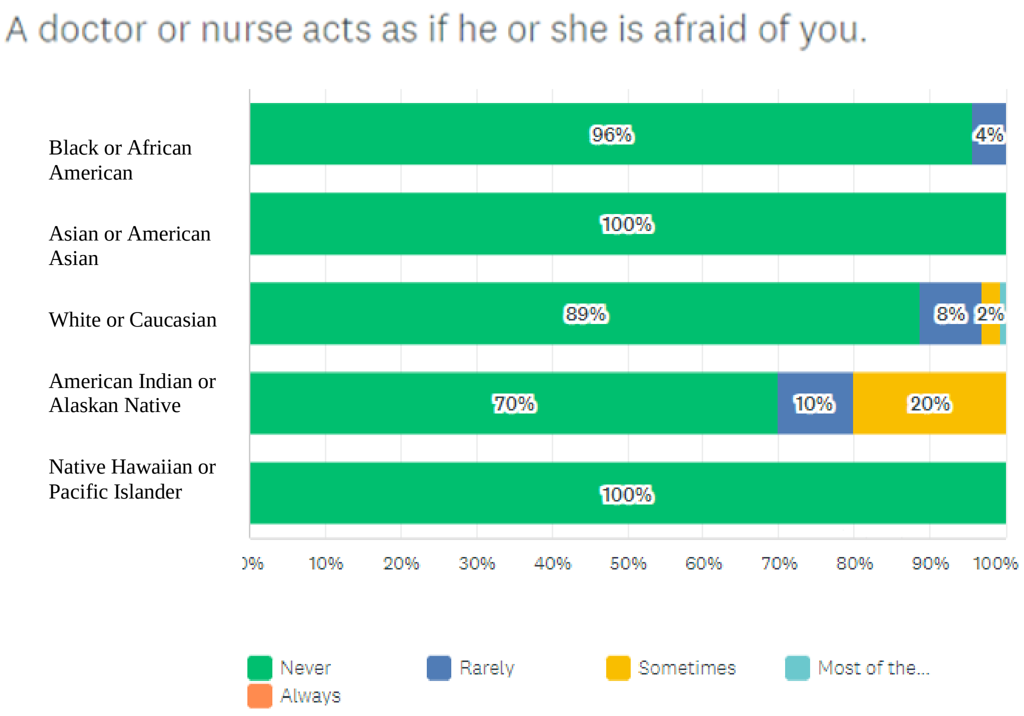


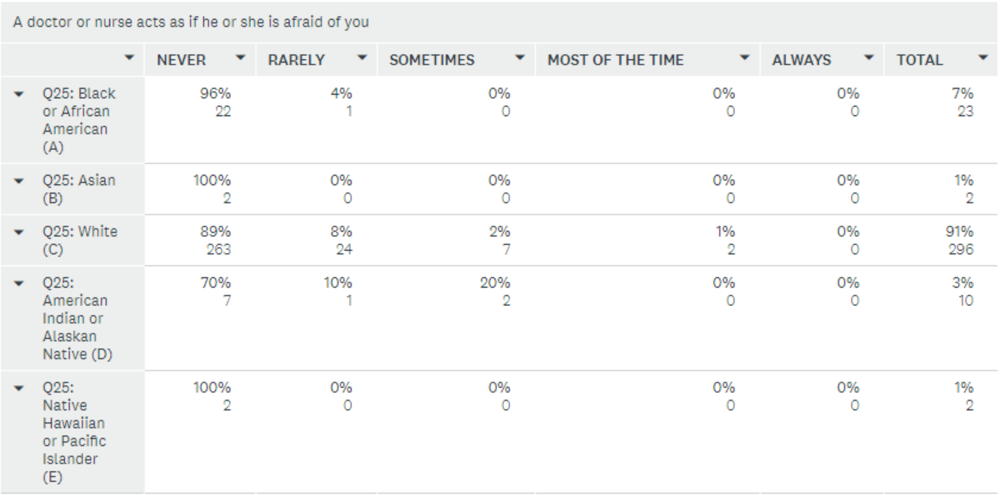
A doctor or nurse acts as if he or she thinks you are not smart

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q25: Black or African American (A)	100% 23	0% 0	0% 0	0% 0	0% 0	7% 23
Q25: Asian (B)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2
Q25: White (C)	81% 240	9% 28	6% 19	3% 8	1% 2	91% 297
Q25: American Indian or Alaskan Native (D)	70% 7	0% 0	20% 2	10% 1	0% 0	3% 10
Q25: Native Hawaiian or Pacific Islander (E)	50% 1	50% 1	0% 0	0% 0	0% 0	1% 2

Figure 23 below compares the question “What is your race?” with the Likert scale responses to the statement “A doctor or nurse acts as if he or she is afraid of you.” The analysis did not highlight any data below as statistically significant.

Figure 23





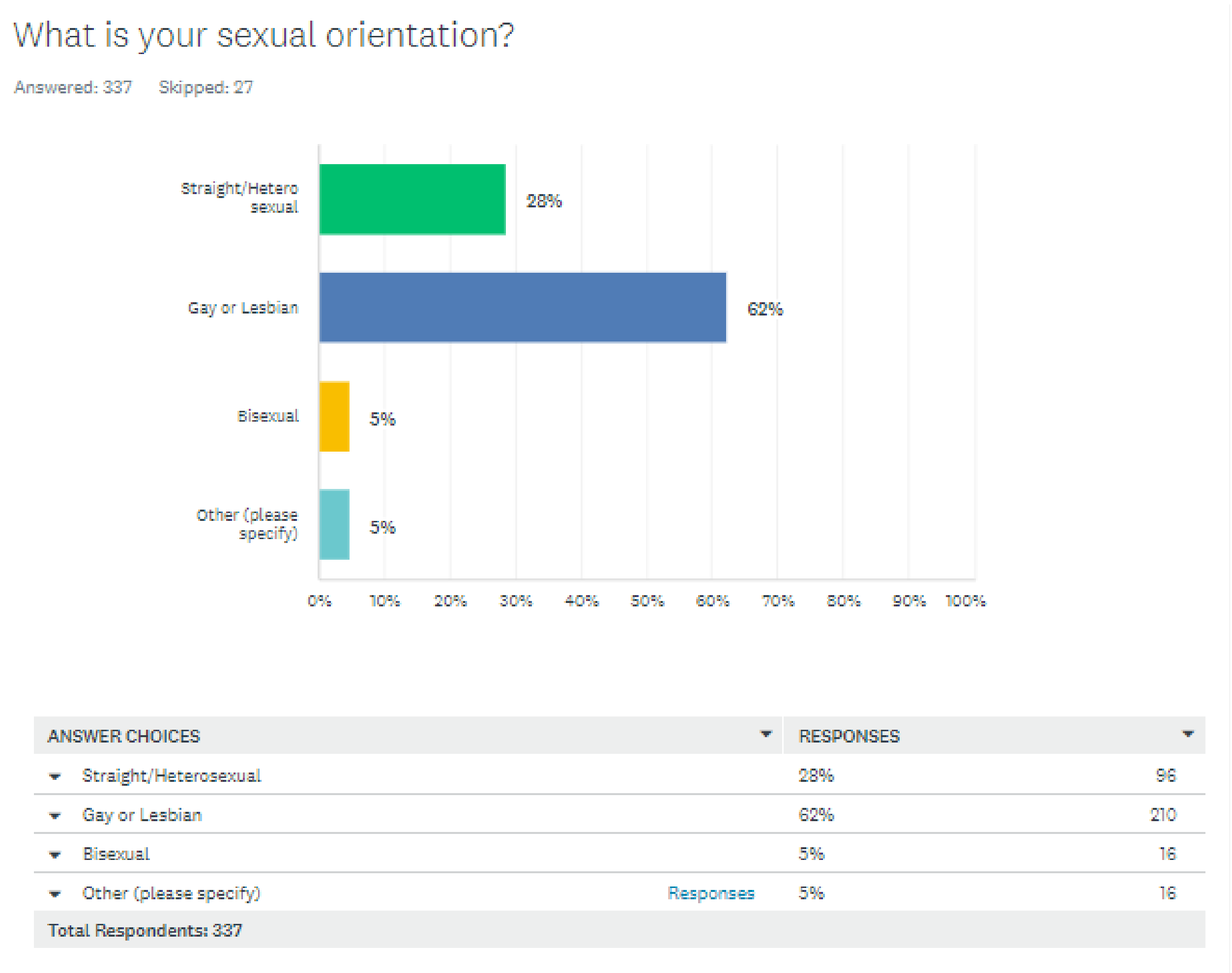
A doctor or nurse acts as if he or she is afraid of you

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q25: Black or African American (A)	96% 22	4% 1	0% 0	0% 0	0% 0	7% 23
Q25: Asian (B)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2
Q25: White (C)	89% 263	8% 24	2% 7	1% 2	0% 0	91% 296
Q25: American Indian or Alaskan Native (D)	70% 7	10% 1	20% 2	0% 0	0% 0	3% 10
Q25: Native Hawaiian or Pacific Islander (E)	100% 2	0% 0	0% 0	0% 0	0% 0	1% 2

Sexual Orientation Reported by Respondents

The last demographic question that we asked members was "What is your sexual orientation?" Sixty-two percent of respondents indicated that they are gay or lesbian, 28% indicated they are straight/heterosexual, while 5% indicated they are bisexual and 5% selected "other" sexual orientation (asexual, pansexual). Several members wrote in this section that they felt this data collection was not necessary, writing phrases such as "private" and "none of your business."

Figure 24



What is your sexual orientation?

Answered: 337 Skipped: 27

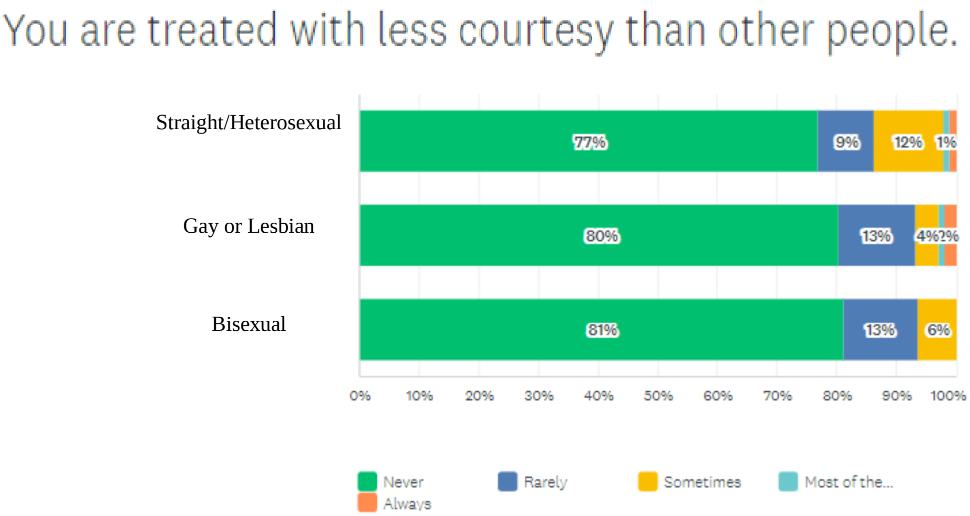
ANSWER CHOICES		RESPONSES	
Straight/Heterosexual		28%	96
Gay or Lesbian		62%	210
Bisexual		5%	16
Other (please specify)	Responses	5%	16
Total Respondents: 337			

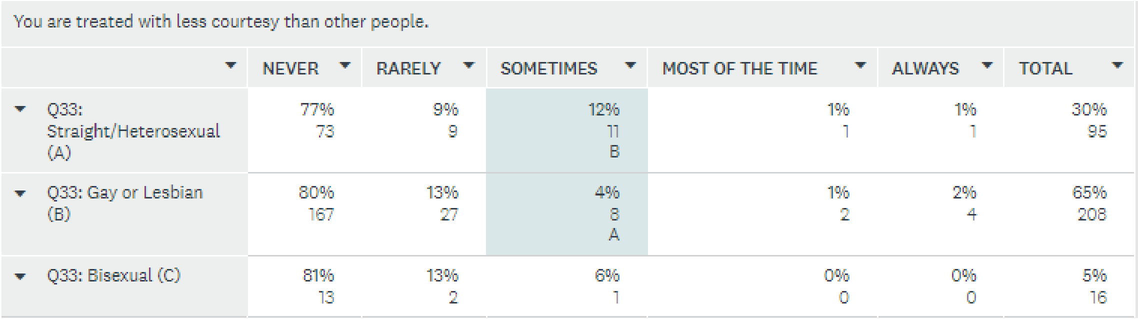
Member Experience Responses Segmented by Sexual Orientation

Figure 25 below compares the question “What is your sexual orientation?” with the Likert scale responses to the statement “You are treated with less courtesy than other people.” The analysis highlighted that the straight/heterosexual group reported receiving less courtesy than others more often than the gay or lesbian group, identified at a 95% confidence level (11 out of 95 straight/heterosexual members and 8 out of 208 gay or lesbian members).

Sixteen percent of Black, Indigenous, and People of Color (BIPOC) respondents indicated they were gay, lesbian, or bisexual, compared to 72% of white/Caucasian respondents. SurveyMonkey highlighted this data as being statistically significant and it shows that a larger proportion of the gay or lesbian group is white/Caucasian (207/284) and BIPOC are more likely to identify as straight/heterosexual (23/32). Data combinations from these two questions are all shown below.

Figure 25



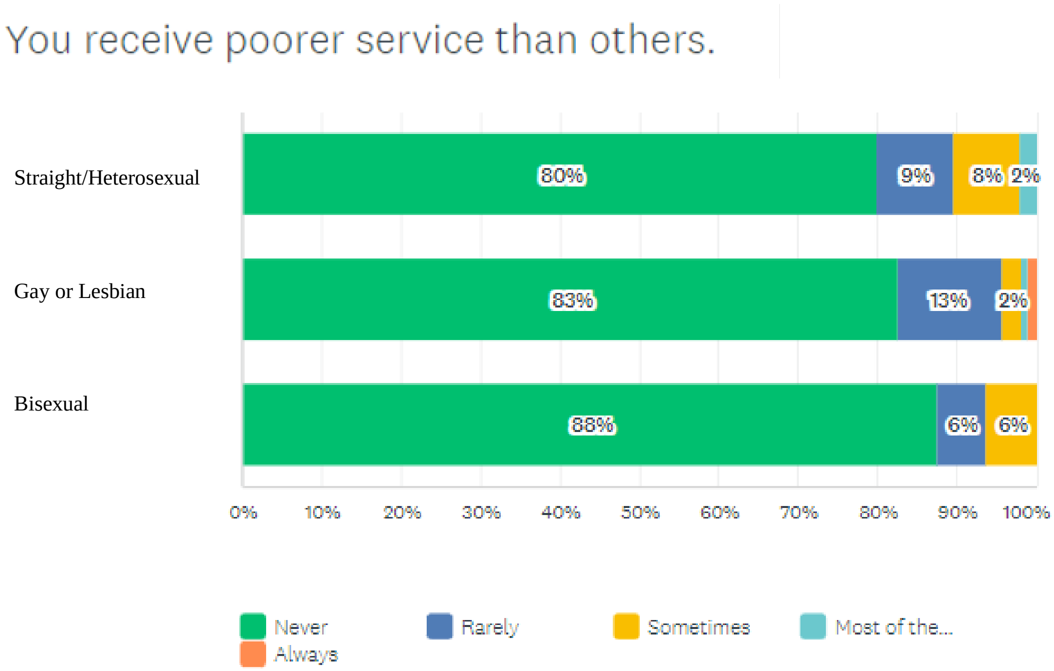


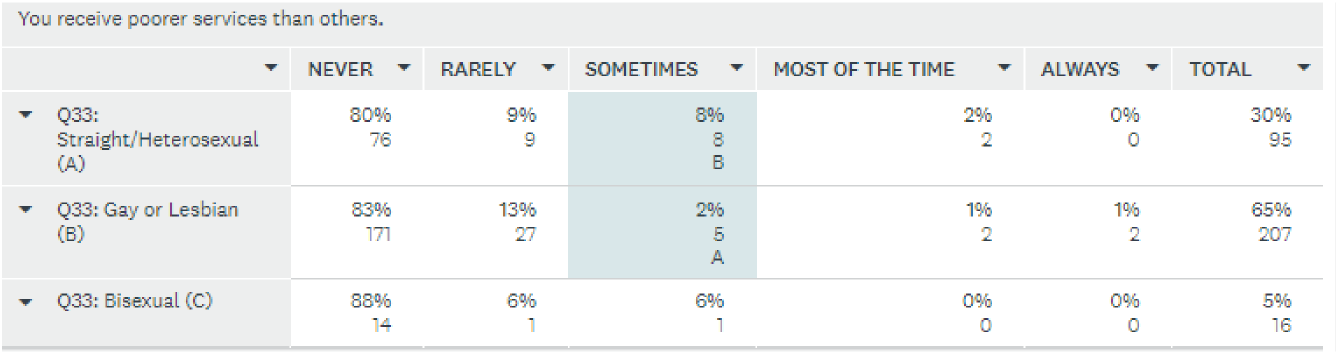
You are treated with less courtesy than other people.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q33: Straight/Heterosexual (A)	77% 73	9% 9	12% 11 B	1% 1	1% 1	30% 95
Q33: Gay or Lesbian (B)	80% 167	13% 27	4% 8 A	1% 2	2% 4	65% 208
Q33: Bisexual (C)	81% 13	13% 2	6% 1	0% 0	0% 0	5% 16

Figure 26 below compares the question: “What is your sexual orientation?” with the Likert scale responses to the statement “You receive poorer service than others.” The analysis did highlight data below as statistically significant noting that the “straight/heterosexual” respondents more often report receiving poorer service than others.

Figure 26



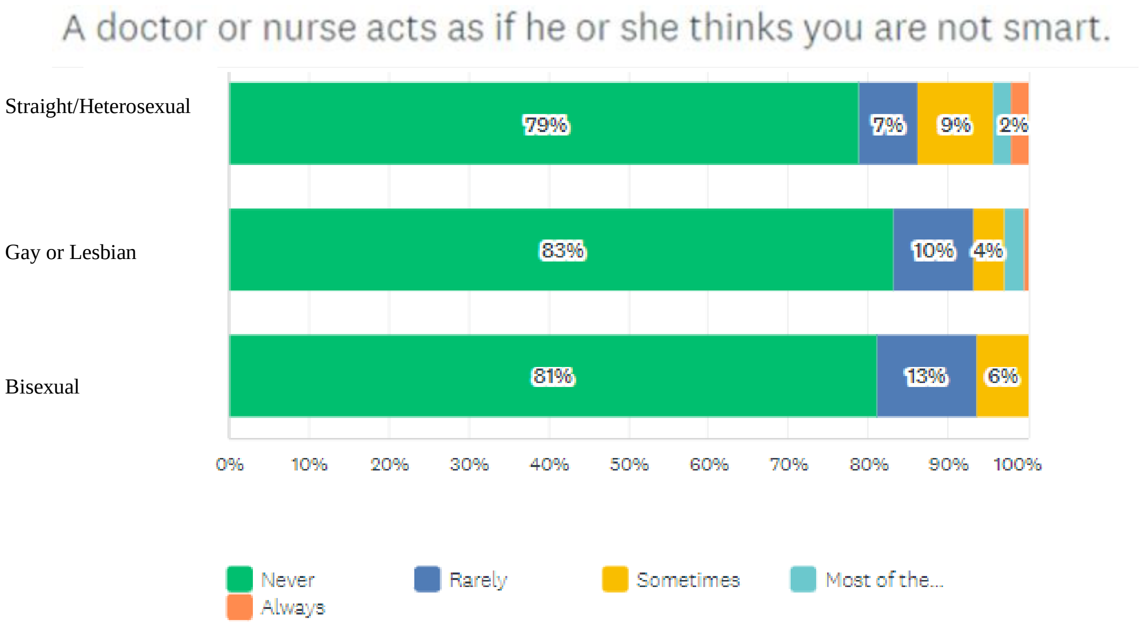


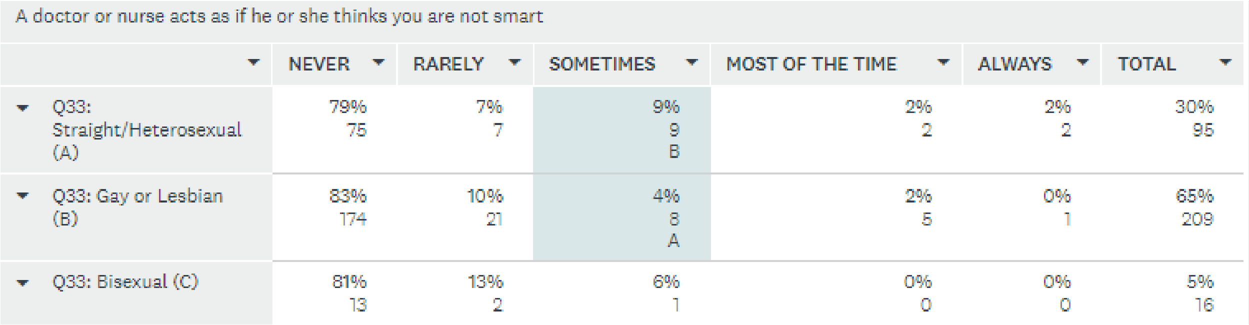
You receive poorer services than others.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q33: Straight/Heterosexual (A)	80% 76	9% 9	8% 8 B	2% 2	0% 0	30% 95
Q33: Gay or Lesbian (B)	83% 171	13% 27	2% 5 A	1% 2	1% 2	65% 207
Q33: Bisexual (C)	88% 14	6% 1	6% 1	0% 0	0% 0	5% 16

Figure 27 below compares the question “What is your sexual orientation?” with the Likert scale responses to the statement “A doctor or nurse acts as if he or she thinks you are not smart.” This analysis highlighted the differences seen in the table below between the straight/heterosexual and gay or lesbian populations. There was a statistically significant higher rate of “sometimes” by straight/heterosexual members.

Figure 27



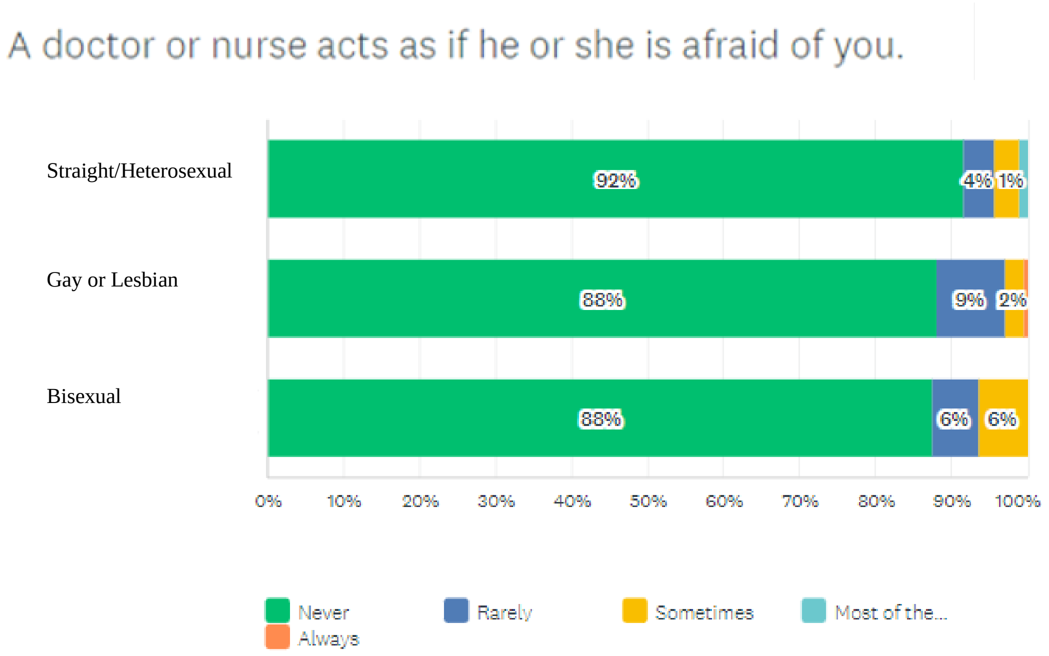


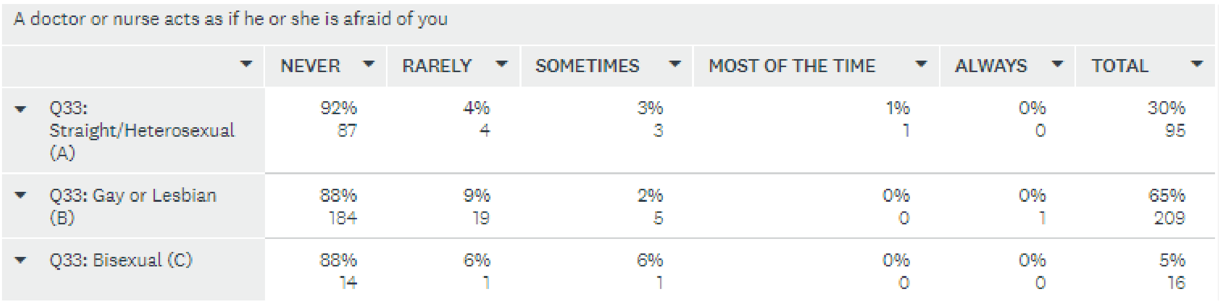
A doctor or nurse acts as if he or she thinks you are not smart

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q33: Straight/Heterosexual (A)	79% 75	7% 7	9% 9 B	2% 2	2% 2	30% 95
Q33: Gay or Lesbian (B)	83% 174	10% 21	4% 8 A	2% 5	0% 1	65% 209
Q33: Bisexual (C)	81% 13	13% 2	6% 1	0% 0	0% 0	5% 16

Figure 28 below compares the question “What is your sexual orientation?” with the Likert scale responses to the statement “A doctor or nurse acts as if he or she is afraid of you.” This analysis did not highlight any data below as statistically significant.

Figure 28





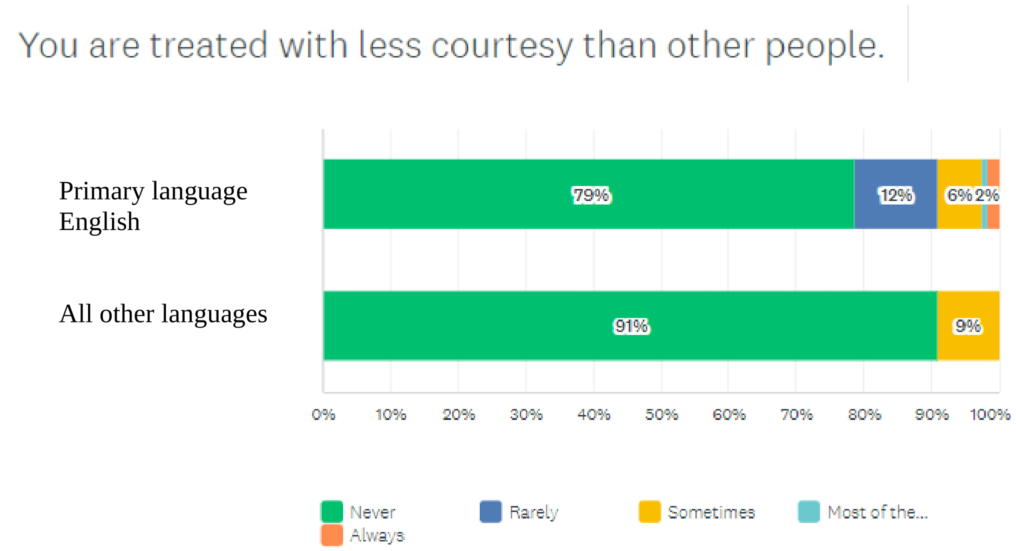
A doctor or nurse acts as if he or she is afraid of you

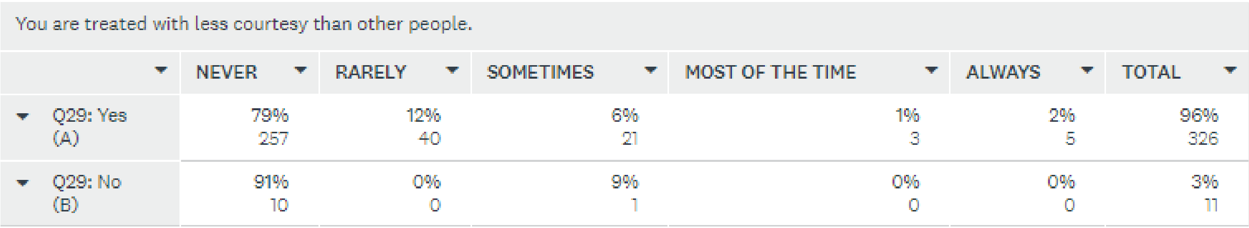
	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q33: Straight/Heterosexual (A)	92% 87	4% 4	3% 3	1% 1	0% 0	30% 95
Q33: Gay or Lesbian (B)	88% 184	9% 19	2% 5	0% 0	0% 1	65% 209
Q33: Bisexual (C)	88% 14	6% 1	6% 1	0% 0	0% 0	5% 16

We can compare the question “Is English your primary language, meaning the language that you speak most often?” with the Likert scale responses to the following statements to help identify areas where health equity can be improved: “You are treated with less courtesy than other people,” “A doctor or nurse acts as if he or she thinks you are not smart,” “You receive poorer service than others” and “A doctor or nurse acts as if he or she is afraid of you.” The results for all four comparisons are seen in figures 29-32 below. This analysis did not identify any of these comparisons as statistically significant

As noted above, the number of non-English speaking respondents was small (n=11), which may explain the unexpected finding that they reported more courteous treatment than English speakers. Although OMS took extra measures to assist all members to respond to this survey (such as including translation instructions in five languages and offering the survey both via mail and online), we recognize that language barriers (e.g., non-English speaking members and members with low literacy) may prevent certain people from responding. Responses may also be colored by social norms. For example, people from cultures that value harmony may avoid reporting discourteous treatment.

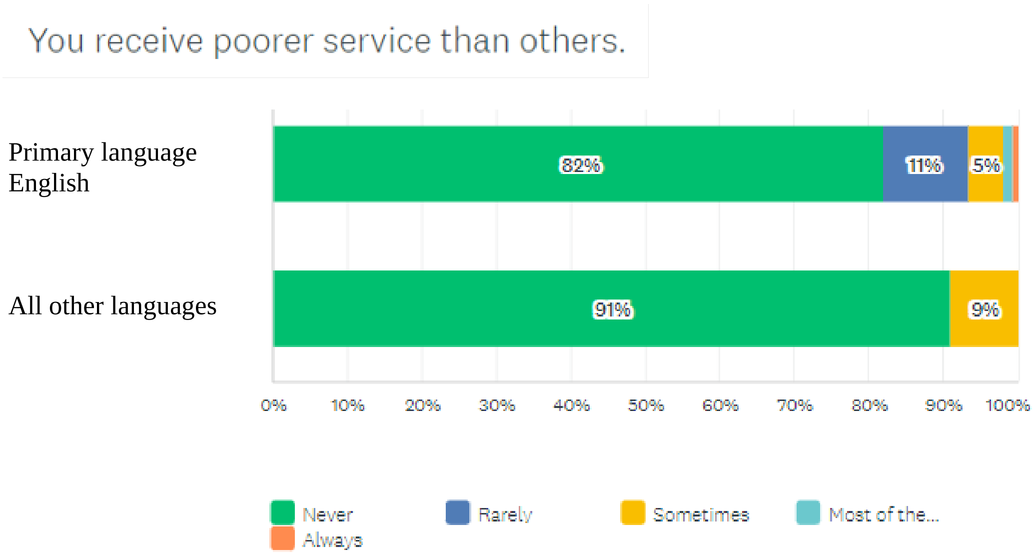
Figure 29

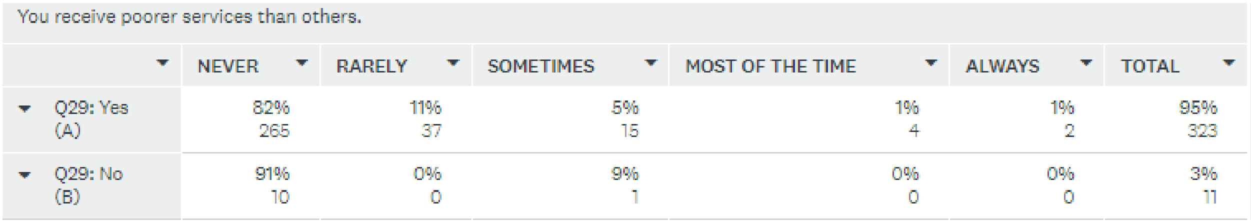



You are treated with less courtesy than other people.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q29: Yes (A)	79% 257	12% 40	6% 21	1% 3	2% 5	96% 326
Q29: No (B)	91% 10	0% 0	9% 1	0% 0	0% 0	3% 11

Figure 30

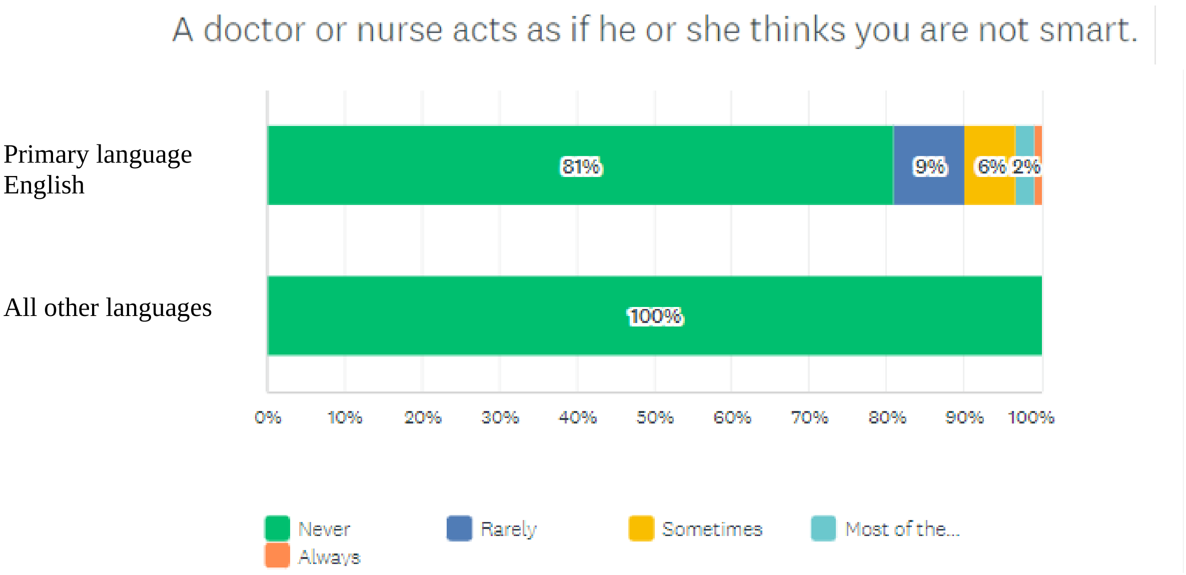


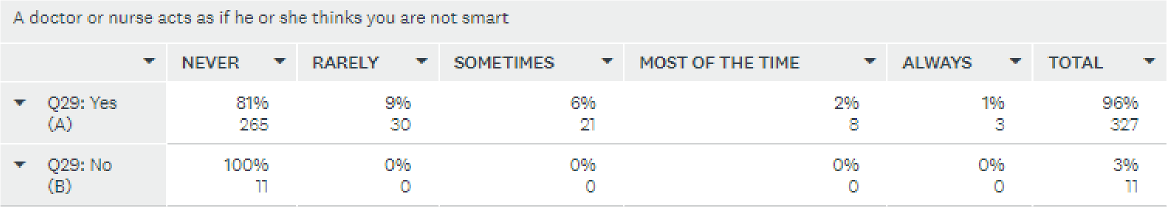


You receive poorer services than others.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q29: Yes (A)	82% 265	11% 37	5% 15	1% 4	1% 2	95% 323
Q29: No (B)	91% 10	0% 0	9% 1	0% 0	0% 0	3% 11

Figure 31

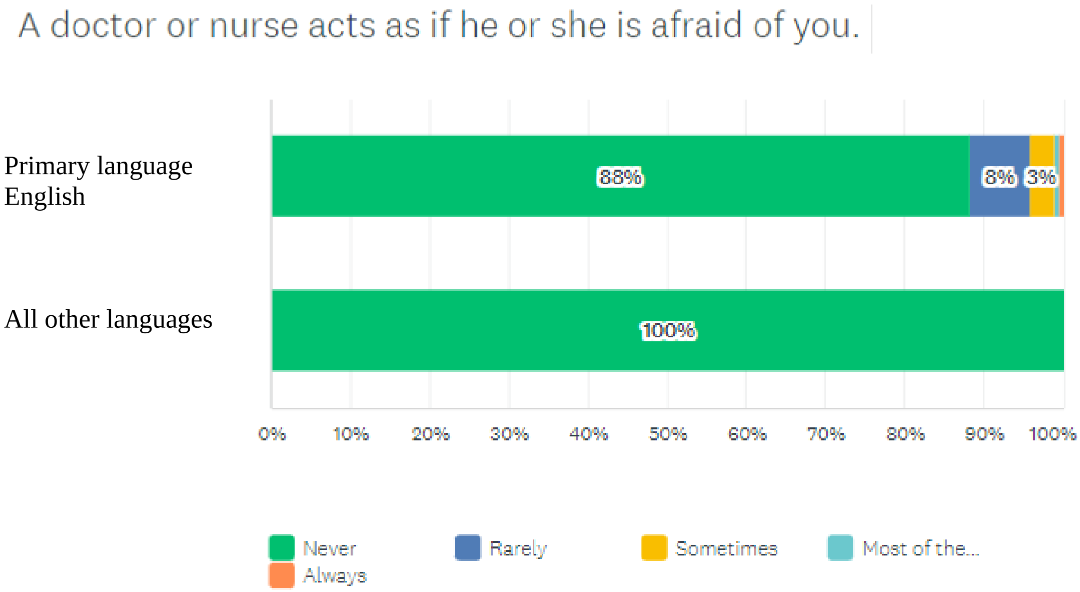


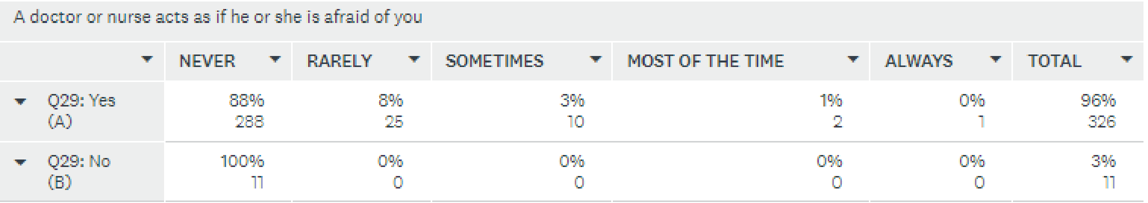


A doctor or nurse acts as if he or she thinks you are not smart

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q29: Yes (A)	81% 265	9% 30	6% 21	2% 8	1% 3	96% 327
Q29: No (B)	100% 11	0% 0	0% 0	0% 0	0% 0	3% 11

Figure 32



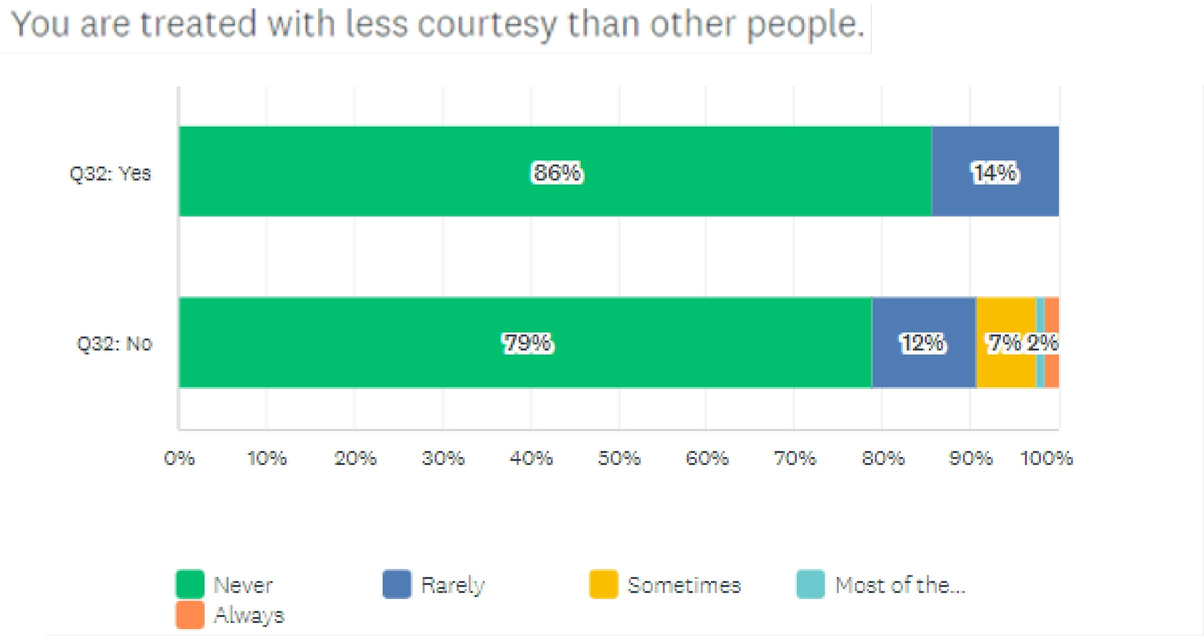


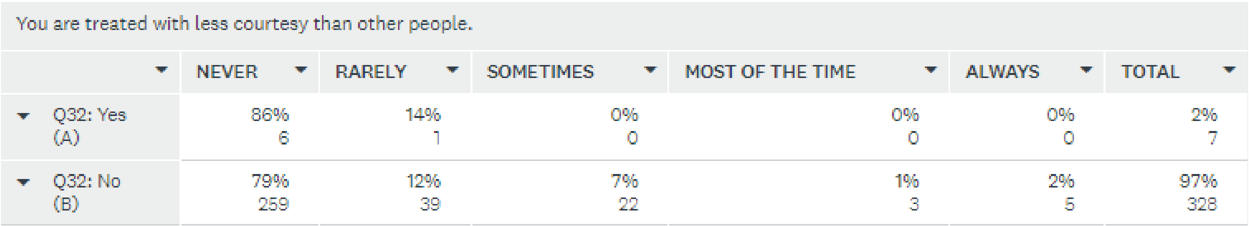
A doctor or nurse acts as if he or she is afraid of you

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q29: Yes (A)	88% 288	8% 25	3% 10	1% 2	0% 1	96% 326
Q29: No (B)	100% 11	0% 0	0% 0	0% 0	0% 0	3% 11

We can compare the question “Do you identify as transgender?” with the Likert scale responses to the following statements to help identify areas where health equity can be improved: “You are treated with less courtesy than other people,” “A doctor or nurse acts as if he or she thinks you are not smart,” “You receive poorer service than others,” and “A doctor or nurse acts as if he or she is afraid of you.” Statistical significance cannot be shown in these comparisons due to the small number of respondents who identify as transgender (7), but the data comparisons are shown in figures 33-36 below. The small number of transgender respondents (n=7) make it difficult to conclude if this result is meaningful.

Figure 33

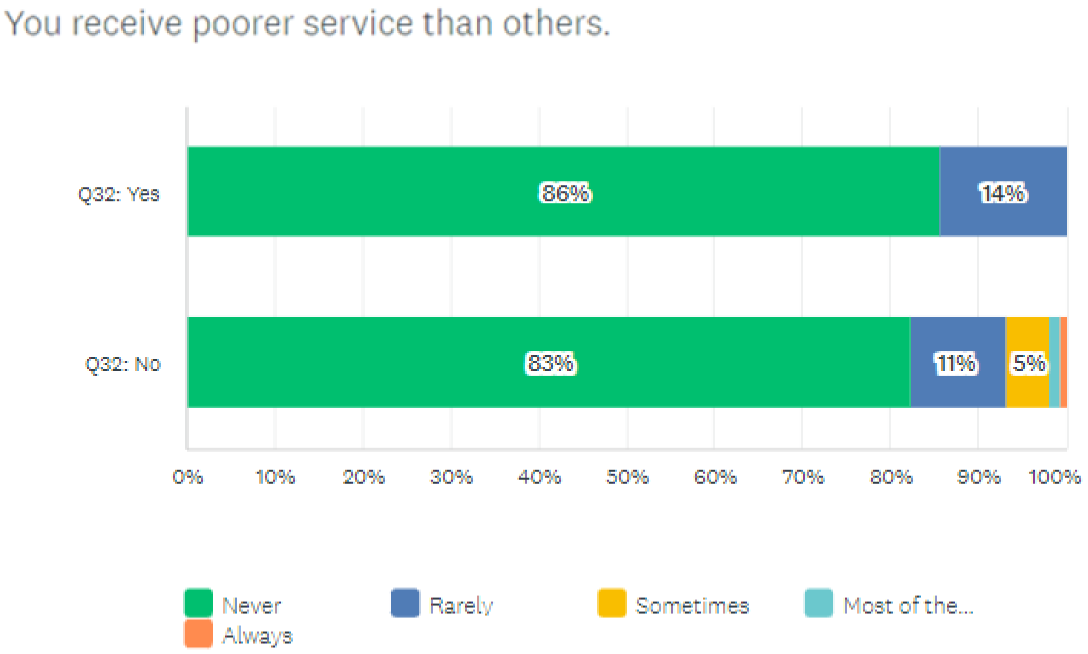


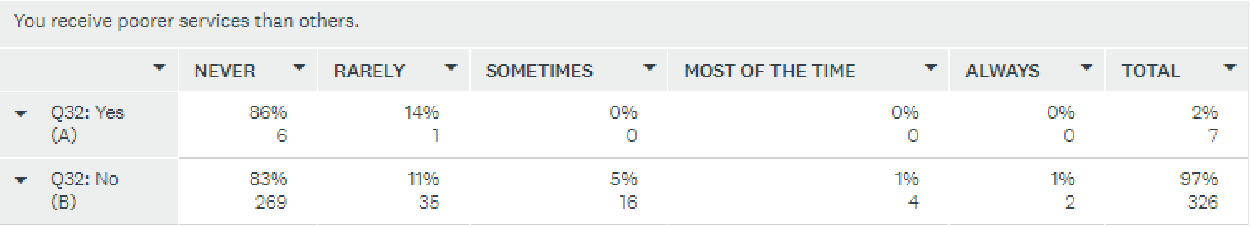


You are treated with less courtesy than other people.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q32: Yes (A)	86% 6	14% 1	0% 0	0% 0	0% 0	2% 7
Q32: No (B)	79% 259	12% 39	7% 22	1% 3	2% 5	97% 328

Figure 34

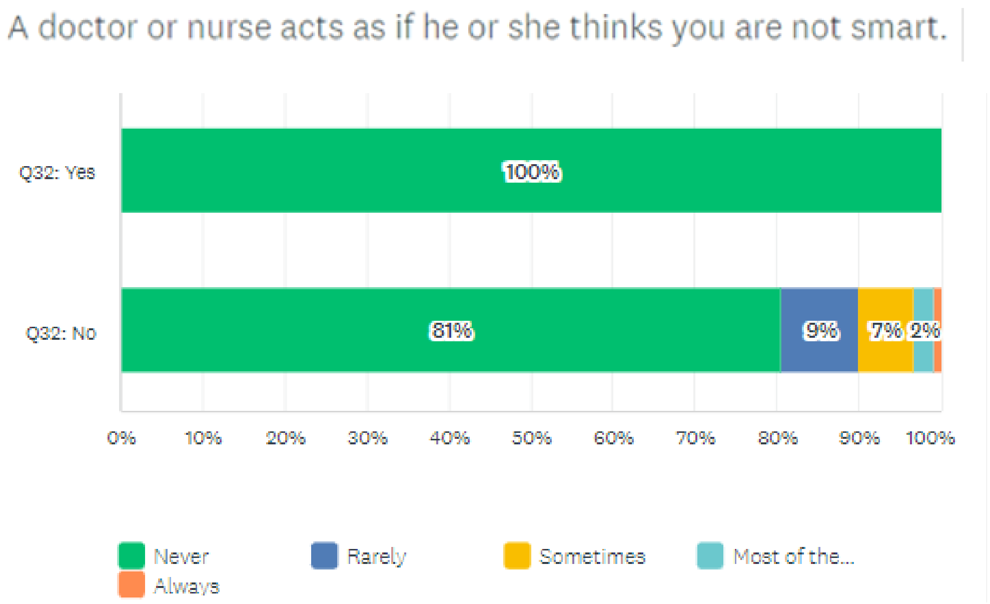


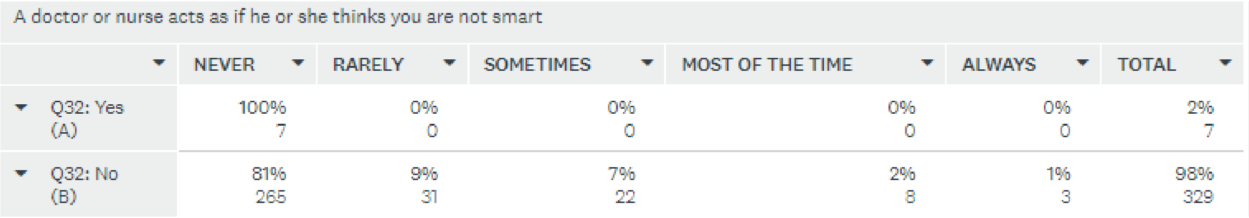


You receive poorer services than others.

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q32: Yes (A)	86% 6	14% 1	0% 0	0% 0	0% 0	2% 7
Q32: No (B)	83% 269	11% 35	5% 16	1% 4	1% 2	97% 326

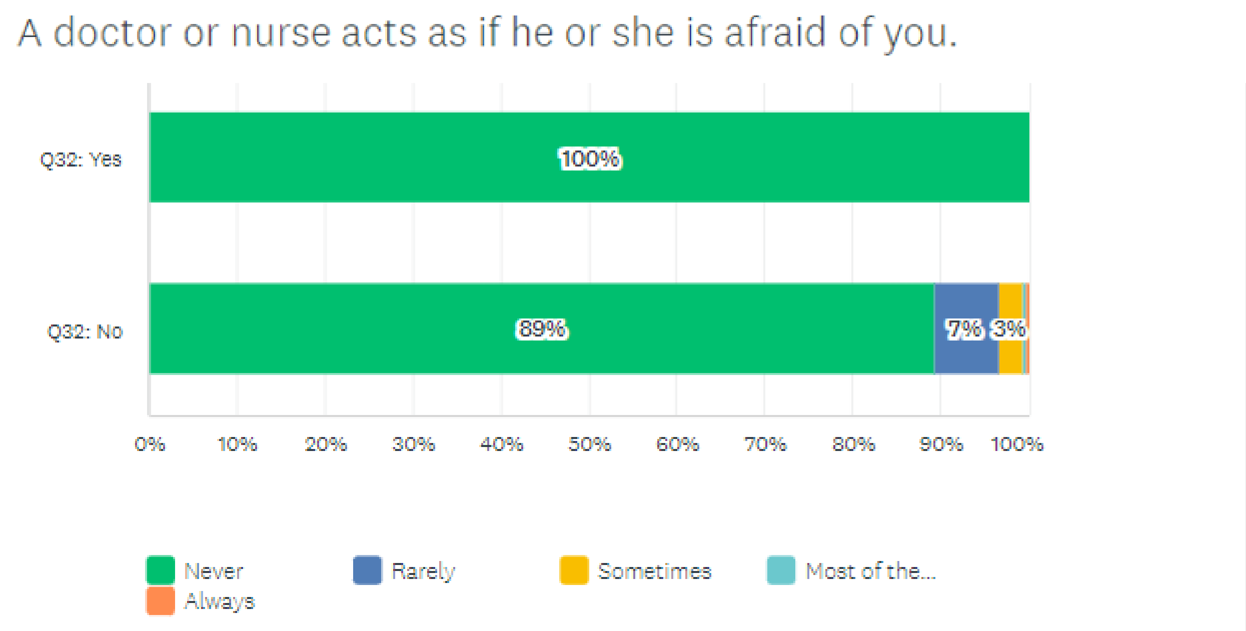
Figure 35

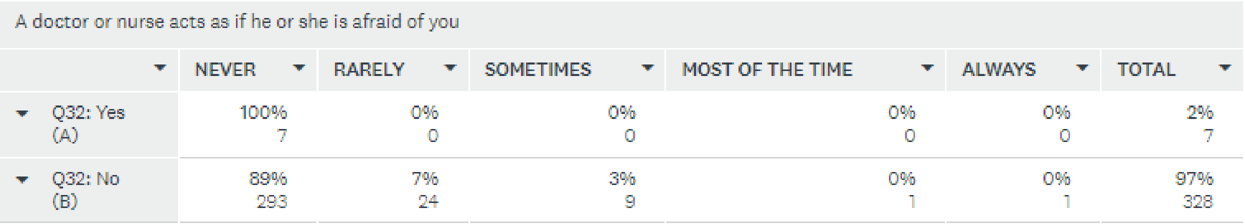



A doctor or nurse acts as if he or she thinks you are not smart

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q32: Yes (A)	100% 7	0% 0	0% 0	0% 0	0% 0	2% 7
Q32: No (B)	81% 265	9% 31	7% 22	2% 8	1% 3	98% 329

Figure 36





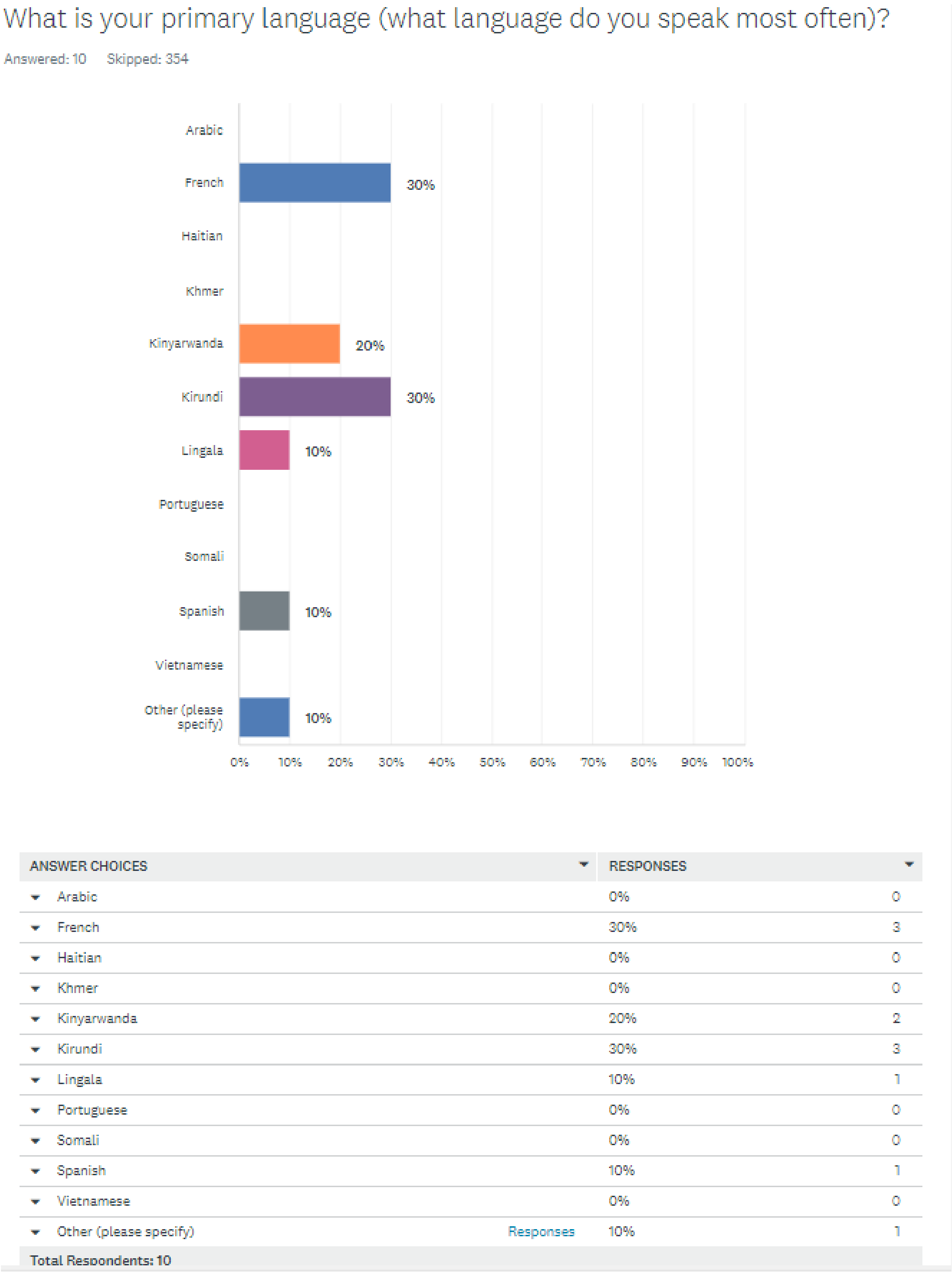
A doctor or nurse acts as if he or she is afraid of you

	NEVER	RARELY	SOMETIMES	MOST OF THE TIME	ALWAYS	TOTAL
Q32: Yes (A)	100% 7	0% 0	0% 0	0% 0	0% 0	2% 7
Q32: No (B)	89% 293	7% 24	3% 9	0% 1	0% 1	97% 328

Language Reported by Respondents

Next, we asked survey participants: “Is English your primary language, meaning the language that you speak most often?” Ninety-seven percent of the 364 respondents indicated that English is their primary language. Of the three percent (10 respondents), who indicated English is NOT their primary language, four chose Kirundi, three indicated “French,” two indicated “Kinyarwanda,” while “Spanish” and “Lingala” were both selected by one recipient.

Figure 37



What is your primary language (what language do you speak most often)?

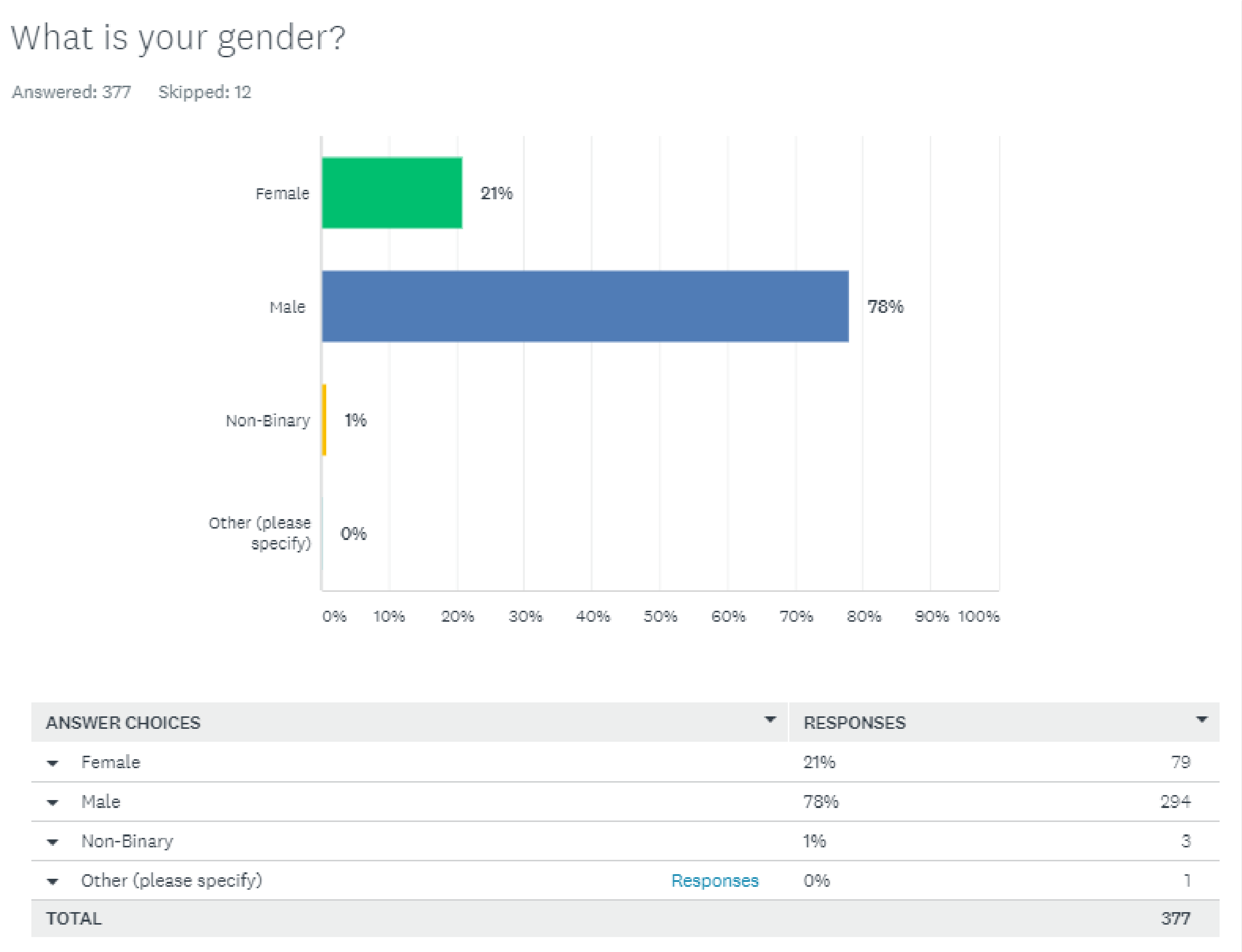
Answered: 10 Skipped: 354

ANSWER CHOICES		RESPONSES	
Arabic		0%	0
French		30%	3
Haitian		0%	0
Khmer		0%	0
Kinyarwanda		20%	2
Kirundi		30%	3
Lingala		10%	1
Portuguese		0%	0
Somali		0%	0
Spanish		10%	1
Vietnamese		0%	0
Other (please specify)	Responses	10%	1
Total Respondents: 10			

Gender Reported by Respondents

We asked survey recipients to identify their gender. Seventy percent of respondents indicated they are “Male” while 21% indicated they are “Female.” Additionally, three members indicated that their gender is non-binary and seven members indicated that they are transgender. See Figure 38.

Figure 38



What is your gender?

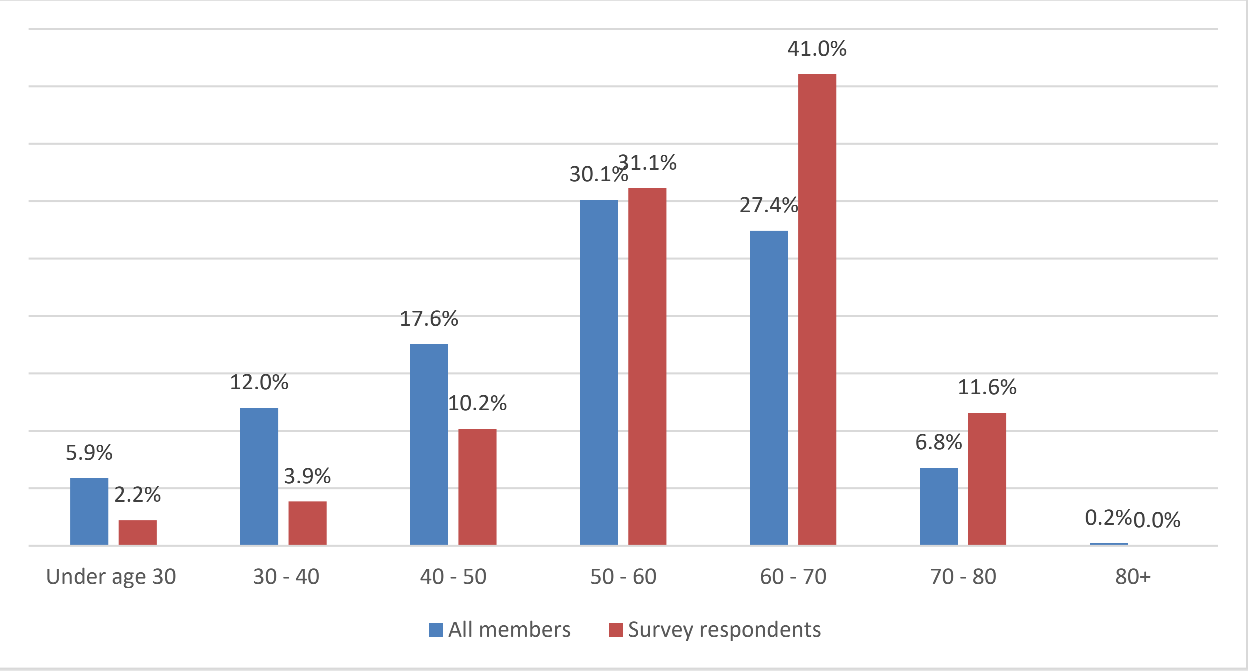
Answered: 377 Skipped: 12

ANSWER CHOICES		RESPONSES	
Female		21%	79
Male		78%	294
Non-Binary		1%	3
Other (please specify)	Responses	0%	1
TOTAL			377

Age Reported by Respondents

Figure 39 shows that member's age 50 and older are over-represented in survey respondents; members younger than 50 are under-represented. A similar over- under-representation was seen in the prior year, though the 2020 survey was also made available online in hopes of encouraging more responses.

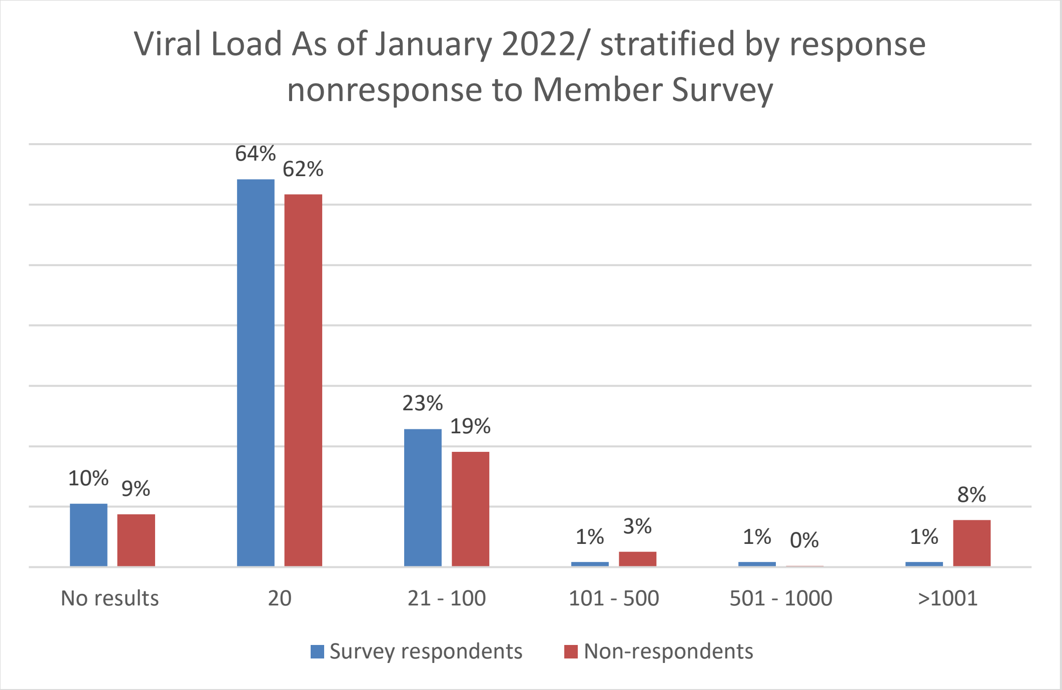
Figure 39: Age groups of Respondents and All Program Members



Viral Load Reported by Respondents

Figure 40 shows that survey respondents were less likely to have a viral load of greater than 1,000. The majority of respondents have an undetectable viral load.

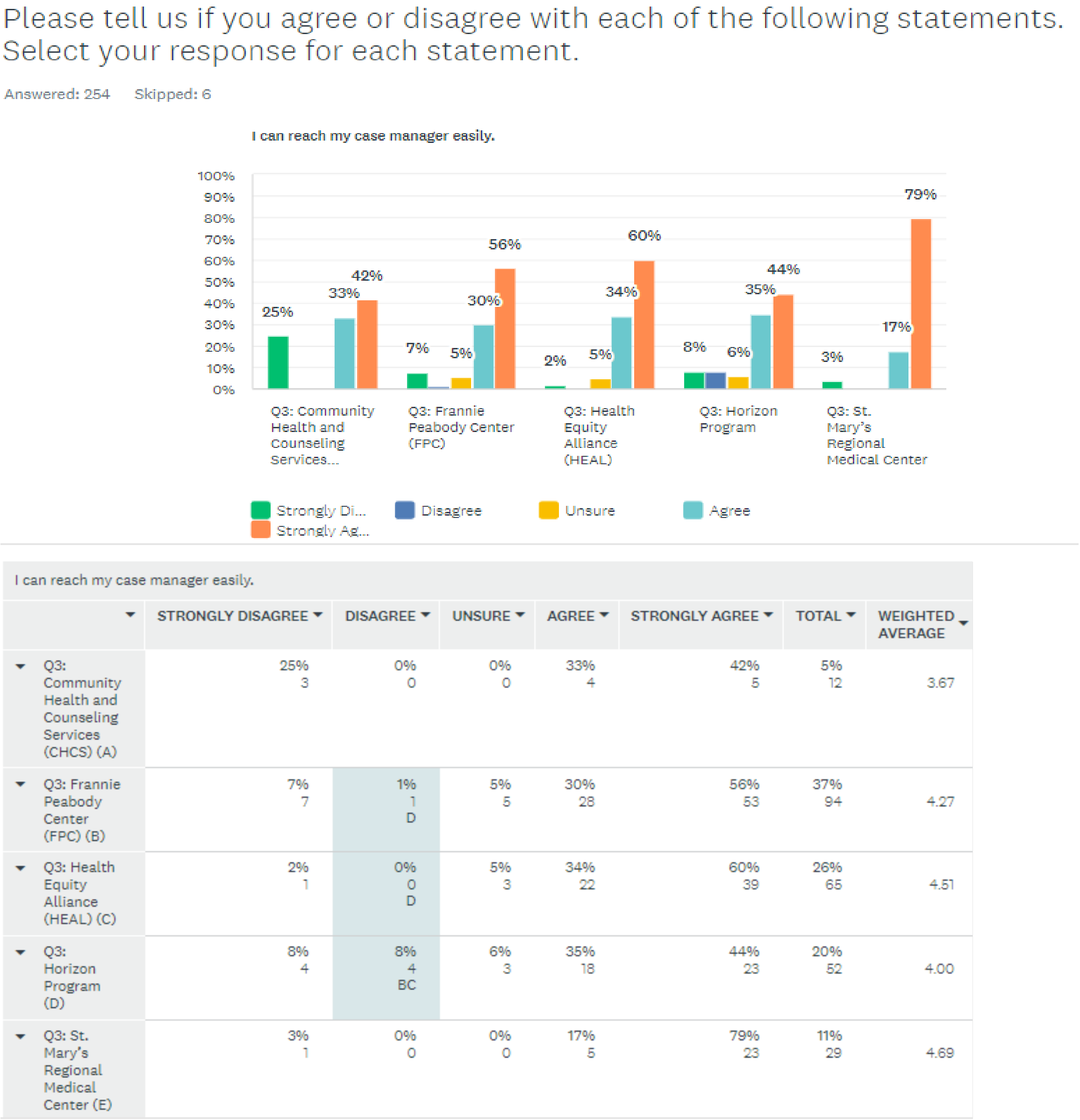
Figure 40



Reported Experience with Case Management Services

The following pages (figures 41-44) show the results to the questions of case management satisfaction segmented by case management agency. The statements that were prompted with the Likert scale are "I can reach my case manager easily," "I am able to see my case manager when I need to," "My case manager helped me find services I needed," and "I would recommend case management to others." St. Mary's Regional Medical Center's weighted average score was significantly higher than the other agencies.

Figure 41



Please tell us if you agree or disagree with each of the following statements. Select your response for each statement.

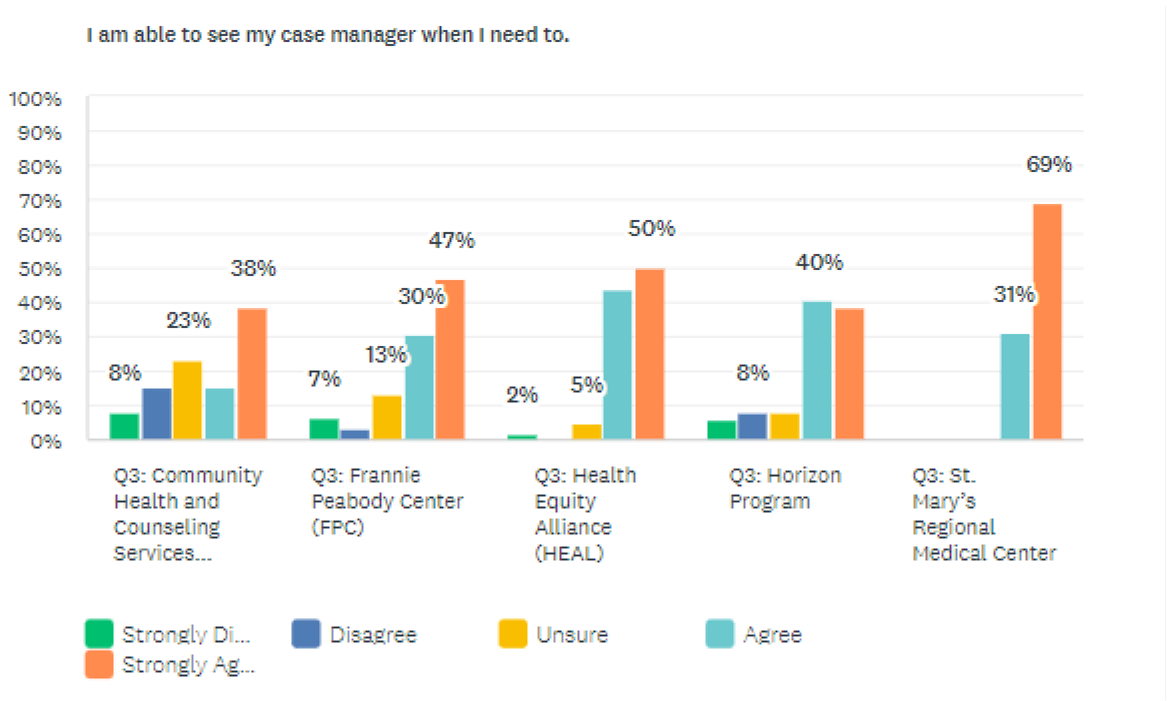
Answered: 254 Skipped: 6

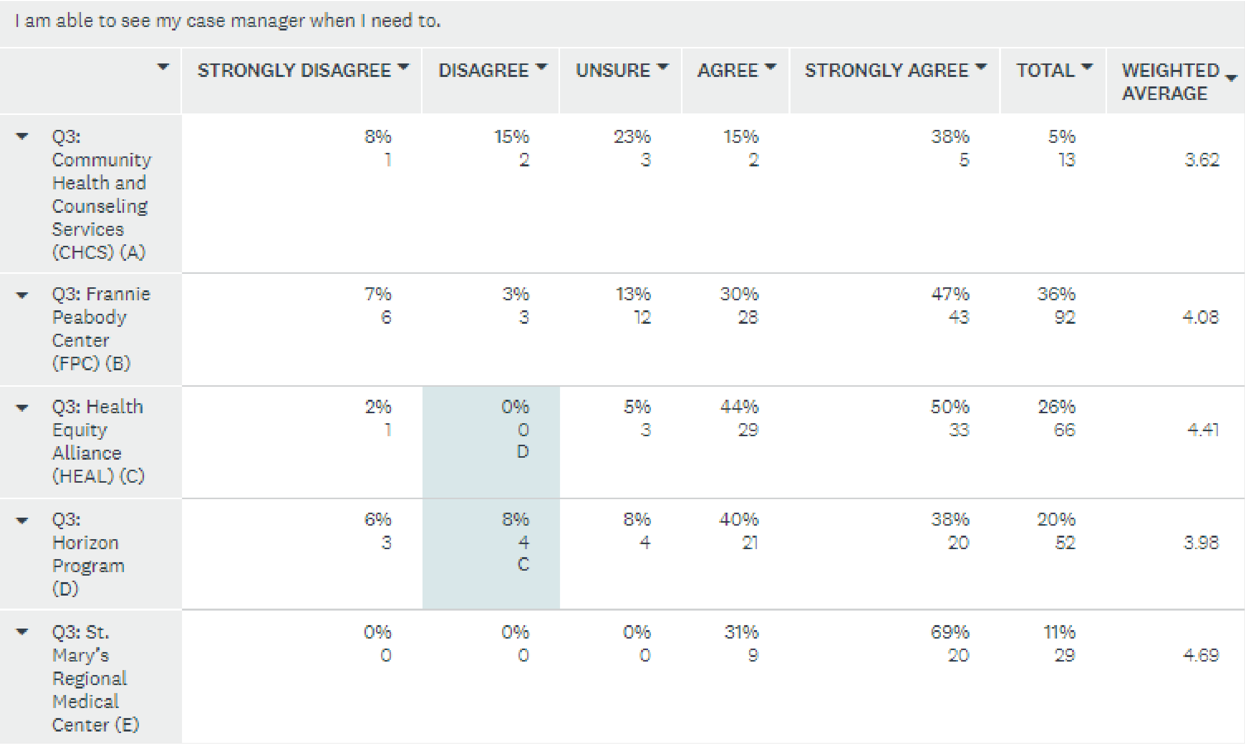
I can reach my case manager easily.

I can reach my case manager easily.

	STRONGLY DISAGREE	DISAGREE	UNSURE	AGREE	STRONGLY AGREE	TOTAL	WEIGHTED AVERAGE
Q3: Community Health and Counseling Services (CHCS) (A)	25% 3	0% 0	0% 0	33% 4	42% 5	5% 12	3.67
Q3: Frannie Peabody Center (FPC) (B)	7% 7	1% 1 D	5% 5	30% 28	56% 53	37% 94	4.27
Q3: Health Equity Alliance (HEAL) (C)	2% 1	0% 0 D	5% 3	34% 22	60% 39	26% 65	4.51
Q3: Horizon Program (D)	8% 4	8% 4 BC	6% 3	35% 18	44% 23	20% 52	4.00
Q3: St. Mary's Regional Medical Center (E)	3% 1	0% 0	0% 0	17% 5	79% 23	11% 29	4.69

Figure 42

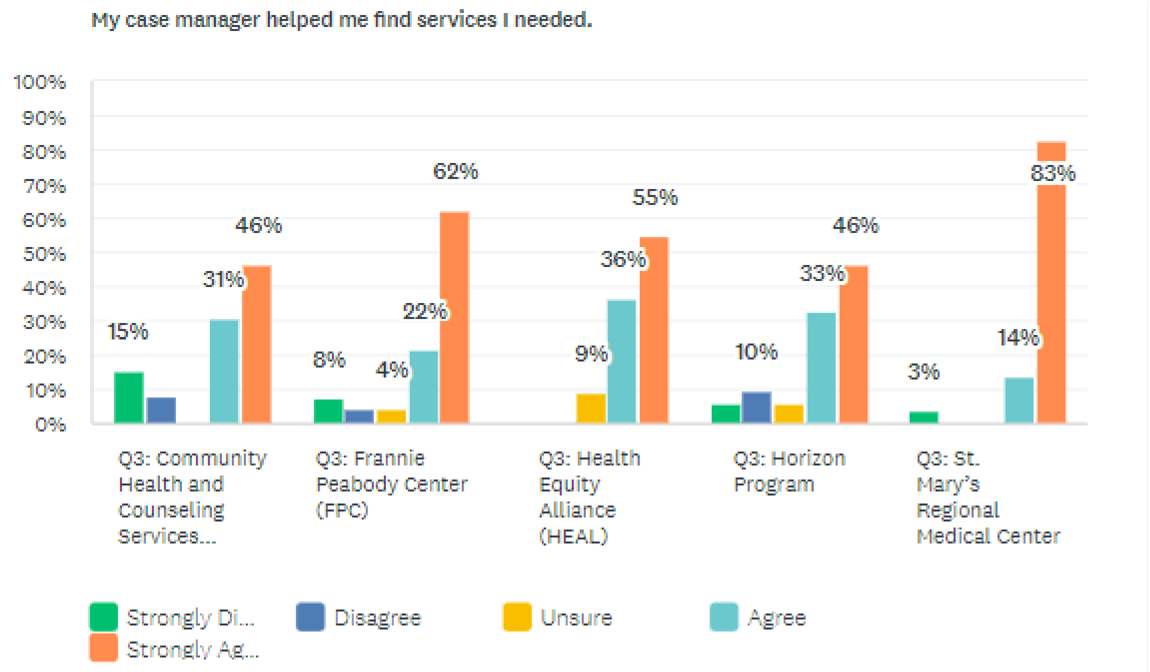


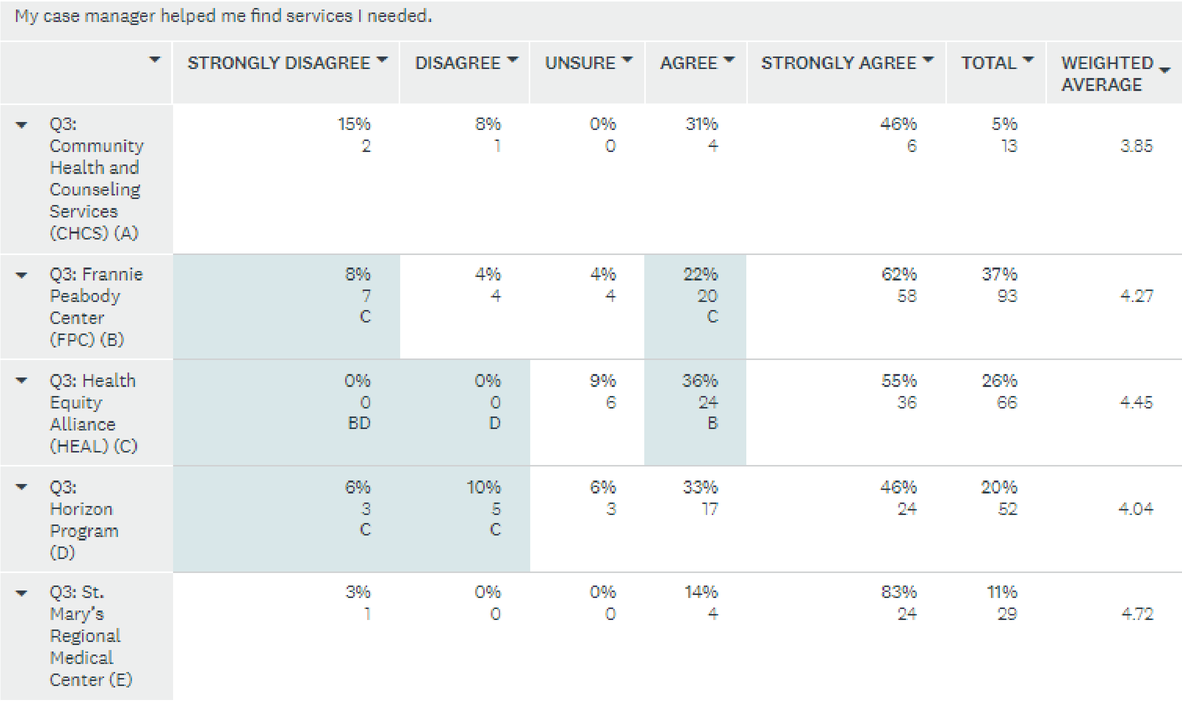


I am able to see my case manager when I need to.

	STRONGLY DISAGREE	DISAGREE	UNSURE	AGREE	STRONGLY AGREE	TOTAL	WEIGHTED AVERAGE
Q3: Community Health and Counseling Services (CHCS) (A)	8% 1	15% 2	23% 3	15% 2	38% 5	5% 13	3.62
Q3: Frannie Peabody Center (FPC) (B)	7% 6	3% 3	13% 12	30% 28	47% 43	36% 92	4.08
Q3: Health Equity Alliance (HEAL) (C)	2% 1	0% 0 D	5% 3	44% 29	50% 33	26% 66	4.41
Q3: Horizon Program (D)	6% 3	8% 4 C	8% 4	40% 21	38% 20	20% 52	3.98
Q3: St. Mary's Regional Medical Center (E)	0% 0	0% 0	0% 0	31% 9	69% 20	11% 29	4.69

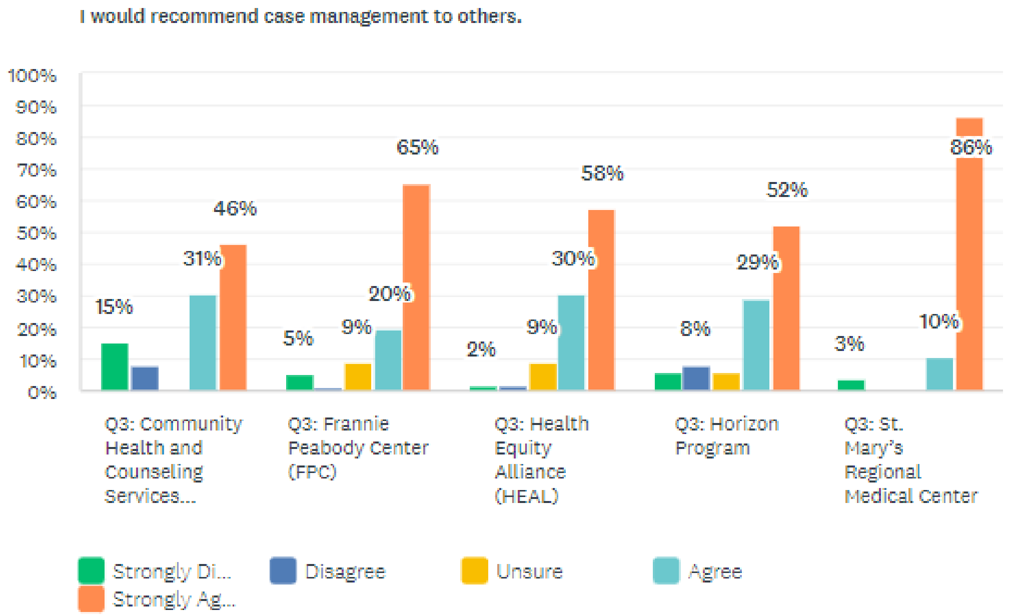
Figure 43

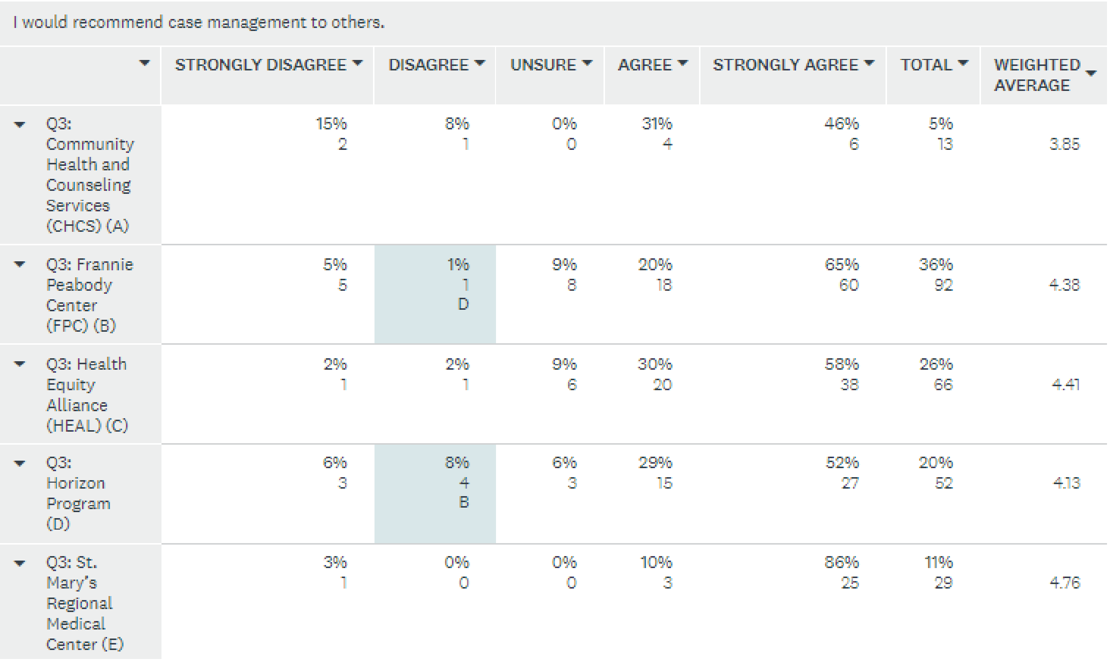



My case manager helped me find services I needed.

	STRONGLY DISAGREE	DISAGREE	UNSURE	AGREE	STRONGLY AGREE	TOTAL	WEIGHTED AVERAGE
Q3: Community Health and Counseling Services (CHCS) (A)	15% 2	8% 1	0% 0	31% 4	46% 6	5% 13	3.85
Q3: Frannie Peabody Center (FPC) (B)	8% 7 C	4% 4	4% 4	22% 20 C	62% 58	37% 93	4.27
Q3: Health Equity Alliance (HEAL) (C)	0% 0 BD	0% 0 D	9% 6	36% 24 B	55% 36	26% 66	4.45
Q3: Horizon Program (D)	6% 3 C	10% 5 C	6% 3	33% 17	46% 24	20% 52	4.04
Q3: St. Mary's Regional Medical Center (E)	3% 1	0% 0	0% 0	14% 4	83% 24	11% 29	4.72

Figure 44





I would recommend case management to others.

	STRONGLY DISAGREE	DISAGREE	UNSURE	AGREE	STRONGLY AGREE	TOTAL	WEIGHTED AVERAGE
Q3: Community Health and Counseling Services (CHCS) (A)	15% 2	8% 1	0% 0	31% 4	46% 6	5% 13	3.85
Q3: Frannie Peabody Center (FPC) (B)	5% 5	1% 1 D	9% 8	20% 18	65% 60	36% 92	4.38
Q3: Health Equity Alliance (HEAL) (C)	2% 1	2% 1	9% 6	30% 20	58% 38	26% 66	4.41
Q3: Horizon Program (D)	6% 3	8% 4 B	6% 3	29% 15	52% 27	20% 52	4.13
Q3: St. Mary's Regional Medical Center (E)	3% 1	0% 0	0% 0	10% 3	86% 25	11% 29	4.76

Discussion:

We analyzed the ages of respondents to assess whether some age groups were over or under-represented. Member's aged 50 and older are over-represented in survey respondents; members younger than 50 are under-represented. This was also true in 2019. To encourage responses from younger members, staff added a QR code to the 2020 survey to allow members to respond online. Additional tactics need to be considered to get responses from younger members.

A similar analysis of viral load revealed that survey respondents and non-respondents are roughly similar except that respondents were less likely to have a viral load of greater than 1,000. Viral suppression, indicated by a viral load of less than or equal to 200, is a sign of successful treatment. Members with high viral loads may need more care and care management supports. Members with higher viral loads likely have different needs and challenges, which may have prevented them from responding to the survey. These members are also more likely to incur higher costs and to benefit from care and case management. The program can explore new ways to elicit these members' feedback.

Most survey respondents reported good physical and mental health. Sixty-six percent reported that their health was good, very good, or excellent. A large majority (89%) reported having a steady place to live and 51% reported never running short on food.

Survey respondents also tended to be receiving the care and medications they needed. Ninety percent reported always getting the medicine needed and 92% reported getting medical care they needed. Ninety-two percent reported that the coronavirus did not prevent them from getting care. Confidence about managing and changing medication regimens was similarly high among respondents.

Generally, in comparison to the 2019 survey, a larger share of respondents reported favorable status. Note that the 2019 survey was conducted in the Fall of 2020 and the 2020 survey was conducted in the Fall of 2021. For example, a slightly lower percentage of members reported that the coronavirus pandemic prevented them from getting care on the 2020 survey than on the 2019 survey (8% in 2020 vs. 10% in 2019). This slight shift to more positive responses may be a product of the lower response rate. The 2020 response rate was 49% compared to 53% in 2019. Those who are able to complete the survey tend to be those who have favorable status to report: they have fewer obstacles to responding. Thus, the data may be missing the higher need members and these members are a larger share of the total group in 2020 than in 2019.

A significant share of respondents did report problems, such as 40% reporting at least occasional food insecurity. The majority of respondents reported receiving case management services (75%) and noted that case management helped them find the services they needed. In addition, 98% percent of those who reported speaking with the Nurse Coordinator found the call at least somewhat helpful. Yet a small but significant share of respondents' report needing food and housing support. In addition to the Maine Supplemental Nutrition Assistance Program (SNAP), the Maine Ryan White Part B Program also provides food assistance for low-income people living with HIV/AIDS. Food cards are available up to once per month for eligible members. The Ryan White Part B Program can also help pay rent, heat, or electricity for eligible members. In addition to the housing assistance through the Ryan White Program, individuals may also be eligible for short-term financial assistance for housing expenses under the Housing Opportunities for persons with AIDS (HOPWA) program. HOPWA is the only Federal program dedicated to the housing needs of people living with HIV/AIDS. In the past, these Ryan White resources were available for individuals with incomes less than 300% of the FPL. As of April 1, 2022, these resources will be available for any eligible member with an income less than 350% of the FPL. The CDC has made this change as an immediate action to help address concerns related to affordability of utilities and access and affordability of food. Although these programs offer financial assistance, the overarching issue of available housing units at affordable rates still exists in Maine.

With the demographic data, we were able to assess whether survey responses varied across races. For the race groups that had significant numbers of members, the race-stratified data did not reveal large disparities in how members reported their patient experience with providers.

Segmenting by sexual orientation, survey respondents reported similar treatment by doctors and nurses. For example, 79% of straight/heterosexual members reported that doctors or nurses never acted as if they think the member is not smart, compared to 83% of gay/lesbian members. Similarly, segmenting by primary language did not reveal large differences in how members reported their patient experience. For example, 91% of members who said that English was not the language they spoke most often reported never being treated with less courtesy than other people, compared to 79% of primary English speakers.

Opportunities for Improvement

- Though the majority of respondents reported they were able to receive the care they needed from their providers, the community and the Program, there are several topics which need additional attention. Forty-seven percent of respondents reported more than 5 days in the last month of poor physical health (47% in 2019).
- Fifty-two percent reported more than 5 days in the last month of poor mental health. (50% in 2019)
- Forty percent reported sometimes or often running out of food and not having money to get more. (54% in 2019)

Behavioral health was also identified in the HIV provider survey as a barrier to effective treatment. There is a shortage of behavioral health care providers accepting new patients. OMS, in partnership with several other DHHS agencies, has been taking several actions to address this crucial workforce shortage including, but not limited to; providing additional funding and programmatic assistance for behavioral health providers across the state, conducting several rate reform efforts to increase provider payments, and expanding telehealth availability.

Staff plan to reach out to HIV Targeted Case Management (TCM) providers and the Ryan White Program to explore how food insecurity might be better addressed. Some TCM agencies have additional resources and funding available, and the Ryan White program offers a monthly food card for eligible members. In addition, the Nurse Coordinator is prioritizing outreach to survey non-respondents, especially those with higher viral loads who are under-represented in the survey. The needs of this population may differ or even be greater than those identified by survey respondents and an online or mailed survey may not be the best approach to those who are experiencing housing instability and/or food insecurity. Staff is considering alternative options to contacting these members/enrollees.

The last part of the survey allows survey participants to add additional comments about any other concerns they have. We received a variety of responses, but the most common concerns were regarding basic health issues (overall health/specific health concerns), transportation, food insecurities, and concerns related to the COVID-19 pandemic. Members reported having trouble accessing care – specifically related to getting appointments and a general fear of contracting the COVID-19 virus. During follow up calls, the Nurse Coordinator discusses the member’s concerns with the goal of addressing barriers and providing appropriate resources to satisfy the members’ unmet needs. When additional assistance or collaboration is necessary, the Nurse will follow up with the members' case manager and/or other service providers.

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[i] Adults Self-Reported Health Status, Kaiser Family Foundation State Health Facts, https://www.kff.org/other/state-indicator/adult-self-reported-health-status/ Accessed 3/10/2022

[ii] Measuring State Level Disparities in Unhealthy Days, State Health Access Data Assistance Center, https://www.shadac.org/news/measuring-unhealthy-days-SHC Accessed 3/10/2022

[iii] McCoy K, Waldrop-Valverde D, Balderson BH, Mahoney C, Catz S. Correlates of Antiretroviral Therapy Adherence among HIV-Infected Older Adults. J Int Assoc Provid AIDS Care. 2016 May;15(3):248-55. doi: 10.1177/2325957416642019. Epub 2016 Apr 12. PMID: 27071744; PMCID: PMC4869721.

Designated
Health Professional Shortage Areas
Statistics

Second Quarter of Fiscal Year 2022
Designated HPSA Quarterly Summary

As of March 31, 2022

Bureau of Health Workforce
Health Resources and Services Administration (HRSA)
U.S. Department of Health & Human Services

Designated Health Professional Shortage Areas Statistics

Table 1. Health Professional Shortage Areas: Number, Population, and Additional Practitioners Needed for Geographic Areas, Population Groups, and Facilities as of March 31, 2022

	Number of Designations(1)	Population of Designated HPSAs(2)	Percent of Need Met(3)	Practitioners Needed to Remove Designations
Primary Medical HPSA Totals	**7,832**	**91,451,216**	**46.85 %**(4)	**16,015**(7)
Geographic Area	1,448	35,431,306	61.72 %	4,135
Population Group	2,107	54,972,482	39.00 %	11,162
Facility	4,277	1,047,428	30.70 %	718
Dental HPSA Totals	**6,927**	**65,865,509**	**30.92 %**(5)	**11,462**(8)
Geographic Area	650	13,331,901	56.08 %	1,319
Population Group	2,083	51,412,454	25.10 %	9,606
Facility	4,194	1,121,154	29.29 %	537
Mental Health HPSA Totals	**6,222**	**148,184,108**	**28.00 %**(6)	**7,420**(9)
Geographic Area	1,170	97,043,487	31.94 %	3,986
Population Group	710	49,716,938	18.10 %	2,883
Facility	4,342	1,423,683	40.65 %	551

Designated Health Professional Shortage Areas Statistics

Table 2. Health Professional Shortage Areas: Rural/Non-Rural Classification as of March 31, 2022

	Number of Designations(1)	Percentage of All Designations(10)	Population of Designated HPSAs	Practitioners Needed to Remove Designations
Primary Medical HPSA Totals	**7,832**		**91,451,216**	**16,015**
Rural	**5,134**	**65.55 %**	**30,014,579**	**4,887**
Geographic Area	1,104	14.10 %	16,969,662	1,970
Population Group	1,256	16.04 %	12,450,603	2,513
Facility	2,774	35.42 %	594,314	404
Non-Rural	**2,312**	**29.52 %**	**44,036,734**	**8,342**
Geographic Area	204	2.60 %	11,815,541	1,421
Population Group	606	7.74 %	31,768,079	6,607
Facility	1,502	19.18 %	453,114	314
Partially Rural(11)	**385**	**4.92 %**	**17,399,903**	**2,786**
Geographic Area	140	1.79 %	6,646,103	744
Population Group	245	3.13 %	10,753,800	2,042
Unknown(12)	**1**	**0.01 %**		
Facility	1	0.01 %		
Dental HPSA Totals	**6,927**		**65,865,509**	**11,462**
Rural	**4,633**	**66.88 %**	**22,674,462**	**3,874**
Geographic Area	567	8.19 %	8,131,244	911
Population Group	1,350	19.49 %	13,946,785	2,684
Facility	2,716	39.21 %	596,433	279
Non-Rural	**2,019**	**29.15 %**	**30,312,187**	**5,455**
Geographic Area	46	0.66 %	3,050,973	230
Population Group	496	7.16 %	26,736,493	4,967
Facility	1,477	21.32 %	524,721	258
Partially Rural(11)	**274**	**3.96 %**	**12,878,860**	**2,133**
Geographic Area	37	0.53 %	2,149,684	178
Population Group	237	3.42 %	10,729,176	1,955
Unknown(12)	**1**	**0.01 %**		
Facility	1	0.01 %		
Mental Health HPSA Totals	**6,222**		**148,184,108**	**7,420**
Rural	**3,771**	**60.61 %**	**35,805,847**	**2,056**

Designated Health Professional Shortage Areas Statistics

	Number of Designations(1)	Percentage of All Designations(10)	Population of Designated HPSAs	Practitioners Needed to Remove Designations
Geographic Area	762	12.25 %	31,198,357	1,486
Population Group	214	3.44 %	3,844,877	262
Facility	2,795	44.92 %	762,613	308
Non-Rural	**2,002**	**32.18 %**	**50,263,642**	**2,673**
Geographic Area	153	2.46 %	21,104,094	812
Population Group	303	4.87 %	28,498,478	1,618
Facility	1,546	24.85 %	661,070	243
Partially Rural(11)	**448**	**7.20 %**	**62,114,619**	**2,691**
Geographic Area	255	4.10 %	44,741,036	1,688
Population Group	193	3.10 %	17,373,583	1,003
Unknown(12)	**1**	**0.02 %**		
Facility	1	0.02 %		

Designated
Health Professional Shortage Areas
Statistics

Table 3. Primary Care Health Professional Shortage Areas, by State, as of March 31, 2022

Primary Care	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[3]	Practitioners Needed to Remove Designations[6]
HPSA Total	**7,832**	**1,448**	**2,107**	**4,277**	**91,451,216**	**46.85 %**	**16,015**
Region 1	**242**	**24**	**57**	**161**	**1,384,819**	**52.91 %**	**222**
Connecticut	43	0	23	20	431,866	58.33 %	61
Maine	76	13	13	50	114,310	45.78 %	21
Massachusetts	65	5	8	52	511,243	40.34 %	104
New Hampshire	30	3	8	19	161,750	71.01 %	17
Rhode Island	13	1	3	9	151,748	67.51 %	17
Vermont	15	2	2	11	13,902	56.53 %	2
Region 2	**260**	**11**	**87**	**162**	**6,845,773**	**27.35 %**	**1,680**
New Jersey	37	0	0	37	31,709	25.54 %	24
New York	179	8	70	101	5,022,567	34.83 %	1,096
Puerto Rico	39	0	17	22	1,685,900	3.14 %	545
U.S. Virgin Islands	5	3	0	2	105,597	58.12 %	15
Region 3	**492**	**104**	**142**	**246**	**5,722,669**	**53.43 %**	**880**
Delaware	11	0	4	7	249,418	17.03 %	74
District of Columbia	15	3	3	9	258,715	69.48 %	26
Maryland	64	10	35	19	1,463,054	41.53 %	283
Pennsylvania	148	16	28	104	537,672	50.78 %	108
Virginia	141	67	25	49	2,427,873	66.39 %	252
West Virginia	113	8	47	58	785,937	47.47 %	137
Region 4	**1,479**	**292**	**563**	**624**	**23,720,068**	**48.33 %**	**4,107**
Alabama	106	43	20	43	2,285,464	62.53 %	286
Florida	283	18	118	147	7,035,908	32.33 %	1,630
Georgia	245	58	104	83	3,294,245	38.85 %	679
Kentucky	225	58	81	86	1,783,964	54.52 %	264
Mississippi	165	53	45	67	1,913,446	52.88 %	300
North Carolina	217	22	98	97	3,021,573	52.26 %	462
South Carolina	101	15	34	52	1,989,007	69.32 %	207
Tennessee	137	25	63	49	2,396,461	65.12 %	279

Designated Health Professional Shortage Areas Statistics

Primary Care	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[3]	Practitioners Needed to Remove Designations[6]
Region 5	**1,205**	**230**	**330**	**645**	**14,427,734**	**54.47 %**	**2,126**
Illinois	271	44	89	138	3,582,940	49.89 %	575
Indiana	124	40	32	52	2,344,036	68.86 %	235
Michigan	288	23	75	190	3,407,639	49.92 %	565
Minnesota	210	55	49	106	1,504,268	56.22 %	206
Ohio	175	43	37	95	2,086,208	48.46 %	352
Wisconsin	137	25	48	64	1,502,643	60.32 %	193
Region 6	**1,008**	**266**	**283**	**459**	**13,476,498**	**54.74 %**	**1,979**
Arkansas	101	18	43	40	659,319	54.34 %	105
Louisiana	176	49	36	91	2,588,942	64.58 %	296
New Mexico	110	28	13	69	1,298,005	38.78 %	254
Oklahoma	189	17	73	99	1,461,114	39.62 %	297
Texas	432	154	118	160	7,469,118	57.19 %	1,027
Region 7	**747**	**69**	**203**	**475**	**3,489,751**	**29.12 %**	**800**
Iowa	134	25	32	77	646,831	48.79 %	105
Kansas	186	18	68	100	812,050	51.16 %	129
Missouri	338	12	103	223	1,955,165	13.84 %	551
Nebraska	89	14	0	75	75,705	25.73 %	15
Region 8	**582**	**176**	**133**	**273**	**3,337,153**	**44.89 %**	**606**
Colorado	126	27	45	54	1,207,400	40.40 %	253
Montana	147	27	37	83	494,937	40.44 %	94
North Dakota	90	46	4	40	224,109	30.54 %	49
South Dakota	105	41	24	40	309,479	37.93 %	56
Utah	68	16	18	34	914,695	57.14 %	130
Wyoming	46	19	5	22	186,533	55.47 %	24
Region 9	**1,016**	**201**	**168**	**647**	**13,078,246**	**42.71 %**	**2,459**
Arizona	238	53	54	131	3,185,244	37.20 %	653
California	652	120	97	435	7,914,292	46.16 %	1,407
Hawaii	32	4	0	28	519,059	43.50 %	87

Designated Health Professional Shortage Areas Statistics

Primary Care	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[3]	Practitioners Needed to Remove Designations[6]
Nevada	74	17	15	42	1,106,399	42.23 %	212
American Samoa	2	1	0	1	55,009	5.45 %	17
Federated States of Micronesia	8	3	1	4	99,673	0.00 %	34
Guam	4	0	1	3	71,615	14.47 %	21
Marshall Islands	2	1	0	1	53,158	0.00 %	18
Northern Mariana Islands	2	1	0	1	53,890	81.81 %	3
Republic of Palau	2	1	0	1	19,907	0.00 %	7
Region 10	**801**	**75**	**141**	**585**	**5,968,505**	**40.38 %**	**1,156**
Alaska	317	16	8	293	282,483	23.73 %	69
Idaho	101	13	33	55	571,646	49.29 %	98
Oregon	167	13	47	107	1,572,823	63.16 %	196
Washington	216	33	53	130	3,541,553	29.59 %	793

Designated Health Professional Shortage Areas Statistics

Table 4. Dental Health Professional Shortage Areas, by State, as of March 31, 2022

Dental Health	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[4]	Practitioners Needed to Remove Designations[7]
HPSA Total	**6,927**	**650**	**2,083**	**4,194**	**65,865,509**	**30.92 %**	**11,462**
Region 1	**239**	**19**	**60**	**160**	**1,302,497**	**35.62 %**	**211**
Connecticut	39	0	19	20	396,404	0.00 %	101
Maine	92	14	29	49	363,874	30.42 %	58
Massachusetts	59	3	4	52	323,972	76.39 %	20
New Hampshire	22	0	3	19	28,328	23.16 %	7
Rhode Island	13	0	4	9	160,491	43.63 %	23
Vermont	14	2	1	11	29,428	53.66 %	2
Region 2	**198**	**3**	**46**	**149**	**3,333,379**	**18.54 %**	**698**
New Jersey	36	0	0	36	42,884	39.83 %	19
New York	134	0	46	88	3,175,913	17.31 %	658
Puerto Rico	24	1	0	23	12,965	16.56 %	4
U.S. Virgin Islands	4	2	0	2	101,617	33.50 %	17
Region 3	**468**	**44**	**188**	**236**	**6,241,983**	**32.60 %**	**1,046**
Delaware	13	0	6	7	381,534	4.98 %	97
District of Columbia	12	0	2	10	82,914	2.41 %	21
Maryland	52	14	20	18	1,665,536	34.92 %	244
Pennsylvania	159	2	57	100	1,980,988	36.33 %	337
Virginia	120	18	56	46	1,325,326	37.11 %	204
West Virginia	112	10	47	55	805,685	28.62 %	143
Region 4	**1,284**	**129**	**573**	**582**	**20,099,717**	**26.19 %**	**3,757**
Alabama	84	0	43	41	1,828,616	20.56 %	376
Florida	256	4	106	146	5,705,709	14.14 %	1,268
Georgia	189	37	94	58	2,153,531	18.14 %	442
Kentucky	166	3	80	83	855,840	17.88 %	180
Mississippi	154	57	33	64	1,870,689	56.43 %	203
North Carolina	198	9	99	90	3,522,832	26.74 %	626
South Carolina	93	16	25	52	1,870,913	44.88 %	263
Tennessee	144	3	93	48	2,291,587	31.58 %	399

Designated
Health Professional Shortage Areas
Statistics

Dental Health	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[4]	Practitioners Needed to Remove Designations[7]
Region 5	**1,103**	**29**	**419**	**655**	**10,147,125**	**30.13 %**	**1,825**
Illinois	245	8	99	138	2,741,664	28.41 %	500
Indiana	104	1	53	50	1,287,312	32.65 %	224
Michigan	251	0	63	188	1,513,245	26.35 %	289
Minnesota	197	15	67	115	1,062,874	39.30 %	161
Ohio	170	4	74	92	2,018,103	27.45 %	385
Wisconsin	136	1	63	72	1,523,927	32.24 %	266
Region 6	**864**	**180**	**226**	**458**	**8,264,169**	**39.88 %**	**1,267**
Arkansas	99	5	54	40	600,621	36.23 %	107
Louisiana	164	33	39	92	2,263,273	50.06 %	281
New Mexico	113	25	20	68	1,187,842	23.72 %	223
Oklahoma	175	6	67	102	1,073,200	34.75 %	180
Texas	313	111	46	156	3,139,233	41.18 %	476
Region 7	**706**	**43**	**187**	**476**	**2,674,729**	**20.53 %**	**519**
Iowa	133	8	46	79	382,528	31.83 %	65
Kansas	177	24	55	98	590,331	38.55 %	82
Missouri	320	11	85	224	1,700,308	11.93 %	372
Nebraska	76	0	1	75	1,562	0.00 %	0
Region 8	**479**	**93**	**121**	**265**	**2,640,487**	**48.32 %**	**329**
Colorado	100	22	30	48	1,133,515	49.88 %	137
Montana	131	13	36	82	381,225	40.66 %	54
North Dakota	66	23	3	40	122,987	50.10 %	12
South Dakota	88	26	23	39	246,126	32.56 %	41
Utah	63	5	24	34	707,273	56.10 %	77
Wyoming	31	4	5	22	49,361	31.78 %	8
Region 9	**843**	**70**	**141**	**632**	**6,054,948**	**28.90 %**	**1,081**
Arizona	218	41	52	125	2,369,432	30.51 %	406
California	503	14	64	425	2,033,019	28.27 %	368
Hawaii	33	0	5	28	266,331	43.37 %	40

Data as of: 04/01/2022

Designated Health Professional Shortage Areas Statistics

Dental Health	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[4]	Practitioners Needed to Remove Designations[7]
Nevada	69	7	19	43	1,040,921	30.36 %	188
American Samoa	2	1	0	1	55,009	0.00 %	14
Federated States of Micronesia	8	4	0	4	91,491	0.00 %	23
Guam	4	0	1	3	71,790	4.85 %	18
Marshall Islands	2	1	0	1	53,158	0.00 %	11
Northern Mariana Islands	2	1	0	1	53,890	22.26 %	8
Republic of Palau	2	1	0	1	19,907	0.00 %	5
Region 10	**743**	**40**	**122**	**581**	**5,106,475**	**40.82 %**	**729**
Alaska	308	13	2	293	170,797	27.11 %	31
Idaho	99	6	39	54	512,766	48.04 %	67
Oregon	151	0	47	104	1,705,051	31.95 %	288
Washington	185	21	34	130	2,717,861	46.18 %	343

Designated Health Professional Shortage Areas Statistics

Table 5. Mental Health Care Health Professional Shortage Areas, by State, as of March 31, 2022

Mental Health Care	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[5]	Practitioners Needed to Remove Designations[8]
HPSA Total	**6,222**	**1,170**	**710**	**4,342**	**148,184,108**	**28.00 %**	**7,420**
Region 1	**212**	**26**	**20**	**166**	**2,785,802**	**28.56 %**	**146**
Connecticut	42	3	11	28	1,541,208	18.70 %	83
Maine	66	15	2	49	358,482	20.78 %	29
Massachusetts	57	1	6	50	307,807	33.04 %	19
New Hampshire	24	5	0	19	183,008	50.73 %	5
Rhode Island	12	2	1	9	395,297	62.91 %	10
Vermont	11	0	0	11			
Region 2	**267**	**14**	**62**	**191**	**5,974,819**	**26.59 %**	**396**
New Jersey	36	0	0	36	42,900	68.18 %	15
New York	182	11	48	123	4,169,792	23.03 %	276
Puerto Rico	45	1	14	30	1,661,985	15.83 %	96
U.S. Virgin Islands	4	2	0	2	100,142	61.36 %	9
Region 3	**411**	**60**	**98**	**253**	**7,431,880**	**31.34 %**	**448**
Delaware	13	0	5	8	289,347	11.59 %	25
District of Columbia	10	1	0	9	152,472	71.89 %	3
Maryland	56	11	23	22	1,560,293	19.40 %	93
Pennsylvania	130	26	5	99	1,938,502	38.43 %	114
Virginia	96	12	28	56	2,703,894	42.01 %	123
West Virginia	106	10	37	59	787,372	13.04 %	90
Region 4	**915**	**138**	**182**	**595**	**32,673,474**	**26.78 %**	**1,765**
Alabama	63	14	9	40	3,226,764	22.71 %	174
Florida	216	24	44	148	7,765,667	20.01 %	450
Georgia	93	22	11	60	6,036,628	43.41 %	215
Kentucky	120	23	14	83	3,425,397	23.57 %	193
Mississippi	83	16	0	67	3,183,507	39.80 %	185
North Carolina	198	25	76	97	3,607,900	13.23 %	202
South Carolina	72	5	13	54	2,271,780	33.72 %	106
Tennessee	70	9	15	46	3,155,831	17.39 %	240

Designated
Health Professional Shortage Areas
Statistics

Mental Health Care	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[5]	Practitioners Needed to Remove Designations[8]
Region 5	**971**	**232**	**74**	**665**	**30,588,477**	**29.37 %**	**1,343**
Illinois	219	66	13	140	9,818,575	21.02 %	428
Indiana	95	34	1	60	6,690,745	31.19 %	288
Michigan	261	52	25	184	5,174,263	32.79 %	224
Minnesota	130	9	10	111	2,414,871	27.32 %	105
Ohio	127	23	10	94	3,745,180	32.45 %	182
Wisconsin	139	48	15	76	2,744,843	39.68 %	116
Region 6	**865**	**292**	**107**	**466**	**24,239,479**	**30.53 %**	**1,123**
Arkansas	54	4	11	39	1,193,989	30.28 %	69
Louisiana	163	52	18	93	3,625,461	26.27 %	165
New Mexico	95	21	5	69	1,619,974	18.18 %	86
Oklahoma	119	4	13	102	2,021,613	32.48 %	97
Texas	434	211	60	163	15,778,442	32.42 %	706
Region 7	**554**	**47**	**23**	**484**	**6,397,263**	**26.71 %**	**289**
Iowa	97	18	1	78	1,988,106	39.94 %	64
Kansas	123	19	2	102	1,357,196	29.02 %	56
Missouri	254	5	20	229	2,000,070	9.72 %	142
Nebraska	80	5	0	75	1,051,891	47.91 %	27
Region 8	**396**	**102**	**18**	**276**	**8,607,206**	**38.72 %**	**357**
Colorado	66	10	6	50	2,898,698	34.69 %	126
Montana	120	29	8	83	987,916	26.70 %	71
North Dakota	71	26	0	45	308,077	18.90 %	16
South Dakota	61	16	3	42	791,497	26.39 %	38
Utah	50	15	1	34	2,921,306	55.14 %	78
Wyoming	28	6	0	22	699,712	41.22 %	28
Region 9	**933**	**181**	**93**	**659**	**21,369,968**	**21.97 %**	**1,194**
Arizona	229	65	31	133	3,449,527	10.48 %	217
California	591	93	54	444	12,956,767	24.06 %	668
Hawaii	32	2	2	28	496,032	14.22 %	28

Data as of: 04/01/2022

Designated
Health Professional Shortage Areas
Statistics

Mental Health Care	Total Designations[1]	Geographic Area	Population Group	Facility	Population of Designated HPSAs	Percent of Need Met[5]	Practitioners Needed to Remove Designations[8]
Nevada	61	13	5	43	4,012,818	28.62 %	235
American Samoa	2	1	0	1	55,009	0.00 %	12
Federated States of Micronesia	8	4	0	4	100,997	0.00 %	17
Guam	4	0	1	3	71,863	0.00 %	5
Marshall Islands	2	1	0	1	153,158	0.00 %	8
Northern Mariana Islands	2	1	0	1	53,890	0.00 %	3
Republic of Palau	2	1	0	1	19,907	0.00 %	1
Region 10	**698**	**78**	**33**	**587**	**8,115,740**	**24.46 %**	**359**
Alaska	316	18	5	293	398,711	18.12 %	17
Idaho	69	10	3	56	2,211,779	30.70 %	81
Oregon	136	13	17	106	2,392,009	29.36 %	114
Washington	177	37	8	132	3,113,241	16.87 %	147

Designated Health Professional Shortage Areas Statistics

Endnotes

(1) The number of designations includes HPSAs that are proposed for withdrawal (P) and HPSAs that have no data (N). Designations are not withdrawn until a Federal Register Notice is published, generally once a year on or around July 1.

(2) The figure reported for the Population of Designated Facility HPSAs for both Primary Care and Dental reflects the number of internees in designated correctional facilities. The figure reported for the Population of Designated Facility HPSAs for Mental Health reflects the number of internees in designated correctional facilities, as well as the average daily inpatient census for state and county mental hospitals designated after September 1, 2015. For reports generated prior to September 1, 2015, the Population of Designated Facility HPSAs for all disciplines included populations served by other public or non-profit facilities. These are facilities that qualify for HPSA designation by demonstrating that even though they are not located in a geographic or population HPSA, they serve the populations of geographic and population HPSAs. As a result, these populations were potentially double counted.

(3) The figure reported for Percent of Need Met for facility HPSAs includes correctional facilities and state mental hospitals. It excludes facilities not located in a HPSA that are designated based on providing services to the population of a geographic or population HPSA. It also excludes facilities automatically designated based on statute, including health center program grantees, Federally Qualified Health Center Look Alikes, Indian Health Service facilities, and rural health clinics that meet National Health Service Corps (NHSC) site requirements.

(4) The percent of need met is computed by dividing the number of primary care physicians available to serve the population of the area, group, or facility by the number of primary care physicians that would be necessary to reduce the population to provider ratio below the threshold for designation so that it would eliminate the designation as a primary care HPSA. Federal regulations stipulate that, in order to be considered as having a shortage of providers, a designation must have a population-to-provider ratio that meets or exceeds a certain threshold. For primary care geographic designations, the population to provider ratio must be at least 3,500 to 1. For primary care population designations or geographic designations in areas with unusually high needs, the threshold is 3,000 to 1. For correctional facilities, the threshold is 1,000:1 and takes into account the average length of stay, and whether or not intake examinations are routinely performed.

(5) The percent of need met is computed by dividing the number of dentists available to serve the population of the area, group, or facility by the number of dentists that would be necessary to reduce the population to provider ratio below the threshold for designation so that it would eliminate the designation as a dental HPSA. Federal regulations stipulate that, in order to be considered as having a shortage of providers, a designation must have a population-to-provider ratio that meets or exceeds a certain threshold. For dental geographic designations, the ratio must be at least 5,000 to 1. For dental population designations or geographic designations in areas with unusually high needs, the threshold is 4,000 to 1. For correctional facilities, the threshold is 1,500:1 and takes into account the average length of stay, and whether or not intake examinations are routinely performed.

(6) The percent of need met is computed by dividing the number of mental health providers available to serve the population of the area, group, or facility by the number of mental health providers that would be necessary to reduce the population to provider ratio below the threshold for designation so that it would eliminate the designation as a mental health HPSA. Federal regulations stipulate that, in order to be considered as having a shortage of providers, a designation must have a population-to-provider ratio that meets or exceeds a certain threshold. Mental health designations may qualify for designation based on the population to psychiatrist ratio, the population to core mental health provider (psychiatrists, clinical psychologists, clinical social workers, psychiatric nurse specialists, and marriage and family therapists) ratio, or the population to both psychiatrist and core mental health provider ratios. For mental health geographic designations based on the ratio of population to psychiatrist ratio, the designation must have a ratio of 30,000 to 1, while for population designations or geographic designations in areas with unusually high needs, the threshold is 20,000 to 1. For mental health geographic designations based on the ratio of population to core mental health providers, the designation must have a ratio of 9,000 to 1, while for population designations or geographic designations in areas with unusually high needs, the threshold is 6,000 to 1. For mental health geographic designations based on the ratios of both population to psychiatrist and population to core mental health providers, the designation must have ratios of 20,000 to 1 (psychiatrists) and 6,000 to 1 (core mental health providers), while for population designations or geographic designations in areas with unusually high needs, the thresholds are 15,000 to 1 (psychiatrists) and 4,500 to 1 (core mental health providers). For correctional facilities, the threshold is 2,000:1 and takes into account the average length of stay, and whether or not intake examinations are routinely performed. For state mental hospitals, the calculation is based on workload units, which are a function of the average daily inpatient census and the number and type of admissions. For correctional facilities and state mental hospitals, psychiatrists are the only provider type counted.

Endnotes

(7) The number of additional primary care physicians needed to achieve a population-to-primary care physician ratio below the thresholds necessary for designation in all designated primary care HPSAs that would result in their removal from designation. The formula used to designate primary care HPSAs does not take into account the availability of additional primary care services provided by nurse practitioners and physician assistants in an area. The figure reported for Practitioners Needed To Remove Designations for facility HPSAs includes correctional facilities. It excludes facilities not located in a HPSA that are designated based on providing services to the population of a geographic or population HPSA. It also excludes facilities automatically designated based on statute, including health center program grantees, Federally Qualified Health Center Look Alikes, Indian Health Service facilities, and rural health clinics that meet NHSC site requirements.

(8) The number of additional dentists needed to achieve a population-to-dentist ratio below the thresholds necessary for designation in all designated dental HPSAs that would result in their removal from designation. The figure reported for Practitioners Needed To Remove Designations for facility HPSAs includes correctional facilities. It excludes facilities not located in a HPSA that are designated based on providing services to the population of a geographic or population HPSA. It also excludes facilities automatically designated based on statute, including health center program grantees, Federally Qualified Health Center Look Alikes, Indian Health Service facilities, and rural health clinics that meet NHSC site requirements.

(9) The number of additional mental health providers needed to achieve a population-to-provider ratio below the thresholds necessary for designation in all designated mental health HPSAs that would result in their removal from designation. While the regulations allow mental health HPSA designations to be based on the psychiatrist to population ratio, the core mental health provider to population ratio, or both in conjunction, most mental health HPSA designations are currently based on the psychiatrists only to population ratio. If a HPSA designation is based on the ratio of population to psychiatrists only, it does not take into account the availability of additional mental health services provided by other mental health providers in the area, such as clinical psychologists, clinical social workers, psychiatric nurse specialists, and marriage and family therapists. The figure reported for Practitioners Needed To Remove Designations for facility HPSAs includes correctional facilities and state mental hospitals. It excludes facilities not located in a HPSA that are designated based on providing services to the population of a geographic or population HPSA. It also excludes facilities automatically designated based on statute, including health center program grantees, Federally Qualified Health Center Look Alikes, Indian Health Service facilities, and rural health clinics that meet NHSC site requirements.

(10) Percentages of all designations classified as rural/non-rural are calculated by dividing the number of designations for the specified subcategory by the total number of designations for each discipline type and multiplying the result by 100. Due to decimal rounding, percentage totals may not equal exactly 100%.

(11) Partially rural designations are those made up of geographic components that have a mixture of rural, non-rural, and unknown statuses.

(12) Designations of unknown rural status may include 1) facility HPSAs whose precise location could not be located on a map (i.e. geocoded) or 2) geographic or population group HPSAs that are made up of some or all areas for which rural status is undefined. Rural status may be undefined where rural information or underlying geographic reference data for administrative boundaries is unavailable for the specified geographic area.

Department of Health and Human Services

State of Maine
Ryan White Part B Program
2021 Satisfaction Survey Report

Tara B. Thomas, MFA
Data & Quality Specialist
Ryan White Part B Program

Introduction

The 2021 Satisfaction Survey was mailed in December 2021. The mailing included:

- A cover letter
- An announcement about changing to annual recertifications (from six-month recertifications)
- The satisfaction survey instrument (slightly modified from the prior year's instrument) with a label at the top with the member's ADAP ID
- An optional form to mail in with the survey to receive a $10 Hannaford food card

These were mailed to all members enrolled in the Program during 2021 who were still active as of December 13, 2021, a total of 877 members.

A total of 472 surveys were returned, for a response rate of 54% (down from 59% the prior year).

Because ADAP IDs were included in the mailing, survey responses were divided into two categories: Members who had utilized at least one Ryan White Part B service in 2021 and members who had not.

A total of 395 respondents (84%) had utilized at least one Ryan White Part B service in 2021 while 77 respondents (16%) had not. These 77 respondents account for about one-third of members who were enrolled in Ryan White Part B in 2021 but did not utilize any services during the calendar year.

Demographics

Generally, the Demographic profile among respondents was similar, although respondents who utilized at least one service were slightly more demographically diverse.

It is worth noting that most (86%) members who did not utilize any Ryan White Part B services in 2021 met the income limit to qualify for food, housing, and dental assistance.

Viral suppression was high among all respondents – 92% of those who utilized a service were virally suppressed at last test in 2021, compared to 95% of those who did not utilize any services.

There was more racial and ethnic diversity among respondents who had utilized a service, with only 76% identified as white compared to 87% of respondents who did not utilize services.

Race/ethnicity	Respondents who utilized at least one RWB service in 2021	Respondents who did not utilize any RWB services in 2021
Native American	1%	0%
Asian	2%	1%
More than one race	5%	1%
Hispanic/Latinx	3%	4%
Black	15%	6%
White	76%	87%

There was more gender diversity among respondents who had utilized a service as well:

Gender	Respondents who utilized at least one RWB service in 2021	Respondents who did not utilize any RWB services in 2021
Transgender	1%	0%
Female	21%	18%
Male	78%	82%

There was little variation among age groups:

Age group	Respondents who utilized at least one RWB service in 2021	Respondents who did not utilize any RWB services in 2021
0-24 years	0%	4%
25-44 years	16%	14%
45-64 years	57%	55%
65-74 years	23%	23%
75+	4%	4%

Satisfaction with Services

A total of 97% of respondents who had utilized at least one service in 2021 indicated that they were "mostly happy" with ADAP/Ryan White Part B. An even greater proportion (99%) of respondents who had not utilized a service indicated that they were mostly happy with ADAP/Ryan White Part B.

Most (94%) of respondents who utilized a service indicated that it was easy to get help from ADAP/Ryan White Part B. Of respondents who indicated that they contacted ADAP/Ryan White Part B for help, 98% indicated that staff were helpful.

When asked "how do you think ADAP/RWB could be better?" responses were generally positive about the program. Suggestions included:

- Increase housing (11)
- Increase food (10)
- Online portal (8)
- Cover more dental procedures/increase dental cap (8)
- Increase caps for assistance (7)
- Improve communication (7)
- Expand services (5)
- More staff/better staff retention/training (5)
- Increase FPL (5)
- Glasses (5)
- Transportation (4)
- Durable medical equipment (3)
- Hearing aids (2)
- Reduce barriers for 90-day fills (2)
- Improve case management (1)
- The application process could be quicker (1)

Generally, respondents either had a case manager and were mostly happy with that service or did not have a case manager and did not want one:

Overall, how do you feel about your Case Manager?	Respondents who utilized at least one RWB service in 2021	Respondents who did not utilize any RWB services in 2021
Mostly happy	65%	45%
Not sure	5%	1%
Don't have/don't want a CM	23%	49%
Don't have a CM but want one	7%	4%
Did not answer	1%	0%

Of all respondents who reported that they had used case management, 88% indicated that their case manager helped with medical needs and appointments and 83% indicated that their case manager helped with insurance and getting medications.

Narrative responses about case management were generally positive.

COVID-19

Most respondents (93%) indicated that they had not been diagnosed with COVID-19 at the time of the survey; most (91%) also indicated that no one who lived with them had been diagnosed with COVID-19. About 90% reported being vaccinated against COVID-19. Those who utilized at least one Ryan White Part B service in 2021 were more likely to have been diagnosed or had a household member diagnosed with COVID-19.

Those who utilized at least one Ryan White Part B service in 2021 were more likely to report being impacted by COVID-19 in the following areas: higher costs, mental health issues, losing a friend or loved one to COVID-19, isolating at home to avoid exposure to COVID-19, and transportation issues. Those who did not utilize services were more likely to report not being impacted by COVID-19.

Those who utilized at least one Ryan White Part B service in 2021 were more likely to report unmet needs related to food, transportation, health care, and phone/internet. Those who did not utilize services were more likely to report not having any unmet needs related to COVID-19.

Summary

In general, members are satisfied with ADAP/Ryan White Part B and find it easy to access services.

Members who have a case manager are generally happy with their case management service. Most who do not have a case manager do not want one.

While a number of respondents had not accessed any Ryan White Part B services in 2021, they represent a significant portion of all members who did not utilize services. Generally, these members had high rates of viral suppression, were satisfied with ADAP/Ryan White Part B, did not identify any specific barriers to accessing ADAP/Ryan White Part B, and were more likely to be white males. However, some (less than 10%) did report unmet needs related to Ryan White Part B services for which they qualified (food, rent, heat, electricity). It is unclear if they were aware that Ryan White Part B assistance was available to them to help meet these needs.

Report on HIV Client Satisfaction with Ryan White Part C Services and Issues with Adherence

--compiled by Michael Edwards, Program Evaluator/QA Assistant, April, 2020

Satisfaction

The Client Satisfaction and Adherence Surveys were distributed by mail in January 2020, garnering returns by 84 clients (67 served by HEAL, 15 by Community Health & Counseling, and 2 uncertain). This represents 42% of the 201 total for the Ryan White service population in 2019. A large majority of the clients responding to the survey were satisfied with the various clinical services provided or facilitated by the program. As shown in the table below, rates for “very” and “fairly satisfied” combined were usually in the 90-100% range. This includes medical case management, HIV physician care, mental health (including substance abuse counseling), medication management, and nutrition education and supplements. Satisfaction with help with dental care and medical travel was only slightly lower--near 80%.

Satisfaction with medical case manager help with accessing services was consistently high, between 89% to 100% for all services except mental health counseling and travel (slightly lower at 84% and 75%). Separate ratings were requested for two key elements of service quality: the sensitivity of the service to the needs of PLWH and the timeliness of the service rendered. On rating choices between ‘good’ and ‘needs improvement’, HIV doctor, case manager, and medication management garnered satisfaction by 90-100% of respondents on both sensitivity and timeliness queries. Somewhat lower percentages of ‘good’ ratings (80%) were garnered for help with dental care on timeliness and MH counseling on sensitivity, and for travel favorable ratings on both indicators reached a lower level at 60-70% among those responding. In the case of help with nutritional supplements, 44% rendered favorable ratings for both sensitivity and timeliness. It should be noted that negative experiences with dental providers and the state funded transportation service for Medicaid clients is beyond the capacity of the Ryan White program to address.

HIV Client Satisfaction (N=69)

		Overall rating of service		Medical Case Manager help accessing		Sensitivity to PLWH	Timeliness
	# responding	% Very satisfied	% Very or fairly satisfied	% Very satisfied	% Very or fairly satisfied	% Good	% Good
Med case management.	65	74%	95%	75%	95%	94%	92%
HIV physician care	68	85%	97%	87%	98%	91%	98%
Dental care	47	64%	81%	79%	96%	88%	80%
MH counseling	21	81%	90%	74%	84%	81%	88%
Nutrition supplements	12	50%	92%	67%	89%	44%	44%
Medications	34	74%	100%	85%	100%	96%	96%
Travel	33	48%	79%	25%	75%	71%	62%

Additional questions addressed Medical Case Management help with medication adherence. Queries on how often case managers discussed CD4 and viral load results with clients and how often they discussed taking HIV medications as prescribed revealed them to be routine topics in regular client visits. As shown in the table below, there was no difference in rates between clients who reported high adherence rates and those reporting missing any doses in the prior 3-month period.

How often does my MCM discuss adherence issues?—*nearly every visit*

	% Discuss CD4 & viral load tests	% Discuss importance of taking ART
All clients responding (N=72)	78%	83%
Adherent >3 mo. (N=47)	83%	87%
Not adherent in 3 mo. (N=25)	68%	77%

The percent of clients who rated their case manager’s help with finding solutions to problems with adherence as excellent or good was close to 100% regardless of client levels of medication adherence.

How well does your MCM help you find solutions for issues that interfere with taking your medications as prescribed?

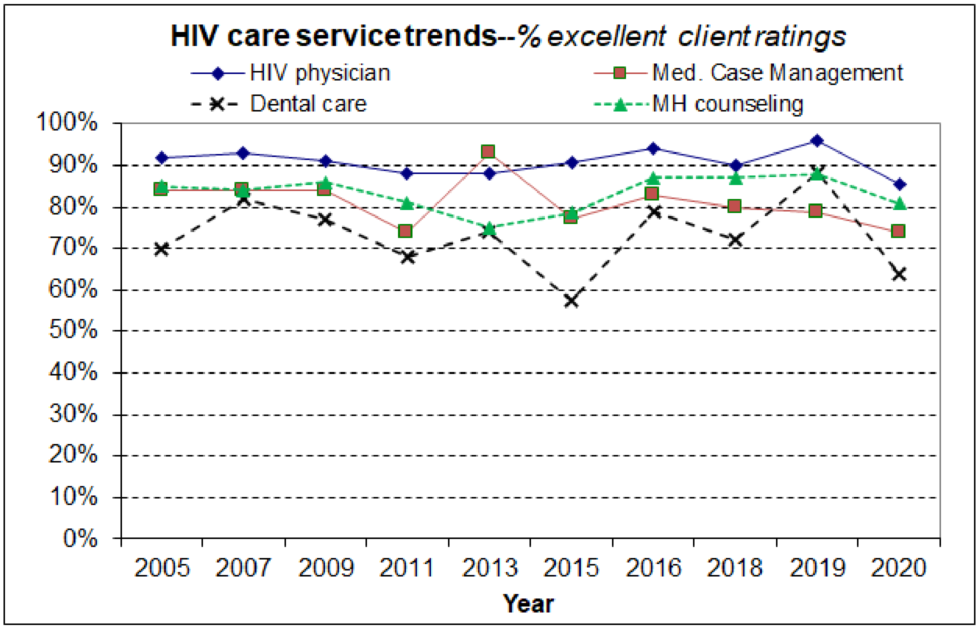
	% Excellent or good	% Excellent
All clients responding (N=70)	94%	66%
Adherent >3 mo. (N=46)	96%	70%
Not adherent <3 mo. (N=24)	92%	60%

A more detailed set of questions was asked of the clients about Medical Case Management (MCM) services, each calling for a simple yes or no response. As shown below, 88% to 100% of clients found that MCM services were satisfactorily delivered with timely communication, effective teamwork with their physician, and engagement of the client in establishing treatment plans.

Percent “Yes” response on queries about Medical Case Management supports

- My MCM and HIV doctor work together to help me—91%
- My MCM discusses HIV with me regularly—88%
- I've been involved in making decisions on my care plan and goals—99%
- My medical care and life runs more smoothly due to help from my MCM—96%

The levels of highest satisfaction with the key Ryan White Part C clinical services are charted below over the 15 years since 2005 in order to reveal any trends. Overall, the pattern over time has been relatively stable and consistent, with client fractions rendering excellent ratings highest for HIV physician care, then mental health and medical case management, followed by dental care. In is unclear if the small declines in excellent ratings between 2019 and 2020 (in the range of 5-10%) for physician, medical case management, and mental health is meaningful, but the potential trend bears watching. The more notable 28% decline in excellent ratings for dental care to 64% is more cause for concern, but the contrast with the 79% very satisfied rating on case manager help with the service should be borne in mind. .



Supplemental Healthcare Survey *(see Appendix B for details on response patterns)*
In order to address program challenges associated with achieving goals in measures of client participation in regular medical care and testing of CD4 and viral loads (under the umbrella term "retention in care"), an additional survey was added this year. The reason was to get client input on a broader range of issues associated with getting and completing appointments, their experiences at their doctor's office and lab, and client needs and assets relevant to achieving standards for HIV patient care. (The survey was composed of questions from the respected instrument "RAND Patient Satisfaction Short-Form Questionnaire—PSQ-18", plus additional questions based on Andersen's "Behavioral Model of Health Services Use.")

For most service related queries in the survey the large majority of clients agree or strongly agree with favorable statements on quality of the services and disagree or strongly disagree with negative statements. In the following, results on measures of clinical performance and of patient needs and resources are presented according overall rates of agreement with positive statements or disagreement with negative statements. Great news is evident from the large number of performance areas that garnered agreement by 80-100% of the clients responding to the statement. The set of statements where agreement rates were 70% or less represent care quality indicators where the client population is more mixed on their views. It would be easy to think of such ratings as comparable to a grade in school of "C" or worse. However, in the absence of comparative data, we can't say whether such scores reflect relatively poor program performance. Nevertheless, such data suggests target issues which may be worthy of efforts for improvement.

Summary of client responses on supplemental survey by response rate

90-100% agreement
Clinical performance
- medical care I receive is excellent overall
- fully confident in doctor's abilities to treat me
- doctor friendly and courteous
- good at explaining reasons for tests
- doctor's staff welcoming

Patient needs and resources
- I believe attending all my appointments is important for my health
- I believe that monitoring my CD4 and Viral Load is important for my health

80-89% agreement
Clinical performance
- able to choose appointment dates that work for me
- scheduling an appointment is easy
- doctor's staff treats me different from other patients *(disagree; only 3% agree)*
- lab staff treat me different from other patients *(disagree; only 6% agree)*

Patient needs and resources
- have to pay more than I can afford *(disagree)*
- don't have enough time to complete labs *(disagree)*
- my ride cancels at last minute *(disagree)*
- I don't feel that I should see my doctor so often *(disagree)*
- I don't have time to complete my labs as often as they are ordered *(disagree)*

60-79% agreement
Clinical performance
- get appointments as soon as I need
- get appointments as often as I need
- get reminder calls
- lab staff should pay more attention to my privacy *(disagree; only 13% agree)*
- lab staff are very concerned about my privacy

Patient needs and resources

- have difficulties with transportation (disagree)
- my ride doesn't have time to wait for me to get lab tests *(disagree)*
- my friends are supportive of my medical care
- my friends are unsupportive or don't know my HIV status
- I am concerned that others will find out my HIV status

40-59% agreement

Patient needs and resources

- difficult to change doctors as often as I have to *(disagree)*
- friends are unsupportive or don't know my HIV status *(disagree)*

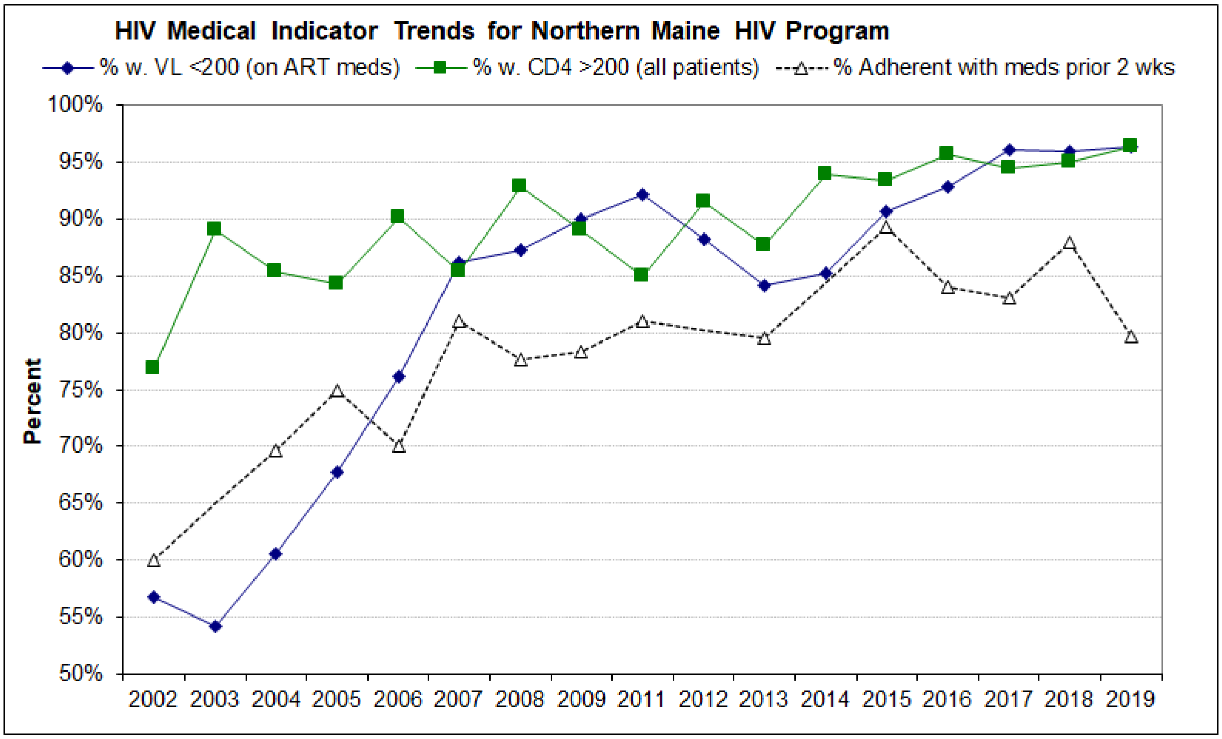
Client Comments and Recommendations *(see Appendix B for details)*

A total of 20 clients provided comments, including 12 with very positive responses on the value of program services to them, 4 with critical input or recommendations, and 4 with disclosure of adverse situations.

Adherence

The rate of clients who were adherent with their ART medications in the prior two weeks was 80%. This represents a 9% decline from 88% in the prior year. Because the measure reflects back in time, the current rate is charted as for 2019 in the graph of performance over time. The overall trend reveals an improvement in adherence rates over the last 15 years which roughly parallels that for two key quality indicators for population outcomes of the program. The percent of all clients on ART with viral suppression (viral load less than 200 per ul) and the fraction of clients with CD4 counts above 200 per ul have leveled at 95-96% over the last few years.

The potential for reduced levels of adherence to impact rates of viral suppression is an area of concern. For reference, missing one daily dose of ART within a two-week period corresponds to a 93% adherence rate (i.e. 13 out of 14 days). This is operationally close to the clinical standard of 95% adherence that research indicates is necessary to avoid resistance to key ART medications.



Despite more clients missing recent doses of ART, there continues to be high level of self-efficacy about achieving good adherence, belief in benefits of treatment, and appreciation of the risk of resistance arising from lack of strict adherence. This is confirmed by the following high fractions of respondents answering “very” or “extremely sure” to questions on those subjects:

- How sure you will be able to take all or most of your medications as directed?—96%
- How sure are you that the medication you are taking will have a positive effect on your health?—88%
- How sure are you that if you do not take the medication exactly as instructed, the HIV in your body will become resistant to HIV medications?—94%

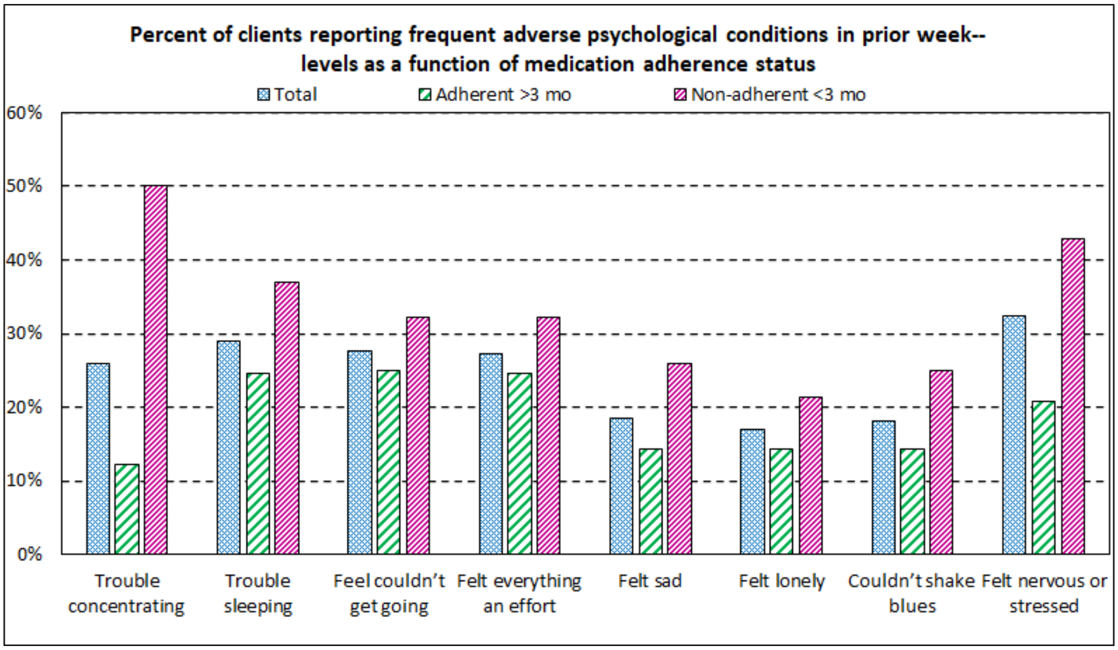
Among the clients who reported ever missing an ART dose in the prior 3 months, the top seven reasons reported for missing doses among the 30 responding clients were as follows:

Reasons for missing HIV medication doses in prior 3 months (“sometimes” or “often”)

- simply forgot—33%
- change in daily routine—29%
- failed to refill Rx—19%
- slept through dose—19%
- busy with other things—16%
- felt depressed/overwhelmed—13%
- felt sick or ill—13%

In recent years, “simple forget” has risen to typically take the number one spot. This frequency pattern for reasons in missing HIV medications has changed over the past 15 years, with progressive reductions in reporting rates on all other reasons except “simply forgot”.

A number of questions on the surveys address emotional well-being issues relevant to capacity for adherence with treatment plans. Clients who were less adherent were consistently more likely to suffer a range of psychological symptoms, including trouble with feelings of depression, loneliness, difficulties in concentrating, low energy, stress and sleep disturbance. The table below reveals that reported rates of “often” or “most of the time” in the prior week were each substantially higher among clients who missed doses within the prior 3 months compared to the adherent group of clients, i.e. four times higher for ‘trouble concentrating’, two times for ‘felt nervous or stressed’ and by 30-80% the other indicators.



Percent of clients reporting frequent adverse psychological conditions in prior week--levels as a function of medication adherence status

The strong association of non-adherence with an array of adverse symptoms is consistent with much literature that points to client problems with depression and stress as contributors to their difficulties maintaining adherence to ART treatment. For four positively framed indicators, there was no notable difference between adherent and non-adherent clients, as shown in the table below.

Lack of association with adherence on clients frequently feeling positive in various spheres in prior month

	Total	Adherent >3 mo	Non-adherent <3 mo	Non-adherent <1 mo
Confident to handle personal problems	64%	57%	57%	61%
Able to control irritations in your life	50%	48%	39%	39%
Felt on top of things	48%	43%	41%	38%
Felt things were going your way	57%	55%	43%	43%

The survey delves into alcohol consumption by clients because of substantial research suggesting that alcohol overuse represents a serious risk factor for ART adherence problems. A substantial fraction of clients report never drinking alcohol, 60%, a rate that does not differ among adherent and non-adherent clients (see table below). However, among those who do drink, rates for drinking near daily, drinking more than 2 drinks per session, and binger drinking (>5 drinks per session) were notably higher for the 3-month non-adherent clients compared to adherent clients. For the subset of clients who were non-adherent on ART in the prior month, the percent of daily drinkers was close to twice that of clients non-adherent in the longer period of 3 months, while the binge drinking rate was about 30% higher. It should be noted that numbers of client with potentially excessive drinking are relatively small. Nevertheless, the association with non-adherence for ART medications suggests an area for Medical Case Managers to address.

Adherence and patterns of alcohol use among clients who drink

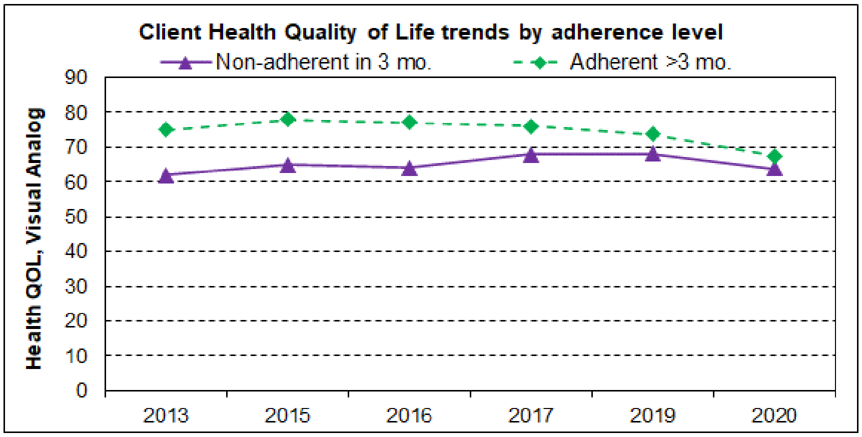
	All clients (N=30)	Adherent >3 mo. (N=19)	Non-adherent in 3 mo. (N=11)	Non-adherent in 1 mo (N=8)
% Who drink at all	40%	39%	41%	43%
% Drinkers who drink near daily	14%	11%	27%	50%
% Drinkers who take >2 drinks/session	21%	11%	36%	33%
% Drinkers who binge drink	17%	11%	27%	38%

Client quality of life, as assessed by the EQ-5D instrument, shows that those in the HIV program suffer from high rates of certain health and functionality issues. This includes roughly half with problems in mobility and carrying out 'usual activities' and a striking 60% with 'anxiety/depression' and over 3/4 with 'pain/discomfort.' Unlike in prior years there was little sign that non-adherent clients were worse off on prevalence of moderate to severe problems with 'pain/discomfort' and 'anxiety/depression'.

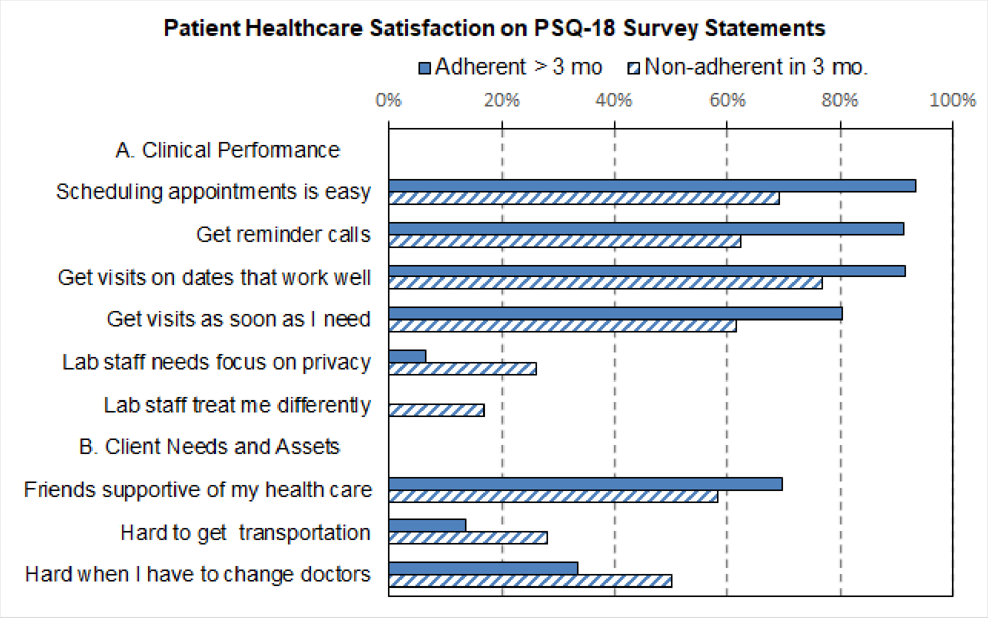
Client Quality of Life subscale response rates for "moderate to severe" problems by adherence level

	All clients	Adherent-- >3 mo	Non-adherent --within 3 mo	Non-adherent --within 1 mo
Mobility	52%	49%	57%	57%
Self-care	19%	16%	24%	21%
Usual activities	53%	56%	48%	42%
Pain/discomfort	77%	74%	82%	78%
Anxiety/depression	60%	60%	61%	61%

The other component of the Quality of Life measure asked clients to mark on a visual analog scale their overall rating of "how good or bad your health is today." The results confirm a trend over the years for lower QOL ratings among the non-adherent clients. The average score out of 100 maximum for clients who missed meds in the prior 3 mo. was 63.8 versus 67.5 for adherent clients. This difference is smaller than in prior years, particularly for the years from 2013-2016 when the difference was statistically significant. The values for 2020 represents small declines 2019 (6% for non-adherent and 8% for adherent clients)..



Finally, we provide results on items from the Supplemental Healthcare Survey which show a 20% or larger difference between adherent and non-adherent clients. These results suggest that there is a notable fraction of non-adherent clients that experience more challenges in making appointments, have greater concerns over their treatment by lab staff. They also report somewhat less support from their friends, have more difficulty getting transportation to appointments, and find it harder when they have to change their doctor.



Summary

The levels of client satisfaction with Ryan White Part C services were high for HIV physician care, medical case management services, mental health counseling, and medication management. Of the 69 clients responding on the satisfaction survey, 90%-100% or higher rated these services good or excellent overall. Satisfaction with dental care and help with travel garnered ratings near 80%, while that for nutrition education and supplements was 50%. A high fraction rated services good on timeliness and sensitivity to issues of PLWH, with travel help and nutrition exceptions with satisfaction below 70% and sensitivity for MH and timeliness for dental care close to 80%.

Fully 94% of clients were satisfied with Medical Case Manager help in working with them on solutions to adherence challenges and over 90% in accessing most Ryan White program services. Roughly 80% found that MCMs discussed medication adherence and HIV test results with them nearly every visit, 90% agreed that their MCM and HIV doctor work together effectively to help them, and almost 100% reported their involvement in care plans and goals. No detectable differences were observed for CHCS service ratings compared to HEAL clients. Also, clients who had trouble with adherence to ART treatment did not differ from those who didn't in levels of satisfaction with the various services or MCM categories of help.

The proportion of clients adherent in taking their ART medications was 80%, based on reporting no reported missed doses in the prior two weeks. This is 9% lower than the 88% rate in the prior year, so renewed vigor in efforts to attain high levels of medication adherence is called for. The good news is that the program continues to show over the last few years outstanding rates of nearly 95% on the key medical outcome measures of viral load suppression and CD4 numbers above 200. Along with improvements in medication efficacy and lower daily "pill count" burden, the overall trend in improvement in adherence since 2002 is likely a major contributor to the progressive improvements in viral load suppression.

Known risk factors for non-adherence were higher among clients who reported missing ART doses in the prior 3 months. These include indicators for depression, including trouble sleeping, concentrating, and low energy. Excessive alcohol use is also well recognized risk factor for poor adherence. While rates of daily drinking, consumption of more than two drinks at a time, and binge drinking were higher for non-adherent clients, it is favorable that over 40% of all clients never drink and only a small numbers of clinically no-adherent clients (3-4 of those missing doses in the prior month) report drinking at levels suggestive of an excess that could undermine medication adherence.

When asked for reasons why medication doses were missed, the answers provide useful clues for their Medical Case Manager, mental health counselor, and HIV physician to work with the clients on strategies to address contributing issues. Thus, for the nearly one-third of non-adherent clients who checked 'simply forgot' or 'change in daily routine' as a reason, help with memory reminder strategies should be a priority. For the nearly 20% who cited failure to renew prescriptions or who slept through their dosage, other practical strategies to overcome the issues may be applied. Fortunately, 'feeling depressed or overwhelmed' was cited as a reason for missed does only 13% of the time. Although this seems a good indicator of the impact of the program's efforts to address mental health issues, continued focus should be maintained on alleviating the above risk factors of stress, anxiety, and correlates of depression among the non-adherent clients, most of which are likely to increase in prevalence in the face of the COVID pandemic.

The Quality of Life measures revealed that differences in past years between adherent and non-adherent clients on levels of chronic pain and 'anxiety/depression' and on overall health status rating have largely disappeared. This trend suggests a good impact of program services in addressing the issues of clients most at risk. However, the disturbingly high rates among all clients with moderate-to-severe problems in these areas (60-70%), as well as the roughly half with problems with mobility and activities of daily living represents an ongoing challenge to effective service to the clients.

Results from the new Supplemental Healthcare survey reinforced the conclusion that the Ryan White program is performing well while at the same time highlighting areas for potential targeting for improvement. In particular, issues of getting timely appointments for medical care, travel barriers, concerns over privacy with lab staff, and difficulties incurred when changing doctors were each more common among the non-adherent set of clients.

In the comments section (see Appendix A), 20 clients provided input, including 12 with praise or gratefulness for the quality of services provided and 4 with complaints or constructive criticism.

APPENDIX A: Summary of Responses to RAND PSQ-18 Survey
Note: Differences of greater than 20% between clients adherent and non-adherent for >3 months are highlighted in bold italics. Also, total percent for agreement and disagreement may not add up to 100% due to responses for "unsure".

Statement rated on level of agreement	**Total**		**Adherent**		**Non-adherent**	
	Agree	Disagree	Agree	Disagree	Agree	Disagree
My doctors treat me in a very friendly and courteous way	97%	1%	98%	2%	96%	0%
My doctors are good about explaining reasons for labs and medical tests	95%	1%	98%	2%	88%	0%
It is difficult to change doctors as often as I have to	38%	32%	***33%***	31%	***50%***	32%
I'm fully confident in the ability of the doctors who treat me	96%	4%	93%	7%	100%	0%
I find it difficult to get transportation to appointments	19%	77%	***14%***	80%	***28%***	71%
My ride doesn't have time to wait for me to complete labs after my ID visit,so I do them on a different day	15%	78%	14%	75%	17%	82%
My ride cancels at the last minute	10%	88%	13%	87%	5%	90%
My friends are supportive of my medical care	66%	13%	***70%***	***19%***	***58%***	***4%***
My friends are unsupportive or don't know my HIV status	32%	58%	33%	58%	30%	57%
I am concerned that others will find out my HIV status	28%	60%	27%	59%	30%	61%
Staff at my infectious disease doctor's office are welcoming	96%	1%	96%	0%	96%	4%
Staff at my infectious disease doctor's office treat me differently than other patients	3%	86%	4%	91***%***	0%	76***%***
I am able to choose an appointment date that works for me	86%	7%	91%	4%	77%	12%
Scheduling appointments is easy	85%	7%	***93%***	***2%***	***69%***	***16%***
I am able to get an appointment as soon I need one	74%	13%	***80%***	***9%***	***62%***	***20%***
I am able to get an appointment as often as I need one	79%	8%	79%	9%	80%	8%
I get reminder calls for infectious disease appointments	79%	14%	***91%***	***7%***	***63%***	***30%***
Staff at the lab treat me differently than other patients	6%	80%	***0%***	***93%***	***17%***	***58%***
Staff at the lab should pay more attention to my privacy	13%	62%	***6%***	***68%***	***26%***	***52%***
Staff at the lab are very concerned about my privacy	70%	3%	***78%***	0%	***58%***	8%
I don't feel like I should have to see my ID provider so often	1%	81%	2%	80%	0%	83%
I believe that attending all of my appointments is important for my health	93%	6%	96%	4%	88%	8%
I believe that monitoring my CD4 and Viral Load is important for my health	99%	0%	100%	0%	96%	0%
I don't have time to see the ID doctor as often as they would like	8%	81%	13%	77%	0%	88%
I don't have time to complete my labs as often as they are ordered	5%	86%	9%	85%	0%	88%
I have to pay for more of my medical care than I can afford	6%	89%	7%	85%	4%	96%
All things considered, the medical care I receive is excellent	92%	1%	91%	2%	92%	0%

APPENDIX B: Client Comments and Recommendations

Twenty clients provided comments, 12 of which comprised praise and 4 of which represented critical input or recommendations for improvement. The complete set is provided below by category:

General program

--praise

- Thank you for keeping me alive. Without the Ryan White program I'd probably be dead.
- Thank you for this beneficial and much needed assistance and all the hard work you do to keep it going.
- Grateful for service provider's dedication and staff.
- Keep up the good work--I'm very appreciative!
- Thank you to all who made this program work. I would have died without the help from you.

--critical input

- Would like to see HIV doctor when needed--wait is too long.
- When I had a tooth extraction, PCDC I received a broken crown next to the site of tooth extraction. I still have the broken crown.
- There really should be a better way for all of the paperwork scheduling. When I lived in Florida they had all of the paperwork for state insurance, Medicare, ADAP, and Ryan White paperwork consolidated to one visit to the office every 6 months. I'm not sure how they did it, but it was much simpler. I am fairly certain that it is a lot of bad communication.

Medical Case Manager

--praise

- [MCM name] is excellent!
- [MCM name] is an amazing case manager!!!
- I feel my case manager does her best.
- I am very pleased with my case manager. Meeting with a new HIV doctor next month. Anxious and excited to see the transition.
- My case manager may not talk to me much about my meds. However, she helps me with a lot of things like food, advanced directive and will, dental, transportation, faxing a copy of my medical insurance cards to you, and pretty much whatever I need.
- I can't say enough about HEAL and my medical case manager. She is prompt, intuitive, smart, friendly and discreet. And I always feel she is "in my corner." I don't know what I'd do without her (honestly). Sincerely and with much respect.
- Very satisfied with Case Manager, ID doctor, treatment team looking out for me. EMMC has some lab techs that are rude and condescending

--critical input

- We had an excellent case manager for most of the year, but new person hasn't been doing anything really.

--Sharing of adverse personal conditions

- Feeling old--heart stuff will do that. Back to hospital this week to fix it.
- My biggest distraction is trying to understand and live within the constraints of the "Medicare/MaineCare prison." Cannot work or earn any money without severe penalties. Cannot volunteer because we don't have resources for clothing, gas and maintenance. At current levels we will never be able to replace our vehicle.
- My answers on this survey are nothing like my prior surveys. [Disclosure of recent family losses not repeated out of PHI security].
- My mental health has been off in the past few weeks. [Disclosure of loss of a pet]

--Other comments

- Define Case Manager and Medical Case Manager?
- I would be interested in the Client Advisory Board.

Maine Integrated Youth Health Survey

Maine 5th and 6th Grade Students

2019

The Maine Integrated Youth Health Survey (MIYHS) asks students about their health and related behaviors.

Among 5th and 6th grade students who completed the survey in 2019:

6%
have ever DRANK ALCOHOL

59%
have a SUGAR-SWEETENED BEVERAGE at least once a day

2%
have ever USED MARIJUANA

23%
EXERCISE for an hour every day

24%
spend 2 or more hours at HOME after school WITHOUT A TRUSTED ADULT

44%
have ever been BULLIED at school

39%
have talked to a parent about the DANGERS of tobacco, alcohol, or drug use in the past year

33%
have two or fewer hours of combined SCREEN TIME daily excluding school work

How YOU can help Maine students stay healthy

Schools

Review and strengthen district wellness, substance use, tobacco, and bullying prevention policies.

Clearly communicate expectations for learning and behavior to all members of the school community.

Strive to make your school a place where students feel adults care about them and that enforce rules fairly.

Provide opportunities for students, families, and the public to be involved in creating a healthy school environment.

Use your school district's local MIYHS data to track the health of your students, and identify areas where students may need more support. For more information on how to access your local MIYHS data, contact: korey.pow@maine.gov.

Families

Make sure you are clear on the rules and policies at your school. Take time to discuss them as a family.

Volunteer to participate in your school district's wellness teams or policy planning committees.

Get involved with after school activities, clubs, sports, or arts programs.

If you think your child's health or safety may be at risk, seek help immediately. Learn about resources in your school and community.

Talk about your family's values and goals. Make it clear you don't approve of behaviors that may put your child's health at risk, such as underage drinking or drug use. Ensure your child can come to you if help is needed, including help for a friend.

Communities

Connect schools with community resources such as hospitals, public health, or prevention programs.

Provide young people with planning and decision-making opportunities to develop leadership skills.

Support after school activities, youth centers, volunteer mentors, and other programs that engage youth.

Model healthy behaviors by restricting tobacco use in public spaces, providing places to be physically active, and increasing healthy eating options.

Use your county and public health district MIYHS data to inform policies, planning, and programs that support the health of young people in your community. More MIYHS data can be found at:

www.maine.gov/MIYHS

For more information on:

Tobacco and Substance Use Prevention: www.preventionforme.org

Suicide Prevention: www.maine.gov/suicide/

Nutrition & Physical Activity: www.letsgo.org

Bullying Prevention: www.maine.gov/doe/bullying

More MIYHS data can be found at: www.maine.gov/MIYHS

Maine Integrated Youth Health Survey

Maine Middle School Students

2019

The Maine Integrated Youth Health Survey (MIYHS) asks students about their health and related behaviors.

Among middle school students who completed the survey in 2019:

4%

DRANK ALCOHOL at least once in the past 30 days

22%

were in the same room as someone smoking cigarettes in the past 7 days

4%

USED MARIJUANA at least once in the past 30 days

18%

have a **SUGAR-SWEETENED BEVERAGE** at least once a day

7%

currently use **E-CIGARETTES**

46%

have ever been **BULLIED** at school

25%

have felt so **SAD** or **HOPELESS** for at least 2 weeks in the past year

20%

have ever seriously considered attempting **SUICIDE**

How YOU can help Maine students stay healthy

Schools

Review and strengthen district wellness, substance use, tobacco, and bullying prevention policies.

Clearly communicate expectations for learning and behavior to all members of the school community.

Strive to make your school a place where students feel adults care about them and that enforce rules fairly.

Provide opportunities for students, families, and the public to be involved in creating a healthy school environment.

Use your school district's local MIYHS data to track the health of your students, and identify areas where students may need more support. For more information on how to access your local MIYHS data, contact: korey.pow@maine.gov.

Families

Make sure you are clear on the rules and policies at your school. Take time to discuss them as a family.

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Get involved with after school activities, clubs, sports, or arts programs.

If you think your child's health or safety may be at risk, seek help immediately. Learn about resources in your school and community.

Talk about your family's values and goals. Make it clear you don't approve of behaviors that may put your child's health at risk, such as underage drinking or drug use. Ensure your child can come to you if help is needed including help for a friend.

Communities

Connect schools with community resources such as hospitals, public health, or prevention programs.

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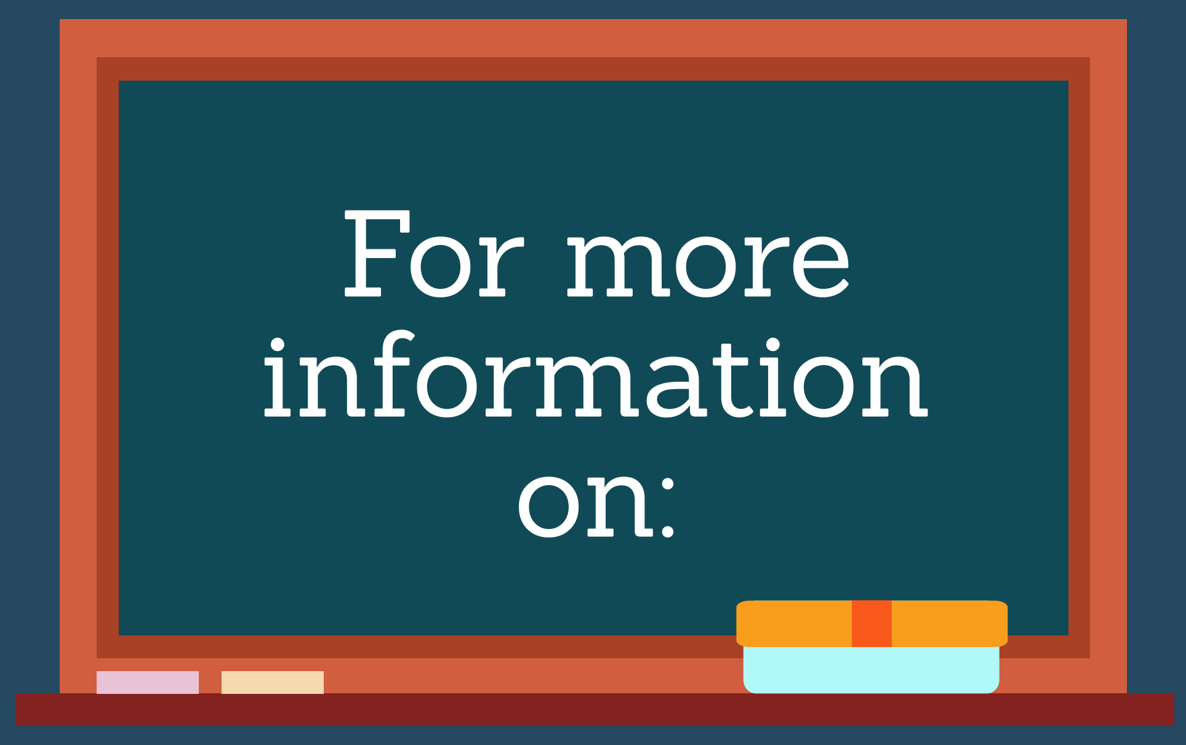

For more information on:

Tobacco and Substance Use Prevention: www.preventionforme.org

Suicide Prevention: www.maine.gov/suicide/

Nutrition & Physical Activity: www.letsgo.org

Bullying Prevention: www.maine.gov/doe/bullying

More MIYHS data can be found at: www.maine.gov/MIYHS

Maine Integrated Youth Health Survey

Maine High School Students

2019

The Maine Integrated Youth Health Survey (MIYHS) asks students about their health and related behaviors.

Among high school students who completed the survey in 2019:

23%

DRANK ALCOHOL at least once in the past 30 days

7%

SMOKED CIGARETTES at least once in the past 30 days

22%

USED MARIJUANA at least once in the past 30 days

66%

are at a **HEALTHY WEIGHT**

29% currently use **E-CIGARETTES**

23% were **BULLIED** at school in the past year

32% have felt so **SAD** or **HOPELESS** for at least 2 weeks in the past year

16% have seriously considered attempting **SUICIDE** in the past year

How YOU can help Maine students stay healthy

Schools

Review and strengthen district wellness, substance use, tobacco, and bullying prevention policies.

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Strive to make your school a place where students feel adults care about them and that enforce rules fairly.

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Talk about your family's values and goals. Make it clear you don't approve of behaviors that may put your child's health at risk, such as underage drinking or drug use. Ensure your child can come to you if help is needed, including help for a friend.

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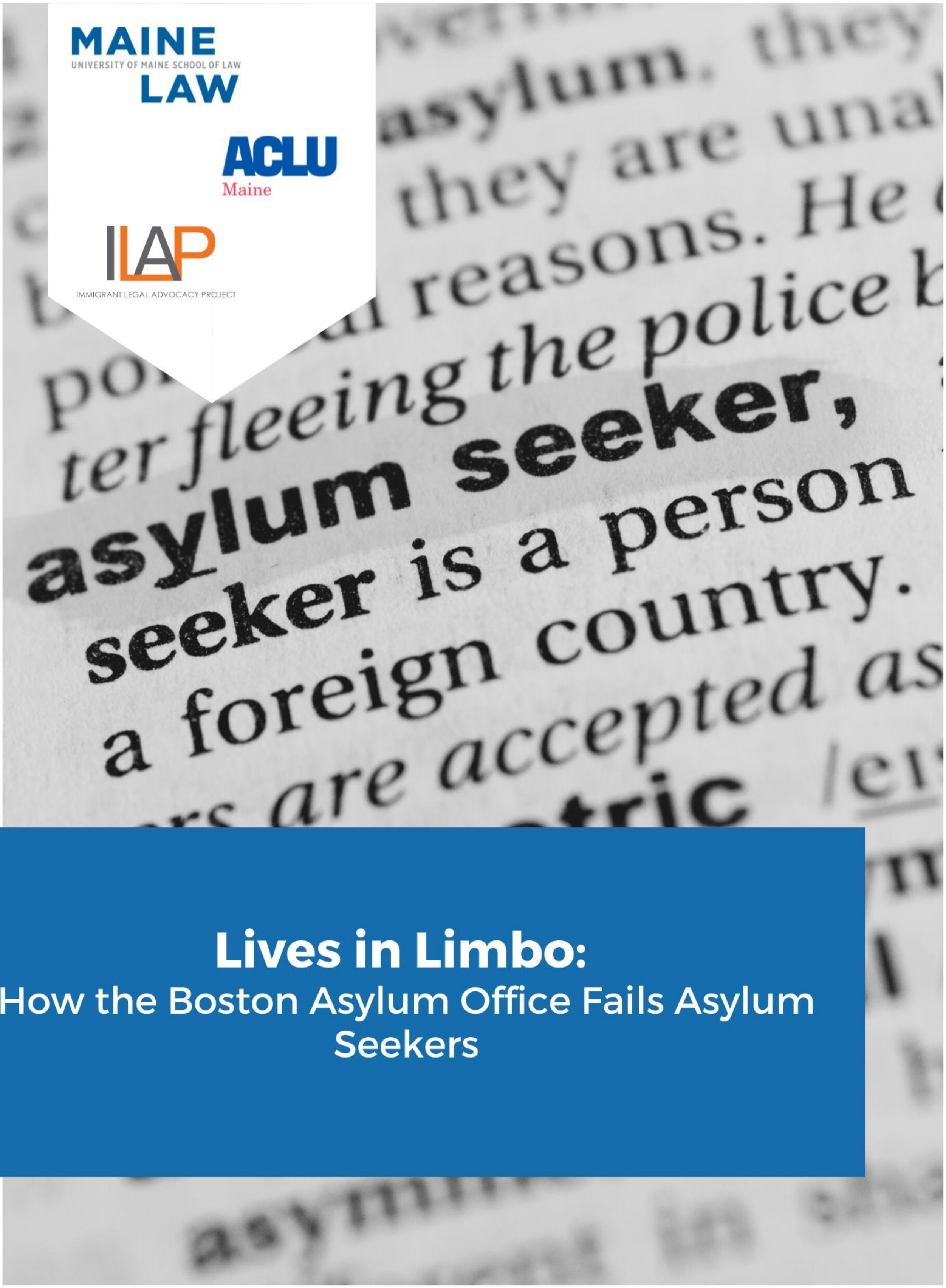
ILAP
IMMIGRANT LEGAL ADVOCACY PROJECT



Lives in Limbo:
How the Boston Asylum Office Fails Asylum Seekers

A Report by the Refugee and Human Rights Clinic at the University of Maine School of Law, Immigrant Legal Advocacy Project, American Civil Liberties Union of Maine, and Basileus Zeno, Ph.D. Political Science at Amherst College

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Refugee and Human Rights Clinic (RHRC). This report was researched and written by Refugee and Human Rights Clinic student attorneys: Emily Gorrivan ('22), Grady Hogan ('22), Jamie Nohr ('23), Camrin Rivera ('22), and Aisha Simon ('23). The data collected from U.S. Citizenship and Immigration Services was analyzed by two talented RHRC volunteers: Adam Fisher and Alex Beach. The data analysis and drafting of this report was overseen by the two supervising professors of the RHRC: Founding Director and Professor Anna Welch and Professor Erica Schair-Cardona.

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Basileus Zeno, Ph.D. Dr. Zeno is a Karl Loewenstein Fellow and Visiting Lecturer in Political Science at Amherst College, a MESA Global Academy Fellow and LSE researcher. He conducted extensive ethnographic fieldwork with Syrian asylum seekers and refugees in the United States. Dr. Zeno provided valuable insight and research into the asylum seeker experience at the Boston Asylum Office. In addition to his extensive ethnographic fieldwork, Dr. Zeno has personal experience as an asylum seeker before the Boston Asylum Office. As such, his personal story is interwoven throughout this report.

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EXECUTIVE SUMMARY

The process of seeking asylum in the United States is long and fraught with stress and hardship. But asylum seekers who apply through the Boston Asylum Office face a unique challenge: an asylum grant rate that is well below the national average. From 2015 to 2020, the Boston Asylum Office, on average, granted a mere 15 percent of asylum applications, with some months granting as low as 1.5 percent of asylum seekers. In contrast, the national average grant rate was nearly *twice* as high: 28 percent.

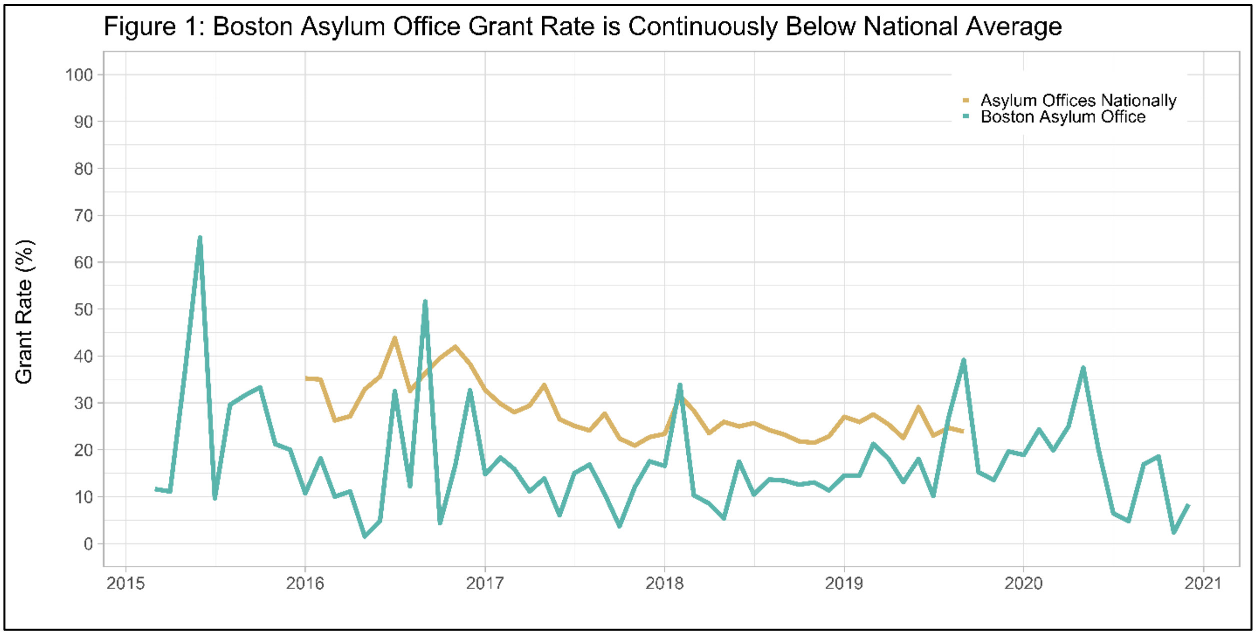

Figure 1: Boston Asylum Office asylum data was collected through a Freedom of Information Act request filed with USCIS and through subsequent litigation regarding the request. *Infra*, METHODOLOGIES. When the Boston Asylum Office first opened in 2015, it had a grant rate of over 60 percent.[1] However, in 2016, the Boston Asylum Office's monthly grant rate dropped as low as 1.5 percent. The national average grant rate, which was reported monthly by USCIS from January 2016 until USCIS stopped regularly sharing this information in September 2019,[2] was approximately 28 percent.

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[1] Grant rates for the Boston Asylum Office were calculated by dividing the total number of reported grants per month by the total number of decisions (referral, grant, recommended approval, notice of intent to deny, denials) made within the same month. *See also infra* METHODOLOGIES.

[2] *See Notes from Previous Engagements*, U.S. CITIZENSHIP AND IMMIGR. SERVS., https://www.uscis.gov/outreach/notes-from-previous-engagements?field_release_date_value%5Bvalue%5D%5Bmonth%5D=&field_release_date_value_1%5Bvalue%5D%5Byear%5D=&items_per_page=10&multiple=&topic_id=9213 (last visited Feb. 6, 2022).

This trend worsened following the election of former President Donald Trump. In Fiscal Year (FY) 2021,[3] the Boston Asylum Office reported a grant rate of a mere 11 percent, while the national average was 27 percent.[4] The Boston Asylum Office has failed to adequately explain why its grant rate has remained far below that of the national average.[5] The result of this disproportionately low grant rate is that people fleeing persecution in their home countries are wrongly denied asylum and the protections afforded to them by international and U.S. law. Asylum seekers may ultimately have to wait years for their cases to be resolved. During this time, they are separated from their family members abroad who often remain in danger. All of this compounds stress and trauma on individuals who have already fled persecution.

This report, which was compiled by analyzing documents produced by U.S. Citizenship and Immigration Services (USCIS) in response to a FOIA request, and interviews of asylees, asylum seekers, immigration attorneys, asylum officers (AOs), and supervisory asylum officers (SAOs), seeks to answer the fundamental question: **Why does the Boston Asylum Office approve such a small percentage of asylum cases?**

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[3] October 2020 through September 2021.

[4] The Boston Asylum Office self-reported to the American Immigration Lawyers Association (AILA) that "[t]he approval percentage in FY 2021 . . . was approximately 11 [percent]" and that the national average during this same period was 27 percent. *AILA New England Newsletter*, AM. IMMIGR. LAW. ASS'N (Dec. 14, 2021) (updating AILA attorneys on Boston Asylum Office Statistics – responses from the October Asylum Liaison Meeting with USCIS).

[5] In February 2022, the Authors contacted the Director of the Boston Asylum Office, Meghann Boyle, for comment on this disparity. Director Boyle gave two reasons for the low approval rates at the Boston Asylum Office: (1) the COVID-19 pandemic restricted the office's ability to conduct substantive interviews, so the office focused heavily on cases that could be decided without interviews; and (2) the office sees a significant amount of filings by applicants who are ineligible for asylum but apply for asylum in order to be referred to immigration court to pursue Cancellation of Removal (a discretionary form of immigration relief only available before an immigration judge in immigration court for noncitizens who have lived in the United States for many years).

However, Director Boyle's explanations are insufficient and cannot account for the disparity between the Boston Asylum Office's low approval rate and the national average. First, the COVID-19 pandemic could not have played a role in the Boston Asylum Office's low approval rates prior to early 2020 and has impacted asylum offices nationwide, not just the Boston Asylum Office. Second, individuals seeking Cancellation of Removal apply to asylum offices across the country, and no data suggests the Boston Asylum Office receives a disproportionate number of these applications. Rather, as this report demonstrates, there are a number of cultural factors that better explain the Boston Asylum Office's low approval rate.

SUMMARY OF FINDINGS

Our research reveals that the Boston Asylum Office is dominated by a culture of suspicion and distrust toward asylum seekers, which is further exacerbated by internal pressures placed on asylum officers. Specifically, our findings demonstrate that:

(1) High denial and referral rates are likely driven by the oversized role that supervisory asylum officers play within the Boston Asylum Office;
(2) Supervisory asylum officers and asylum officers demonstrate bias that contributes to the low approval rates;
(3) Asylum officers experience high levels of burnout and compassion fatigue, which leads to low approval rates;
(4) Asylum officers face pressure from time constraints, which is exacerbated by the continually growing backlog of asylum cases;
(5) Because of internal pressures, asylum officers cut corners when conducting their job responsibilities, which violates asylum seekers' due process rights; and
(6) Rather than exploring the merits of the asylum seeker's claim, asylum officers put an improper amount of weight on the asylum seeker's credibility and focus on immaterial, peripheral details within their asylum case.

The findings in this report are particularly salient in light of recent proposals to sidestep the immigration courts and have even more asylum cases handled by USCIS asylum offices.[6] Currently, when an asylum officer decides not to grant an asylum application, they either deny the case (for those applicants otherwise in the United States on a valid visa) or refer the case to the Department of Justice's immigration courts (for those applicants who are not in the United States on a valid visa). When an asylum seeker is referred to immigration court, they have another chance to plead their case for asylum. Thus, the immigration courts serve as an important backstop to the improper deportation (*i.e.*, removal) of asylum seekers, especially when asylum officers are not adjudicating cases in a fundamentally fair manner or in accordance with domestic law and international treaties. In fact, many affirmative asylum applications that are referred to immigration court are ultimately granted asylum,[7] indicating that cases referred to immigration court from USCIS asylum offices often meet the standards for asylum.

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[6] *Fact Sheet: The Biden Administration Blueprint for a Fair, Orderly and Humane Immigration System*, WHITE HOUSE (July 27, 2021), https://www.whitehouse.gov/briefing-room/statements-releases/2021/07/27/fact-sheet-the-biden-administration-blueprint-for-a-fair-orderly-and-humane-immigration-system/.

[7] HUM. RTS. FIRST, PROTECTION POSTPONED: ASYLUM OFFICE BACKLOGS CAUSE SUFFERING, SEPARATE FAMILIES, AND UNDERMINE INTEGRATION 1-4 (Apr. 9, 2021), https://www.humanrightsfirst.org/sites/default/files/ProtectionPostponed.pdf.

Nationally, the immigration courts have an average asylum grant rate of approximately 40 percent,[8] which is significantly higher than the Boston Asylum Office's 15 percent average.[9] As demonstrated in Table 1 below, *the Boston Asylum Office has the second-lowest average grant rate* when compared with asylum offices across the country.[10]

Table 1: Grant Rates of Asylum Offices Nation-Wide

Asylum Office	Grant Rate
San Francisco	52.4%
New Orleans	46.4%
Los Angeles	36.0%
Chicago	32.4%
Arlington	27.1%
Houston	25.9%
Newark	24.6%
Miami	20.7%
Boston	**15.5%**
New York	10.6%

Table 1 shows the average grant rate, as self-reported by USCIS, for each asylum office between January 2016 and September 2019.[11] Only the New York Asylum Office has an average grant rate lower than the Boston Asylum Office.

While the Boston Asylum Office is clearly an outlier, Table 1 also shows that a number of asylum offices also maintain grant rates below that of the national average (28 percent). Indeed, if the findings highlighted within this report are also occurring within asylum offices across the U.S., and the proposed policy to remove immigration courts as the backstop to asylum offices is effectuated, we can expect to see many more asylum seekers with legitimate claims deported from the United States without the due process that our federal laws and international treaties demand. Because persecution is at the core of asylum claims, denying legitimate claims without proper due process exposes asylum seekers to the very persecution from which they have fled.

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[8] *See* TRAC Immigration, *Asylum Decisions*, https://trac.syr.edu/phptools/immigration/asylum/ (last visited Mar. 4, 2022) (showing the average immigration court grant rate from October 2000 to January 2022 is 40 percent, or 255,214 asylum grants out of a total of 638,611 decisions).

[9] The 15 percent grant rate at the Boston Asylum Office was calculated from the compelled FOIA production of the USCIS database. This rate is similar to that calculated from the voluntarily released USCIS data (15.5 percent), which was released to the public each month between January 2016 and 2019. *See* U.S. CITIZENSHIP AND IMMIGR. SERVS., *supra* note 2. The Authors use the 15 percent grant rate obtained through the FOIA litigation because it captures data both before and after the publicly released data and is, therefore, a better indication of the Boston Asylum Office's average grant rate since it first opened in 2015 through mid-2020. *See infra* METHODOLOGIES.

[10] Notably, many asylum offices also have approval rates below that of the immigration courts. As explained further below, referrals from asylum offices add to the U.S.'s growing backlog in the immigration courts. This, in turn, results in meaningful detriments to asylum seekers, such as remaining in legal limbo, being separated from their family members for many more years, and subjecting them to an intentionally adversarial setting. *Infra* IMPACTS. All of these consequences are underscored by the fact that many asylum seekers in immigration court proceedings are eligible for asylum. *See* HUM. RTS. FIRST, *supra* note 7, at 1-4.

[11] *See* U.S. CITIZENSHIP AND IMMIGR. SERVS., *supra* note 2.

INTRODUCTION

> *Everyone has the right to seek and to enjoy in other countries asylum from persecution.*
> *– Universal Declaration of Human Rights, Article 14.*

A. The Affirmative Asylum Process

In 1980, through the passage of the Refugee Act,[12] the United States created the contemporary asylum relief system. In that Act, the United States codified federal laws to implement international treaties and agreements that it had entered over a decade earlier.[13] **As a result, both the United States' international agreements and its federal laws create a legal framework for the federal government to comply with the principles of due process, nonrefoulement, and assimilation and naturalization of refugees.**

Due Process. The United States may not expel an asylum seeker unless it is found that the asylum seeker is not eligible for relief in accordance with the due process of federal and international law.

Nonrefoulement. Under international and domestic law, the United States cannot return or expel a refugee to a place where their life or freedom would be threatened or to a place where there is a substantial risk that they will be tortured.

Assimilation and Naturalization. U.S. regulations promise to, as far as possible, facilitate the assimilation and naturalization of refugees. This is implemented, for example, by creating a legal pathway to U.S. citizenship and providing work authorization for asylum seekers.

An asylum seeker who is not otherwise in removal (*i.e.*, deportation) proceedings may voluntarily file an "affirmative asylum application" with the USCIS Asylum Division, which is housed within the Department of Homeland Security.[14] To be eligible for asylum, the asylum seeker must demonstrate that they previously suffered persecution in the country from which they are fleeing *or* that they have a well-founded fear of persecution in the future. The persecution must have been on account of race, religion, nationality, membership in a particular social group, or political opinion. Once an asylum seeker files their application and supporting evidence with USCIS, the asylum seeker is interviewed by a USCIS asylum officer (AO). For the majority of asylum seekers, an AO is the first government official to hear their case.

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[12] *See* The Immigration and Nationality Act, 8 U.S.C. 1101-1537, Refugee Act of 1980, 94 Stat. 102.

[13] *See* United Nations Protocol Relating to the Status of Refugees, Art. I(a), 19 U.S.T. 6223 (1967) (ratified by the U.S. in 1968); *INS v. Cardoza-Fonesca*, 480 U.S. 421, 436-37 (1987) ("If one thing is clear from the legislative history of . . . the entire 1980 Act, it is that one of Congress' primary purposes was to bring United States refugee law into conformance with the 1967 United Nations Protocol Relating to the Status of Refugees.").

[14] The Department of Homeland Security (DHS) was created after 9/11 in November 2002 and reshaped immigration policy in the United States in the name of protecting national security. "Astronomical budgets and agency structures that funnel money away from national security and toward anti-immigrant hysterics are made possible by the uniquely malleable mission of DHS and the incredibly wide and specialized set of agencies that fall under its authority." Elizabeth F. Cohen, ILLEGAL: HOW AMERICA'S LAWLESS IMMIGRATION REGIME THREATENS US ALL 176 (Basic Books, 2020).

U.S. regulations require that affirmative asylum applicants receive a non-adversarial interview with an AO to determine whether they are eligible for asylum.[15] A non-adversarial interview means that the AO is *not* supposed to be confrontational with the asylum seeker, which differs from civil and criminal court proceedings. For example, USCIS trains its AOs that interrogating or arguing with an asylum seeker is "inappropriate."[16] Rather, AOs should be "neutral decision-maker[s]" and the atmosphere and tone of the interview must be "neutral and professional" regardless of "a difficult or challenging [asylum seeker] or representative, or an [asylum seeker] whom the [AO] suspect[s] is being evasive or untruthful."[17] U.S. law requires that asylum interviews be conducted within 45 days of filing.[18] However, this standard is rarely met, and the application process often extends many years.[19]

In addition to the interview, asylum seekers may submit evidence, such as statements, photographs, documentation, and country conditions reports with their application to help prove their case. AOs review applications, conduct interviews, research country conditions, and ultimately decide whether the applicant will be granted asylum. The AO's decision is *always* reviewed by a supervisory asylum officer (SAO).[20] If an AO and the SAO believe that the individual qualifies, then USCIS will grant the individual asylum. However, if an AO and the SAO do not believe that the individual qualifies for asylum, then the individual is typically referred to immigration court for removal (*i.e.*, deportation) proceedings.[21]

Asylum interviews at the Boston Asylum Office, like all other asylum offices around the country, occur behind closed doors with only the AO, the asylum applicant and their interpreter and/or attorney (if applicable) present. There are no audio transcripts of asylum interviews documenting what occurs during the interview. The only written record of what occurs during an asylum interview is the AO's notes that they take during the interview. Where these notes do not reflect the complete transcript of what is said during an interview, these notes are, by their nature, incomplete and often riddled with errors.

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[15] 8 CFR § 208.9(b).

[16] *Interviewing – Introduction to the Non-Adversarial Interview*, RAIO Directorate – Officer Training, 15-16 (Dec. 20, 2019).

[17] *Id.*

[18] 8 USC § 1158(d)(5)(A)(ii).

[19] HUM. RTS. FIRST, *supra* note 7, at 4.

[20] *Affirmative Asylum Procedures Manual*, U.S. CITIZENSHIP AND IMMIGR. SERVS., RAIO, Asylum Division, 27 (May 17, 2016), https://www.uscis.gov/sites/default/files/document/guides/AAPM-2016.pdf (last visited Mar. 4, 2022).

[21] Many affirmative asylum applications that are referred to immigration court are ultimately granted asylum, indicating that cases referred to immigration court from USCIS often meet the standards for asylum (*i.e.*, have merit). *See* HUM. RTS. FIRST, *supra* note 7, at 1-4.

Without an accurate transcript or recording of what happens during the closed-door asylum interview, improper practices can occur with impunity, especially if an asylum seeker does not have an attorney present to bear witness to the interview. Accurate records of asylum interviews are also important because the records are used to impeach asylum seekers in immigration court. Although immigration court yields a better result for asylum seekers than the asylum process overall, having more accurate interview records could only improve the accuracy of immigration court proceedings.

> ***"Without a lawyer there to observe the interview, you can do what you want as an officer. When there wasn't a lawyer observing my interviews, I sometimes drilled the applicant more than I normally would. I might not show as much compassion . . . because I knew that someone wasn't watching me."***
>
> *Former Asylum Officer, February 2022*

AOs and SAOs are located at one of ten asylum offices across the United States. The Boston Asylum Office serves those living in Massachusetts, Rhode Island, New Hampshire, and Maine. The Boston Asylum Office opened in 2015 as a permanent sub-office of the Newark, New Jersey Asylum Office. Before 2015, Boston's cases were within the sole purview of the Newark Asylum Office, which now serves New Jersey, Delaware, Connecticut, Vermont, parts of New York, and Pennsylvania. In 2020, the Boston Asylum Office became an independent office and is no longer a sub-office of the Newark Asylum Office.

B. Impetus for this Report: The Boston Asylum Office's Low Grant Rates

Pre-2015

Before the Boston Asylum Office opened in 2015, RHRC and ILAP had historically represented asylum seekers before the Newark Asylum Office with above average success, as compared with average national asylum grant rates.

2015

After the Boston Asylum Office opened, RHRC and ILAP witnessed a dramatic drop of the grant rates for their clients.[22] They also observed that clients from certain countries fared far worse than asylum seekers from other countries.[23] What is more, many of the Authors' asylum cases that were later adjudicated within the immigration courts were eventually granted asylum,[24] validating that their cases met the legal standards and should have been granted asylum by the Boston Asylum Office in the first place.[25]

2019

Seeking to understand the reasons behind this notable change in approval rates, the Authors filed a Freedom of Information Act (FOIA) request with USCIS. Despite filing a request to expedite, USCIS did not produce a response within a reasonable time.

2020

Because of this lack of transparency and after a year of inquiries and waiting, in 2020, the Authors filed a complaint in federal court against USCIS seeking to compel a response. [26] In response to the litigation, USCIS produced 6,121 pages—a vast majority of which were heavily redacted—and a large database of the Boston Asylum Office's asylum seeker application data that spanned from 2015 to 2020.[27]

2021-Present

To supplement the information produced by USCIS, the Authors conducted interviews of asylees,[28] asylum seekers, immigration attorneys who represented countless asylum seekers at the Boston Asylum Office, and former AOs and SAOs from asylum offices across the country.[29]

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[22] *Supra* Figure 1.

[23] *Infra* Table 2.

[24] Typically, *years* after their case was referred to immigration court.

[25] This trend has also been documented on a larger scale. *See* Hum. Rts. First, *supra* note 7, at 1-4.

[26] This lawsuit is still pending. *See ACLU of Maine Foundation v. U.S. Citizenship and Immigration Services*, ACLU of Me., https://www.aclumaine.org/en/cases/aclu-maine-foundation-v-us-citizenship-and-immigration-services (last visited Feb. 6, 2022); *see also* Basileus Zeno, *Trump may be gone, but the U.S. asylum system is still broken*, Washington Post (Aug. 12, 2021, 5:21 PM), https://www.washingtonpost.com/opinions/2021/08/12/trump-may-be-gone-us-asylum-system-is-still-broken/.

[27] *See infra* Methodologies.

[28] "Asylees" refers to asylum seekers who have been granted asylum either through an affirmative asylum process with USCIS or defensively through the immigration court.

[29] The Authors were unable to interview current or former AOs or SAOs from the Boston Asylum Office, despite their many attempts. Many AOs and SAOs, regardless of whether they worked at the Boston Asylum Office or another asylum office, were hesitant or unwilling to be interviewed out of fear of potential repercussions. As such, all of the interviewed AOs and SAOs worked at various asylum offices throughout the country. Nonetheless, interviews with these former AOs and SAOs provided the Authors in-depth insights into the likely culture of the Boston Asylum

DR. BASILEUS ZENO'S STORY

An elucidating example of the treatment asylum seekers experience at the Boston Asylum Office is that of Dr. Basileus Zeno, a co-author of this Report who not only has conducted extensive ethnographic research into the U.S. asylum system but also has a lived experience as an asylum seeker before the Boston Asylum Office. When the Arab Spring spread to Syria in 2011, Basileus, who was working on his Ph.D., openly protested the oppressive al-Assad dictatorship. As a result of his opposition to the regime and the harsh crackdown that followed, Basileus could no longer remain in Syria. He and his wife came to the United States on student visas in August 2012, and Basileus applied for asylum in Ohio in July 2013. The couple eventually moved to Massachusetts in 2015 to start their Ph.D.s at the University of Massachusetts Amherst, at which point Basileus's asylum application was transferred to the Boston Asylum Office.

During the *eight years* that they spent waiting for USCIS to adjudicate their asylum claims, the couple completed their master's degrees and Ph.D.s, and had a U.S. born child. During this time, they also continued to advocate for peace and democracy in Syria, and Basileus worked with institutions advocating for nonviolent conflict resolutions.

The U.S. asylum process was designed to help individuals like Basileus, and his should have been an open and shut case. But then came Basileus's interviews at the Boston Asylum Office. Although an asylum interview should be non-adversarial, the AOs at Basileus's multiple interviews ignored the extensive documentation he provided, manufactured inconsistencies by relying on stereotypes of Arabic words, and focused on minutiae unrelated to his asylum claim. Despite the extensive documentation showing that the Syrian government was targeting, arresting, torturing, and murdering people like Basileus and that vocal opponents like him needed protection, the Boston Asylum Office denied Basileus's claim for asylum in May 2021, with no appeal possible. The Boston Asylum Office asserted that he had not satisfied his evidentiary burden and questioned his credibility. Confounded, Basileus filed a Freedom of Information Act request to learn more about what led to the ultimate denial of his application. However, due to extensive redactions, the FOIA response provided no additional insight into the Boston Asylum Office's decision. Ultimately, Basileus and his wife left the United States for Canada in December 2021 to pursue employment-based visas as university professors. Basileus is one of the lucky few with this alternative path available to him but unfortunately securing employment and relocating to Canada is not an option for most individuals denied asylum in the United States.

Office. These stories were further corroborated by numerous interviews with asylum seekers and immigration attorneys, all of whom had countless experiences to draw from while practicing before the Boston Asylum Office.

FINDINGS

In many regards, Basileus's experiences exemplify how the Boston Asylum Office treats asylum seekers generally. As such, Basileus's story is interwoven throughout this Report's findings, impacts, and conclusion.

The findings detailed in this section demonstrate that the Boston Asylum Office is failing asylum seekers in violation of its international obligations and domestic law. This failure creates additional uncertainty and trauma for asylum seekers, and causes unquantifiable ripples into the lives of their families. Our findings strongly suggest that the Boston Asylum Office's disparately high referral rates are driven by a culture of suspicion toward asylum seekers and an overwhelming predisposition to refer asylum seekers to immigration court. This culture to refer is only amplified by the pressures that AOs feel while adjudicating asylum applications, and the lack of transparency in USCIS' asylum offices allows this culture of suspicion and unwarranted referrals to continue unfettered.

> *“It's always easier to refer a case. You want to give a good record of evidence. But, all things being equal, no interview is perfect. And the less you develop the record, the more injurious the record. . . . [There are] a lot of shortcuts if you want to refer.”*
>
> *Former Asylum Officer, October 2021*

AOs are strongly incentivized to cut corners where possible and refer cases at higher rates because of a compounding incentive to align their decisions with the SAOs' predispositions to refer, growing caseloads, and AO job requirements. As a result, AOs may conduct surface-level interviews, skim the asylum seeker's application, conduct inadequate country conditions research, or recycle prior written decisions. For instance, some immigration attorneys had the impression that AOs were writing decisions to refer while the AO was still conducting the interview. Immigration attorneys who have worked with the Boston Asylum Office commonly shared that AOs appear to be finding the easiest way to refer or deny cases. This often is applied through a “rule of threes,” where the AO focuses on finding three immaterial inconsistencies within the asylum seeker's story rather than focusing on the merits of their claim.

In addition to resorting to tactics that produce high referral rates, the culture and pressures cause some AOs to burn out quickly, and the turnover with the AOs position is high. Likewise, AOs' demanding caseloads and job duties leave little time for additional training, reflection, or self-care within the workplace. These are all crucial for AO well-being and continuing to improve their efficacy at adjudicating asylum applications in a way that adheres to the law.

We address each of our specific findings below, in turn.

A. The Boston Asylum Office's High Referral Rates are Driven by the Outsized Role of Supervisory Asylum Officers.

The Boston Asylum Office's overwhelming tendency to refer and deny asylum applications is driven by the outsized role SAOs play within the Office. One former SAO who is familiar with the Boston Asylum Office explained that the AOs and the SAOs initially hired at the Boston Asylum Office "tended to be people who did not grant [asylum] that much," and noted that SAOs are given "a lot of leeway" in refusing to give the asylum seeker the "benefit of the doubt." This former SAO went on to add that the Boston Asylum Office "is a planet that has lost its rotational orbit . . . [AOs] are intimidated . . . [and some AOs] have a culture of suspicion hinging on paranoia."

> ***"If you don't have a supportive management staff, it's a lost cause, like trying to swim upstream against unbelievably powerful undercurrents."***
>
> *Former Supervisory Asylum Officer, November 2021*

Former AOs unanimously attested to the outsized influence SAOs have in an AO's asylum decision-making process. **In particular, two aspects of the AO's position highly incentivize AOs to write asylum decisions that align with their supervisor's predispositions: (1) the asylum decision review process, and (2) the employee performance review process.**

When an asylum office has SAOs who are suspicious of asylum seekers and who have a predisposition to refer cases to immigration court—such as the Boston Asylum Office—AOs are strongly incentivized to modify their decisions to match the perceived preference of their SAO. As a result, the office's asylum referral and denial rates skyrocket.

(1) Asylum Decision Review

Current USCIS policies require that SAOs review *all* AO casework and an SAO *must* approve the AO's asylum decision before that decision becomes final.[30] The Affirmative Asylum Procedures Manual states that AOs "must be given substantial deference" and that disagreements between SAOs and AOs ought to be elevated to the Director.[31] Yet, our research reveals that the supervisory review process seldom works as the Manual prescribes.

In practice, SAOs exercise an improper degree of influence over the outcome of an asylum case. Former AOs interviewed explained that many AOs are hesitant to write an asylum decision that they believe their SAO may disagree with. This is because, among other disincentives, doing so can create substantially increased workloads. If an AO disagrees with their SAO in a particular case, the SAO may require the AO to further substantiate their decision by re-interviewing the asylum seeker, conducting further fact investigation, or researching more country conditions.

For example, one asylum seeker whose case was decided by the Boston Asylum Office, shared that they were certain that the AO was being monitored during the interview because they could see the AO's computer screen showing the supervisor's comments and notes during the interview. The AO even told the asylum seeker that if the asylum decision were up to the AO, the AO would grant their asylum case.

Former AOs also noted that they are not provided additional time or given a break in their caseloads to further substantiate their decisions. When an SAO disagrees with an AO's initial decision, the AO must often re-write that decision, and AOs are not given any additional time (or sufficient time) in their schedule to re-write decisions where interviews often occupy the majority of their workload. Accordingly, disagreement with an SAO can be fatal to an AO being able to keep up with their workload. Therefore, if the AO believes their SAO has a predisposition to refer, they may recommend a referral—despite their own inclination to grant—in order to not fall behind.

Additionally, AOs tailor their interviews around what types of questions their SAO may require that they ask before they can refer or grant a case, influencing how the AO conducts their interviews and fact investigations and diminishing the AO's autonomy. This influence is striking given that the AO interviews the asylum seeker and reviews the asylum seeker's application. In contrast, the SAOs rarely interact with asylum seekers. Thus, despite their distinct roles, the AO is incentivized to understand the SAO's questions and predisposition in order to save time in adjudicating cases and, as detailed in the next section, for their job protection.

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[30] *Asylum Officer Basic Training Course: Corps Values and Goals*, U.S. CITIZENSHIP AND IMMIGR. SERVS., RAIO, Asylum Division (Sept. 13, 2006), https://www.aila.org/infonet/aobtc-corps-values-goals; *Affirmative Asylum Procedures Manual*, U.S. CITIZENSHIP AND IMMIGR. SERVS., RAIO, Asylum Division, 27 (May 17, 2016), https://www.uscis.gov/sites/default/files/document/guides/AAPM-2016.pdf.

[31] *Affirmative Asylum Procedures Manual*, U.S. CITIZENSHIP AND IMMIGR. SERVS., RAIO, Asylum Division, 27 (May 17, 2016), https://www.uscis.gov/sites/default/files/document/guides/AAPM-2016.pdf.

(2) Performance Reviews

AOs are subject to the Performance Work Plan (PWP), which is the “primary tool” that SAOs use to assess performance.[32] The PWPs are written by the SAOs and “rate Asylum Officers on critical qualitative elements of the job, including . . . decision writing.”[33] This system provides SAOs with an unchecked abundance of power and influence over AOs and their decision making.

Notably, former AOs indicated that they were often hesitant or unwilling to disagree with their SAO out of fear that they might receive a negative mark on their PWP. Conversely, AOs receive positive PWP marks when they turn around decisions quickly. An AO’s PWP is based on a numerical score. When an SAO returns an AO’s case because, for example, the SAO has further questions or disagrees with the decision, the AO’s numerical score is affected. This means that an AO will get a negative numerical score for disagreeing with an SAO. These negative scores can result in probation and job loss. Indeed, disagreements with an SAO can directly affect whether an AO continues to work within an asylum office.

> ***“** You cannot fight for every case or you'll seem combative and insubordinate so you have to make decisions on which cases you are willing to go against the grain and which ones you fall in line. **”***
>
> *Former Asylum Officer, February 2022*

B. Asylum Officers Exhibit Bias in the Asylum-Decision Making Process, which Contributes to the Boston Asylum Office’s Low Grant Rates.

Humans are not neutral. We are biased, we are discriminatory.
People have a very hard time being a neutral adjudicator. There
are very few people who can naturally put their biases aside.
– Former Asylum Officer, October 2021

Asylum outcomes in the United States are “highly reliant on the individual decision maker.”[34] AOs and SAOs exhibit various biases in the asylum decision-making process, which contributes to the low grant rates within the Boston Asylum Office. Most significantly, AOs and SAOs in the Boston Asylum Office tend to be biased against asylum seekers from certain countries.

Our research strongly suggests that the Boston Asylum Office does not approach applications from certain countries with a neutral stance, but rather presumes they must be fraudulent or pose a security threat. Like any government program, there are going to be instances of individuals seeking to take advantage of the system, and fraud certainly occurs.

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[32] *Asylum Officer Basic Training Course: Corps Values and Goals*, U.S. CITIZENSHIP AND IMMIGR. SERVS., RAIO, Asylum Division 8 (Sept. 13, 2006), https://www.aila.org/infonet/aobtc-corps-values-goals.

[33] *Id.*

[34] Rebecca Hamlin, *Ideology, International Law, and the INS: The Development of American Asylum Policies 1948-Present*, 47 POLITY 320, 334 (2015).

Nonetheless, *the majority of asylum applications are not fraudulent.* For example, as detailed in the chart below, the Boston Asylum Office grants a mere 4 percent of asylum applicants from the Democratic Republic of Congo (DRC) despite the U.S. Department of State's acknowledgment that "significant human rights" abuses occur there, which include "unlawful and arbitrary killings, . . . forced disappearances, [and] torture," all committed by DRC security forces against its citizens.[35]

As shown in Table 2 below, the data collected from the FOIA response corroborates the Boston Asylum Office's bias against asylum seekers from certain countries.

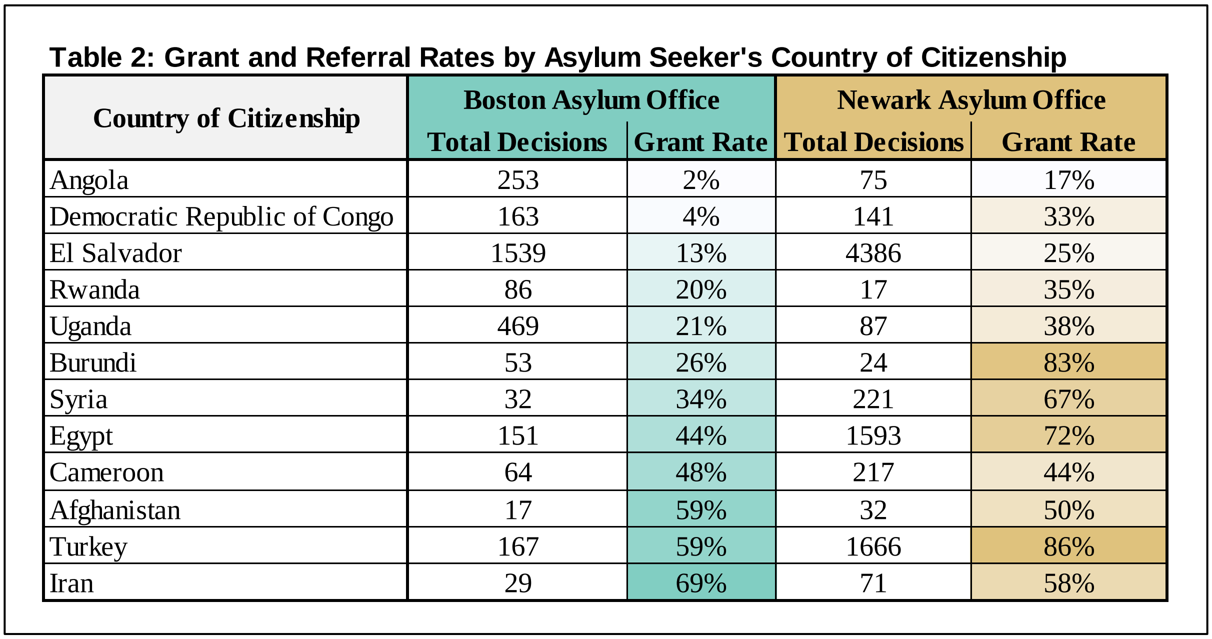

Table 2: Grant and Referral Rates by Asylum Seeker's Country of Citizenship

Country of Citizenship	Boston Asylum Office		Newark Asylum Office	
	Total Decisions	Grant Rate	Total Decisions	Grant Rate
Angola	253	2%	75	17%
Democratic Republic of Congo	163	4%	141	33%
El Salvador	1539	13%	4386	25%
Rwanda	86	20%	17	35%
Uganda	469	21%	87	38%
Burundi	53	26%	24	83%
Syria	32	34%	221	67%
Egypt	151	44%	1593	72%
Cameroon	64	48%	217	44%
Afghanistan	17	59%	32	50%
Turkey	167	59%	1666	86%
Iran	29	69%	71	58%

Table 2 shows the average grant rate based on the asylum seeker's citizenship, as indicated on their asylum application, between 2015 and 2020, for the Boston and Newark Asylum Offices.[36] Countries displayed within this table were chosen because they were specifically named within AO trainings received from the FOIA response, or because they provide useful examples of countries that received particularly favorable or unfavorable treatment by the Boston Asylum Office, as compared to the grant rates of the Newark Asylum Offices. Notably, some countries (*e.g.*, Angola, Democratic Republic of Congo, Rwanda, and Burundi) all have much lower grant rates in the Boston Asylum Office as compared to the Newark Asylum Office. This trend is further corroborated by the Author's experiences at the Boston Asylum Office that resulted in this report. The Newark Asylum Office is useful for comparison for this data because, prior to the creation of the Boston Asylum Office, the Newark Asylum Office adjudicated affirmative asylum cases for the same geographical region and had a higher average grant rate than the Boston Asylum Office. *See* INTRODUCTION. Thus, differences in grant rates between countries is most likely a byproduct of the specific office cultures and operations—and not the asylum seeker populations that each office serves.

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[35] U.S. DEP'T OF STATE, DEMOCRATIC REPUBLIC OF CONGO 2020 HUMAN RIGHTS REPORT (Mar. 30, 2021), https://www.state.gov/reports/2020-country-reports-on-human-rights-practices/democratic-republic-of-the-congo/.

[36] Boston Asylum Office asylum data was collected through the Freedom of Information Act request filed with USCIS, and subsequent litigation regarding the request, for both the Boston Asylum Office and Newark Asylum Office. *Infra*, METHODOLOGIES.

Erroneously viewing all cases as potentially fraudulent is not surprising given that, according to the documents produced through the FOIA response, the vast majority of the Boston Asylum Office's employee trainings focus on fraud. Specifically, in response to our FOIA request that asked to see the trainings used in the Boston Asylum Office, USCIS produced 21 trainings, 14 of which addressed fraudulent applications or issues of credibility. As one former AO explained, "constantly hearing about fraud and credibility issues kind of puts you in the mindset of there being a lot of fraud."

Similarly, a bias against non-English speakers is apparent at the Boston Asylum Office. As demonstrated in Figure 2 below, English-speaking asylum seekers are nearly *twice* as likely to be granted asylum as compared to non-English speakers. Conversely, non-English speakers are referred to immigration courts 80 percent of the time, while English speakers are referred to immigration court only 58 percent of the time.[37] This trend might be corroborative of the disparate treatment of the countries in Table 2, as English is not the prominently spoken language within those twelve countries. Alternatively, this trend might also be explained by implicit biases for traits that are commonly associated with English-speakers, such as higher education levels and socioeconomic status.

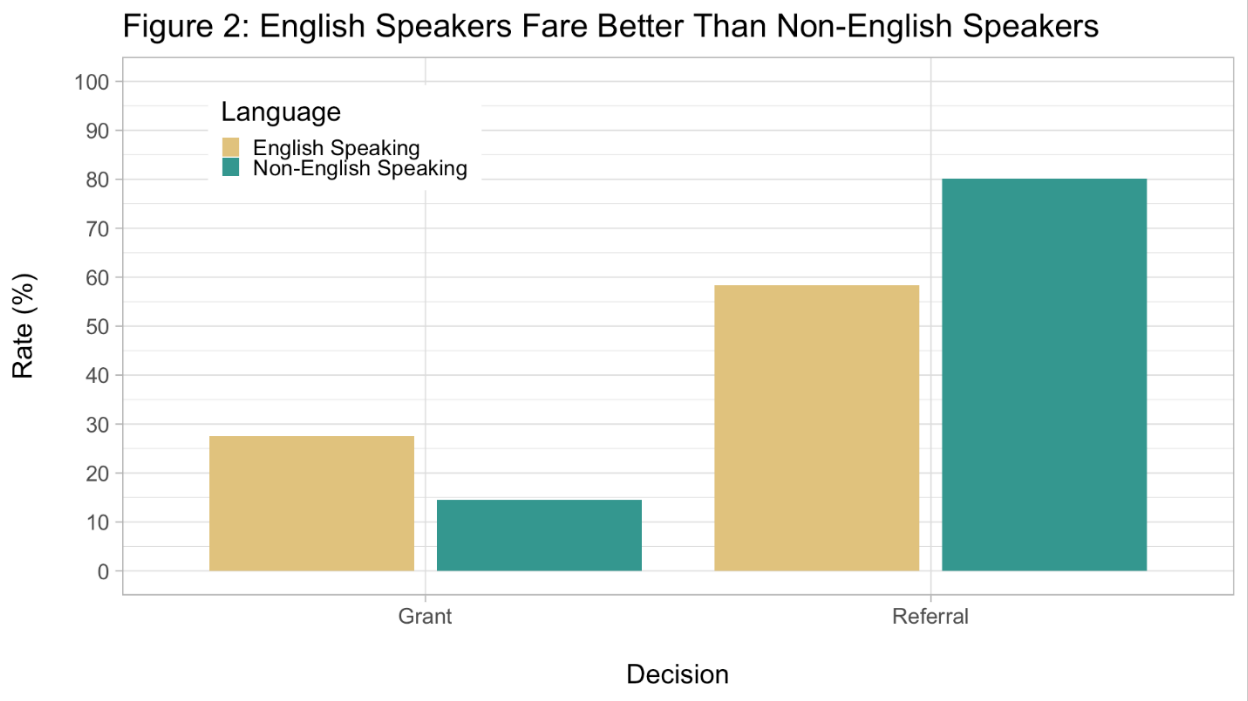

Figure 2 shows the grant and referral rates for English and non-English speaking asylum seekers at the Boston Asylum Office.[38] English speakers have an average grant rate of 27.5 percent of the time and a referral rate of 58.4 percent. In contrast, non-English speakers only were granted asylum 14.6 percent of the time and had an average referral rate of 80.1 percent.

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[37] This, in turn, leaves asylum seekers in legal limbo and drains government resources. *See infra* IMPACTS.

[38] This data was calculated from the databases that USCIS provided through the litigation of the FOIA Request, and contains decisions made between 2015 and 2020. *Infra* METHODOLOGIES. The category "non-English speaker" also represents application data that contained "unknown" for the language.

C. Pressures from Time Constraints and Caseloads Incentivize Asylum Officers to Cut Corners.

AOs have a complex and essential list of responsibilities that they must complete to ensure that an asylum seeker's application is provided due process. However, AOs are incentivized to cut corners in these responsibilities while adjudicating cases because, in addition to the reasons listed above, they are not provided adequate time to complete their relatively large caseloads.

To assure that an asylum seeker's application is adjudicated thoroughly and meets the requirements of due process, an AO is responsible for completing the following non-exhaustive list of job duties:

> ❝ ***If you could just do the interviews in the timeframe that it needs to be done in and push off the other cases, but [you can't because] you're scheduled. You have attorneys waiting in the waiting room, you're thinking about that. There's so much you have to do because you don't just do the interview and the write up, you do fingerprints, background security checks, pulling all of the programs, then a whole sheet you have to check.*** ❞
>
> *Former Asylum Officer, October 2021*

- Adequately understand ever-changing U.S. asylum laws, including case law
- Review and become familiar with each asylum seeker's case–often consisting of hundreds of pages of documents–prior to the interview
- Research the country conditions and specific details of each asylum seeker's case
- Run background checks
- Build rapport with asylum seekers prior to starting the interview
- Consider what questions to ask in the interview, which typically lasts three to four hours
- Discern which topics need further investigation in the interview
- Be sensitive to the asylum seeker's experienced trauma
- Monitor the amount of time spent on each topic
- Create a written record of the questions asked and the asylum seeker's responses during the interview to serve as the basis for a written decision
- Utilize interpreters to effectively communicate with asylum seekers during the interview
- Conduct at least two interviews per day
- Act as the adjudicator and analyze the facts of the case within the relevant asylum law and write a three- to five-page recommended decision to grant asylum, deny, or refer to immigration court
- Prepare for supervisory review of their recommended decision
- Conduct additional investigations and interviews if requested by the SAO

Former AOs and SAOs note that it is difficult to execute all their assigned duties fully and effectively because of the pressures from time constraints and caseloads. The Boston Asylum Office, on average, receives approximately 5,600 asylum applications per year.[39] However, the office is unable to effectively adjudicate asylum cases it receives within the timeframe mandated by domestic and international law.[40] Because the Boston Asylum Office has received far more applications per year than it can adjudicate, the backlog of cases has continued to grow.[41]

The data reveals that, on average, the Boston Asylum Office adjudicates 30.5 percent of the applications that it receives each year. When the adjudication rate of asylum applications is below 100 percent, some applications will inevitably be reviewed the following year. In the case of the Boston Asylum Office, approximately 70 percent of its new cases are added to the backlog each year. As a result, the Boston Asylum Office's backlog has grown to over 20,000 pending asylum applications.[42] The upshot of this backlog is that most asylum applicants must wait *years* for their asylum interview. For many applicants this delay in adjudication worsened when the Trump Administration instituted a "Last-in, first-out" (LIFO) policy.[43] Rather than resolving cases chronologically based on when they were filed, under LIFO asylum offices prioritize the newest applications while asylum seekers with older applications remain in legal limbo for longer.

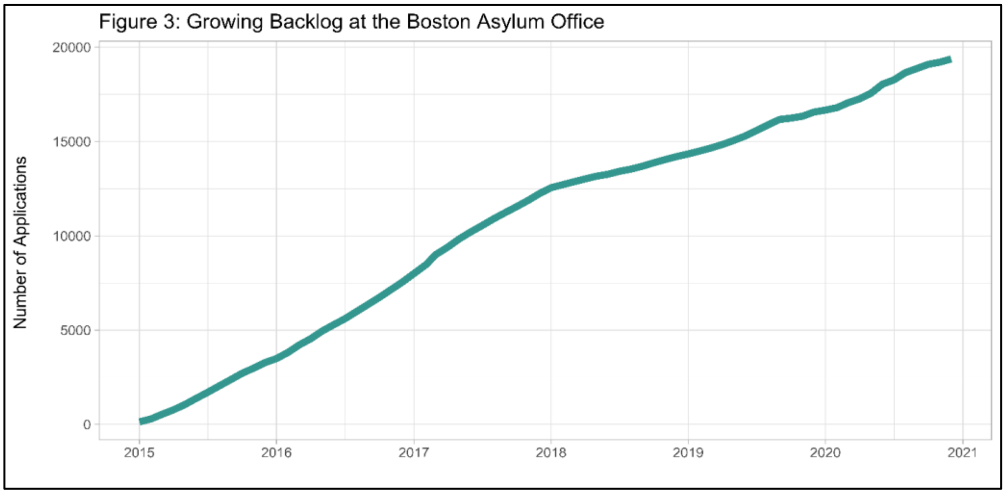

Figure 3 shows the accumulating number of asylum cases at the Boston Asylum Office that have yet to receive a decision.[44] Toward the end of 2020, the Boston Asylum Office had nearly 20,000 pending asylum applications.

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[39] This number decreased to 3,119 cases in 2020. This decrease may reflect "Remain in Mexico" policies and the COVID-19 Pandemic.

[40] *See* 8 U.S.C. § 1158(d)(5)(A)(iii) ("[I]n the absence of exceptional circumstances, final administrative adjudication of the asylum application, not including administrative appeal, shall be completed within 180 days after the date an application is filed.").

[41] This backlog is not unique to the Boston Asylum Office. Nationally, the backlog reached a "historic high" during the Trump Administration, with over 386,000 pending applications by the end of fiscal year 2020. HUM. RTS. FIRST, *supra* note 7.

[42] The Boston Asylum Office self-reported to the American Immigration Lawyers Association that, as of December 2021, it has 20,400 pending asylum applications. *AILA New England Newsletter*, AM. IMMIGR. LAW. ASS'N (Dec. 14, 2021) (updating AILA attorneys on Boston Asylum Office Statistics – responses from the October Asylum Liaison Meeting with USCIS).

[43] *See* Hawthorne Smith, Ph.D. *How the Asylum Backlog Affects Torture Survivors and What the Biden Administration Can Do to Fix It*, Ctr. for Migration Stud. (Feb. 25, 2021), http://doi.org/10.14240/cmsesy022521.

[44] This data was calculated from the databases that USCIS provided through the litigation of the FOIA Request filed by the ACLU of Maine, Maine Law's Refugee and Human Rights Clinic, and the Immigrant Legal Advocacy Project, and contains decisions made between 2015 and 2020. *Infra* METHODOLOGIES.

This accumulation of asylum applications adds pressure to AOs' daily tasks and decisions. AOs have job responsibilities essential to ensuring that we protect those fleeing persecution, ensure asylum seekers receive a decision based on the principles of due process, and meet our domestic and international obligations. These aims and our laws are undermined by AOs cutting corners because they feel the pressure to adjudicate cases in too short time periods.

In fact, many former AOs shared that they felt as though they needed to rush through parts of their preparations and interviews or cut corners to adequately do their jobs. One AO stated that she coped with the time constraints by rushing through her written decisions, neglecting the research and analysis she thought was necessary to do her job well.

> *The interview might be rushed because the interview shouldn't take too long. This probably makes decisions more likely to be negative because if [the asylum seekers] don't have enough time to tell [their] story [then you] don't have a story that shows your eligibility for asylum.*
>
> – Former Asylum Officer, December 2021

Likewise, former AOs also indicated that some AOs may "recycle" decisions:

> *There is a perverse incentive. [AOs have a] stack of cases and have to manage [their] own time. All [cases] must be turned around in a three to five-day period of interviewing . . . AOs ends up recycling the same decision, plugging in new facts. That is very problematic for so many reasons. [When decisions are recycled,] an applicant, and any evidence submitted along with their application, do not have the same opportunity for review for each individual claim. [It's] always easier to refer.*
>
> – Former Asylum Officer, December 2021

Additionally, one possible explanation for the trend shown in Figure 2 (English speakers fare better than non-English speakers), aside from bias, might be the additional time constraints that are placed on AOs when they need to communicate with an asylum seeker through an interpreter. Adding an interpreter to the interview causes the interview to move more slowly because there is a necessary delay after each question and answer while the interpreter communicates what is being said. Because AOs are under such strict time constraints, they may be unable to extend the interview duration when necessary. Thus, adding an interpreter to the interview can significantly reduce how much of the asylum seeker's story the AO can hear. This, in turn, limits the facts that the AO can rely upon when reaching their decision, further decreasing the odds of an asylum grant. As one former AO put it:

> *[I]t takes more time to have a conversation with an interpreter. So, if the interview is one hour and ten minutes (which is what it is supposed to be in training) and there is an interpreter, you get less information in an hour and ten minutes.*
>
> – Former Asylum Officer, December 2021

AOs must manage numerous job responsibilities that are essential to ensure that an asylum seeker's due process is protected. However, completing these duties is feasible *only if* AOs are provided adequate time. Because of the aforementioned time constraints and caseloads that AOs face, many AOs cut corners where possible and are thus unable to fully and fairly adjudicate asylum cases.

D. Burnout and Compassion Fatigue Negatively Affect How Asylum Officers Approach Asylum Cases.

The rigors of the AO position described in the preceding section result in high levels of burnout and compassion fatigue. Former AOs expressed that the longer they stayed in the role, the more desensitized they became to the traumatic experiences of asylum seekers. They also explained that this compassion fatigue impacts the AO's credibility assessment of asylum seekers. One former AO shared that the "statements of applicants become so mundane [that they] lose salience in this process."

> ***“Compassion fatigue is a universal problem among AOs and there is no training on it. It definitely made me less likely to approve [applications]. You definitely lose compassion, which I think blinds you to someone. Not everyone can express themselves in a way that seems credible and so when your compassion fatigue is there and they don't seem credible you think to yourself, 'I'm going to deny this person, I'm so sick of this shit.'”***
>
> *Former Asylum Officer, October 2021*

Interviews with asylum seekers and their attorneys indicate that AOs at the Boston Asylum Office are frequently dismissive of an asylum seeker's trauma. One attorney commented that, "[AOs] are extremely jaded." The attorneys further indicate that AOs sometimes become frustrated and even combative with applicants, which is counterproductive for assessing an asylum seeker's claim and violates the requirement that asylum interviews be conducted in a non-adversarial manner.

> ***“Most of them, it's like they really don't care. I've had clients break down in the interview because they are describing these horrible experiences, and the officer is dismissive.”***
>
> *Attorney, November 2021*

E. Asylum Officers Place an Inordinate Focus on Credibility and Immaterial, Peripheral Details of a Case to Find “Inconsistencies” that Lead to Denials and Referrals to Immigration Court.

AOs commonly deny or refer asylum cases based on a determination that an applicant is not credible. Yet such determinations are not made by earnestly questioning applicants about the substance of their claims. Instead, our research suggests that AOs at the Boston Asylum Office look for *any* reason, no matter how insignificant or tangential, to find that an asylum seeker is not credible. In stark contrast to international refugee law (which does not require a credibility determination), U.S. lawmakers incorporated an explicit credibility requirement post-9/11 by way of the Real ID Act. Moreover, although credibility is *only one* factor in an asylum determination,[45] AOs treat it as the “single most salient issue” in practice.[46]

Interviews with asylum seekers, AOs and immigration attorneys confirm that, most often, AOs find support for their negative credibility assessments by pointing to “inconsistencies” within an asylum seeker’s story.

> **“*The default - and this is an internal unwritten rule - is that you default to credibility assessments. The rule is a rule of threes. If there are three inconsistencies or not sufficient candidness (things that are highly subjective and easy to write up and very difficult to critique on the supervisory end), identifying three areas of credibility issues is fatal to an applicant’s decision.*”**
>
> *Former Asylum Officer, December 2021*

> **“*They are looking really purposefully and aggressively toward any indication that there is an inconsistency or any indication that there is a lack of credibility and asking confusing and adversarial questions to try to trip-up clients into misstating a minor or irrelevant fact or detail.*”**
>
> *Attorney, November 2021*

Former AOs explained an unwritten “rule of threes,” where a finding of three inconsistencies in an asylum seeker’s testimony is sufficient to refer the individual to immigration court for removal proceedings. Yet these “inconsistencies” rarely concern a material fact to an applicant’s asylum claim. Rather, AOs focus on minor discrepancies about peripheral matters.

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[45] 8 U.S.C. § 1158(b)(1)(B)(ii)-(iii).

[46] Bridget M. Haas, *Asylum Officers, Suspicion, and the Ambivalent Enactment of Technologies of Truth*, *in* Technologies of Suspicion and the Ethics of Obligation in Political Asylum 105, 111 (2019).

Aside from being peripheral to the heart of an asylum claim, the inconsistencies that lead to denials and referrals in many instances have simple and innocent explanations. Inconsistencies can be caused by the fallibility of the human memory. Asylum seekers frequently wait *years* between filing their application and receiving an asylum interview. These long delays can affect an asylum seeker's memories of their application's specific details.

> ***❝ The entire strategy that they have is to try to note as many inconsistencies or to create as many inconsistencies and make note of them as possible. And that was it, they would spend a lot of time on small issues, confusing the client, distracting them, and never really asking about persecution because they would have enough to find material inconsistency and refer it. It seemed like [the AOs] were doing the bare minimum. ❞***
>
> *Attorney, August 2021*

Other inconsistencies might be caused by misunderstandings created by language barriers and cultural differences. Moreover, because persecution is at the center of an asylum claim, an asylum seeker may suffer from the types of memory loss that is common amongst survivors of trauma.

Indeed, attorneys stated that many of their clients suffer from depression and post-traumatic stress disorder, and struggle with the disorder's common symptom of memory loss. Further, research has shown that the assumption that truth telling is connected to remembering details like dates, names, and numbers, clearly and consistently, is questionable even in the case of those who have not had to flee violence and persecution or experienced trauma.[47]

Regardless of the asylum seeker's reason for having a less-than-perfect memory, an AO's expectation that the asylum seeker recall tangential facts to their stories with precise accuracy is ignorant of human psychology, illogical, and contrary to the U.S.' federal law and international obligations. Nonetheless, AOs at the Boston Asylum Office spend a disproportionate amount of the interview focusing on these minor and perceived inconsistencies. These inconsistencies, in turn, serve as the basis for denying a case or referring a case to immigration court.

Basileus Zeno: Knowing how important the interview is to the asylum process, Basileus and his attorney prepared extensively for it. Nothing, however, prepared him for the AO's belittling treatment and focus on details immaterial to his claim. During his first interview in March 2017, the AO spent a disproportionate amount of time asking about Basileus's taxi driver for a trip he took from Damascus to Beirut when he left Syria for the last time in July 2012. Later in October 2018, at a second follow-up interview to clarify inconsistencies, the AO referenced a set of specific questions and concerns raised by the SAO, which focused almost solely on details surrounding Basileus's religion and marriage in Lebanon and how he got his Syrian passport in 2011. Despite submitting an official marriage certificate and photographs, the SAO doubted Basileus's marriage and questioned the priest's religion based on the SAO's ignorant and stereotypical understanding of Arabic words and names. Almost none of the questions related to the first interview or the substance of Basileus' asylum claim.

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[47] *See* CAROL BOHMER & AMY SHUMAN, REJECTING REFUGEES: POLITICAL ASYLUM IN THE 21ST CENTURY 134-144 (Routledge 2007).

IMPACTS

A. On the Asylum Seeker and their Family

The Boston Asylum Office's high referral rates have significant and harmful impacts on asylum seekers and the asylum seekers' families. The impacts keep families in ongoing danger, strain family bonds, prevent family reunification, leave asylum seekers in legal limbo, compound experienced trauma, and erode mental health.

(1) Family Members Remain in Danger Abroad

Delays in the process of obtaining asylum prevent immediate family members left abroad from joining the asylum seeker in the United States.[48] Many remain vulnerable to violence or danger in their home country (often the reason the asylum seeker was forced to flee), and others may seek refuge in unstable, secondary countries where they remain without legal status while waiting for permission to join their family member in the United States. Many asylum seekers shared that they are plagued by fear for their family members left behind because their family continues to be threatened. For example, one asylum seeker fled to the United States to protect themselves and their family, leaving behind their spouse and young children. While the asylum seeker's case was pending, the spouse and children died under suspicious circumstances. The Boston Asylum Office referred this case to immigration court. In another example, an asylum seeker waiting years for an asylum interview learned their spouse had been murdered in their home country. Their children were left in the care of a relative who fled to a neighboring country where the relative and one child died in tragic circumstances. This case was also referred by the Boston Asylum Office to the immigration court where it is still pending more than seven years after the asylum application was originally filed. Both asylum seekers carry feelings of guilt because they left their families believing it was the best way to protect them but found instead that refuge did not come soon enough. Unfortunately, these scenarios are all too common.

(2) Family Bonds Strained by Separation

Many asylum applicants find that their family relationships suffer due to the prolonged separation.[49] For example, one attorney interviewed for the report spoke of a former asylum seeker who, because of a ten-year delay in the adjudication of his case after a referral from the Boston Asylum Office, was unable to reunite with his wife and children. The wife abandoned their marriage, and the asylum seeker's relationship with his kids suffered immensely; the kids felt betrayed and left behind by their father. In another example, an asylum applicant was able to flee her home country with her infant child, but her husband was unable to secure a visa to escape with her. She lost her initial asylum case before the Boston Asylum Office and, given backlogs in the immigration court, she faces a years' long wait for her case to be adjudicated in court. To date, eight years have passed since she has seen her husband, and their child has spent the majority of their young life without a father.

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[48] If an individual is granted asylum, they can petition for immediate family members to receive asylee status through the "derivative" asylum process. *See Derivative Refugee/Asylee Status for Your Children*, U.S. CITIZENSHIP AND IMMIGR. SERVS., https://www.uscis.gov/forms/explore-my-options/derivative-refugeeasylum-status-for-your-children (Jul. 9, 2020); *Derivative Refugee/Asylee Status for Your Spouse*, U.S. CITIZENSHIP AND IMMIGR. SERVS., https://www.uscis.gov/forms/explore-my-options/derivative-refugeeasylee-status-for-your-spouse (Aug. 6, 2020).
[49] *See* HUM. RTS. FIRST, *supra* note 7, at 5.

(3) Legal Limbo

In their attempts to build a new life, the prolonged limbo of an asylum seeker's immigration status exposes them to forms of "legal violence"[50] by leaving them without access to supports such as federal student aid, social services for their children, or educational opportunities. When an asylum seeker's case is referred to immigration court, this legal limbo is often extended for multiple years.[51] A former asylum seeker expressed her frustration, "I wanted to apply for graduate schools, but I asked myself, 'what if they forced me to leave after six months? Why should I apply?' I am totally lost, and we have no place to go."[52]

This legal limbo can be particularly challenging for asylum seekers who have children born in the United States and are U.S. citizens, as those children may struggle to fully integrate due to the uncertainty of their parent's status. One child, born while their mother was seeking asylum in the United States, spent the first four years of their life here before moving to Belgium after the mother abandoned her asylum claim. The delayed adjudication and later denial of her expedited request by the Boston Asylum Office meant that she was separated from her husband for four years and contributed to her severe depression and economic instability. The child has had a difficult time transitioning to a new life in Belgium.

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[50] Cecilia Menjívar and Leisy Abrego, *Legal violence: Immigration law and the lives of Central American immigrants*, 117.5 Am. J. of Soc. 1380-1421 (2012).

[51] *See* Jasmine Aguilera, *A Record-Breaking 1.6 Million People are now Mired in U.S. Immigration Court Backlogs*, TIME (Jan. 20, 2022, 11:31 AM) https://time.com/6140280/immigration-court-backlog/; TRAC Immigration, *Immigration Court Backlog Now Growing Faster Than Ever, Burying Judges in an Avalanche of cases* (Jan. 18, 2022), https://trac.syr.edu/immigration/reports/675/.

[52] Basileus Zeno, *Dignity and humiliation: Identity formation among Syrian refugees*, MIDDLE E. LAW AND GOVERNANCE, 9(3), 282, 297 (2017).

(4) Compounding Trauma

> *“ He didn’t get a fair chance, [he] got treated like garbage. He said, 'she did not see me as a human. I will always remember how she treated me.' ”*
>
> *Attorney, November 2021*

> *“ The client was a survivor of torture and [the officer] laughed multiple times throughout the client telling his story . . . She checked her text messages during the interview. The client was horrified, was so embarrassed and so humiliated. He’s pouring out his heart to this person and she’s laughing . . . and yet when she is engaged, she’s cross-examining him up and down . . . The respect for the situation and for the client was not there. ”*
>
> *Former Asylum Officer, December*

At the root of an asylum seeker’s claim is one or more experiences of persecution, which usually leads to trauma. During their asylum interview with an AO, asylum seekers are required to relive this trauma as they retell their stories.

If the case is not granted at the asylum office and is referred to immigration court, which is the most likely outcome for the Boston Asylum Office, the asylum seeker will have to revisit this trauma yet again—but this time in an intentionally adversarial setting. Each step along the process compounds the trauma experienced by the asylum seeker.

Most asylum cases referred to immigration court are ultimately granted by an immigration judge.[53] This suggests that these cases could have been granted by the AO and that asylum seekers are unnecessarily forced to continually relive the sources of their trauma.

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[53] HUM. RTS. FIRST, *supra* note 7, at 1-4.

(5) Mental Health Deterioration

The combined effects of prolonged separation from family members, uncertainty of legal status, and compounded trauma has a detrimental effect on the mental health of asylum seekers. They may suffer from depression, anxiety, and endure nervous breakdowns. For example, one asylum seeker, who became a U.S. citizen in 2019, still has nightmares about being deported and separated from her U.S.-born child. She stated that she wakes weeping and screaming with an intense need to hold her child.

> “*[My client is] having severe depression. This has derailed his life. It has really destroyed his life . . . I’ve never seen an individual on the brink of a nervous breakdown. I don’t know if he’ll survive this or overcome this.*”
>
> *Attorney, November 2021*

Basileus Zeno: While waiting for his pending asylum decision, Basileus endured many of the hardships that come to those without permanent status in the United States, including not seeing his family for almost a decade and facing difficulties maintaining his bank account or renewing his driving license. Additionally, after the Boston Asylum Office denied Basileus’s asylum case in May 2021, he and his wife were forced to defend their Ph.D. dissertations earlier than planned in order to keep their visa status. Ultimately, after almost a decade of seeking asylum, Basileus and his family lost any hope of finding refuge in the United States. Consequently, they left the United States for Canada in December 2021, where they had new jobs and were forced to rebuild their life yet again. Two weeks before leaving the United States, the Boston Asylum Office sent Basileus a notice requesting to “reopen” his case, seeking a fourth interview in January 2022. The notice arrived far too late and could not undo the years of damage inflicted by the Boston Asylum Office’s traumatizing and humiliating treatment of him and his family.

B. On the Asylum System

(1) Delayed Process and Negative Impacts on Immigration Courts

Because asylum office referrals feed directly into the immigration court backlogs, the Boston Asylum Office’s above-average referral rate is unnecessarily inundating the immigration courts with cases. The asylum process can take years, not only because of massive backlog within asylum offices,[54] but also because immigration courts around the country also face a significant backlog. In the immigration courts, the national backlog reached nearly *1.6 million* pending cases by the end of December 2021—marking its “highest level ever.”[55]

> ***“Last time [my client] and I went to court (March/April 2020) the Judge couldn’t find his file and made him come back. The Judge said he would 'squeeze him in' and their hearing was scheduled for two years later in 2022. It can delay people’s lives. ”***
>
> *Attorney, November 2021*

Re-adjudicating a case in immigration court—just to ultimately grant asylum—increases the courts’ untenable backlog as well as administrative costs, which are ultimately shifted to the taxpayers. The impact of this delay creates additional challenges for asylum seekers to show, often many years after their initial application, that they meet the requirements of asylum. Attorneys reported that memory issues arise, and witnesses may no longer be able to testify. Furthermore, even minor errors in the court system may result in years-long delay in cases.

(2) Negative Impacts on Obtaining Representation

Having an attorney can dramatically improve an asylum seeker’s overall odds of an approval.[56] However, because of the Boston Asylum Office’s low grant rate, pro bono attorneys and legal aid organizations are often hesitant to take on affirmative asylum cases.

> ***“[The AO] asked me to sign a document that said I voluntarily agreed to use of this interpreter. And I said no . . . And she said, 'Well this is not what . . . other attorneys are doing.' I felt intensely uncomfortable. Do I push this issue, or do I sign something that is incorrect that will go into the record? . . . I ended up signing it [and I was] intensely uncomfortable. [I] did it because I didn’t want to anger her [or] to influence her decision. But I regret that. ”***
>
> *Attorney, August 2021*

Additionally, attorneys may feel that their ability to advocate effectively for their client is undermined by AOs and the structure and culture of the Boston Asylum Office. Specifically, during interviews, attorneys have stated that they feel pressured to acquiesce to an AO’s actions—they may be hesitant to correct an AO because they fear that a negative interaction or perception will adversely impact their client.

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[54] According to numbers provided by the Boston Asylum Office and distributed in the AILA New England Newsletter in December 2021, there are currently 20,400 cases pending in the Boston Asylum Office, and 423,200 cases pending in asylum offices nationwide. *AILA New England Newsletter*, AM. IMMIGR. LAW. ASS’N (Dec. 14, 2021) (updating AILA attorneys on Boston Asylum Office Statistics – responses from the October Asylum Liaison Meeting with USCIS).

[55] *Immigration Court Backlog Now Growing Faster Than Ever, Burying Judges in an Avalanche of cases*, TRAC IMMIGRATION (Jan. 18, 2022), https://trac.syr.edu/immigration/reports/675/.

[56] See HUM. RTS. FIRST, *supra* note 7, at 11.

RECOMMENDATIONS

Our research and data illustrate that there are critical steps that need to be taken to provide asylum seekers the rights guaranteed to them by federal law and international obligations. In doing so, the Authors recognize the need for deeper research and study in this area. These recommendations are not meant to be all inclusive, nor provide specific direction on how to improve the asylum system as a whole, but rather highlight what the Authors found to be some particularly egregious systemic problems that require attention.

(1) The U.S. Government Accountability Office should investigate the Boston Asylum Office and replace asylum officers and supervisory asylum officers who demonstrate bias or lack of cultural literacy.

(2) Ensure a neutral and non-adversarial asylum decision-making process by mitigating the outsized control that supervisory asylum officers have over asylum officer decision making. For example, this could be achieved by not tying an asylum officer's performance review to whether the asylum officer agrees with their supervisor's opinion. Or, as the Boston Asylum Office grows in size, this could also be achieved by adopting policies that have a rotation of supervisors per asylum officer, or creating a random supervisory review of asylum officer decision making. Regardless of the means, best practices for performance reviews are to incorporate 360 degree evaluations, in which asylum officers would be evaluated for how well they complete all aspects of their job, including considering feedback from asylum applicants, attorneys and others with whom they interact. Moreover, asylum officers ought to be given sufficient and anonymous opportunity to evaluate supervisory asylum officers.

(3) Increase transparency in asylum office interviews by creating audio recordings of the asylum interviews and making the recordings readily available to applicants and attorneys. Currently, asylum interviews are conducted behind closed doors with just the asylum officers, the asylum seeker and/or an interpreter and attorney, if applicable. There is no written transcript other than the asylum officer's notes, which may be incomplete and are often erroneous. For cases referred to immigration court, the asylum officer notes are then relied upon by Immigration and Customs Enforcement attorneys in immigration court as they try to impugn the asylum seeker's credibility. Ensuring a verbatim record of what took place in the asylum interview will help level the playing field for asylum seekers who must later appear in immigration court.

(4) Limit asylum officers' adjudication requirements to one asylum interview per day, which would provide asylum officers with additional time to more thoroughly complete their job duties and comply with the due process requirements of federal and international law.

(5) Implement rigorous hiring standards that focus on hiring asylum officers and supervisory asylum officers with language skills and cultural literacy and, once hired, provide asylum officers with support through mentorships and employee wellness programs.

(6) Improve trainings by focusing on implicit bias and racism, particularly on how implicit biases operate and how to mitigate bias. Additionally, increase quality trainings on trauma, compassion fatigue, and cultural literacy. Provide trainings on how to elicit testimony through a cultural literacy lens, which should also include practical examples and opportunities for mock interviews. These trainings should focus on positive approaches to elicit testimony necessary to adequately assess a claim and draft a legally sufficient assessment.

(7) Revise emphasis and orientation of trainings away from "trying to find the lie" to "trying to get the truth." Fraud and credibility trainings should consider asylum seekers' experiences, such as trauma, memory loss, and cultural differences, all of which might influence whether an asylum officer finds the asylum seeker credible.

(8) Use a paper-based adjudications process (similar to the adjudication process used for Special Immigrant Juvenile Status, VAWA, U-visas cases, among others) when it is clear asylum should be granted based upon the evidence submitted, there are no security concerns in the case, and where the claim is supported by ample country conditions research. This approach preserves resources by saving interviews for situations where the outcome is less certain, or for situations where there are credibility or security concerns. This would greatly reduce the backlog, allow many current cases to be processed much quicker, and enhance security by preserving interview resources for where they are needed most: on cases with more complicated security and credibility concerns.

(9) End the "last-in, first-out" (LIFO) policy that prioritizes adjudication of recently-filed asylum applications. This policy dramatically extends the wait times for the hundreds of thousands of asylum applicants with long-pending cases. USCIS should return to its prior "first-in, first-out" (FIFO) policy, which it abandoned for LIFO in January 2018.

CONCLUSION

This report emanated from the Authors' desire to understand the downward trend of affirmative asylum approvals. Our research reveals that the Boston Asylum Office has rejected a growing number of asylum seekers based on practices that violate domestic law and international obligations. Between 2015 and 2020 the Boston Asylum Office's average approval rate was just 15 percent,[57] undermining USCIS's promise in its mission statement: "fairness, integrity and respect for all we serve."[58] The Boston Asylum Office's practices harm asylum seekers and their families and wastes taxpayer dollars by needlessly referring cases to immigration court, a process that adds to the already massive backlog of immigration court cases and drains government resources.

The problems we identified within this report stem, in part, from systemic failures in national asylum policies and procedures pervasive in all asylum offices around the country. Indeed, the asylum backlog, time constraints, burnout, and compassion fatigue faced by AOs in the Boston Asylum Office are not unique to that office. Many presidential administrations have sought to fix the asylum backlog and broken system through bypassing the adversarial immigration courts and granting more authority to asylum offices.[59] However, without first fixing the unjust adjudications and procedures in the asylum offices, this report elucidates the countless failures that would occur should these proposals become a reality.

Unless asylum offices nationwide are thoroughly evaluated for the issues identified in this report, asylum seekers will continue to be harmed by a system that is seemingly unaware of its own failings and consistently violates international obligations and federal law. Until systemic biases are rooted out, time constraints are lessened, and burnout and compassion fatigue are adequately addressed, recent proposals such as the one to allocate more asylum decision-making authority to asylum officers should give the public pause. Our findings show that without fixing an asylum office's cultures of suspicion and distrust toward asylum seekers, in conjunction with the internal pressures placed on asylum officers, our asylum system will continue to perpetuate injustices against asylum seekers and their families, and ultimately run contrary to the laws and values of our nation.

Like so many who apply for asylum at the Boston Asylum Office, Basileus came with the hope of seeking refuge from an authoritarian regime that brutally turned on its own people. He and his wife rebuilt their life from scratch in the United States, had a baby, and succeeded as professors and scholars against all odds. However, the Boston Asylum Office forced them to spend years in legal limbo facing a "violent ordeal of legal necessity untethered from truth."[60] The Boston Asylum Office's mistreatment of Basileus and its decision to deny his asylum claims contributed to his suffering. But this loss is also ours: the United States is now deprived of an individual with so much to contribute.

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[57] *See supra* note 1.

[58] *Mission and Core Values*, U.S. CITIZENSHIP AND IMM. SERVS., https://www.uscis.gov/about-us/mission-and-core-values (Feb. 9, 2022).

[59] *See, e.g.*, *FACT SHEET: The Biden Administration Blueprint for a Fair, Orderly and Humane Immigration System*, WHITE HOUSE (July 27, 2021), https://www.whitehouse.gov/briefing-room/statements-releases/2021/07/27/fact-sheet-the-biden-administration-blueprint-for-a-fair-orderly-and-humane-immigration-system/.

[60] Basileus Zeno, Unpublished Doctoral Dissertations (2395), *Chapter 5: Not True but Necessary: (Auto)-Ethnography of Legal Violence.* U. MASS. AMHERST (2021), https://doi.org/10.7275/23882657 (contained within *Uprising and Displacement: Ethnographies of Violence and Identity-(Re)Formation Among Syrians*).

METHODOLOGIES

This report is based on both quantitative and qualitative methods. It was created by analyzing documents and data received from FOIA production, as well as interviews with asylees, asylum seekers,[61] immigration attorneys, former asylum officers, and former supervisory asylum officers. Specifically, we conducted more than 100 semi-structured and open-ended interviews, which were obtained through purposeful sampling. We also benefited from the insights of immigration attorneys who have represented countless asylum seekers before the Boston Asylum Office, and who shared their personal observations and the experiences of their anonymized clients.

A. Boston Asylum Office FOIA Request

On July 12, 2019, the ACLU of Maine, Maine Law's Refugee and Human Rights Clinic, and the Immigrant Legal Advocacy Project submitted a FOIA request to USCIS. The goal was to understand why the Boston Asylum Office's approval rates for affirmative asylum cases were substantially lower than rates from asylum offices across the country. Specifically, this request sought "all records regarding the Boston and Newark Asylum Offices' policies, procedures, objectives, and decisions rendered in the affirmative asylum decision making process, regarding affirmative asylum applicants since January 2010 who applied for affirmative asylum at the Newark or Boston Asylum Offices."

One year after filing the original FOIA, USCIS had not produced any documents. Thus, the ACLU of Maine, Maine Law's Refugee and Human Rights Clinic, and the Immigrant Legal Advocacy Project filed a complaint in the U.S. District Court for the District of Maine against USCIS for failing to comply with the FOIA.[62] In response to the complaint, USCIS agreed to produce approximately 6,121 responsive pages. Among these pages were emails, memos, trainings, and asylum officer adjudicator logs. However, these documents were heavily redacted. These extensive redactions are currently being challenged.[63] The Authors conducted a document review of all documents produced by USCIS.

B. USCIS Decision Spreadsheet

As part of the FOIA request, USCIS produced a database of the affirmative asylum applications filed between 2010-2020 in the Boston Asylum Office (25,634 applications) and in the Newark Asylum Office (105,235 applications). For each application, the database included:

- The U.S. state from which the asylum seeker applied;
- The asylum seeker's zip code;

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[61] The Authors were careful to only interview former asylum seekers who had been granted or denied asylum or forced to abandon their asylum and whose cases would not be negatively impacted as a result of sharing their experiences with the Boston Asylum Office.

[62] This lawsuit is still pending as of March 15, 2022. *See ACLU of Maine Foundation v. U.S. Citizenship and Immigration Services*, ACLU OF ME., https://www.aclumaine.org/en/cases/aclu-maine-foundation-v-us-citizenship-and-immigration-services (last visited Mar. 11, 2022).

[63] *See id.*

- The asylum seeker's country of birth, citizenship, gender, ethnicity, language, and age at filing;
- The date that the asylum seeker filed for asylum;
- The date of the asylum seeker's interview;
- The date that the asylum office made a decision;
- The decision made on the asylum seeker's application and very brief reasoning;
- The AO and SAO assigned to the asylum seeker's application;
- Whether the asylum seeker was represented by an attorney.

The Authors removed clearly erroneous data and duplicate entries (totaling 451 applications or 0.3 percent of total applications) and analyzed the data using the computer programming language R. This data was supplemented with data from USCIS Quarterly Stakeholder Reports, which USCIS has not published since 2019.[64]

C. Interviews

The Authors conducted numerous interviews with former SAOs, former AOs, immigration attorneys, asylum seekers, and asylees. The interviews were conducted between 2015 and 2022, and ranged from one to three hours in length. The interviews were conducted in private settings with the consent of the participants who were well informed about the objective of the study and that they would receive no personal benefits as compensation for their participation.

The authors conducted a total of 102 interviews: 78 interviews with asylees and asylum seekers, 19 interviews with immigration attorneys, and 5 interviews with former asylum officers and supervisory asylum officers.[65] Interviews with asylum seekers and asylees were conducted in the interviewee's preferred language of communication, which included English, Arabic, and French. Interviews with immigration attorneys and asylum officers were very insightful as they shared their countless experiences practicing before the Boston Asylum Office and compared it to other asylum offices across the country.

The Authors received approval of the Institutional Review Board (IRB) before conducting any of its human research. The IRB approval for this study helped to assure that the human participant's rights and information were protected throughout this study. In addition, the Authors obtained a Certificate of Confidentiality through the National Institute of Health to protect the privacy of the individuals that agreed to be interviewed for this Report. This additional certificate provides federal, state, and local protection against civil, criminal, administrative, legislative, and other proceedings for participants.

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[64] *See id.* USCIS voluntarily reported their affirmative asylum outcomes from January 2016 to September 2019 for each of its national offices. This data was compiled and analyzed by the Refugee and Human Rights Clinic.

[65] The Authors were unable to interview former AOs or SAOs from the Boston Asylum Office, despite their many attempts. *See supra* note 29.

Syringe Service Programs in Maine

2021 Annual Report

A Report to the State of Maine Legislature
Joint Standing Committee on Health and Human Services
and
Joint Standing Committee on Judiciary

Submitted by:
Maine Center for Disease Control and Prevention
Maine Department of Health and Human Services
January 2022

Table of Contents

About this Report

Maine law 22 MRSA c.252-A, §1341, Hypodermic Apparatus Exchange Programs, requires the Maine Center for Disease Control and Prevention to file an annual report to the Legislature's Judiciary Committee, and Health and Human Services Committee on the status of syringe service programs certified under this section.

The reporting period for this report is November 1, 2020, through October 31, 2021.

Report Author

This report was prepared by the following staff of the Viral Hepatitis Prevention Unit, within the Maine Center for Disease Control and Prevention's Infectious Disease Prevention Program.

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A Brief Overview of Syringe Service Programs in Maine

During the reporting period, Maine had 17 certified Syringe Service Programs (SSP) operating in the communities of Portland, Augusta, Waterville, Bangor, Belfast, Ellsworth, Sanford, Calais, Lewiston, Caribou, Deer Isle, Rockland, and Machias. Under the Governor's Executive Order 27 issued during this reporting period, sites had the option of mailing supplies and educational materials in accordance with COVID-19 social distancing practices. These 17 locations are operated by seven organizations; City of Portland, MaineGeneral Medical Center, Maine Access Points, TriCounty Mental Health Services, Amistad, Wabanaki Public Health and Wellness, and Health Equity Alliance. The location in Portland, operated by the City of Portland, is Maine's first, opening in 1998. Wabanaki Public Health and Wellness' Bangor site is the newest location, opening in July 2021. Church of Safe Injection (CoSI) was the newest agency to certify in 2021 in the following locations: Bethel, Dixfield, Rumford, Lewiston, and Westbrook. However, CoSI was not operational during the reporting period. All certified SSPs are required to submit their data quarterly to the Maine Center for Disease Control and Prevention (Maine CDC).

In 2021, Maine's SSPs:

- Collected 2,024,707 used syringes
- Distributed 2,703,080 new syringes
- Had 5,284 enrolled participants
- Enrolled 1,865 new participants
- Made 5,481 referrals to services such as primary care, STD clinics, HIV and hepatitis testing, substance use treatment, peer support, recovery coaches, overdose aftercare, food, housing, transportation, health insurance benefits, mental health services, and other social supports.
- Conducted 78 HIV tests
- Distributed naloxone to 1,492 individuals

Executive Summary

The Maine Department of Health and Human Services' (DHHS) Center for Disease Control and Prevention (Maine CDC) is authorized by 22 MRSA c.252-A, §1341(1) ("Hypodermic Apparatus Exchange Programs") to certify hypodermic apparatus exchange programs (also known as Syringe Service Programs) to facilitate the prevention of HIV and other blood borne pathogens. This report is required by statute (22 MRSA c.252-A, §1341(3)), and reflects the syringe service activities conducted by the certified program sites in Maine for the period from November 1, 2020 to October 31, 2021.

PL 2017, Ch. 507 established the certification of Syringe Service Programs (SSP) by DHHS for those programs that meet the requirements established by statute (22 MRSA c.252-A, §1341(2)). Additional regulatory rules were also promulgated through this statute (10-144 CMR c.252). PL 2018, Ch. 464, (introduced as LD 1707, *An Act To Reduce the Cost of Care Resulting from Blood-borne Infectious Diseases*) provided ongoing funds to support SSPs.

In 2019, Maine CDC released the "Vulnerability Assessment for Opioid Overdoses and Bloodborne Infections Associated with Non-Sterile Injection Drug Use in Maine."[1] This report shows the geographic areas where residents are at highest risk of opioid overdoses and bloodborne infections from injection drug use. These most vulnerable areas are Kennebec County, Penobscot County, the Portland area of Cumberland County, Somerset County, and Washington County. The Vulnerability Assessment makes recommendations for interventions that strategically allocate resources to the highest risk areas, including to support the opening of SSPs in the most vulnerable areas and expand the operating hours and staff at the already existing SSP locations.

In response to the vulnerability assessment, Governor Janet Mills announced additional funding, through the Fund for Healthy Maine, for the two-year budget cycle making available approximately $2 million for both existing, certified SSPs and newly certified SSPs. This initiative allowed for the expansion of certified SSPs sites from seven, in 2019, to eleven in 2020, across five agencies.

In January 2021, building on the success of the previous two-year funding award through the Fund for Health Maine, Maine CDC was awarded $800,000 through the Opioid Use Disorder Prevention and Treatment Fund to continue supporting SSPs through June 30, 2022. This funding allowed for further expansion to 22 sites across eight agencies.

During this reporting period, SSPs were supported through the ongoing General Fund appropriation and the Opioid Use Disorder Prevention and Treatment Fund. No federal funds were used to support SSP activities at the sites during this reporting period. The ban on using federal funds to support SSP activities was lifted on January 6, 2016.[2]

In March of 2020, Governor Janet Mills proclaimed a State of Civil Emergency for the state of Maine to respond to and reduce the transmission of SARS-nCoV-2 (COVID-19). The pandemic dramatically changed how SSPs operated due to infection control measures, social distancing, and COVID-19 safety

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[1] Maine Center for Disease Control and Prevention (2019). Vulnerability Assessment for Opioid Overdoses and Bloodborne Infections Associated with Non-Sterile Injection Drug Use in Maine. https://www.maine.gov/dhhs/mecdc/navtabs/documents/Maine-CDC-Vulnerabilty-Assessment-Report.pdf

[2] *Harm Reduction Coalition*. National Minority Aids Council Briefing, Federal Funding for Syringe Exchange, https://harmreduction.org/wp-content/uploads/2012/01/Syringe-Exchange-June-4-NMAC.pdf

precautions. In response to the pandemic's effect on people who inject drugs, effective March 30th, Governor Janet Mills issued Executive Order 27 (EO27) ("An Order Regarding State Certified Hypodermic Apparatus Exchange Programs"), which reduced barriers to clients of SSPs to continue operation in ways that reduce the spread of COVID-19 in keeping with US CDC's interim guidance for syringe services programs.[3]

Under EO27, syringe service programs were allowed to suspend the one-to-one needle exchange limit, resulting in a needs-based exchange; SSPs could expand their operation outside of their approved physical location so long as it is within the same municipality and Maine CDC was notified; hours of operation could be expanded or contracted with Maine CDC notification; and SSPs could mail supplies (including biohazard waste containers) to the extent permitted by federal law.

In January 2021, Maine released the "Maine Opioid Response: 2021 Strategic Action Plan" [4] to address the epidemic of substance use disorder (SUD), particularly opioid use disorder (OUD) and its impact in the state. One of the strategies provided, Strategy 17, aims to "increase awareness, understanding, and utilization of harm reduction strategies and resources." Under Strategy 17, Maine aims to continue to fund and expand sterile syringe access in 2021 and to prioritize the evaluation of safe supply programs and implementation effective harm reduction programs in the future.

On February 24, 2021, Governor Mills further expanded services to SSPs through Executive Order 33 (EO33) ("An Order Amending Executive Orders 16 FY 19/20, 21 FY 19/20, 27 FY 19/20, and 36 FY 19/20"). EO33 allowed SSPs to offer services outside of their certified location so long as it was within the county in which they were originally certified. This greatly increased access for clients who were transitory across city limits due to the COVID-19 pandemic.

On June 20, 2021, EO33 was extended through Executive Order 98 (EO98) ("An Order Providing an Orderly Transition Following the Termination of the State of Civil Emergency"). It extended the provisions in EO33 through August 30, 2021. Thus, many of the data reported in the 2021 Annual Report reflect the result of 10 months of COVID-19 accommodations and provisions.

In July of 2021, the Legislature repealed, and Governor Mills signed into law, the decriminalization of possession and furnishing of syringes with residual amounts of any scheduled drug and drug testing equipment. PL 2021, Ch. 434 further removed language considering syringes as 'drug paraphernalia' (17-A MRSA c.434, §1106, §1107, §1110, and §1111(5)). Those changes went into effect on October 18, 2021.

Seven state-certified SSPs operated 17 sites in Maine during this reporting period:

- The City of Portland operates one site in Portland.
- Amistad operates one site in Portland.
- Down East AIDS Network/Health Equity Alliance operates sites in Bangor, Ellsworth, Machias, Belfast, Rockland, Deer Isle, and Calais.

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[3] *US Centers for Disease Control and Prevention.* Interim Guidance for Syringe Services Programs, https://www.cdc.gov/coronavirus/2019-ncov/php/syringe-service-programs.html

[4] *State of Maine. Governor's Office of Policy Innovation and the Future.* Maine Opioid Response: 2021 Strategic Action Plan. https://www.maine.gov/future/sites/maine.gov.future/files/inline-files/Strategic%20Action%20Plan%202021.Full%20Plan.1.31.21%20FINAL.pdf

- MaineGeneral Medical Center/Health Reach Harm Reduction operates sites in Augusta and Waterville.
- Maine Access Points operates sites in Sanford, Caribou, Machias, and Calais. Under EO27, Maine Access Points also operated a mailing syringe service program.
- Tri-County Mental Health Services operates a site in Lewiston.
- Wabanaki Public Health and Wellness operates a site in Bangor.

For agency-specific information and data, please see Attachments A through Q.

Syringe Service Programs have significant, measurable benefits for the communities they serve:

- Reduce the risk of bloodborne infection, like hepatitis B and C and HIV, and prevent outbreaks[5]
- Reduce new hepatitis C and HIV cases by an estimated 50%[6]
- Provide an important link to other health services, including bloodborne pathogen testing, treatment for hepatitis B and C and HIV, and medication-assisted treatment (MAT) for opioid use disorder[7]
- When a person who participates in an SSP is enrolled in MAT for opioid dependency, the transmission of bloodborne pathogens is reduced by two-thirds[8,9]
- New enrollees in SSPs are five times more likely to participate in a substance use recovery program and three times more likely to stop injecting drugs than people who use drugs who are not enrolled in an SSP[10]

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[5] *Centers for Disease Control and Prevention.* Syringe Service Programs Fact Sheet, https://www.cdc.gov/ssp/syringe-services-programs-factsheet.html

[6] Platt L, Minozzi S, Reed J, et al. Needle syringe programmes and opioid substitution therapy for preventing hepatitis C transmission in people who inject drugs. Cochrane Database Syst Rev. 2017;9:CD012021. doi:10.1002/14651858.CD012021.pub2.

[7] *Centers for Disease Control and Prevention.* HIV and Injection Drug Use, HIV and Injection Drug Use – Vital Signs – CDC. Centers for Disease Control and Prevention. Published December 2016.

[8] Platt L, Minozzi S, Reed J, et al. Needle syringe programmes and opioid substitution therapy for preventing hepatitis C transmission in people who inject drugs. Cochrane Database Syst Rev. 2017;9:CD012021. doi:10.1002/14651858.CD012021.pub2.

[9] Fernandes RM, Cary M, Duarte G, et al. Effectiveness of needle and syringe programmes in people who inject drugs – An overview of systematic reviews. BMC Public Health. 2017;17(1):309. doi:10.1186/s12889-017-4210-2.

[10] Des Jarlais DC, Nugent A, Solberg A, Feelemyer J, Mermin J, Holtzman D. Syringe service programs for persons who inject drugs in urban, suburban, and rural areas — United States, 2013. MMWR Morb Mortal Wkly Rep. 2015;64(48):1337-1341. doi:10.15585/ mmwr.mm6448a3.

- SSPs help to prevent overdose deaths by providing naloxone to members, and teaching enrollees how to recognize an overdose and administer that naloxone[11],[12],[13],[14],[15],[16]
- SSPs reduce the number of discarded used syringes in communities[17]

Maine has seen a sharp increase in cases of hepatitis A, hepatitis B, and hepatitis C in recent years, attributed to the ongoing opioid crisis. From 2014 to 2020, acute hepatitis A rates increased 1,700%, acute hepatitis B rates increased 233% and acute hepatitis C rates increased 565%. These figures reflect new, acute cases, which serve as an indicator of the rising burden of these illnesses. Since 2019, Maine continues to be part of a widespread person-to-person outbreak of hepatitis A across the United States.

The COVID-19 pandemic has greatly impacted the disease burden among certain groups at increased risk of acquiring hepatitis A, like people who use drugs (injection or non-injection), people experiencing unstable housing or homelessness, and people who are currently or recently incarcerated. Among these groups access to hygienic supplies, housing, and vaccines has been difficult during the pandemic.

In 2019, the last year federal data are available, Maine had the highest acute hepatitis B rate, the 4th highest acute hepatitis C rate, and the 14th highest opioid overdose death rate in the United States.[18] Public health officials identified a link between the opioid epidemic and the spread of bloodborne infections such as human immunodeficiency virus (HIV), hepatitis B, and hepatitis C.[19] In Maine, as is nationwide[20], the highest risk factor for acquiring hepatitis B and hepatitis C is injection drug use. Viral hepatitis can be spread by sharing syringes, needles, and injection equipment, such as water, tourniquets, cotton, drug cookers, contaminated surfaces, or the drugs themselves. Fatal overdoses rose

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[11] Seal KH, Thawley R, Gee L. Naloxone distribution and cardiopulmonary resuscitation training for injection drug users to prevent heroin overdose death: A pilot intervention study. J Urban Health. 2005;82(2):303–311. doi:10.1093/jurban/jti053.

[12] Galea S, Worthington N, Piper TM, Nandi VV, Curtis M, Rosenthal DM. Provision of naloxone to injection drug users as an overdose prevention strategy: Early evidence from a pilot study in New York City. Addict Behav. 2006;31(5):907-912. doi:10.1016/j. addbeh.2005.07.020.

[13] Tobin KE, Sherman SG, Beilenson P, Welsh C, Latkin CA. Evaluation of the Staying Alive programme: Training injection drug users to properly administer naloxone and save lives. Int J Drug Policy. 2009;20(2):131-136. doi:10.1016/j.drugpo.2008.03.002.

[14] Doe-Simkins M, Walley AY, Epstein A, Moyer P. Saved by the nose: Bystander-administered intranasal naloxone hydrochloride for opioid overdose. Am J Public Health. 2009;99(5):788-791. doi:10.2105/ajph.2008.146647.

[15] Bennett AS, Bell A, Tomedi L, Hulsey EG, Kral AH. Characteristics of an overdose prevention, response, and naloxone distribution program in Pittsburgh and Allegheny County, Pennsylvania. J Urban Health. 2011;88(6):1020-1030. doi:10.1007/s11524-011-9600-7.

[16] Leece PN, Hopkins S, Marshall C, Orkin A, Gassanov MA, Shahin RM. Development and implementation of an opioid overdose prevention and response program in Toronto, Ontario. Can J Public Health. 2013;104(3):e200-204.

[17] Tookes HE, Kral AH, Wenger LD, et al. A comparison of syringe disposal practices among injection drug users in a city with versus a city without needle and syringe programs. Drug Alcohol Depend. 2012;123(1-3):255-259. doi:10.1016/j.drugalcdep.2011.12.001.

[18] *Centers for Disease Control and Prevention.* 2019 Viral Hepatitis Surveillance Report. https://www.cdc.gov/hepatitis/statistics/SurveillanceRpts.htm. Published July 2021.

[19] *Centers for Disease Control and Prevention.* Viral Hepatitis Surveillance – United States, 2018. https://www.cdc.gov/hepatitis/statistics/SurveillanceRpts.htm

[20] *Centers for Disease Control and Prevention.* Syringe Services Programs Fact Sheet, https://www.cdc.gov/ssp/syringe-services-programs-factsheet.html

33% from 2019 to 2020 in Maine. Eighty-three percent of deaths were cases by opioids. The number of drug deaths continues to remain high in 2021.[21]

Viral hepatitis is a leading cause of liver cancer and the most common reason for liver transplantation among adults in the United States.[22] People chronically infected with hepatitis B are 100 times more likely to develop liver cancer than uninfected people.[23] People with hepatitis C are more than twice as likely to die from heart disease than people without hepatitis C.[24]

All certified SSPs are required to submit their data annually to the Maine CDC. In 2021, 5,403 individuals were enrolled in SSPs. This is a 5.7% decrease from 2020. Current statute and DHHS regulation require a one-to-one exchange except in the initial enrollment exchange when ten unused syringes can be distributed for future exchanges. However, under EO27, effective March 15th, 2020 through August 30, 2021, SSPs were able to suspend the one-to-one limit during the State of Civil Emergency. The certified SSPs collected a total of 2,024,707 used syringes from the 5,403 enrolled individuals, which is an average of 375 syringes exchanged per person. The 2,024,707 used syringes were collected during 20,391 exchange events. An *exchange event* is when an individual visits a SSP to exchange one or more used syringes and/or to receive support services. This is an average of 99 syringes exchanged per visit. The 5,403 enrolled individuals visited certified SSPs 20,391 times in 2021, which is an average of 3.8 visits per person. This is an increase over 2020, when the average number of visits per person was 2.9.

In 2021, though the number of clients enrolled decreased SSPs were able to increase the number of new enrollees compared to 2020. There was also a 132% increase in the number of referrals from 2020 to 2021. There were 226 referrals for HIV testing, 105 referrals for STD testing, and 269 referrals for Hepatitis C testing offered. SSP staff made a total of 180 referrals to primary care providers, 390 to substance use treatment programs, and 233 to housing assistance programs. There were 609 referrals to peer support or recovery coaches. There were 475 referrals made to food assistance programs and food pantries. Additionally, there were 150 referrals to overdose aftercare for those clients who experienced a nonfatal drug overdose. There were 282 referrals to General Assistance and basic needs programs. There were 114 referrals to wound care. SSPs were able to make referrals for clients to COVID-19 testing, vaccine, and support programs. Many SSPs serve as either Tier 1 or Tier 2 naloxone distribution sites. Of the 1,492 referrals to the overdose prevention education and naloxone distribution program served clients in Bangor, Sanford, Caribou, and Portland.

Much of the data submitted in 2021 is greatly affected by the pandemic and expansion of SSP rules to allow for more comprehensive harm reduction services. To comply with pandemic protocols, much of the data on syringe collection and disposal are underreported. However, despite operational challenges due to the pandemic, many agencies were able to work collaboratively with their local jurisdictions to provide biohazard sharps disposal boxes in key hotspots in their respective towns. Many SSPs provided educational brochures and communication from Maine's Department of Environmental Protection on safe disposal of household medical sharps. This allowed clients to safely dispose of syringes while maintaining social distancing guidelines. SSPs were an essential resource for many clients particularly those who are unstably housed by providing hygiene kits, food, masks, hand sanitizer, and warm clothing to clients.

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[21] Maine Drug Data Hub, https://mainedrugdata.org/

[22] Centers for Disease Control and Prevention, https://www.cdc.gov/hepatitis

[23] Centers for Disease Control and Prevention, https://www.cdc.gov/hepatitis

[24] Ibid.

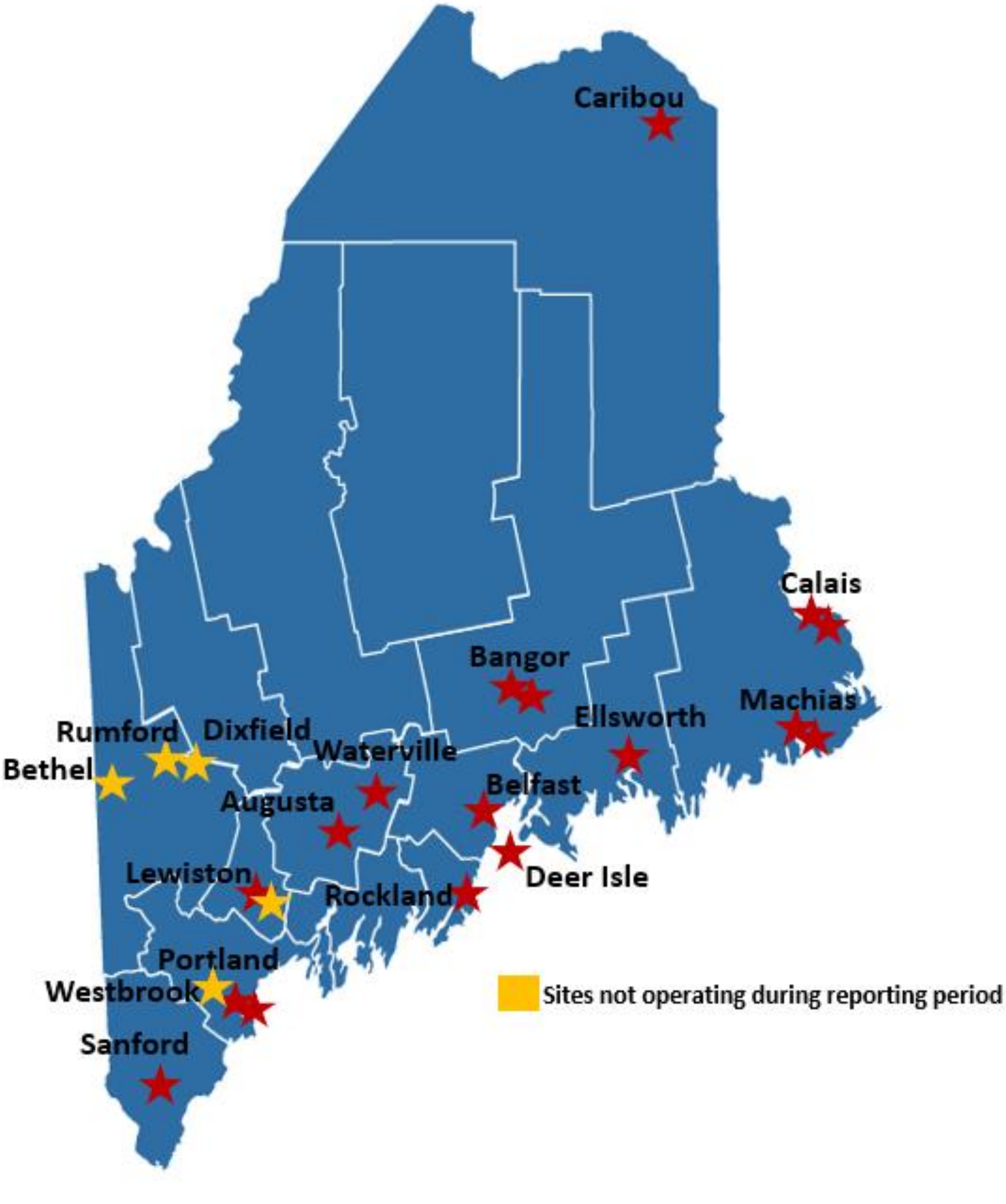
Syringe Service Programs Report for 2021; Reporting Period 11/1/2020 – 10/31/2021

Seven state certified SSPs operated 17 sites in Maine during this reporting period.

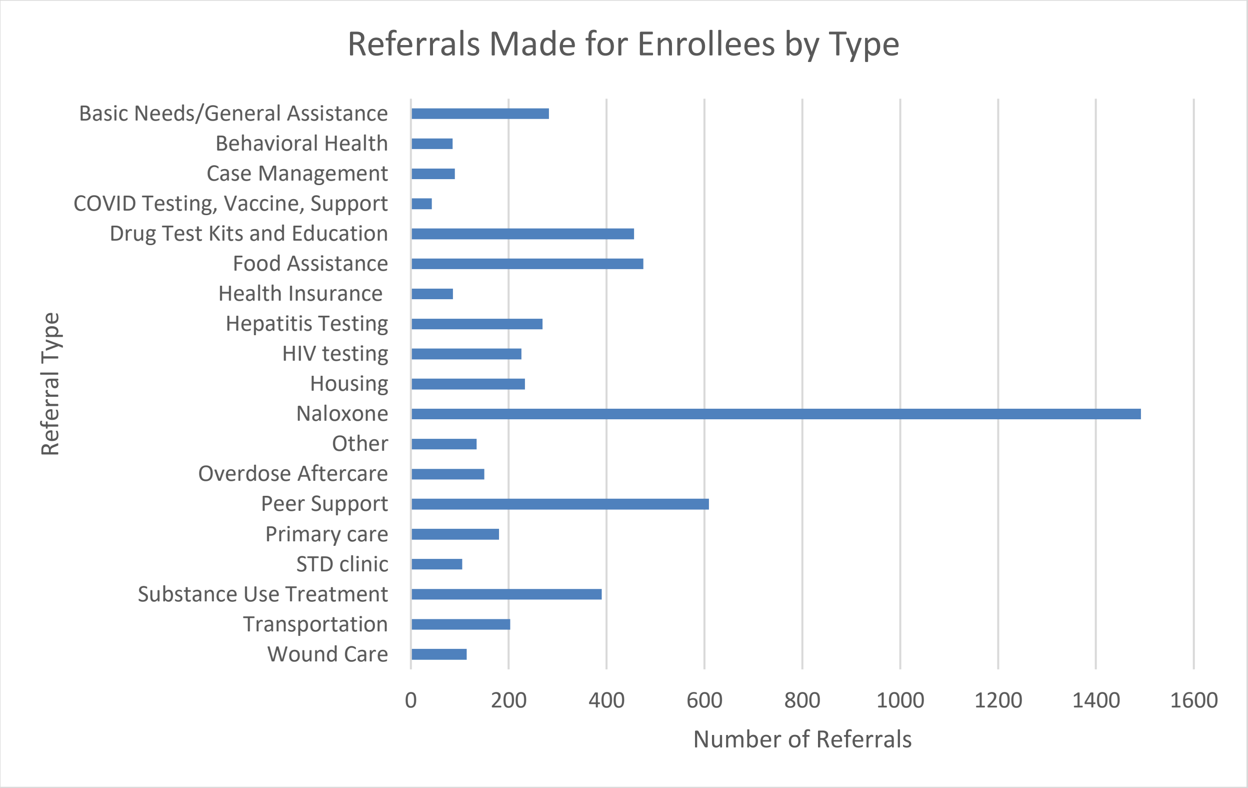
Agency	Site Location	Certification Date
Amistad	Portland	November 2020
Church of Safe Injection*	Bethel	September 2021
Church of Safe Injection*	Dixfield	September 2021
Church of Safe Injection*	Rumford	September 2021
Church of Safe Injection*	Lewiston	September 2021
Church of Safe Injection*	Westbrook	September 2021
City of Portland	Portland	September 1998
Health Equity Alliance	Ellsworth	July 2014
Health Equity Alliance	Bangor	July 2014
Health Equity Alliance	Machias	July 2014
Health Equity Alliance	Belfast	March 2019
Health Equity Alliance	Calais	February 2020
Health Equity Alliance	Rockland	February 2020
Health Equity Alliance	Deer Isle	February 2021
Health Reach Harm Reduction	Augusta	December 2004
Health Reach Harm Reduction	Waterville	February 2018
Maine Access Points	Sanford	February 2020
Maine Access Points	Calais	February 2020
Maine Access Points	Machias	March 2021
Maine Access Points	Caribou	February 2020
TriCounty Mental Health Services	Lewiston	March 2020
Wabanaki Public Health and Wellness	Bangor	February 2021

*The Church of Safe Injection was certified but did not being operations in within this reporting period

Map 1.1 - Location of Syringe Service Program sites in Maine.

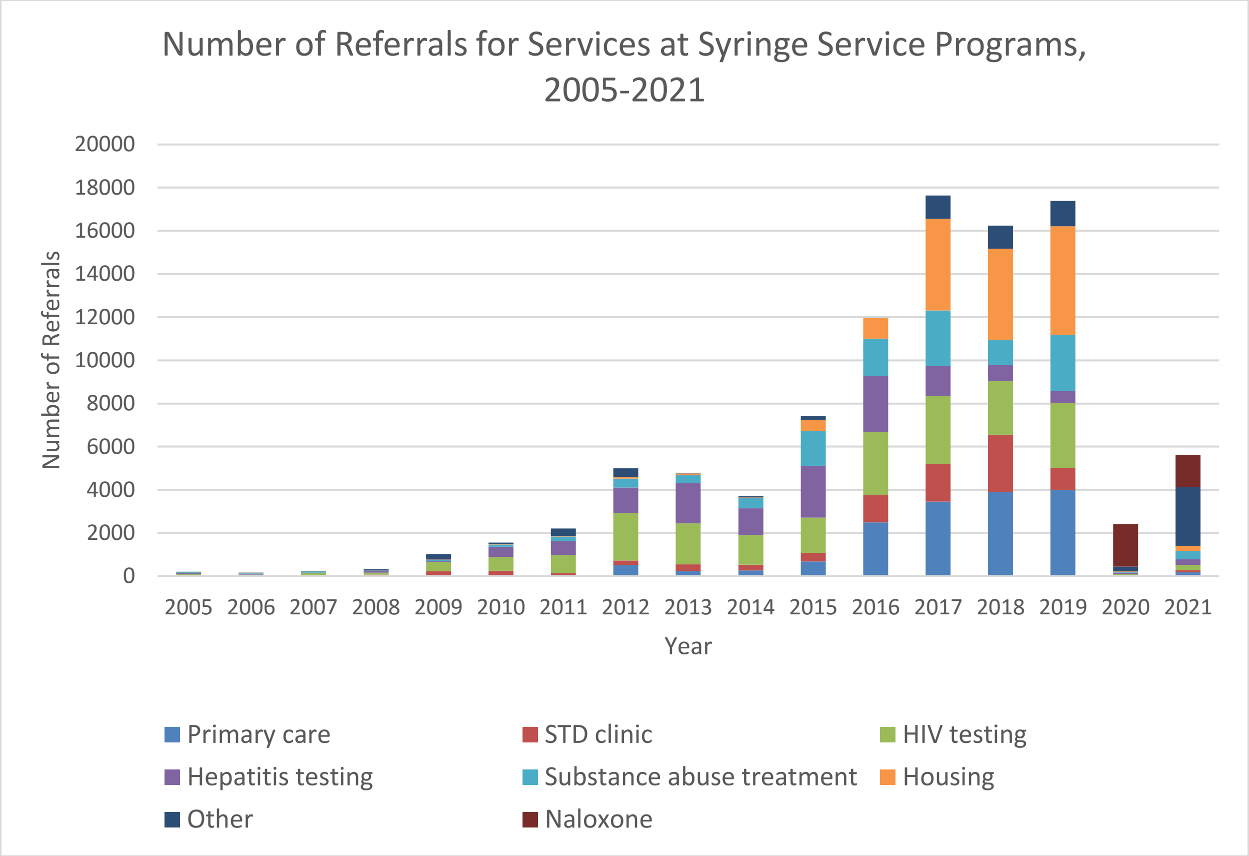


Graph 1.1 Referrals made for enrollees by type, 2021



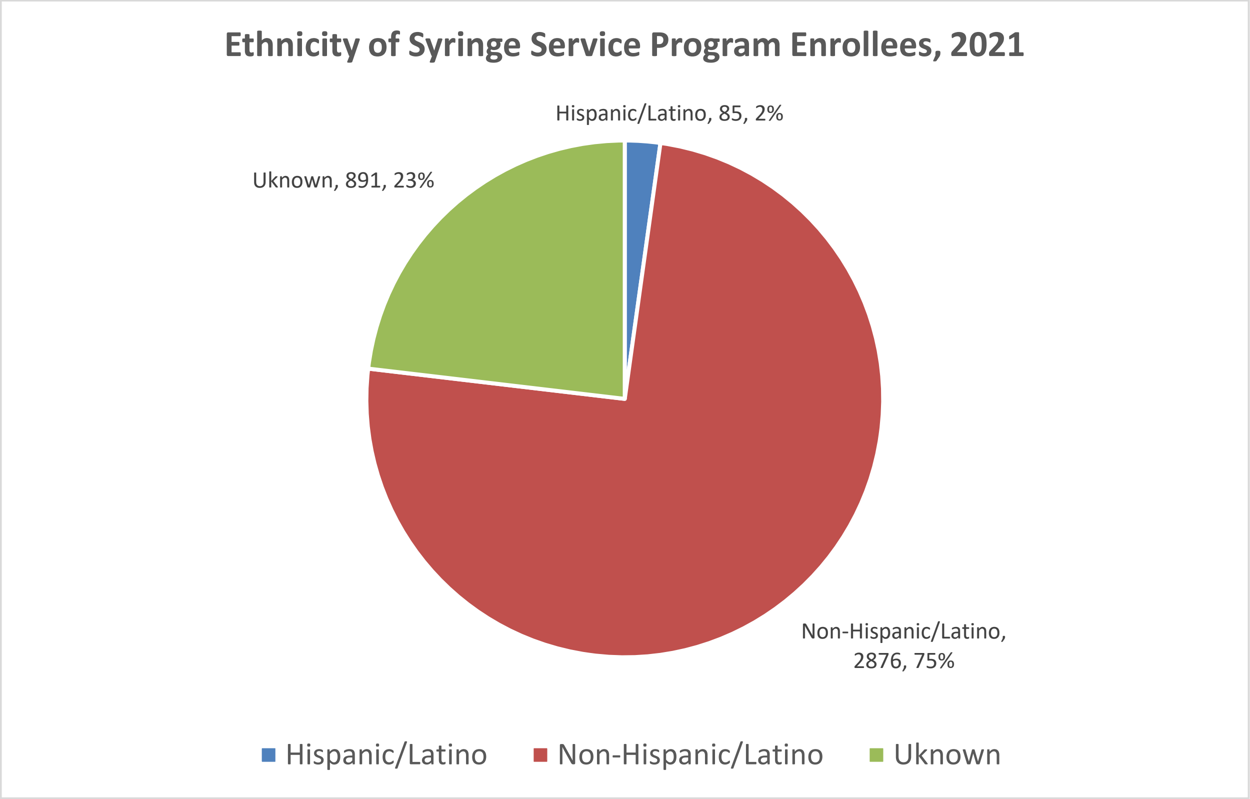
From 11/01/2020 to 10/31/2021, Syringe Service Program enrollees received 180 referrals for primary care, 105 referral for STD clinic services, 226 referrals for HIV testing, 269 referrals for hepatitis testing, 390 referrals for substance use disorder treatment, 233 referrals for housing, 609 referrals for peer support/recovery coaching, 150 for overdose aftercare, 475 for food assistance, 90 for case management, 85 for behavioral and mental health, 282 for basic needs and General Assistance, 456 for drug testing kits and education, 43 for COVID-19 testing, vaccine and support,86 for health insurance enrollment, 203 for transformation assistance, and 232 other referrals. Other referrals includes: legal assistance, education support, financial education and assistance, intimate partner violence, community organizing, daycare/child supports among others. As noted previously, COVID-19 had a significant impact on services, including referrals, in 2021.

Graph 2.1 Referrals made for services at syringe service programs, 2005-2021



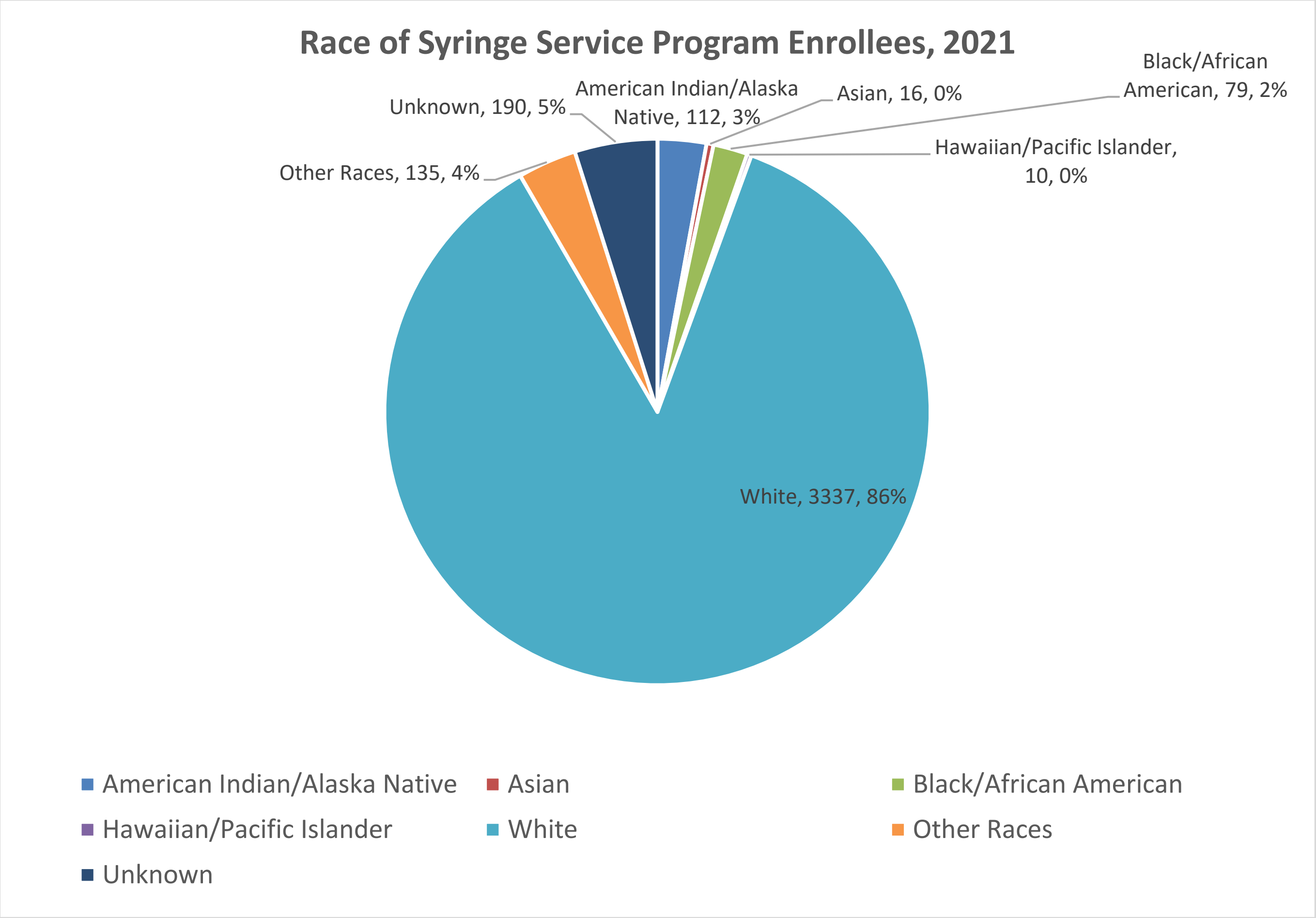
As noted previously, COVID-19 has a significant impact on services including referrals. However, the number of referrals has increased 132% in 2021 from 2020.

Graph 3.1 - 2021 Enrollee Demographics by Ethnicity



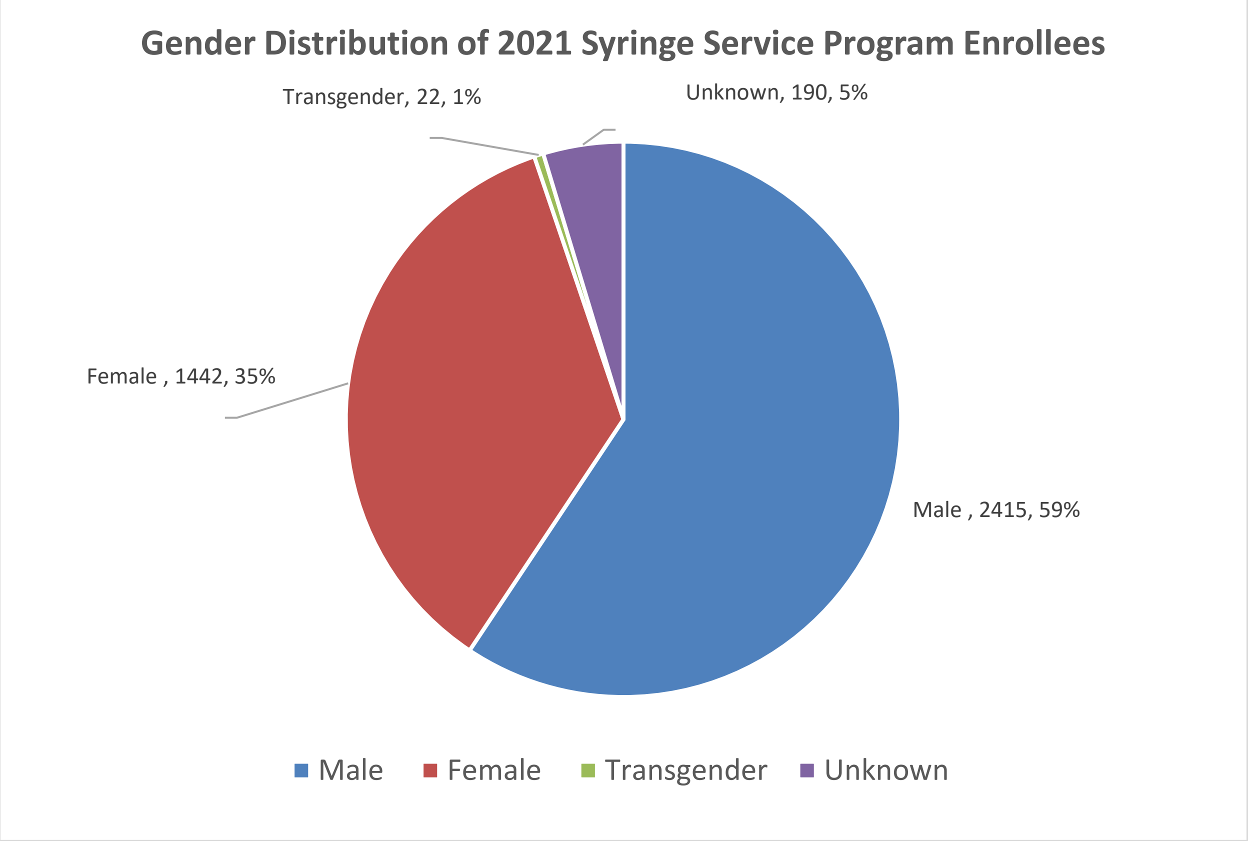
From 11/01/2020 to 10/31/2021 2% of program enrollees identified as Hispanic/Latino, which is slightly higher than the percent (1.8%) of Hispanic/Latino identified persons in Maine. **Note: enrollees can decline to provide demographic information.**

Graph 3.2 - 2021 Enrollee Demographics by Race



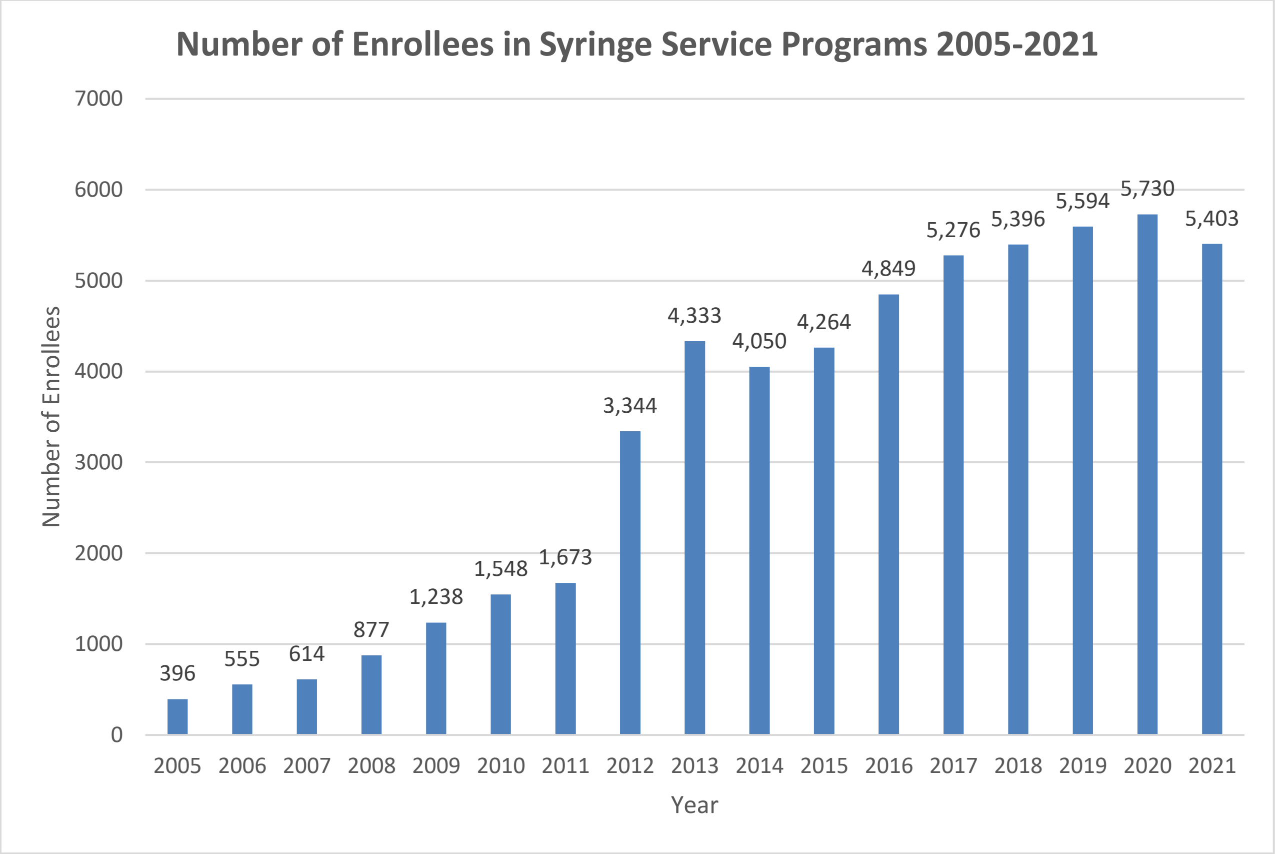
From 11/01/2020 to 10/31/2021, 112 (3%) of program enrollees identified as American Indian/Alaska Native, which is higher than the percent (.7%) of American Indian/Alaska Native identified persons in Maine. The percent of Black/African American persons is also slightly higher than the state percent (1.7%). **Note: enrollees can decline to provide demographics**

Graph 4.1 - Gender Distribution of 2021 Syringe Service Programs Enrollees



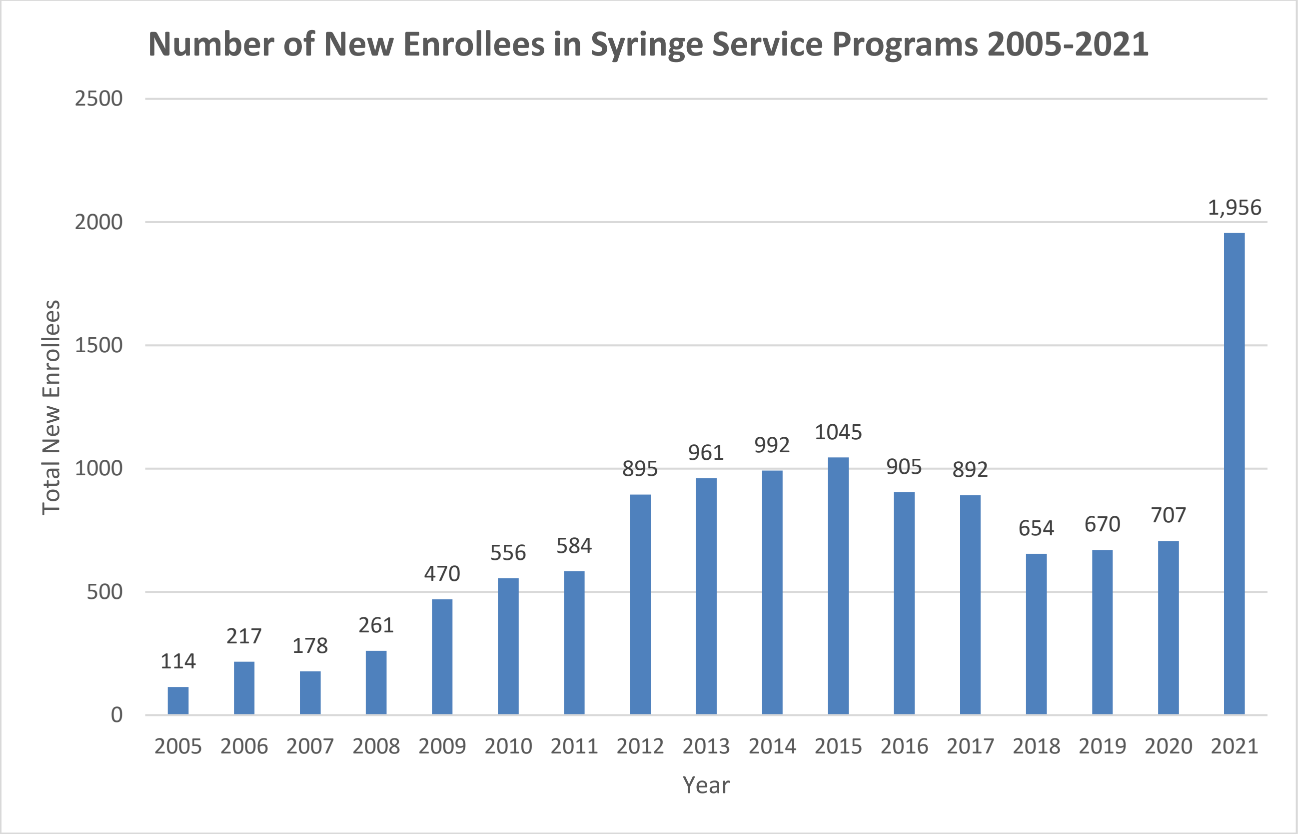
From 11/01/2020 to 10/31/2021, 59% of Syringe Service Program enrollees were male, 35% of enrollees were female, and 1% were transgender. **Note: enrollees can decline to provide demographics.**

Graph 5.1 - Total Number of Enrollees in Syringe Service Programs, 2005-2021



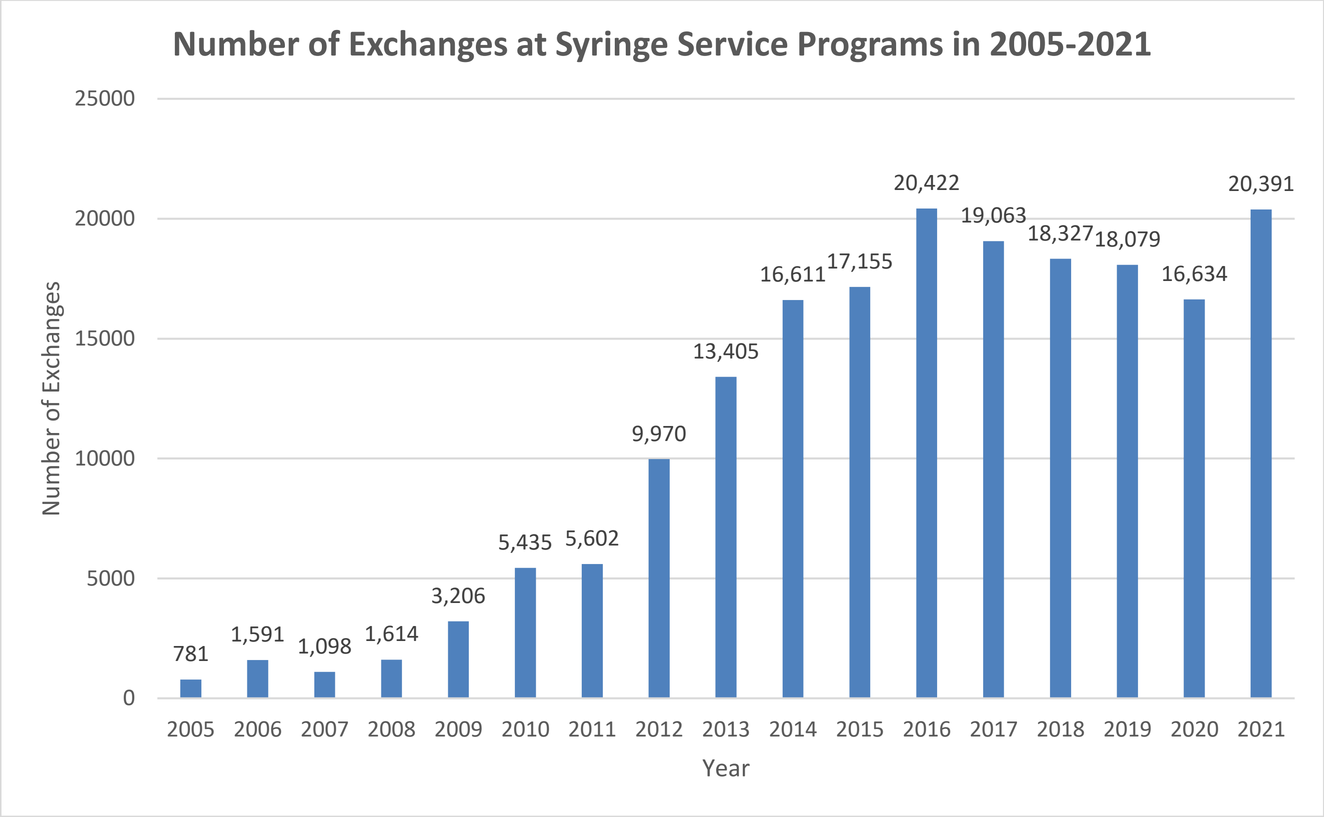
Graph 5.1 highlights the total number of enrollees in Syringe Service Programs since 2005. There was a decrease in the number of enrollees in 2021.

Graph 6.1 - New Enrollees in Syringe Service Programs, 2005-2021



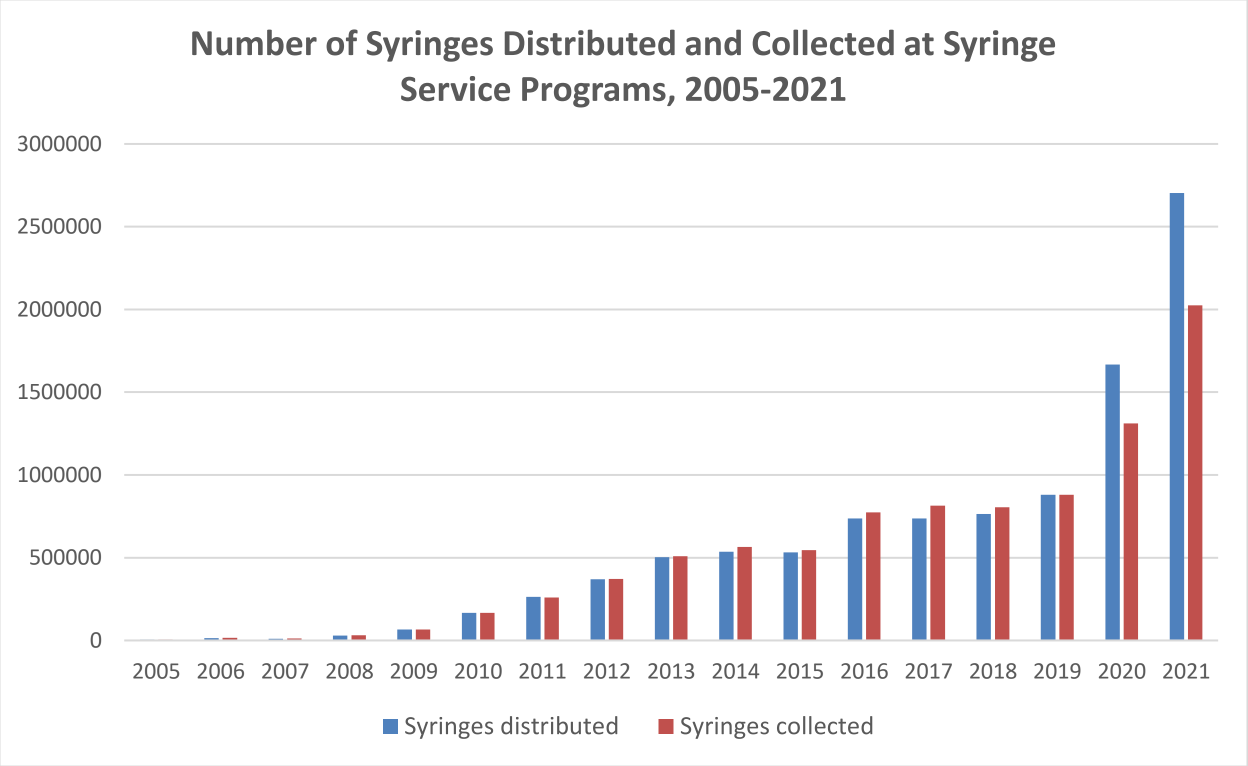
Graph 6.1 shows the total *new* enrollees in Syringe Service Programs since 2005. There was a continual increase in new enrollees from 2005 to 2015, followed by three years of decrease in new enrollees in 2016 to 2018. Since 2018, there has been an increase in new enrollees. 2021 saw the highest number of new enrollees and the highest increase of new enrollees, with a 178% increase.

Graph 7.1 - Total Number of Exchanges at Syringe Service Programs in 2005-2021



Graph 7.1 shows the number of exchanges (face-to-face or by mail interactions, not number of syringes) completed at Syringe Service Programs since 2005. Exchange events have increased from 2005 to 2016, followed by a decrease in events from 2017 to 2020. 2021 showed an increase in the number of exchanges at SSPs, the second highest number since data has been collected.

Graph 8.1 - Total Number of Syringes Distributed and Collected at Syringe Service Programs, 2005-2021.



Graph 8.1 highlights the increase in both the number of syringes distributed and collected since 2005. In 2021, there were 2,024,707 syringes collected and 2,703,080 syringes distributed.

Attachments

Attachment A; Amistad-Portland

Annual Report 11/1/2020-10/31/2021
Operator: Amistad
Location of Site: 835 Forest Ave, Portland, ME 04101
Established Date: March 16, 2021

Indicator	Quantity
Total enrolled	511
New enrollees, total	511
Number of HIV Tests conducted with new enrollees	
Total number of HIV Tests conducted with exchange consumers	
Number of syringes collected, total	73903
Number of syringes disposed, total	73903
Number of syringes distributed without exchange at enrollment	
Syringes distributed, total	137285
Number of initial exchange kits distributed	
Total exchanges	1827
Number of off-site exchanges	1813
Total referrals made	952
Total number of clients who receive a “starter kit”	

Number of Referrals Made	Quantity
Primary Care	29
STD clinic	12
HIV testing	13
Hepatitis Testing	25
Substance Abuse Treatment	73
Housing	50
Peer Support	139
Overdose Aftercare	5
Food Assistance	96
Case Management	8
Other: Mainecare Enrollment	86
Other: Medical/Mental Health provider	49
Other: General Assistance/Hotel	76
Other: Basic Needs (tents, clothes, outdoor supplies, etc.)	150
Other: transportation	126
Other: Legal supports	15
Total Referrals Made	952

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	5	23	2	8	0	0	0	0
Non-Hisp/Lat	57	167	31	76	0	0	2	3
TOTALS	62	190	33	84	0	0	2	3
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	0	0	0	2	0	0	0	0
Asian	0	0	0	0	0	0	0	0
Blk/Af. Am	5	15	2	8	0	0	0	0
H/P.I.	0	8	0	0	0	0	0	0
White	57	167	31	74	0	0	2	3
Other races	0	0	0	0	0	0	0	0
TOTALS	62	190	33	84	0	0	2	3

Attachment B; City of Portland-Portland

Annual Report 11/1/2020-10/31/2021
Operator: Portland Public Health
On site exchanges: 103 India Street, Portland, ME (moved to 39 Forest Ave 11/16/21)
Outreach: Corner of Oxford and Elm Streets, Portland, ME
Established Date: 1993

Indicator	1/1-10/31/21	11/1-12/31/21
Total enrolled	1492	**Unknown**
New enrollees, total	313	**Unknown**
Number of HIV Tests conducted with new enrollees	Unknown	**Unknown**
Total number of HIV Tests conducted with exchange consumers	13	**Unknown**
Number of syringes collected, total	281311	**46697**
Number of syringes disposed, total	281311	**46697**
Number of syringes distributed without exchange at enrollment	50377	**Unknown**
Syringes distributed, total	327508	**43136**
Number of initial exchange kits distributed	222	**Unknown**
Total exchanges	4720	**Unknown**
Number of off-site exchanges	2099	**Unknown**
Total referrals made	777	**Unknown**
Total number of clients who receive a “starter kit”	222	**Unknown**

Number of Referrals Made	1/1-10/31/21	11/1-12/31/21
Primary Care	15	**Unknown**
STD clinic	80	**Unknown**
HIV and/or Hepatitis C testing	190	**Unknown**
Substance Abuse Treatment	24	**Unknown**
Housing	73	**Unknown**
Peer Support	0	**Unknown**
Overdose Aftercare	0	**Unknown**
Food Assistance	173	**Unknown**
Case Management	0	**Unknown**
Other: Patient Care Navigator	71	**Unknown**
Other: Personal care items	2	**Unknown**
Other: General Assistance	8	**Unknown**
Other: Naloxone distribution	141	**Unknown**
Other:	0	**Unknown**
Other:	0	**Unknown**
Total Referrals Made	777	**Unknown**

Enrollee Demographics 1/1-10/31/21 only*								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	<5	0	0	0	0	0	0
Non-Hisp/Lat	0	<5	0	<5	0	0	0	0
Unknown	74	512	59	228	<5	<5	0	0
TOTALS	74	517	59	230	<5	<5	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	0	<5	0	0	0	0	0	0
Asian	0	<5	<5	1	0	0	0	0
Blk/Af. Am	0	7	<5	10	0	0	0	0
H/P.I.	0	0	0	0	0	0	0	0
White	48	394	37	182	<5	<5	0	0
Other races	<5	<5	0	<5	0	0	0	0
Unknown	25	111	18	35	<5	0	0	0
TOTALS	74	517	59	230	<5	<5	0	0
***Demographic information was not collected for those who only received naloxone**								

Attachment C; Tri-County-Lewiston

Annual Report 11/1/2020-10/31/2021
Operator: Tri-County Mental Health Services
Location of Site: Lewiston
Established Date: May 2020

Indicator	Quantity
Total enrolled	22
New enrollees, total	16
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	15250
Number of syringes disposed, total	15250
Number of syringes distributed without exchange at enrollment	7270
Syringes distributed, total	22520
Number of initial exchange kits distributed	16
Total exchanges	85
Number of off-site exchanges	10
Total referrals made	26
Total number of clients who receive a “starter kit”	16

Number of Referrals Made	Quantity
Primary Care	
STD clinic	
HIV testing	
Hepatitis Testing	
Substance Abuse Treatment	16
Housing	
Peer Support	
Overdose Aftercare	
Food Assistance	
Case Management	10
Other:	
Other:	
Other:	
Other:	
Other:	
Other:	
Total Referrals Made	26

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino								
Non-Hisp/Lat								
TOTALS								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN								
Asian								
Blk/Af. Am								
H/P.I.								
White	1	9	1	5				
Other races								
TOTALS	**1**	**9**	**1**	**5**	**0**	**0**	**0**	**0**

Attachment C; MaineGeneral Medical Center-Waterville

Annual Report 11/1/2020-10/31/2021
Operator: MaineGeneral Medical Center
Location of Site: Thayer Center for Health
149 North Street, Terrace Level, Waterville
Established Date: March 2018

Indicator	**Quantity**
Total enrolled	113
New enrollees, total	52
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	4
Number of syringes collected, total	72680
Number of syringes disposed, total	72680
Number of syringes distributed without exchange at enrollment	5278
Syringes distributed, total	89758
Number of initial exchange kits distributed	25
Total exchanges	246
Number of off-site exchanges	0
Total referrals made	133
Total number of clients who receive a “starter kit”	25

Number of Referrals Made	**Quantity**
Primary Care	27
STD clinic	0
HIV testing	0
Hepatitis Testing	2
Substance Abuse Treatment	17
Housing	10
Peer Support	9
Overdose Aftercare	0
Food Assistance	35
Case Management	0
Other: Dental	1
Other: Education	9
Other: Emergency Department	0
Other: Express Care	4
Other: MaineGeneral Financial Counseling	0
Other:Eye care	0
Other: Family Violence Project	0
Other: Resource Connection	15
Other: Patient Navigation	0
Other: Behavioral Health	3
Other: Transportation	1
Other: Outpatient Counseling	0
Total Referrals Made	133

Enrollee Demographics

Clients Served	Male 18-29	Male 30+	Female 18-29	Female 30+	Trans M-F 18-29	Trans M-F 30+	Trans F-M 18-29	Trans F-M 30+
Hisp/Latino	0	3	0	0	0	0	0	0
Non-Hisp/Lat	10	36	5	26	0	0	0	0
TOTALS	**10**	**39**	**5**	**26**	**0**	**0**	**0**	**0**
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	1	0	0	0	0			
Asian	1	0	0	0	0			
Blk/Af. Am	0	2	0	0	0			
H/P.I.	0	0	0	0	0			
White	8	42	7	26	0			
Other races	0	0	0	0	0			
TOTALS	**10**	**44**	**7**	**26**	**0**	**0**	**0**	**0**

Attachment D; MaineGeneral Medical Center-Augusta

Annual Report 11/1/2020-10/31/2021
Operator: MaineGeneral Medical Center
Location of Site: 9 Green Street, Augusta
Established Date: December 2004

Indicator	Quantity
Total enrolled	973
New enrollees, total	99
Number of HIV Tests conducted with new enrollees	2
Total number of HIV Tests conducted with exchange consumers	27
Number of syringes collected, total	282987
Number of syringes disposed, total	282987
Number of syringes distributed without exchange at enrollment	9520
Syringes distributed, total	316047
Number of initial exchange kits distributed	88
Total exchanges	1065
Number of off-site exchanges	0
Total referrals made	154
Total number of clients who receive a “starter kit”	88

Number of Referrals Made	Quantity
Primary Care	47
STD clinic	1
HIV testing	0
Hepatitis Testing	4
Substance Abuse Treatment	21
Housing	17
Peer Support	0
Overdose Aftercare	0
Food Assistance	46
Case Management	1
Other: Dental	5
Other: Education	1
Other: Emergency Department	2
Other: Express Care	1
Other: MaineGeneral Financial Counseling	2
Other:Eye care	1
Other: Family Violence Project	1
Other: Resource Connection	3
Other: Patient Navigation	0
Other: Behavioral Health	0
Other: Transportation	0
Other: Outpatient Counseling	1
Total Referrals Made	154

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	2	10	3	8			0	0
Non-Hisp/Lat	59	492	73	312			1	1
TOTALS	**61**	**502**	**76**	**320**	**0**	**0**	**1**	**1**
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	1	24	1	16				
Asian	1	3	0	5				
Blk/Af. Am	1	2	0	1				
H/P.I.	0	0	0	0				
White	60	472	74	299			1	1
Other races	0	4	2	1				
TOTALS	**63**	**505**	**77**	**322**	**0**	**0**	**1**	**1**

Attachment E; Maine Access Points-Mail

Annual Report 11/1/2020-10/31/2021
Operator: Maine Access Points
Location of Site: Statewide Mail
Established Date: 2020

Indicator	Quantity
Total enrolled	289
New enrollees, total	171
Number of HIV Tests conducted with new enrollees	7
Total number of HIV Tests conducted with exchange consumers	19
Number of syringes collected, total	0
Number of syringes disposed, total	0
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	268155
Number of initial exchange kits distributed	0
Total exchanges	621
Number of off-site exchanges	621
Total referrals made	626
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	12
STD clinic	2
HIV testing	5
Hepatitis Testing	22
Substance Abuse Treatment	41
Peer Support	92
Overdose Aftercare	81
Food Assistance	1
Other: Drug checking education and fentanyl test strips	169
Other: Overdose prevention education and naloxone distribution	185
Other: Wound care/ Health education	15
Other: Transportation	1
Total Referrals Made	626

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	1	0	0				
Non-Hisp/Lat	2	21	8	13				
TOTALS	2	22	8	13	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN		1						
Asian								
Blk/Af. Am		3		1				
H/P.I.		1						
White	2	17	8	12				
Other races								
TOTALS	2	22	8	13	0	0	0	0

Attachment F; Maine Access Points-Caribou

Annual Report 11/1/2020-10/31/2021
Operator: Maine Access Points
Location of Site: Caribou
Established Date: 2021

Indicator	Quantity
Total enrolled	144
New enrollees, total	101
Number of HIV Tests conducted with new enrollees	4
Total number of HIV Tests conducted with exchange consumers	7
Number of syringes collected, total	55367
Number of syringes disposed, total	55367
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	155845
Number of initial exchange kits distributed	0
Total exchanges	487
Number of off-site exchanges	465
Total referrals made	572
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	5
STD clinic	0
HIV testing	3
Hepatitis Testing	1
Substance Abuse Treatment	9
Housing	16
Peer Support	103
Overdose Aftercare	9
Food Assistance	13
Other: Clothing services	6
Other: Community Organizing	9
Other: Mental health services	2
Other: Drug checking education and fentanyl test strips	117
Other: Overdose prevention education and naloxone distribution	216
Other: Legal assistance	0
Other: Education/ work	0
Other: Wound care/ Health education	40
Other: Transportation	22
Other: Intimate Partern Violence	1
Total Referrals Made	572

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	0						
Non-Hisp/Lat	18	38	14	29				
TOTALS	**18**	**38**	**14**	**29**	**0**	**0**	**0**	**0**
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	1	3	1	1				
Asian				1				
Blk/Af. Am		2						
H/P.I.								
White	17	33	13	26				
Other races								
TOTALS	**18**	**38**	**14**	**28**	**0**	**0**	**0**	**0**

Attachment G; Maine Access Points-Sanford

Annual Report 11/1/2020-10/31/2021
Operator: Maine Access Points
Location of Site: Sanford
Established Date: 2020

Indicator	Quantity
Total enrolled	131
New enrollees, total	45
Number of HIV Tests conducted with new enrollees	3
Total number of HIV Tests conducted with exchange consumers	6
Number of syringes collected, total	232076
Number of syringes disposed, total	232076
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	333131
Number of initial exchange kits distributed	0
Total exchanges	1264
Number of off-site exchanges	1256
Total referrals made	652
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	6
STD clinic	7
HIV testing	11
Hepatitis Testing	6
Substance Abuse Treatment	61
Housing	19
Peer Support	130
Overdose Aftercare	13
Food Assistance	29
Case Management	0
Other: Clothing services	25
Other: Community Organizing	14
Other: Mental health services	2
Other: Drug checking education and fentanyl test strips	80
Other: Overdose prevention education and naloxone distribution	154
Other: Legal assistance	8
Other: Education/ work	5
Other: Wound care/ Health education	48
Other: Transportation	32
Other: Intimate Partern Violence	2
Total Referrals Made	652

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	1	0	0				
Non-Hisp/Lat	2	21	8	13				
TOTALS	2	22	8	13	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN		1						
Asian								
Blk/Af. Am		3		1				
H/P.I.		1						
White	2	17	8	12				
Other races								
TOTALS	2	22	8	13	0	0	0	0

Attachment H; Maine Access Points-Machias

Annual Report 11/1/2020-10/31/2021
Operator: Maine Access Points
Location of Site: Machias
Established Date: 2021

Indicator	Quantity
Total enrolled	39
New enrollees, total	39
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	10520
Number of syringes disposed, total	10520
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	11900
Number of initial exchange kits distributed	0
Total exchanges	76
Number of off-site exchanges	34
Total referrals made	382
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	15
STD clinic	1
HIV testing	1
Hepatitis Testing	7
Substance Abuse Treatment	63
Housing	25
Peer Support	67
Overdose Aftercare	18
Food Assistance	11
Other: Clothing services	3
Other: Community Organizing	7
Other: Mental health services	12
Other: Drug checking education and fentanyl test strips	39
Other: Overdose prevention education and naloxone distribution	59
Other: Legal assistance	5
Other: Education/ work	2
Other: Wound care/ Health education	8
Other: COVID-testing/ vaccine	12
Other: COVID Rental Assistance	15
Other: Pet supports/ clinic	2
Other: Transportation	9
Other: Intimate Partern Violence	1
Total Referrals Made	382

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino								
Non-Hisp/Lat								
TOTALS	0	0	0	0	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN								
Asian								
Blk/Af. Am								
H/P.I.								
White								
Other races								
TOTALS	0	0	0	0	0	0	0	0

Attachment I; Maine Access Points-Calais

Annual Report 11/1/2020-10/31/2021
Operator: Maine Access Points
Location of Site: Calais
Established Date: 2020

Indicator	Quantity
Total enrolled	63
New enrollees, total	27
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	174000
Number of syringes disposed, total	174000
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	32800
Number of initial exchange kits distributed	0
Total exchanges	156
Number of off-site exchanges	156
Total referrals made	412
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	10
STD clinic	2
HIV testing	0
Hepatitis Testing	9
Substance Abuse Treatment	62
Housing	22
Peer Support	69
Overdose Aftercare	24
Food Assistance	15
Other: Clothing services	12
Other: Community Organizing	16
Other: Mental health services	16
Other: Drug checking education and fentanyl test strips	51
Other: Overdose prevention education and naloxone distribution	57
Other: Legal assistance	3
Other: Education/ work	10
Other: Wound care/ Health education	3
Other: COVID-testing/ vaccine	6
Other: COVID Rental Assistance	10
Other: Daycare & child mental health supports	3
Other: Transportation	12
Other: Intimate Partern Violence	0
Total Referrals Made	412

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino								
Non-Hisp/Lat	2	14	4	9	0	0	0	0
TOTALS	**2**	**14**	**4**	**9**	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN		1	1	1				
Asian								
Blk/Af. Am								
H/P.I.								
White	2	11	3	5				
Other races								
TOTALS	**2**	**12**	**4**	**6**	0	0	0	0

Attachment J; Health Equity Alliance-Bangor

Annual Report 11/1/2020-10/31/2021
Operator: Down East AIDS Network/Health Equity Alliance
Location of Site: 304 Hancock Street Suite 3B, Bangor, ME 04401
Established Date: 2002

Indicator	Quantity
Total enrolled	1236
New enrollees, total	497
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	617841
Number of syringes disposed, total	617841
Number of syringes distributed without exchange at enrollment	1370
Syringes distributed, total	793836
Number of initial exchange kits distributed	137
Total exchanges	7553
Number of off-site exchanges	67
Total referrals made	604
Total number of clients who receive a “starter kit”	137

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	1
Hepatitis Testing	1
Substance Abuse Treatment	2
Housing	1
Peer Support	0
Overdose Aftercare	0
Food Assistance	56
Case Management	0
Other: Substance Use Education/Naloxone	543
Other:	
Other:	
Other:	
Other:	
Other:	
Total Referrals Made	604

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	6	4	1	4				1
Non-Hisp/Lat	209	392	137	237	0	4	3	1
TOTALS	215	396	138	241	0	4	3	2
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	8	13	11	17		0	0	0
Asian	1	0	0	0		0	0	0
Blk/Af. Am	3	6	1	2		0	0	0
H/P.I.	0	0	0	0		0	0	0
White	179	336	118	197		4	2	1
Other races	24	41	8	27		0	1	1
TOTALS	215	396	138	241	0	4	3	2

Attachment K; Health Equity Alliance-Ellsworth

Annual Report 11/1/2020-10/31/2021
Operator: Down East AIDS Network/Health Equity Alliance
Location of Site: 5 Long Lane Suite 1, Ellsworth, ME 04605
Established Date: 2000

Indicator	Quantity
Total enrolled	327
New enrollees, total	71
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	148770
Number of syringes disposed, total	148770
Number of syringes distributed without exchange at enrollment	1620
Syringes distributed, total	153565
Number of initial exchange kits distributed	162
Total exchanges	2172
Number of off-site exchanges	0
Total referrals made	86
Total number of clients who receive a “starter kit”	162

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	0
Hepatitis Testing	0
Substance Abuse Treatment	0
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other: Substance Use Education/Naloxone	86
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	86

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	1	0	0	0	0	0	0
Non-Hisp/Lat	46	130	25	72	0	1	0	2
TOTALS	46	131	25	72	0	1	0	2
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	0	2	0	1		0		0
Asian	0	1	0	0		0		0
Blk/Af. Am	0	1	0	0		0		0
H/P.I.	0	0	0	0		0		0
White	44	120	24	67		1		2
Other races	2	7	1	4		0		0
Uknown data	46	131	25	72	0	1	0	2
TOTALS	92	262	50	144	0	2	0	4

Attachment L; Health Equity Alliance-Machias

Annual Report 11/1/2020-10/31/2021
Operator: Down East AIDS Network/Health Equity Alliance
Location of Site: 7 VIP Drive, Machias, ME 04654
Established Date: 2014

Indicator	Quantity
Total enrolled	36
New enrollees, total	4
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	9535
Number of syringes disposed, total	9535
Number of syringes distributed without exchange at enrollment	40
Syringes distributed, total	11500
Number of initial exchange kits distributed	4
Total exchanges	74
Number of off-site exchanges	0
Total referrals made	43
Total number of clients who receive a “starter kit”	4

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	0
Hepatitis Testing	0
Substance Abuse Treatment	0
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other: Substance Use Education/Naloxone	43
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	43

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	0	0	0	0	0	0	0
Non-Hisp/Lat	6	16	5	9	0	0	0	0
TOTALS	6	16	5	9	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN								
Asian								
Blk/Af. Am								
H/P.I.								
White	5	14	3	8				
Other races	1	2	2	1				
TOTALS	6	16	5	9	0	0	0	0

Attachment M; Health Equity Alliance-Calais

Annual Report 11/1/2020-10/31/2021
Operator: Down East AIDS Network/Health Equity Alliance
Location of Site: 10 Barket Street, Calais, ME 04619
Established Date: 2020

Indicator	Quantity
Total enrolled	15
New enrollees, total	0
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	2500
Number of syringes disposed, total	2500
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	3000
Number of initial exchange kits distributed	0
Total exchanges	6
Number of off-site exchanges	0
Total referrals made	0
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	0
Hepatitis Testing	0
Substance Abuse Treatment	0
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	0

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	0	0	0	0	0	0	0
Non-Hisp/Lat	0	0	0	0	0	0	0	0
Unknown	2	6	2	5	0	0	0	0
TOTALS	2	6	2	5	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	0	1	0	0				
Asian	0	0	0	0				
Blk/Af. Am	0	0	0	0				
H/P.I.	0	0	0	0				
White	2	5	2	5				
Other races	0	0	0	0				
TOTALS	2	6	2	5	0	0	0	0

Attachment N; Health Equity Alliance- Rockland

Annual Report 11/1/2020-10/31/2021
Operator: Down East AIDS Network/Health Equity Alliance
Location of Site: 11 White Street, Rockland, ME 04841
Established Date: 2020
***Note due to staffing and location changes there is insufficient data to report**

Indicator	Quantity
Total enrolled	0
New enrollees, total	0
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	0
Number of syringes disposed, total	0
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	0
Number of initial exchange kits distributed	0
Total exchanges	0
Number of off-site exchanges	0
Total referrals made	0
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	0
Hepatitis Testing	0
Substance Abuse Treatment	0
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	0

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino								
Non-Hisp/Lat								
TOTALS	0	0	0	0	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN								
Asian								
Blk/Af. Am								
H/P.I.								
White								
Other races								
TOTALS								

Attachment O; Health Equity Alliance-Belfast

Annual Report 11/1/2020-10/31/2021
Operator: Down East AIDS Network/Health Equity Alliance
Location of Site: 147 Waldo Avenue, Belfast, ME 04915
Established Date: 2019

Indicator	Quantity
Total enrolled	7
New enrollees, total	5
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	1140
Number of syringes disposed, total	1140
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	2574
Number of initial exchange kits distributed	0
Total exchanges	23
Number of off-site exchanges	0
Total referrals made	5
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	0
Hepatitis Testing	0
Substance Abuse Treatment	0
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other: Substance Use Education/Naloxone	5
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	5

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0	0	0	0				
Non-Hisp/Lat	2	2	1	2				
TOTALS	2	2	1	2	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	0	0	0	0				
Asian	0	0	0	0				
Blk/Af. Am	0	0	0	0				
H/P.I.	0	0	0	0				
White	2	2	1	2				
Other races	0	0	0	0				
TOTALS	2	2	1	2	0	0	0	0

Attachment P; Health Equity Alliance-Deer Isle

Annual Report 11/1/2020-10/31/2021
Operator: Downeast AIDS Network/Health Equity Alliance
Location of Site: 627 N. Deer Isle Road, Deer Isle, ME 04627
Established Date: 2021

Indicator	Quantity
Total enrolled	3
New enrollees, total	3
Number of HIV Tests conducted with new enrollees	0
Total number of HIV Tests conducted with exchange consumers	0
Number of syringes collected, total	130
Number of syringes disposed, total	130
Number of syringes distributed without exchange at enrollment	140
Syringes distributed, total	520
Number of initial exchange kits distributed	3
Total exchanges	16
Number of off-site exchanges	0
Total referrals made	3
Total number of clients who receive a “starter kit”	3

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	0
Hepatitis Testing	0
Substance Abuse Treatment	0
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other: Substance Use Education/Naloxone	3
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	0

Enrollee Demographics

Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino	0							
Non-Hisp/Lat	0							
TOTALS	0	0	0	0	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN	0							
Asian	0							
Blk/Af. Am	0							
H/P.I.	0							
White	0							
Other races	0							
TOTALS	0	0	0	0	0	0	0	0

Attachment Q; Wabanaki Public Health and Wellness-Bangor

Annual Report 11/1/2020-10/31/2021
Operator: Wabanaki Public Health and Wellness
Location of Site: 157 Park Street 32A Bangor,ME
Established Date: 2021

Indicator	Quantity
Total enrolled	2
New enrollees, total	2
Number of HIV Tests conducted with new enrollees	2
Total number of HIV Tests conducted with exchange consumers	2
Number of syringes collected, total	0
Number of syringes disposed, total	0
Number of syringes distributed without exchange at enrollment	0
Syringes distributed, total	0
Number of initial exchange kits distributed	0
Total exchanges	0
Number of off-site exchanges	0
Total referrals made	5
Total number of clients who receive a “starter kit”	0

Number of Referrals Made	Quantity
Primary Care	0
STD clinic	0
HIV testing	2
Hepatitis Testing	2
Substance Abuse Treatment	1
Housing	0
Peer Support	0
Overdose Aftercare	0
Food Assistance	0
Case Management	0
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Other:	0
Total Referrals Made	5

Enrollee Demographics								
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
Hisp/Latino								
Non-Hisp/Lat				2				
TOTALS	0	0	0	2	0	0	0	0
Clients Served	**Male 18-29**	**Male 30+**	**Female 18-29**	**Female 30+**	**Trans M-F 18-29**	**Trans M-F 30+**	**Trans F-M 18-29**	**Trans F-M 30+**
AI/AN				2				
Asian								
Blk/Af. Am								
H/P.I.								
White								
Other races								
TOTALS	0	0	0	2	0	0	0	0

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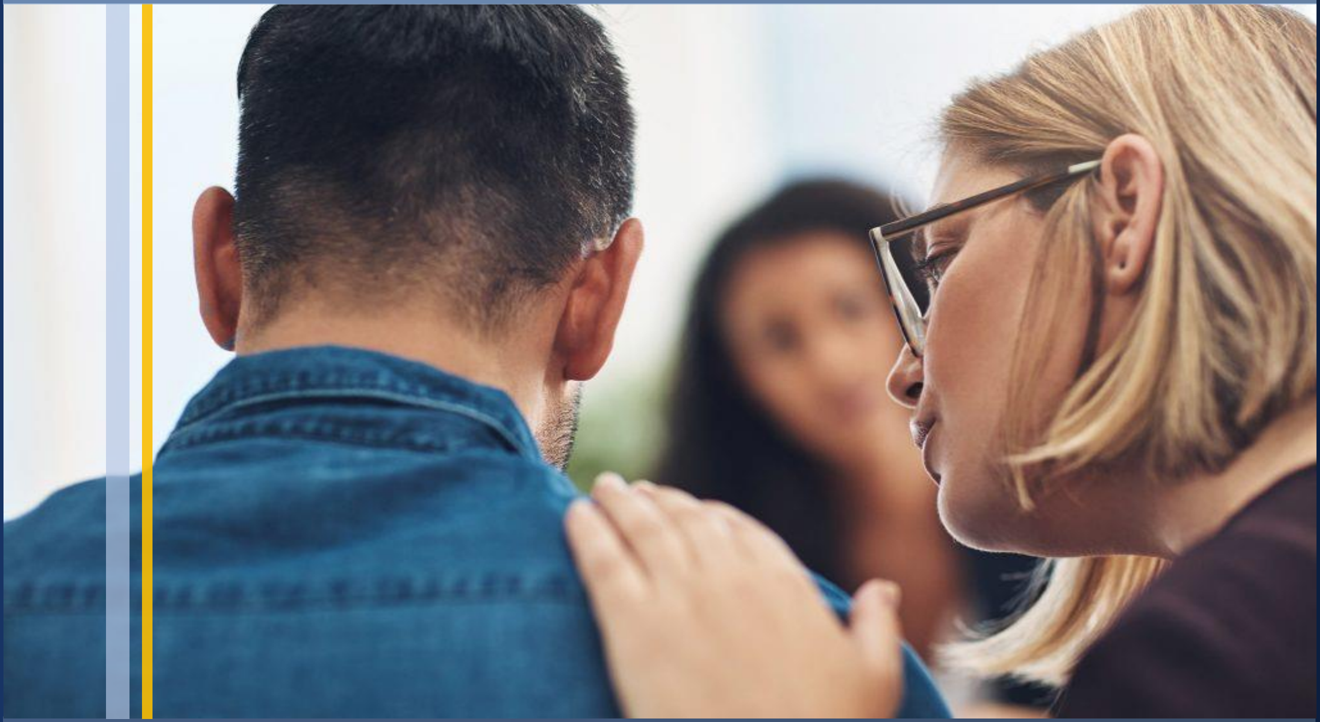

Vulnerability Assessment for Opioid Overdoses and Bloodborne Infections Associated with Non-Sterile Injection Drug Use in Maine

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July 2019

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Maine Center for Disease Control

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Executive Summary

In 2017, Maine had the sixth highest opioid overdose death rate in the United States with a rate of 29.9 deaths per 100,000 persons per year compared to the national average of 14.5 deaths per 100,000 persons per year (National Institute of Drug Abuse, 2019). Public health officials have identified a link between the growing opioid epidemic and the spread of bloodborne infections such as human immunodeficiency virus (HIV), Hepatitis B, and Hepatitis C, especially within non-urban communities (Van Handel et al., 2016). To address the opioid epidemic, and specifically bloodborne infections associated with non-sterile injection opioid use, the U.S. Centers for Disease Control (U.S. CDC) developed a vulnerability index to identify communities at risk for opioid overdoses and bloodborne infections (Van Handel et al., 2016).

The U.S. CDC is funding state governments to conduct jurisdiction-level vulnerability assessments to identify sub-state areas at high risk for opioid overdoses and bloodborne infections associated with nonsterile injection drug use. The Maine Center for Disease Control and Prevention (Maine CDC), a unit within Maine Department of Health and Human Services was awarded the vulnerability assessment grant from the U.S. CDC; it contracted Public Consulting Group, Inc. (PCG) to oversee the coordination of the assessment.

The aims of the vulnerability assessment were to:

1. Use a data-driven social indicator approach to identify sub-state areas at high risk for opioid overdoses and bloodborne infections associated with non-sterile injection opioid use
2. Use findings from the vulnerability assessment to make recommendations for interventions that strategically allocate services to sub-state areas at greatest risk

The assessment was conducted from February to July of 2019. It was guided by a 15-member Vulnerability Assessment Stakeholder Group representing 13 organizations throughout Maine. It employed a multi-step approach to achieve its aims. Steps included compiling a list of 120 candidate indicator variables; using two statistical approaches to identify the most vulnerable areas (Social Vulnerability Index and Poisson regression modelling); reviewing the literature and national best practices for prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice approaches; evaluating existing services available in the most vulnerable areas in Maine; and making recommendations for strategically placed interventions

Opioid-related statistical analyses were conducted at the county and subcounty levels, but bloodborne infection analyses only were done at the county level because data were not available at the subcounty level. The bloodborne infection analyses indicated that Penobscot, Kennebec, and Washington Counties were the most vulnerable followed by Androscoggin, Somerset, and Waldo Counties.

Findings from the opioid-related statistical analyses revealed nine highly vulnerable subcounty areas (Portland area of Cumberland County, the northern and southern areas of Kennebec County, the northern and Bangor areas of Penobscot County, the northern and southern areas of Somerset County, and the northern and southern areas of Washington County). The Portland area of Cumberland County, the southern area Kennebec County, and the entirety of Washington County were the most vulnerable areas.

After synthesizing the opioid-related findings with the bloodborne infection findings, this assessment identified five sub-state areas that interventions should target: *Kennebec County*, *Penobscot County*, *the Portland area of Cumberland County*, *Somerset County*, and *Washington County*.

Overall, the evaluation of existing prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice services in the most vulnerable areas revealed a lack of services in Somerset County, northern Penobscot County, and Washington County (especially in the northern area). The Portland Area of Cumberland County, Augusta area of Kennebec County, and Bangor area of Penobscot County have the most services.

Harm reduction services, including naloxone, syringe exchange programs, and pre-exposure prophylaxis (PrEP), are available in many sub-state areas. However, it is unclear if there is adequate availability of naloxone in the most vulnerable areas due to a lack of data at the sub-state level. Regarding PrEP, the state has compiled a list of PrEP providers, but findings from recent healthcare provider surveys suggest that providers are underprescribing it. There are only seven certified syringe exchange locations statewide and the programs have limited operating hours. There are no syringe exchanges in three of the most vulnerable areas: Somerset County, the northern area of Penobscot County, and the northern area of Washington County. Other states, such as Nevada and Minnesota, have taken innovative approaches to increasing access to clean syringes including allowing the purchase of syringes from vending machines and pharmacies.

A variety of treatment and recovery services are located throughout Maine. Services investigated include *2-1-1 Maine*, substance use treatment providers, Opioid Health Homes (OHHs), medication-assisted treatment (MAT) providers (methadone and buprenorphine), recovery community centers, recovery residences, and general healthcare providers (hospitals, mental health providers, Rural Health Clinics, and Federally Qualified Health Centers). Currently, no centralized clearinghouse of treatment and recovery services exists in Maine, making it difficult to determine if the information compiled for this assessment is up to date and comprehensive. Maine should explore creating a treatment and recovery services web-based database, which is updated on an ongoing basis to help providers and patients find available services. The database should include information about services provided, location, capacity, waitlists, and costs. Maine can utilize the expertise of nearby states, such as Massachusetts and Rhode Island, that recently created databases.

Among the most vulnerable counties, Somerset County has the fewest substance use treatment providers, all located only in the southernmost area of the county. Furthermore, there are no Opioid Health Homes in Somerset County, the northern area of Washington County, and the northern area of Penobscot County. There are ten methadone clinics and 742 buprenorphine providers in Maine, but coverage is limited in northern Washington County, the very northern area of Penobscot County, and most of Somerset County (buprenorphine providers are only located in the southernmost area). Strategies used by other states to increase the number of MAT providers include providing DATA 2000 waiver training to facilitate provider participation in MAT (Virginia) and enacting laws that require all health care facilities have a physician who is authorized to prescribe MAT (Maryland).

There are seven recovery community centers in Maine, but neither Kennebec County nor Somerset County have one. Similarly, despite there being 101 recovery residences in Maine, none exist in Somerset County and northern Washington County. Furthermore, fewer than one-third of recovery residences in Maine allow residents to take MAT.

Maine has six Adult Drug Treatment Courts (ADTCs) and three Family Treatment Drug Courts (FTDCs). However, access is restricted to individuals in certain counties. Residents of Kennebec and Somerset Counties do not have access to an ADTC, and residents of Cumberland, Somerset, and Washington Counties do not have access to a FTDC. Maine also has an alternative sentencing program, open to any resident in Maine, but it requires the participant to pay for the program. Regarding law enforcement, it is unclear how many local law enforcement agencies in Maine have pre-charge diversion programs. Thus, a thorough assessment should be conducted to determine where pre-charge diversion programs are needed. Several county jails in Maine have started offering MAT to inmates, but among the most vulnerable counties, neither Somerset County nor Washington County jails currently provide MAT to inmates.

Recommendations

Findings from this assessment indicate several areas of focus for improved services in the most vulnerable areas in Maine. With the help of the stakeholder group, PCG developed two sets of recommendations. The first set is intended for the Maine CDC HIV, STD, and Viral Hepatitis Program and specifically focus on short-term recommendations associated with bloodborne infections. The second set include both opioid overdose and bloodborne infection recommendations and most will require coordination among multiple state and/or private agencies.

Maine CDC HIV, STD, and Viral Hepatitis Program Recommendations

Prevention

1. Work with community prevention organizations to incorporate overdose and bloodborne infection prevention into the services they provide. Prioritize working with organizations in the most vulnerable areas.
2. Continue working with community partners in the most vulnerable areas and encourage them to increase access to free or reduced-cost HIV, Hepatitis B, and Hepatitis C testing. Assist them with implementing non-invasive testing methods such as rapid HIV testing via oral swabs and Hepatitis C testing via finger pricks.

Harm Reduction

1. Research additional sources of state, federal, and private funding for syringe exchange programs. Use funding to open syringe exchange programs in Somerset County and northern Washington County and expand operating hours and staff at the seven existing exchange locations.
2. Continue to provide PrEP education to healthcare providers and patients and focus efforts in the most vulnerable areas.

Treatment and Recovery

1. Explore ways to increase availability of telehealth for hepatitis.

Recommendations for Other State Government and/or Private Agencies

Prevention

1. Encourage the Maine Department of Education and Maine CDC's Division of Disease Prevention to implement evidence-based substance use and bloodborne infection prevention programs in schools. Programs should specifically target high-risk youth, such as those who have experienced adverse childhood experiences.
2. Work with the Maine legislature on legislation requiring that HIV, Hepatitis B, and Hepatitis C testing be offered to all individuals receiving hospital or primary care services. Look to the 2010 New York state law that mandates HIV testing be offered to all people between the ages of 13 and 64 who are receiving hospital or primary care services.

Harm Reduction

1. Investigate the feasibility of implementing innovative syringe exchange programs such as satellite syringe exchange units, vending machines, and pharmacy exchanges.
2. Explore implementing a safe injection site pilot program in the most vulnerable urban areas, such as Bangor and Portland.
3. Thoroughly assess naloxone availability in the most vulnerable areas and investigate ways to expand access if needed.
4. Implement comprehensive case management programs for active substance users, especially in the most vulnerable areas. Programs should not require an individual be enrolled in substance use treatment to receive services.

Treatment and Recovery

1. Employ strategies used by other states to increase the number of MAT providers in the most vulnerable areas, especially in Somerset County and northern Washington County. For example, Virginia conducts trainings on addiction treatment that include a DATA 2000 waiver training to encourage MAT participation and Maryland law requires that all health care facilities have a physician who is authorized to prescribe MAT.
2. Encourage organizations in the most vulnerable areas to become Opioid Health Home hubs, especially organizations in Somerset County and northern Washington County. This will ensure that all individuals in treatment and recovery have access to comprehensive case management services.
3. Develop a centralized web-based database of treatment and recovery services, similar to Massachusetts and Rhode Island, which is updated on an ongoing basis and contains information about capacity, waitlists, services provided, location, and cost.
4. Provide screening, brief intervention, and referral to treatment (SBIRT) trainings to staff (clinical and non-clinical) at general healthcare organizations. Look to programs being implemented in other states, such as the ASSERT program in Connecticut and Massachusetts.
5. Encourage providers at general healthcare organizations to become Opioid Health Home spokes, buprenorphine prescribers, PrEP prescribers, and to incorporate bloodborne infection testing into their clinical workflows.
6. Increase the availability of telehealth for MAT, HIV, Hepatitis B, and Hepatitis C.
7. Work with the Maine Association of Recovery Residences to increase the number of recovery residences in areas outside of Cumberland County and require that residencies accept individuals on MAT.

8. Assist the Portland Recovery Community Center, which serves as the Maine Recovery Hub, in opening centers in vulnerable areas that do not currently have one (Kennebec County and Somerset County).
9. Partner with the Maine State Housing Authority, Community Housing of Maine, local jurisdictions, and other local community organizations to create homelessness programs based on the Housing First model. Prioritize opening programs in vulnerable areas that currently do not have programs.

Law Enforcement and Criminal Justice

1. Encourage the Maine Judicial Branch to expand access to Adult Drug Treatment Courts and Family Treatment Drug Courts.
2. Explore sources of funding to reduce the participation cost of alternative sentencing programs so that all eligible individuals can participate.
3. Assess what law enforcement and other first responder agencies (*e.g.,* fire department, EMS) are doing to address the opioid epidemic in the most vulnerable areas. Work with the agencies to implement programs like the Portland Police Department's *Law Enforcement Addiction Advocacy Program (LEAAP)*, Gloucester, Massachusetts' *Angel Project*, and Lucas County Ohio's *Drug Abuse Response Team*.
4. Work with the Somerset and Washington County sheriff's departments to implement MAT in county jails.

Introduction and Background

In 2017, Maine had the sixth-highest opioid overdose death rate in the United States, with a rate of 29.9 deaths per 100,000 persons per year compared to the national average of 14.5 deaths per 100,000 persons per year (National Institute of Drug Abuse, 2019). Public health officials have identified a link between the growing opioid epidemic and the spread of bloodborne infections such as human immunodeficiency virus (HIV), Hepatitis B, and Hepatitis C, especially within non-urban communities (Van Handel et al., 2016). Given Maine's high opioid overdose rate, it is plausible that non-sterile injection opioid use is contributing to the increase in rates of new bloodborne infections in Maine. Rates of acute Hepatitis B and C have increased by 457 percent and 314 percent, respectively, since 2015 [Maine Center for Disease Control and Prevention (Maine CDC), 2018a; Maine CDC 2018b].

To address the opioid epidemic and specifically bloodborne infections associated with non-sterile injection opioid use, the U.S. Centers for Disease Control (U.S. CDC) developed a vulnerability index to identify communities at risk for opioid overdoses and bloodborne infections (Van Handel et al., 2016). Subsequently, states such as Tennessee have conducted similar vulnerability assessments to identify communities that are particularly vulnerable so that prevention and intervention services can be mounted where they are needed most (Rickles et al., 2018).

Building upon findings from the national and Tennessee assessments, the U.S. CDC funded state governments to conduct jurisdiction-level vulnerability assessments to identify sub-state areas at high risk for opioid overdoses and bloodborne infections associated with nonsterile injection opioid use. The Maine CDC, a unit within Maine's Department of Health and Human Services, was awarded the vulnerability assessment grant from the U.S. CDC; it contracted with Public Consulting Group, Inc. (PCG) to oversee the coordination of the assessment. The assessment was conducted from February through July of 2019.

The aims of the vulnerability assessment were to:

1. Use a data-driven social indicator approach to identify sub-state areas at high risk for opioid overdoses and bloodborne infections associated with non-sterile injection opioid use.
2. Use findings from the vulnerability assessment to make recommendations for interventions that strategically allocate services to sub-state areas at greatest risk.

Methodology

This section describes the methods used in the assessment including the role of the stakeholder group; identification of indicator and outcome variables; determination of sub-state areas; statistical methods used to identify the most vulnerable sub-state areas; research on existing services and resources; and recommendations for strategically-placed interventions.

Stakeholder group

The vulnerability assessment was guided by a 15-member Vulnerability Assessment Stakeholder Group representing 13 organizations throughout Maine, Table 1. Although many existing groups understand elements of the issues that were addressed in this vulnerability assessment, none had detailed knowledge of all the subject areas to constitute a proper stakeholder group. Therefore, we formulated a stakeholder group that was explicitly tied to existing groups through a delegation model. We also expanded it to encompass people with knowledge of subjects not adequately represented by existing groups. By asking existing groups to send delegates to the Vulnerability Assessment Stakeholder Group, we broadened the reach of the group without over-burdening its size and current demand of participants.

The vulnerability assessment was guided by a 15-member stakeholder group representing 13 organizations throughout Maine.

Table 1. Organizations Represented in the Vulnerability Assessment Stakeholder Group

American Liver Foundation
Cumberland County Sheriff's Department
Health Equity Alliance
India Street Public Health Center
Maine CDC HIV, STD, and Viral Hepatitis Program
Maine Emergency Medical Services
Maine Health Data Organization
Maine General Medical Center/Health Reach Harm Reduction
Northern New England Poison Control Center
Prescription Monitoring Advisory Council
Statewide Epidemiology Outcomes Workgroup
Syndromic Surveillance Stakeholder Workgroup
University of New England

Meeting and Agenda Topics

The stakeholder group met five times over the course of the project.

Meeting 1: Project Goals, Stakeholder Group Role, and Assessment Methodology

Agenda topics: Purpose of the vulnerability assessment; role of stakeholder group; suggestions for additional representation; discussion of data sources, use agreements and methods; initial discussion of candidate indicator and outcome variables; data sources for use in Maine and their administrators or coordinators; discussion of groups and resources already addressing reductions in opioid overdoses and bloodborne infections (protective resources).

Meeting 2: Assessment Methodology and Indicator and Outcome List Finalization

Agenda topics: Detailed review of methodology for conducting the vulnerability assessment; finalization of candidate indicator and outcome variables.

Meeting 3: Review of Results and Themes for Intervention Plan

Agenda topics: Review of initial findings; discussion and identification of patterns; methods for collecting information on protective resources and services.

Meeting 4: Comprehensive Results Review and Intervention Plan

Agenda topics: Review of findings on available resources and services (*e.g.,* prevention, harm reduction, treatment, criminal justice) in the most vulnerable communities; discussion of initial recommendations for strategically place interventions.

Meeting 5: Plan to Allocate Services and Disseminate Information

Agenda topics: Finalization of recommendations for strategically placed interventions; discussion of ways to disseminate findings to key stakeholders including dashboards, fact sheets, and presentations at public health and healthcare provider meetings or conferences.

Identification of Indicator and Outcome Variables

PCG conducted a literature review and compiled a list of indicator and outcome variables associated with opioid overdoses and bloodborne infections linked to non-sterile injection opioid use. During the first stakeholder group meeting, the group members added additional indicators based on their experiences and expertise. In total, the initial candidate list was composed of 120 indicator variables and seven outcome variables. The number of indicator variables was greater than the national and Tennessee assessments, which included 48 and 78 indicator variables, respectively (Rickles et al., 2018; Van Handel et al., 2016).

The initial candidate list was composed of 120 indicator variables and seven outcome variables.

During the second stakeholder meeting 78 indicator variables were eliminated and 42 were retained. All seven outcome variables were retained. The list was reduced using the following exclusion criteria:

1. Not available at sub-state level
2. Not likely to be strongly related to opioid overdoses or bloodborne infections associated with non-sterile injection opioid use in Maine
3. Not likely to vary between sub-state areas
4. Overlaps strongly with another indicator
5. Stems from a poor-quality data source

Of the 42 indicators, 15 were eliminated and 27 were retained using the data-driven approach.

Following the second stakeholder meeting. PCG further reduced the size of the indicator list using a data-driven approach. An indicator was eliminated if it 1) had insufficient raw counts at that sub-state level (*e.g.,* county, subcounty) or 2) was strongly correlated with other indicators. Of those strongly correlated, the indicator with the highest quality data was retained. Of the 42 indicators, 15 were eliminated and 27 were retained using the data-driven approach.

Table 2 contains information about the 27 indicator variables including their operational definitions, data sources, and years. The most recent three years of data were used when available, and the number of years used ranged from one to five. When multiple years of data were available, the average was used in the analyses. Table 3 contains similar information about the seven outcome variables. In total, eleven indicator data sources and four outcome data sources were used in the statistical analyses.

Table 2. Finalized List of Indicator Variables and Associated Data Sources

Data Source	Indicator	Operational Definition	Level & Years
American Community Survey	Population decline	Population decline between 2000 and 2017	County and ZIP code 2013–2017*
	Population age 18–29	Population age 18–29 divided by the estimated total county/subcounty population	
	Population age 36–54	Population age 36–54 (age group with highest overdose rate in Maine) divided by the estimated total county/subcounty population	
	Median household income	Median household income for each jurisdiction	
	Poverty	Number of persons in poverty divided by the estimated total county/subcounty population	
	Adults without a high school diploma	Number of persons aged ≥25 years with less than a 12th grade education divided by the total county/subcounty population aged ≥ 25 years	
	Unemployment	Number of civilian persons unemployed and actively seeking work divided by the estimated total county/subcounty population aged ≥ 16 years	
	Vacant housing units	Number of vacant housing units divided by the total number of housing units in a county/subcounty	
	Disability	Number of persons with a disability dived by the total county/subcounty population	
	Households without vehicle access	Number of households with a vehicle divided by total households per county/subcounty	
	Uninsured	Number of persons uninsured divided by the total county/subcounty population	
Uniformed Crime Reporting	Violent crimes	Number of violent crimes (murder, nonnegligent manslaughter, forcible rape, robbery, and aggravated assault) divided by the total county/subcounty population	County 2015–2017
	Property crimes	Number of property crimes (burglary, larceny-theft, motor vehicle theft, and arson) divided by the total county/subcounty population	
	Drug-related arrests	Number of drug-related arrests divided by the total county/subcounty population	
	Total arrests	Total arrests divided by the total county/subcounty population	
	Operating under the influence	Number of arrests for operating under the influence divided by the total county/subcounty population	

Data Source	Indicator	Operational Definition	Level & Years
2-1-1 Maine	Information calls for mental health services	Number of information calls for mental health services to *2-1-1 Maine* divided by the total county/subcounty population	County and ZIP code 2015–2017
	Information calls for substance use services	Number of information calls for substance use services to *2-1-1 Maine* divided by the total county/subcounty population	
National Provider Identifier Registry	Primary care providers	Number of primary care providers [National Provider Identifier (NPI) codes: 208D00000X, 207Q00000X 207R00000X, 364SA2200X 364SF0001X, 363LA2200X, 363LF0000X 363LP2300X, 363AM0700X] divided by the total county/subcounty population	County and ZIP code 2019
	Mental health providers	Number of mental health providers (NPI codes: 64SP0808X, 2084P0800X, 101Y00000X, 106H00000X, 103T00000X, 104100000X, 363LP0808X) divided by total county/subcounty population	
SAMHSA Treatment Locator	Buprenorphine providers	Number of buprenorphine providers divided by the total county/subcounty population	County and ZIP code 2019
	Methadone clinics	Is there a methadone clinic present within the jurisdiction? (1 = yes)	
Prescription Drug Monitoring Program	Prescribed doses of schedule II-IV drugs	Number of prescribed doses of schedule II-IV drugs divided by the total county/subcounty population	County and ZIP code 2015–2017
Northern New England Poison Center	Poison control calls regarding opioid use	Number of calls to Northern New England Poison Center from health centers about opioid abuse cases divided by the total county/subcounty population	County and ZIP code 2016–2018
	Poison control calls regarding opioid-related suicide attempts	Number of calls to Northern New England Poison Center call from health centers about opioid-related suicide attempts divided by the total county/subcounty population	
Maine Drug Enforcement Agency	Opioid and derivatives drug sale investigations	Number of Maine Drug Enforcement Agency opioid and opioid derivative sale investigations divided by the total county/subcounty population	County and ZIP code 2017–2018
	Non-opioid illicit drug sale investigations	Number of Maine Drug Enforcement Agency non-opioid illicit drug sale investigations divided by the total county/subcounty population	

Data Source	Indicator	Operational Definition	Level & Years
Behavioral Risk Factor Surveillance Survey	Adults reporting poor/fair health	Percentage of adults reporting fair or poor health (age-adjusted)	County and ZIP code 2015–2017
	Adults reporting poor physical health	Average number of physically unhealthy days reported in past 30 days (age-adjusted).	
	Adults with poor mental health	Number of mentally unhealthy days reported in past 30 days (age-adjusted)	
	Current smokers	Number of current cigarette smokers (smoke every day or somedays) divided by the total county/subcounty population	
	Adults at-risk for heavy alcohol consumption	Number of male respondents who reported having more than two drinks per day and female respondents who reported having more than one drink per day divided by the total county/subcounty population	
	Adults who did not go to the doctor due to cost	Number of persons who could not access medical care because of cost divided by total county/subcounty population	
Maine Syndromic Surveillance	Mental health-related emergency department visits	Mental health-related emergency department visits (ICD-10-CM F20 - F48) divided by the total county/subcounty population	County and ZIP code 2017–2018
Maine Vital Statistics	Suicides	Number suicides divided by the total county/subcounty population	County and ZIP code 2015–2017
	Injury-related fatalities	Number of injury deaths divided by the total county/subcounty population	

***Due to small populations in the counties and subcounty areas, we used five-year estimates for all ACS analyses. See U.S. Census ACS guidance at https://www.census.gov/programs-surveys/acs/guidance/estimates.html**

Table 3. Finalized List of Outcome Variables and Associated Data Sources

Data Source	Outcome	Operational Definition	Level & Years
Maine CDC Infectious Disease Surveillance	Acute Hepatis C	Number of acute hepatitis C divided by total county/subcounty population	County 2015–2017
	Acute Hepatitis B	Number of acute hepatitis B cases divided by total county/subcounty population	
	HIV	Number of HIV cases divided by total county/subcounty population	
Maine Syndromic Surveillance	Non-fatal overdoses, opioids only (excluding heroin/fentanyl)	Number of emergency department visits due to non-fatal opioid overdoses (excluding heroin/fentanyl) divided by total county/subcounty population	County & ZIP code 2017–2018
	Non-fatal overdoses, heroin/fentanyl only	Number of emergency department visits due to non-fatal heroin/fentanyl overdoses divided by total county/subcounty population	

Data Source	Outcome	Operational Definition	Level & Years
Maine Emergency Medical Services	Naloxone administration rate	Number of Maine Emergency Medical Services naloxone administration incidents divided by total county/subcounty population	County and ZIP code 2015–2017
Maine Vital Statistics	Opioid-related mortality rate	Number of overdose deaths attributed to any opioids divided by total county/subcounty population	County and ZIP code 2015–2017

Determination of Sub-State Areas

The vulnerability assessment included both county and subcounty analyses. It was important to conduct analyses at the subcounty level because of the large size and diversity within of Maine's 16 counties. Additionally, the small number of counties inhibited the use of statistical techniques such as Poisson regression.

Analyses could not be conducted at ZIP code level due to the small population in most of Maine's 433 ZIP Code Tabulation Areas (ZTCAs), which resulted in very small raw counts of each indicator and outcome variable. PCG met with Michelle Van Handel, the U.S. CDC Project Officer for the assessment and the first author on the national vulnerability assessment (Van Handel et al, 2016), for guidance on subcounty analyses. She advised dividing counties into two or three smaller subcounty areas.

The vulnerability assessment included both county and subcounty analyses, a decision influenced by geographic and demographic factors.

The 16 counties were divided into a total of 31 areas which included three counties whose populations were too small to divide and 28 subcounty areas (See Table 4). Counties were divided either into urban and rural areas, coastal and inland areas (east and west), or northern and southern areas. Data for each subcounty were then extracted using ZTCAs. See Figures A-1 and A-2 in Appendix A for maps of the county and subcounty areas.

Table 4. Counties and Associated Subcounty Areas

County	Subcounty Area
Androscoggin	1. Lewiston/Auburn and everything to the south (Androscoggin_South) 2. Everything north of Lewiston/Auburn (Androscoggin_North)
Aroostook	1. Houlton and everything to the south (Aroostook_South) 2. Caribou and everything to the north (Aroostook_North)
Cumberland	1. Portland peninsula, area just west of city to airport, and South Portland (Cumberland_Portland) 2. Suburbs outside of Portland on the east side of the county (Cumberland_East) 3. Everything at Sebago Lake and west (Cumberland_West)
Franklin	4. Farmington and everything to the south (Franklin_South) 5. Everything north of Farmington (Franklin_North)
Hancock	Did not divide
Kennebec	1. Augusta and everything to the south (Kennebec_South) 2. Waterville and everything to the north (Kennebec_North)
Knox	Did not divide
Lincoln	1. Wiscasset and everything to the west (Lincoln_West) 2. Waldoboro and everything to the east (Lincoln_East)
Oxford	1. Paris and everything to the south (Oxford_South) 2. Rumford and everything to the north (Oxford_North)
Penobscot	1. Bangor and Old Town (Penobscot_Bangor) 2. Everything to the west of Bangor and Old Town (Penobscot_West) 3. Everything to the north of Bangor and Old Town (Penobscot_North)
Piscataquis	Did not divide
Sagadahoc	1. Everything west of the water (Sagadahoc_West) 2. Everything east of the water (Sagadahoc_East)
Somerset	1. Skowhegan and everything to the south (Somerset_South) 2. Everything else north of Skowhegan (Somerset_North)
Waldo	1. Everything coastal in the east (Waldo_East) 2. Everything else inland in the west (Waldo_West)
Washington	1. Southern coast including Jonesboro, Machias, and Lubec (Washington_South) 2. Everything else to the north including Calais (Washington_North)
York	1. Everything on Interstate 95 and the eastern coast (York_East) 2. Everything else to the west (York_West)

Indentification of Most Vulnerable Sub-State Areas

Following completion of the steps outlined above, PCG took a multi-step approach, similar to the one used in the national (Van Handel et al., 2016) and Tennessee (Rickles et al., 2018) assessments, to identify counties and subcounty areas with greatest vulnerability to opioid overdoses and bloodborne infections associated with non-sterile injection drug use. Two methods recommend by the U.S. CDC were used: 1) Poisson regression and 2) Social vulnerability index (SVI).

The SVI was used in both the county and subcounty analyses and the Poisson regression only was used in the subcounty analyses because it could not be performed at the county level, given the small number of counties in Maine. Thus, Poisson regression was not used for the bloodborne infection-related outcomes due to lack of available subcounty data.

Poisson Regression Modelling

Stepwise Poisson regression modeling was conducted using standard R packages to identify indicator variables showing statistically significant associations with the opioid-related outcome variables (non-fatal opioid overdoses, non-fatal heroin/fentanyl overdoses, naloxone administration incidents, and opioid-related mortalities) and identify the most vulnerable subcounty areas. Separate Poisson regression models were run for each outcome.

Prior to conducting the stepwise Poisson regressions, 16 of the 27 indicators were eliminated and 11 were retained. The 11 retained indicators varied by outcome. To determine which indicators would be retained, 5,000 simulations of seven randomly selected indicators were conducted for each outcome. Then, the most consistent top three statistically significant protective factors and top eight statistically significant risk factors were selected for each outcome.

Protective factor ▶ An indicator that was *negatively* associated with the outcome, meaning that higher levels of the indicator were associated with lower rates of the given outcome

Risk factor ▶ An indicator that was *positively* associated with the outcome, meaning that higher levels of the indicator were associated with higher rates of that outcome

After identifying the indicators, separate stepwise Poisson regression models were run for each outcome with the aim of finding the most parsimonious model that had the best fit with the fewest number of statistically significant indicators. A composite vulnerability score then was calculated for each subcounty area using the statistically significant indicator variables for that outcome.

More specifically, for each subcounty area, PCG multiplied the subcounty area's value for each indicator variable by the indicator variable's regression coefficient from the final regression model and summed to produce an overall vulnerability score (Rickles et al., 2018; Van Handel et al., 2016). Then, the subcounty areas were ranked for each outcome by their composite vulnerability score from lowest to highest, with higher scores indicating higher vulnerability.

Social Vulnerability Index

The SVI is a methodology previously used by the U.S. CDC (Flanagan et al., 2011) to determine geographical areas most vulnerable to public health emergencies. It was originally developed for natural disasters, but now is being applied to other public health emergencies, including the opioid epidemic. Unlike Poisson regression, SVI is a descriptive statistics approach and does not assess if the indicator variables are associated with the outcome variables.

Before conducting the SVI analyses, 16 of the 27 indicators were eliminated and 11 were retained. The 11 indicators were chosen using the Poisson regression results as a starting point and covered five domains: *substance use*, *mental health*, *physical health*, *socioeconomic*, and *law enforcement* (See Table 5). Next, for each sub-state area, a percentile rank was calculated for each of the 11 indictors. Then, a composite vulnerability score was created for each sub-state area that was a sum of the individual indicator percentile ranks. Finally, the subcounty areas were ranked by their composite vulnerability score from lowest to highest, with higher scores indicating higher vulnerability.

Table 5. Social Vulnerability Index Domains and Associated Indicators

Domain	Indicator
Substance Use	*2-1-1 Maine* substance use referral calls (*per capita* rate)
	Doses of schedule II–IV drugs prescribed (*per capita* rate)
Mental health	Mental health-related emergency department visits (*per capita* rate)
	Number of poor mental health days in the past month (*per capita* rate)
Physical Health	Injury-related mortality (*per capita* rate)
	Number of poor physical health days in past month (*per capita*)
Socioeconomic	Adults without high school diploma (*per capita* rate)
	Unemployment (*per capita* rate)
Law Enforcement	Maine DEA investigations of opioid sales (*per capita* rate)
	Maine DEA investigations of non-opioid illicit drug sales (*per capita* rate)

Research on Existing Services and Resouces

To achieve the second aim of the assessment—to use findings to make recommendations for interventions that strategically allocate services to sub-state areas at greatest risk—PCG first undertook an evaluation of existing services and resources. Reviews of the literature and national best practices were conducted to identify what prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice services and approaches communities are using across the country to address opioid overdoses and bloodborne infections associated with non-sterile injection opioid use. We then determined their existence and prevalence in Maine.

These would include *prevention* approaches such as outreach, educational groups, and community coalitions; *harm reduction* approaches such as syringe exchange programs, pre-exposure prophylaxis (PrEP), and naloxone administration; *treatment* approaches such as substance use treatment providers, recovery residences, recovery centers, methadone clinics, buprenorphine providers, and mental health providers; and *law enforcement/criminal justice approaches* such as diversion programs and drug courts.

Recommendations for Strategically-Placed Interventions

The final step in the assessment involved synthesizing the results from the statistical analyses with information gleaned from the literature search for risk factors, a review of existing resources in Maine, and identification of successful interventions used in other states to develop a list of potential recommendations for addressing opioid overdoses and bloodborne infections in the most vulnerable communities in Maine. As part of this process, PCG worked with the Maine CDC and the stakeholder group to identify gaps in services and prioritize recommendations.

Results

Opioid Overdoses and Mortalies

County rates

Per capita rates of non-fatal opioid overdoses, non-fatal heroin/fentanyl overdoses, naloxone administration incidents, and opioid-related mortalities consistently were highest in Kennebec, Washington, and Penobscot Counties. Additionally, Cumberland County was ranked in the top five for non-fatal opioid overdoses, non-fatal heroin/fentanyl overdoses, and naloxone administration incidents, while Somerset was ranked in the top five for non-fatal opioid overdoses, non-fatal heroin/fentanyl overdoses, and opioid-related mortalities.

It is noteworthy that there was a consistent pattern of higher *per capita* rates seen in counties along Interstate 95, namely Cumberland, Kennebec, and Penobscot Counties and to a lesser extent York and Androscoggin Counties.

Table 6 lists the top five counties with the highest rate for each of the opioid-related outcomes. See Figures A-3 to A-6 in Appendix A for county rate maps of each opioid-related outcome.

Table 6. Most Vulnerable Counties Based on Rates

County*	Non-Fatal Opioid Overdoses	Non-Fatal Heroin/Fentanyl Overdoses	Naloxone Administration Incidents	Opioid-Related Mortalities
Androscoggin				
Cumberland	✓	✓	✓	
Kennebec	✓	✓	✓	✓
Lincoln				✓
Penobscot	✓	✓	✓	✓
Piscataquis				
Somerset	✓	✓		✓
Washington	✓	✓	✓	✓
York			✓	

***Checkmark indicates that the county's rate was ranked in the top five for that particular outcome.**

Subcounty rates

Per capita rates for all four opioid-overdose outcomes were generally the highest in southern Kennebec County, the Portland area of Cumberland County, and northern and southern Washington County (entire county). Additionally, subcounty data indicated that metro areas often had higher *per capita* rates of opioid overdoses than lower-density areas in a given county.

For example, the Portland area of Cumberland County and Bangor area of Penobscot County had higher *per capita* rates of non-fatal opioid overdoses, non-fatal heroin/fentanyl overdoses, and naloxone administration incidents compared to the more rural areas. Portland also had a higher *per capita* opioid mortality rate than the other areas of Cumberland County.

Table 7 lists the top five subcounty areas with the highest rate for each of the opioid-related outcomes. See Tables A-1 to A-4 in Appendix A for the subcounty rates for each opioid-related overdose outcome. It was not possible to create subcounty maps.

Table 7. Most Vulnerable Subcounty Areas Based on Rates

Subcounty area*	Non-Fatal Opioid Overdoses	Non-Fatal Heroin/Fentanyl Overdoses	Naloxone Administration Incidents	Opioid-Related Mortalities
Cumberland_Portland	✓	✓	✓	✓
Kennebec_North	✓			
Kennebec_South	✓	✓	✓	✓
Lincoln_West				✓
Penobscot_Bangor		✓		
Washington_North	✓	✓	✓	✓
Washington_South	✓	✓	✓	✓
York_East			✓	

*** Checkmark indicates that the subcounty area’s rate was ranked in the top five for that particular outcome.**

Social Vulnerability Index (SVI) Results

Results of the county-level SVI analyses revealed that Somerset, Washington, Penobscot, Piscataquis, and Kennebec Counties were the most vulnerable counties. These findings are consistent with those from the subcounty SVI analyses that showed that the entirety of Piscataquis and Washington Counties as well as the northern area of Penobscot County and the southern area of Somerset County were most vulnerable. See Table 8 for county SVI rankings and Table 9 for subcounty SVI rankings. Figure A-10 in Appendix A contains a county map of SVI scores.

Table 8. County SVI Rankings

County	SVI Score*
Hancock	0
Cumberland	0.07
Waldo	0.13
Sagadahoc	0.20
Aroostook	0.27
York	0.27
Knox	0.40
Lincoln	0.47
Oxford	0.53
Androscoggin	0.60
Franklin	0.67
Kennebec	0.73
Piscataquis	0.80
Penobscot	0.87
Washington	0.93
Somerset	1

SVI scores range from 0 to 1. *Counties with higher SVI scores are more vulnerable

Table 9. Subcounty SVI Rankings

County	SVI Score*
Cumberland_East	0
Hancock	0.03
Sagadahoc_West	0.07
Lincoln_West	0.1
York_West	0.13
Knox	0.17
Waldo_East	0.2
Aroostook_North	0.23
Waldo_West	0.27
Lincoln_West	0.3
Oxford_South	0.3
Cumberland_Portland	0.37
York_East	0.4
Androscoggin_North	0.43
Franklin_South	0.47
Franklin_North	0.5
Sagadahoc_East	0.53
Aroostook_South	0.57
Androscoggin_South	0.6
Cumberland_West	0.63
Penobscot_Bangor	0.67
Kennebec_North	0.7
Penobscot_West	0.73
Kennebec_South	0.77
Oxford_North	0.8
Somerset_North	0.83
Piscataquis	0.87
Washington_South	0.9
Penobscot_North	0.93
Somerset_South	0.97
Washington_North	1

SVI scores range from 0 to 1. *Counties with higher SVI scores are more vulnerable.

Poisson Regression Results

Non-Fatal Opioid Overdoses

Results of the Poisson regression analyses revealed that *per capita* rates of injury-related mortalities, doses of prescribed schedule II–IV drugs, opioid-related poison control calls, and *2-1-1 Maine* substance abuse referral calls were statistically significant positive predictors of non-fatal opioid overdoses meaning that higher *per capita* rates of these indicators were predictive of higher non-fatal opioid-overdose *per capita* rates. *Per capita* rates of MDEA opioid-related sale investigations and vacant housing were statistically significant negative predictors meaning that higher rates of these indicator were predictive of lower non-fatal opioid overdose *per capita* rates.

Table 10 lists the 11 indictors included in the non-fatal opioid overdose Poisson regression model with their associated statistical significance information and indication if they were statistically significant positive or negative predictors.

Table 10. Non-Fatal Opioid-Related Overdose Indicators

Indicator	Statistical Significance (*P*- Value)
Doses of prescribed schedule II–IV drug[1]	< 0.0001
Injury-related mortality[1]	< 0.0001
MDEA opioid-related sales investigations[2]	< 0.0001
2-1-1 Maine substance use-related referral calls[1]	< 0.01
Opioid-related poison control calls[1]	< 0.01
Vacant housing[2]	< 0.0001
Buprenorphine providers	*n.s.*
Mental health-related ED visit	*n.s.*
Adults without a high school diploma	*n.s.*
Population age 18 to 29	*n.s.*
Uninsured	*n.s.*

[1] Statistically significant positive predictors of non-fatal opioid overdoses

[2] Statistically significant negative predictors of non-fatal opioid overdoses

Abbreviations: n.s.= indicator that was not a statistically significant predictor of non-fatal opioid overdoses

When the subcounty areas were ranked by the composite vulnerability scores, the Portland area of Cumberland County, southern and northern areas of Kennebec County, the northern area of Washington County, and the southern area of Somerset County were at greatest risk for non-fatal opioid overdoses. These counties are consistent with those with the highest non-fatal opioid overdose *per capita* rates. See Table 11 for the regression rank, *per capita* rate rank, and *per capita* rate for each subcounty area.

Table 11. Non-Fatal Opioid Overdose Subcounty Rankings and *Per Capita* Rates

Subcounty Area	Regression Rank	Rate Rank	Rate
Franklin_North	1	1	32.89
Lincoln_East	2	13	89.43
Hancock	3	3	64.28
Waldo_East	4	2	49.44
York_West	5	18	104.61
Cumberland_East	6	9	82.20
Androscoggin_North	7	12	88.03
Oxford_South	8	6	65.75
Aroostook_North	9	8	76.23
Knox	10	7	71.79
Waldo_West	11	5	65.46
Aroostook_South	12	4	65.10
Franklin_South	13	14	95.89
Lincoln_West	14	15	98.27
York_East	15	16	100.53
Oxford_North	16	22	110.95
Somerset_North	17	20	109.27
Sagadahoc_West	18	10	82.74
Penobscot_West	19	11	87.98
Piscataquis	20	23	111.59
Sagadahoc_East	21	19	105.99
Cumberland_West	22	17	103.25
Washington_South	23	29	154.91
Androscoggin_South	24	24	114.82
Penobscot_Bangor	25	26	130.06
Penobscot_North	26	21	109.74
Kennebec_North	27	27	139.69
Somerset_North	28	25	122.53
Washington_North	29	28	143.57
Kennebec_South	30	30	174.07
Cumberland_Portland	31	31	198.91

***Subcounty areas are ordered by Poisson regression composite vulnerability scores. Higher rankings for the regression and rates are indicative of greater vulnerability.**

Non-Fatal Heroin/Fentanyl overdoses

Results of the Poisson regression analyses revealed that *per capita* rates of buprenorphine providers, *2-1-1 Maine* substance abuse referral calls, and adult residents without a high school diploma were statistically significant positive predictors of non-fatal heroin/fentanyl overdoses, meaning that higher *per capita* rates of these indicators were predictive of higher non-fatal heroin/fentanyl overdose *per capita* rates. *Per capita* rates of MDEA opioid-related sales investigations, vacant housing, and residents who were current daily smokers were statistically significant negative predictors, meaning that higher rates of these indicators were predictive of lower non-fatal heroin/fentanyl overdose rates. Table 12 lists the 11 indictors included in the non-fatal heroin/fentanyl overdose Poisson regression model, along with their associated statistical significance information and indication if they were statistically significant positive or negative predictors.

Table 12. Non-Fatal Heroin/Fentanyl Overdose Indicators

Indicator	Statistical Significance (*P*- Value)
Buprenorphine providers[1]	< 0.0001
Current daily smokers[2]	< 0.01
***2-1-1 Maine* substance use-related referral calls[1]**	< 0.001
MDEA opioid-related sales investigations[2]	< 0.0001
Adults without high school diploma[1]	< 0.01
Vacant housing[2]	< 0.0001
Injury-related mortality	*n.s.*
Mental health providers	*n.s.*
Mental health-related ED visit rate	*n.s.*
Opioid-related poison control calls	*n.s.*
Population age 18 to 29	*n.s.*

[1] **Statistically significant positive predictors of non-fatal heroin/fentanyl overdoses**

[2] **Statistically significant negative predictors of non-fatal heroin/fentanyl overdoses**

Abbreviations: n.s.= indicator that was not a statistically significant predictor of non-fatal heroin/fentanyl overdoses

When the subcounty areas were ranked by composite vulnerability scores calculated from the regression results, the Portland area of Cumberland County, the northern and southern areas of Washington County, the southern area of Kennebec County, and the northern area of Penobscot County were at greatest risk for non-fatal heroin/fentanyl overdoses. These counties are similar to those with the highest non-fatal heroin/fentanyl overdose *per capita* rates. See Table 13 for the regression rank, *per capita* rate rank, and *per capita* rate for each subcounty area.

Table 13. Non-Fatal Opioid Overdose Subcounty Rankings and *Per Capita* Rates

Subcounty Area*	Regression Rank	Rate Rank	Rate
Lincoln_East	1	5	24.67
Aroostook_South	2	3	15.50
Waldo_East	3	2	14.83
York_West	4	15	36.41
Knox	5	6	27.71
Oxford_North	6	7	27.74
Franklin_North	7	1	13.15
Waldo_West	8	4	18.33
Hancock	9	8	28.36
York_East	10	19	41.85
Somerset_North	11	22	46.83
Oxford_South	12	9	28.93
Lincoln_West	13	12	33.69
Penobscot_West	14	14	36.09
Aroostook_North	15	10	29.54
Sagadahoc_East	16	23	47.11
Franklin_South	17	25	54.79
Androscoggin_North	18	11	31.24
Sagadahoc_West	19	16	38.61
Cumberland_West	20	18	40.72
Androscoggin_South	21	21	45.15
Somerset_South	22	20	43.67
Cumberland_East	23	13	34.53
Piscataquis	24	17	39.21
Kennebec_North	25	26	57.94
Penobscot_Bangor	26	27	60.13
Penobscot_North	27	24	53.87
Washington_South	28	31	106.84
Kennebec_South	29	30	98.68
Washington_North	30	28	75.56
Cumberland_Portland	31	29	78.14

***Subcounty areas are ordered by Poisson regression composite vulnerability scores. Higher rankings for the regression and rates are indicative of greater vulnerability.**

Naloxone Administration Incidents

Results of the Poisson regression analyses revealed that *per capita* rates of mental health providers, injury-related mortalities, *2-1-1 Maine* substance abuse referral calls, buprenorphine providers, and doses of prescribed schedule II–IV drugs as well as the population change since 2000 were statistically significant positive predictors of naloxone administration incidents. Higher rates of these indicators were predictive of higher non-fatal opioid-overdose rates. *Per capita* rates of MDEA opioid-related sales investigations was a statistically significant negative predictor, meaning that more *per capita* sale investigations were predictive of lower naloxone administration incident rates. Table 14 lists the 11 indictors included in the naloxone administration Poisson regression model, along with their associated statistical significance information and indication if they were statistically significant positive or negative predictors.

Table 14. Naloxone Administration Incident Indicators

Indicator	Statistical Significance (*P*- Value)
Buprenorphine providers[1]	< 0.0001
Doses of prescribed schedule II–IV drugs[1]	< 0.0001
Injury-related mortality rate[1]	< 0.0001
MDEA opioid-related sales investigations[2]	< 0.0001
Mental health providers[1]	< 0.0001
Population change since 2000[1]	< 0.0001
Substance use-related referral calls [1]	< 0.0001
Adults without a high school diploma	*n.s.*
MDEA non-opioid illicit drug sales investigation rate	*n.s.*
Mental health-related ED visit rate	*n.s.*
Methadone clinics	*n.s.*

[1] **Statistically significant positive predictors of naloxone administration incidents**

[2] **Statistically significant negative predictors of naloxone administration incidents**

Abbreviations: n.s.= indicator that was not a statistically significant predictor of naloxone administration incidents

When the subcounty areas were ranked by the composite vulnerability scores calculated from the regression results, the Portland area of Cumberland County, the northern and southern areas of Washington County, the Bangor area of Penobscot County, and the southern area of Kennebec County were at greatest risk for naloxone administration. These subcounty areas are fairly similar to those with the highest naloxone administration incident *per capita* rates. See Table 15 for the regression rank, *per capita* rate rank, and *per capita* rate for each subcounty area.

Table 15. Naloxone Administration Incidents Subcounty Rankings and *Per Capita* Rates

Subcounty Area*	Regression Rank	Rate Rank	Rate
Lincoln_East	1	8	96.63
Aroostook_North	2	3	73.90
Androscoggin_North	3	4	76.22
Sagadahoc_West	4	6	79.98
Franklin_South	5	10	107.31
Waldo_West	6	2	69.58
Waldo_East	7	11	107.35
Sagadahoc_East	8	15	126.60
Hancock	9	14	121.95
Franklin_North	10	9	98.66
Aroostook_South	11	1	41.71
Oxford_North	12	16	135.40
Oxford_South	13	12	108.23
Penobscot_West	14	21	166.49
Penobscot_North	15	7	96.06
Knox	16	5	78.09
Lincoln_West	17	20	161.91
Androscoggin_South	18	1	41.71
York_East	19	29	290.52
Somerset_North	20	18	141.77
Piscataquis	21	22	168.90
York_West	22	25	216.41
Cumberland_West	23	13	117.80
Kennebec_North	24	23	204.65
Cumberland_East	25	17	137.26
Somerset_South	26	19	141.77
Washington_South	27	27	260.75
Kennebec_South	28	28	274.27
Penobscot_Bangor	29	26	227.50
Washington_North	30	31	341.45
Cumberland_Portland	31	30	305.91

***Subcounty areas are ordered by Poisson regression composite vulnerability scores. Higher rankings for the regression and rates are indicative of greater vulnerability.**

Opioid-Related Mortalities

Results of the Poisson regression analyses revealed that *per capita* rates of buprenorphine providers and mental-health related emergency department visits were statistically significant positive predictors of opioid-related mortalities meaning that higher *per capita* rates of these indicators were predictive of higher opioid-related mortality *per capita* rates. Table 16 lists the 11 indictors included in the opioid-related mortality Poisson regression model, along with their associated statistical significance information and indication if they were statistically significant positive or negative predictors.

Table 16. Opioid-Related Mortalities Indicators

Indicator	Statistical Significance (*P*- Value)
Buprenorphine provider rate[1]	< 0.01
Mental health-related ED visit rate[1]	< 0.05
Adults at-risk for heavy alcohol use	*n.s.*
Adults without a high school diploma	*n.s.*
Current daily smokers	*n.s.*
Disability rate	*n.s.*
Doses of prescribed schedule II–IV drugs	*n.s.*
***2-1-1 Maine* mental health referral calls**	*n.s.*
MDEA opioid-related sales investigations	*n.s.*
Methadone clinics	*n.s.*
Mental health providers	*n.s.*

[1] Statistically significant positive predictors of opioid-related mortalities

Abbreviations: n.s.= indicator that was not a statistically significant predictor of opioid-related mortalities

When the subcounty areas were ranked by the composite vulnerability scores calculated from the Poisson regression results, the northern area of Penobscot County, southern area of Kennebec County, Portland area of Cumberland County, and the northern and southern areas of Washington County were at greatest risk for opioid-related mortalities. These counties are fairly similar to those with the highest opioid-related mortality *per capita* rates. See Table 17 for the regression rank, *per capita* rate rank, and *per capita* rate for each subcounty area.

Table 17. Opioid-Related Mortality Subcounty Rankings and *Per Capita* Rates

Subcounty Area*	Regression Rank	Rate Rank	Rate
York_West	1	12	8.55
Sagadahoc_East	2	9	7.85
Sagadahoc_West	3	1	3.68
Penobscot_West	4	24	15.04
York_East	5	22	14.43
Oxford_South	6	3	5.26
Cumberland_West	7	13	8.73
Aroostook_South	8	11	8.27
Waldo_West	9	14	8.73
Franklin_South	10	8	7.61
Franklin_North	11	15	8.77
Lincoln_East	12	2	4.11
Androscoggin_North	13	4	6.35
Somerset_North	14	5	6.94
Cumberland_East	15	6	7.54
Hancock	16	18	13.23
Lincoln_West	17	29	24.33
Androscoggin_North	18	23	14.86
Oxford_North	19	17	11.77
Knox	20	16	10.92
Waldo_East	21	10	8.24
Aroostook_North	22	4	6.35
Penobscot_Bangor	23	20	13.98
Somerset_South	24	26	17.79
Piscataquis	25	21	14.07
Kennebec_North	26	25	15.18
Penobscot_North	27	19	13.30
Kennebec_South	28	28	21.47
Cumberland_Portland	29	27	17.85
Washington_South	30	30	28.49
Washington_North	31	31	30.23

***Subcounty areas are ordered by Poisson regression composite vulnerability scores. Higher rankings for the regression and rates are indicative of greater vulnerability.**

Summary of Opiod-Related Results

County

The synthesis of the SVI result and *per capita* opioid-related rates indicated that Penobscot and Washington Counties were the most vulnerable to the opioid epidemic, followed by Kennebec and Somerset Counties. Further, although Androscoggin and Piscataquis are not the most vulnerable counties in-terms of *per capita* rates, these counties may be at risk for an increase in rates based on the results of the SVI analyses. Table 18 lists the counties that were ranked in the top five for either the SVI or an opioid-related outcome.

Penobscot and Washington Counties are most vulnerable to the opioid epidemic, followed by Kennebec and Somerset Counties.

Table 18. Counties Most Vulnerable to Opioid Overdoses and Mortalities

County*	SVI	Non-Fatal Opioid Overdoses	Non-Fatal Heroin/Fentanyl Overdoses	Naloxone Administration Incidents	Opioid-Related Mortalities
Androscoggin	✓				
Cumberland		✓	✓	✓	
Kennebec		✓	✓	✓	✓
Lincoln					✓
Penobscot	✓	✓	✓	✓	✓
Piscataquis	✓				
Somerset	✓	✓	✓		✓
Washington	✓	✓	✓	✓	✓
York				✓	

***Checkmark indicates the county was ranked in the top five for the SVI or that opioid-related outcome.**

Subcounty

Taken together, findings from the SVI and the Poisson Regression analyses revealed that nine subcounty areas are highly vulnerable. The Portland area of Cumberland County, the southern area of Kennebec County, and the entirety of Washington County are at greatest risk. Table 19 lists the subcounty areas that were ranked in the top five for the SVI or an opioid-related Poisson regression model.

At the subcounty level, the Portland area of Cumberland County, the southern area of Kennebec County, and all of Washington County are at greatest risk.

Table 19. Subcounty Areas Most Vulnerable to Opioid Overdoses and Mortalities

Subcounty Area*	Social Vulnerability Index	Non-Fatal Opioid Overdoses	Non-Fatal Heroin/Fentanyl Overdoses	Naloxone Administration Incidents	Opioid-Related Mortalities
Cumberland_Portland		✓	✓	✓	✓
Kennebec_South		✓	✓	✓	✓
Kennebec_North	✓	✓			
Penobscot_Bangor				✓	
Penobscot_North			✓		✓
Piscataquis	✓				
Somerset_South	✓	✓			
Washington_North	✓	✓	✓	✓	✓
Washington_South	✓		✓	✓	✓

***Checkmark indicates the subcounty area was ranked in the top five for the SVI or that opioid-related regression model**

Bloodborne Infection Results

County Rates

Per capita county rates varied between the three bloodborne infections, but Kennebec, Washington, and Penobscot Counties consistently had higher rates. High rates of acute Hepatitis B and C were found in eastern counties, namely Penobscot, Washington, Hancock, and Androscoggin Counties. High rates of HIV incidents were found in southern counties with larger metro areas, namely Cumberland, Androscoggin, and Kennebec. See Figures A-7 to A-9 in Appendix A for county rate maps of each of the three bloodborne infection outcomes.

SVI Results

Results of the county-level SVI analyses revealed that Somerset, Washington, Penobscot, Piscataquis, and Kennebec Counties were the most vulnerable counties. See Table 20 for county SVI rankings.

Table 20. SVI Ranking for Bloodborne Infections Associated with Non-Sterile Drug Injections

County	SVI Score*	County	SVI Score
Hancock	0	Oxford	0.53
Cumberland	0.07	Androscoggin	0.60
Waldo	0.13	Franklin	0.67
Sagadahoc	0.20	Kennebec	0.73
Aroostook	0.27	Piscataquis	0.80
York	0.27	Penobscot	0.87
Knox	0.40	Washington	0.93
Lincoln	0.47	Somerset	1

***SVI scores range from 0 to 1. Counties with higher SVI scores are more vulnerable**

Summary of Bloodborne Infection Results

The synthesis of the SVI results and *per capita* bloodborne infection rates indicated that Penobscot, Kennebec, and Washington Counties are most vulnerable to bloodborne infections, followed by Androscoggin, Somerset, and Waldo Counties. Further, although Piscataquis was not a vulnerable county in terms of *per capita* rates, it may be at risk for an outbreak based on the results of the SVI analyses. Table 21 lists the counties that were ranked in the top five for the SVI or a bloodborne infection outcome.

The synthesis of the SVI results and *per capita* bloodborne infection rates indicated that Penobscot, Kennebec, and Washington Counties are most vulnerable to bloodborne infections.

Table 21. Counties Most Vulnerable to Bloodborne Infections Associated Non-Sterile Injection Drug Use

County*	SVI	HIV	Acute Hepatis C	Acute Hepatitis B
Androscoggin		✓		✓
Cumberland				✓
Kennebec	✓		✓	✓
Knox			✓	
Hancock			✓	
Penobscot	✓	✓	✓	✓
Piscataquis	✓			
Somerset	✓	✓		
Waldo		✓		✓
Washington	✓	✓	✓	

***Checkmark indicates the county area was ranked in the top five for the SVI or that bloodborne infection outcome**

Intervention Target Areas

There was a large degree of overlap in the opioid and bloodborne infection results. It is important to consider both counties and subcounty areas because bloodborne infection analyses only were included in county-level analyses.

Top Priority Counties

1. Penobscot
2. Washington
3. Kennebec
4. Somerset

Top Priority Subcounty Areas

1. Portland area of Cumberland
2. Southern Kennebec
3. Northern and southern Washington (entire county)

Combining the subcounty and county results, the assessment determined that the Portland area of Cumberland County, Kennebec County, Penobscot County, Washington County, and Somerset County should be targeted.

Existing Services and Gaps in Services

The review of national best practices, services in other states, and existing services in Maine helped to identify gaps in prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice services in the most vulnerable areas. The subsequent sections discuss the findings from the review.

Prevention

Maine currently has several federally funded opioid use prevention initiatives including *Drug Free Communities (DFC)* and community coalitions; the *Strategic Prevention Framework for Prescription Drugs (SPF-Rx)* program; the *Partnerships for Success (PFS 2015)*; the *Statewide Epidemiology Outcomes Workgroup (SEOW)*; and *the Prescription Drug Overdose: Prevention for States* program.

The DFC program is housed in the Office of National Drug Control Policy and provides funding to local communities throughout the country to identify and respond to substance use at the local level [Community Anti-Drug Coalitions of America (CADCA), 2019)]. Evaluation studies have shown that DFCs have contributed to reductions in substance use to levels lower than national averages. The program initially was founded in 1998 and the number of grantees has grown to more than 2000 nationally since then. Grantees receive up to $125,000 per year for up to five years and are eligible to reapply after completion of the initial funding period.

Despite the increased number of grantees, only about 33 percent of organizations that submit applications receive funding. In Maine, there currently are 18 community organizations receiving DFC funding (See Figure B-1 in Appendix B). In addition to DFCs, there are non-DFC funded drug-free community coalitions throughout Maine. Currently, there is no publicly available list of non-DFC community coalitions in Maine.

SPF-Rx and *PFS 2015* are substance use prevention programs funded by the U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) and managed by the Maine CDC. The overarching goal of *SPF-Rx* is to decrease the number of individuals living with opioid use disorder (Maine CDC, 2018c). A core goal of the *PFS 2015* program is to reduce prescription drug misuse among individuals 12 to 25 years of age (Maine CDC, 2018d).

Both *SPF-Rx* and *PFS 2015* utilize SAMHSA's Strategic Prevention Framework (SPF) model, which is designed to build capacity and infrastructure at the state and local levels to support substance use prevention efforts; support communities in identifying prescription drug misuse problems and mount programs to address them; and prevent the onset and reduce the progression of prescription drug misuse in the community (Maine CDC, 2018c; Maine CDC 2018d).

PFS 2015 and *SPF-Rx* use statewide and community-level strategies including public awareness campaigns, training and resources for medical professionals, promotion of prescription drug monitoring program (PDMP) registration, and drug take-back days. Figure B-2 in Appendix B illustrates the 21 community prevention organizations receiving *SPF-Rx* and *PFS 2015* funding. Currently, all organizations receive funding from both programs. Although a community prevention organization is not located in every county in Maine, all counties are reached because many organizations are responsible for more than one county.

Maine's *SEOW*, which is supported by the Maine CDC and funded by *PFS 2015*, employs an epidemiological analyst/SEOW Coordinator to track substance use consumption, protective factors, and consequences associated with substances (including prescription drugs/opioids) (Maine CDC 2018d). The *SEOW* focuses on substance use prevention rather than treatment. The SEOW Coordinator also is responsible for disseminating the findings using a variety of methods including a data dashboard, webinars, issue briefs, and annual statewide profile.

The *Prevention for States* program is funded by the U.S. CDC and managed by the Maine Office of Substance Abuse and Mental Health Services (SAMHS), which oversees the PDMP (Maine SAMHS, 2018). The overall goal of *Prevention for States* is to prevent and reduce prescription drug overdoses by strengthening resources needed to enhance the PDMP and supporting targeted interventions in high-burden communities. The 2018 *Prevention for States* evaluation report revealed that registration in the PDMP increased by 38 percent from 2017 to 2018; use of the PDMP increased, as evidenced by solicited reports (queries), which increased by 450% since 2015; and there was a 23 percent reduction in the number of prescriptions dispensed and a 28 percent reduction in the overall dosage of opioid agonists since 2015 (Maine SAMHS, 2018).

In addition to the existing prevention programs, Governor Janet Mills has outlined prevention initiatives in her *2019 Opioid Response Plan*, including implementing prevention programs in schools and high-risk areas and improving training and awareness of health care professional (Office of the Governor Janet T. Mills, 2019a).

Harm Reduction

Harm reduction aims to reduce the negative consequences associated with continued substance use. It accepts that an individual may continue to use the substance and focuses on minimizing consequences (Harm Reduction Coalition, 2019). Comprehensive harm reduction typically includes easy access to naloxone, syringe exchange programs, and pre-exposure prophylaxis (PrEP) [National Center on Addiction and Substance Abuse (CASA), 2017].

Naloxone

Although naloxone is available in communities throughout Maine, Governor Janet Mills has recognized the urgent need to expand availability. In her *2019 Opioid Response Plan*, the governor outlined key initiatives to expand access including allocating U.S. SAMHSA funds to purchase 35,000 doses of naloxone for distribution throughout the state (Office of the Governor Janet T. Mills, 2019a). Other naloxone initiatives in the governor's *Opioid Response Plan* include training family and friends of those at risk of an overdose on naloxone administration; encouraging providers prescribing more than 100 morphine milligram equivalents (MME) to co-prescribe naloxone; and evaluating the efficacy of naloxone distribution boxes in state owned and occupied facilities. Although not specifically related to naloxone, a Good Samaritan Law was passed in March of 2019 (LD 329, 2019), which exempts persons who report a drug-related medical emergency from criminal liability (Office of the Governor Janet T. Mills, 2019a).

Syringe Exchange Programs

There are three certified syringe exchange programs in Maine that operate exchanges in seven locations. See Figure B-3 in Appendix B for a map of the seven syringe exchange locations. The organizations managing the syringe exchanges and their associated exchange locations include the 1) City of Portland (Portland); 2) Maine General Medical Center/Health Reach Harm Reduction (Augusta and Waterville); and 3) Health Equity Alliance (Bangor, Belfast, Ellsworth, and Machias). There are no syringe exchange programs in three of the most vulnerable areas: Somerset County, northern Penobscot County, and northern Washington County

In general, the seven syringe exchanges have limited operating hours and only provide services a few days a week. This is largely due to the limited state and federal funding and the fact that most of the funding comes from private donations. In 2018 and 2019, Maine allocated $75,000 per year in funding to certified syringe exchange programs and it is not clear if this funding will continue after 2019 (LD 1707, 2018). This funding is managed by the Maine CDC, who distributes it to the three certified syringe exchange programs. In 2019, a bill (LD 1689, 2019) was proposed that would allocate an estimated $1.7 million dollars in state funding to exchanges, but the bill has been tabled in committee. Currently, no federal funds are allocated to support syringe exchanges despite the ban on the use of federal funding being lifted in January of 2016.

The review also found innovative syringe exchange programs in other states. For example, Nevada has a vending machine program, which provides sterile syringes, alcohol wipes, safe sex supplies, and a sharps disposal box that registered individuals can access twice a week (CASA, 2017). The Minnesota Department of Health's Pharmacy Syringe Access Initiative is a program enabling the purchase of clean syringes from pharmacies throughout the state, including many large pharmacy chains (*e.g.,* CVS, Walgreens, Walmart). This program also has a web-based database where individuals can locate participating pharmacies in their counties (Minnesota Department of Health, 2019)

Pre-Exposure Prophylaxis (PrEP)

PrEP in an FDA approved HIV prevention medication in which people who have tested negative for HIV take Truvada® once a day to reduce their risk of infection. It can be prescribed by licensed healthcare providers (*e.g.,* primary care providers) and an individual's insurance company may cover some or all of the cost. Currently, no state funding is allocated for PrEP, but it is covered by MaineCare. Gilead, the makers of PrEP, also offers the *Gilead Advancing Access* program, which provides financial support and/or assistance with co-payments (Frannie Peabody Center, 2019). Additionally, the Patient Access Network Foundation and the Patient Access Foundation both offer payment assistance for PrEP (Frannie Peabody Center, 2019).

The Maine CDC maintains a list of providers who prescribe PrEP, but report that it is under-prescribed. Results of two Maine CDC HIV, STD and Viral Hepatitis Program surveys revealed that few healthcare providers are prescribing PrEP despite being aware of it (Maine CDC, 2016). Currently, the Maine CDC is educating providers throughout the state to ensure that high-risk individuals are prescribed PrEP.

Treatment and Recovery

A variety of treatment and recovery services are located throughout Maine. Services include *2-1-1 Maine*, substance use treatment providers, Opioid Health Homes (OHHs), medication-assisted treatment (MAT) providers, recovery community centers, and recovery residences. There is some overlap in services provided between the different categories. For example, all Opioid Health Homes and many substance use treatment providers also prescribe MAT.

It is noteworthy that no centralized clearinghouse of treatment and recovery services in Maine exists that contains information about capacity, waitlists, location, and services provided. This made it difficult to determine if the information compiled for this assessment is up-to-date and comprehensive. Maine has started to address this issue. For example, in July of 2019, the state announced that Washington County and the Department of Health and Human Services will work with Healthy Acadia on a pilot project to create a phone system, available to anyone in Washington County to locate substance use disorder treatment and recovery services (Teboe, 2019).

Additionally, *2-1-1 Maine* maintains an updated resource list for a variety of services, including substance use treatment and recovery (*2-1-1 Maine*, 2019). The Opioid Task Force is compiling service information and exploring methods for creating a centralized list. Other states, such as Massachusetts and Rhode Island, recently have created web-based service databases. Rhode Island required its Department of Health to develop and maintain a real-time database of available inpatient and outpatient services (CASA, 2017), and Massachusetts created the *Massachusetts Behavioral Health Access* website, which helps providers locate openings (Massachusetts Behavioral Health Access, 2019).

2-1-1 Maine

2-1-1 Maine is a toll-free helpline that provides information and referrals for substance use treatment, including outpatient facilities, hospitals, and prevention programs, support groups, and other support services (*e.g.,* childcare, transportation, parenting skill development). Their seven Resource Coordinators are located throughout the state and are responsible for working with local organizations to ensure that the resource list is up to date (*2-1-1 Maine*, 2019).

Substance Use Treatment Providers

The U.S. SAMHSA Behavioral Health Treatment Services Locator (US SAMHSA, 2019a) lists 157 substance use treatment providers in Maine. Providers on the list include individual providers, medical practices, and community treatment organizations. Figure B-4 in Appendix B illustrates the locations of the substance use treatment providers in Maine. Among the vulnerable areas, only the Portland area of Cumberland County has a substantial number of providers.

Kennebec County has several providers in the Augusta and Waterville areas, but few in other areas of the county. Similarly, Penobscot has many providers in the Bangor area, but very few in other areas of the county. Washington County has a small number of providers in the southern inland and coastal areas, but very few in the northern areas, and Somerset has the fewest providers of the most vulnerable areas.

Opioid Health Homes

The 62 Opioid Health Homes (OHHs) in Maine utilize a “hub and spoke” team-based care model approach. Figure B-5 in Appendix B illustrates the locations of the OHHs in Maine. OHHs provide integrated, office-based MAT, dependency counseling, and comprehensive care management for eligible MaineCare members and uninsured individuals with opioid use disorder (MaineCare Services, 2019). The OHH “hub” is an intensive outpatient program (IOP) that treats patients in the acute phase of the recovery process. The hubs also are responsible for connecting patients to other social services. After the individual is stabilized, their long-term care is transferred to “spokes,” typically primary care providers in the individual’s local community (MaineHealth, 2019). There are no OHHs in Somerset County, northern Washington County, or northern Penobscot County.

Medication Assisted Treatment

Currently, there are ten methadone clinics (U.S. SAMHSA, 2019b) and 742 buprenorphine providers (U.S. SAMHSA, 2019c) in Maine. Among the most vulnerable areas, there are no methadone clinics in Somerset County. There are three in Penobscot County (Bangor), three in Cumberland County (Portland, South Portland, Westbrook), one in Kennebec County (Waterville), and one in Washington County (Calais).

Buprenorphine providers are located throughout Maine, but coverage is limited in northern Washington County, the very northern area of Penobscot County, and a majority of Somerset County (providers are only located in the southernmost area). In recent years, other states have employed various strategies to increase the number of MAT providers. For example, Virginia conducts trainings on addiction treatment that include a DATA 2000 waiver training, which the federal government requires that physicians complete to prescribe buprenorphine. Maryland law requires that all health care facilities have a physician who is authorized to prescribe MAT (CASA, 2017).

Recovery Community Centers

Recovery community centers are non-profit centers that offer local networks of non-medical, recovery support services (Recovery Research Institute, 2019). There are seven recovery community centers in Maine, and the Portland Recovery Community Center serves as the Maine Recovery Hub providing technical support to organizations throughout the state. Figure B-6 in Appendix B illustrates the recovery community center locations in Maine. Neither Kennebec County nor Somerset County have a recovery community center.

Recovery Residences

There are 101 recovery residences located throughout Maine (See Figure B-7 in Appendix B). Recovery residences include peer-run houses, monitored sober living homes, supervised housing, and residential treatment housing (U.S. SAMHSA, 2019d). In addition to person-specific services, residences typically require attendance at Narcotics Anonymous (NA) or Alcoholics Anonymous (AA) meetings and employment (U.S. SAMHSA, 2019c). There are no recovery residences in Somerset County or Washington County. In Kennebec County, a majority of residences are in the Augusta area, and Penobscot County has few residences outside of Bangor. Currently, only 28 of the 101 recovery residences in the state allow residents to take MAT (See Figure B-8 in Appendix B).

General Medical Services

This assessment also inventoried general medical services including hospitals, rural health clinics, Federally Qualified Health Centers, and mental health providers. Figures B-9 to B-12 in Appendix B illustrate the locations of the general medical services in Mane. Overall, Somerset County, northern Penobscot County, and northern Washington County have very few general medical services.

Although it is not known if the general medical services inventoried offer substance use prevention or treatment services, they could potentially be encouraged to implement substance use programs in the future. For example, the state could provide screening, brief intervention, and referral to treatment (SBIRT) trainings and encourage providers to become OHH spokes, buprenorphine prescribers, and PrEP prescribers. Maine can also implement similar programs to those being implemented in other states. For example, Project ASSERT is an emergency department program in Connecticut and Massachusetts where non-clinician health advocates conduct SBIRT, and New York has a program that incorporates SBIRT into primary care practices and emergency departments (CASA, 2017).

Law Enforcement and Criminal Justice

Drug Treatment Courts

The six Adult Drug Treatment Courts (ADTCs) in Maine are located in Alfred (York County), Portland (Cumberland County), Auburn (Androscoggin County), Bangor (Penobscot County), Machias (Washington County), and Calais (Washington County) (See Figure B-13 in Appendix B). ADTCs are open to adults 18 years and older who have committed nonviolent crimes or probation violations and have a diagnosed substance use disorder (State of Maine Judicial Branch, 2019a). Offenders must be residents in a county where there is an ADTC to participate. Unfortunately, there are no ADTCs in Kennebec and Somerset Counties, which are two of the most vulnerable counties. ADTC programs involve judicial monitoring, treatment, case management services, and other services such as housing, employment, and medical care. After successfully completing the program, offenders receive a reduced sentence.

Maine has three Family Treatment Drug Courts (FTDCs) that are located in Augusta (Kennebec County), Lewiston (Androscoggin), and Bangor (Penobscot). These are civil courts that work with parents with substance use disorders whose children are at risk of abuse or neglect due to the parents' drug use (State of Maine Judicial Branch, 2019b). FTDCs integrate substance use disorder treatment, child welfare services, mental health, and social services agencies. Maine's three FTDCs work with families with open Department of Health and Human Services Child Protective cases in Androscoggin, Franklin, Oxford, Kennebec, Penobscot, and Piscataquis Counties (also shown in Figure B-13 in Appendix B). Among the most vulnerable counties, Cumberland, Somerset, and Washington do not have access to a FTDC.

Alternative Sentencing Programs

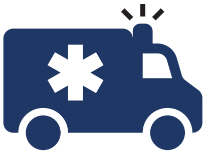
In addition to treatment courts, Maine also has an alternative sentencing program, which offers first- and second-time non-violent offenders an alternative to jail (Maine Pretrial Services, 2017). This program is open to any resident in Maine, but a judge must sentence an offender to the program. The offenders serve the equivalent of his or her sentence in a residential setting where they perform community service daily and attend substance use education nightly. Offenders must pay for the cost of the program.

Law Enforcement and First Responder Interventions

It is unclear how many local law enforcement agencies in Maine have implemented pre-charge diversion programs for individuals with substance use disorders. In their 2017 report, the Maine Opioid Collaborative Law Enforcement Task Force recommended that the state support and encourage effective pre-charge law enforcement programs. More specifically, the task force stated that the state should "develop treatment/recovery resources in each prosecutorial district that would be available to all law enforcement agencies in that jurisdiction to contact for treatment/recovery services" (Maine Opioid Collaborative Law Enforcement Task Force, 2017).

Maine should prioritize working with law enforcement and other first responder agencies (*e.g.,* fire departments, emergency medical services) in the most vulnerable areas and assess what they are doing to address the opioid epidemic in their jurisdictions. Additionally, the state should look to successful programs being implemented in Maine and other states.

In 2016, the Portland Police Department started the Law Enforcement Addiction Advocacy Program (LEAAP). The LEAAP Substance Use Disorder Liaison targets known drug users and provides support and treatment options, educates police officers and the community, and provides assistance to family members and friends in need of help for their loved ones with substance use disorders (City of Portland, 2019) Further, in April of 2019, Knox County announced a new initiative involving a collaboration between the county's four law enforcement agencies and local health care and community organizations. The goal of the collaboration is to create a network of addiction and recovery resources (Abbot, 2019).



Outside of Maine, the Gloucester Police Department in Massachusetts created the Angel Project that permits individuals to turn in their drugs without being arrested and connects them to a volunteer who guides them to treatment programs (CASA, 2017). In Ohio, the Lucas County Sheriff's Office's Drug Abuse Response Team connects law enforcement officers with individuals who have experienced an overdose. Officers help individuals through the recovery process for two years (CASA, 2017). In Manchester, New Hampshire, every fire station is designated as a safe environment for individuals with substance use disorder who are seeking treatment. An individual can come to any station 24 hours day and a firefighter will take them to a treatment facility (City of Manchester, 2019).

Substance Use Disorder Treatment in Jails and Prisons

It is imperative that jails and prisons provide evidence-based treatments for individuals with substance use disorders (CASA, 2017). Penobscot, Kennebec, and Cumberland Counties recently began providing MAT to inmates. Currently, neither Somerset County nor Washington County jails provide MAT. Maine will begin offering MAT to inmates at several state correctional facilities, including the Maine Correctional Center, the Bolduc Correctional Facility, and the Southern Maine Women's Reentry Center. Inmates must be within six months of release to participate in this pilot program (Abbate, 2019).

Summary of Services in the Most Vulnerable Areas

Overall, the evaluation of existing prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice services in the most vulnerable areas revealed a lack of services in Somerset County, northern Penobscot County, and Washington County (especially in the northern area). The Portland area of Cumberland County, Augusta area of Kennebec, and Bangor area of Penobscot County have access to the most services.

Overall Assessment Summary, Recommendations, and Dissemination Plan

The vulnerability assessment described in this report used the U.S. CDC's vulnerability index methodology (Van Handel et al., 2016) to identify communities in Maine that are particularly vulnerable to opioid overdoses and bloodborne infections associated with non-sterile injection opioid use.

The aims of the assessment were to:

1. Use a data-driven social indicator approach to identify sub-state areas at high risk for opioid overdoses and bloodborne infections associated with non-sterile injection opioid use
2. Use findings from the vulnerability assessment to make recommendations for interventions that strategically allocate services to sub-state areas at greatest risk

The assessment was conducted from February to July of 2019. It was guided by a 15-member Vulnerability Assessment Stakeholder Group representing 13 organizations throughout Maine. It employed a multi-step approach to achieve its aims. Steps included compiling a list of 120 candidate indicator variables; using two statistical approaches to identify the most vulnerable areas (Social Vulnerability Index and Poisson regression modelling); reviewing the literature and national best practices for prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice approaches; evaluating existing services available in the most vulnerable areas in Maine; and making recommendations for strategically placed interventions

Opioid-related statistical analyses were conducted at the county and subcounty levels, but bloodborne infection analyses only were done at the county level because data were not available at the subcounty level. The bloodborne infection analyses indicated that Penobscot, Kennebec, and Washington Counties were the most vulnerable followed by Androscoggin, Somerset, and Waldo Counties.

Findings from the opioid-related statistical analyses revealed nine highly vulnerable subcounty areas (Portland area of Cumberland County, the northern and southern areas of Kennebec County, the northern and Bangor areas of Penobscot County, the northern and southern areas of Somerset County, and the northern and southern areas of Washington County). The Portland area of Cumberland County, the southern area Kennebec County, and the entirety of Washington County were the most vulnerable areas.

After synthesizing the opioid-related findings with the bloodborne infection findings, this assessment identified five sub-state areas that interventions should target: Kennebec County, Penobscot County, the Portland area of Cumberland County, Somerset County, and Washington County.

Overall, the evaluation of existing prevention, harm reduction, treatment/recovery, and law enforcement/criminal justice services in the most vulnerable areas of Maine revealed a lack of services in Somerset County, northern Penobscot County, and Washington County (especially in the northern area). The Portland Area of Cumberland County, Augusta area of Kennebec, and Bangor area of Penobscot County have access to the most services.

Recommendations

Findings from this assessment indicate several areas of focus for improved services in the most vulnerable areas in Maine. With the help of the stakeholder group, PCG developed two sets of recommendations. The first set is intended for the Maine CDC HIV, STD, and Viral Hepatitis Program, and specifically focus on short-term recommendations associated with bloodborne infections. The second set include both opioid overdose and bloodborne infection recommendations and most will require coordination among multiple state and/or private agencies.

Maine CDC HIV, STD, and Viral Hepatitis Program Recommendations

Prevention

1. Work with community prevention organizations to incorporate overdose and bloodborne infection prevention into the services they provide. Prioritize working with organizations in the most vulnerable areas.
2. Continue working with community partners in the most vulnerable areas and encourage them to increase access to free or reduced cost HIV, Hepatitis B, and Hepatitis C testing. Assist them with implementing non-invasive testing methods such as rapid HIV testing via oral swabs and Hepatitis C testing via finger pricks.

Harm Reduction

1. Research additional sources of state, federal, and private funding for syringe exchange programs. Use funding to open syringe exchange programs in Somerset County and northern Washington County and expand operating hours and staff at the seven existing exchange locations.
2. Continue to provide PrEP education to healthcare providers and patients and focus efforts in the most vulnerable areas.

Treatment and Recovery

1. Explore ways to increase availability of telehealth for hepatitis.

Recommendations for Other State Government and/or Private Agencies

Prevention

1. Encourage the Maine Department of Education and Maine CDC's Division of Disease Prevention to implement evidence-based substance use and bloodborne infection prevention programs in schools. Programs should specifically target high-risk youth, such as those who have experienced adverse childhood experiences.
2. Work with the Maine legislature on legislation requiring that HIV, Hepatitis B, and Hepatitis C testing be offered to all individuals receiving hospital or primary care services. Look to the 2010 New York state law that mandates HIV testing be offered to all people between the ages of 13 and 64 who are receiving hospital or primary care services.

Harm Reduction

1. Investigate the feasibility of implementing innovative syringe exchange programs such as satellite syringe exchange units, vending machines, and pharmacy exchanges.
2. Explore implementing a safe injection site pilot program in the most vulnerable urban areas, such as Bangor and Portland.
3. Thoroughly assess naloxone availability in the most vulnerable areas and investigate ways to expand access if needed.
4. Implement comprehensive case management programs for active substance users, especially in the most vulnerable areas. Programs should not require an individual be enrolled in substance use treatment to receive services.

Treatment and Recovery

1. Employ strategies used by other states to increase the number of MAT providers in the most vulnerable areas, especially in Somerset County and northern Washington County. For example, Virginia conducts trainings on addiction treatment that include a DATA 2000 waiver training to encourage MAT participation and Maryland law requires that all health care facilities have a physician who is authorized to prescribe MAT.
2. Encourage organizations in the most vulnerable areas to become Opioid Health Home hubs, especially organizations in Somerset County and northern Washington County. This will ensure that all individuals in treatment and recovery have access to comprehensive case management services.
3. Develop a centralized web-based database of treatment and recovery services, similar to Massachusetts and Rhode Island, which is updated on an ongoing basis and contains information about capacity, waitlists, services provided, location, and cost.
4. Provide screening, brief intervention, and referral to treatment (SBIRT) trainings to staff (clinical and non-clinical) at general healthcare organizations. Look to programs being implemented in other states, such as the ASSERT program in Connecticut and Massachusetts.

5. Encourage providers at general healthcare organizations to become Opioid Health Home spokes, buprenorphine prescribers, PrEP prescribers, and to incorporate bloodborne infection testing into their clinical workflows.
6. Increase the availability of telehealth for MAT, HIV, Hepatitis B, and Hepatitis C.
7. Work with the Maine Association of Recovery Residences to increase the number of recovery residences in areas outside of Cumberland County and require that residencies accept individuals on MAT.
8. Assist the Portland Recovery Community Center, which serves as the Maine Recovery Hub, in opening centers in vulnerable areas that do not currently have one (Kennebec County and Somerset County).
9. Partner with the Maine State Housing Authority, Community Housing of Maine, local jurisdictions, and other local community organizations to create homelessness programs based on the "Housing First" model. Prioritize opening programs in vulnerable areas that currently do not have programs.

Law Enforcement and Criminal Justice

1. Encourage the Maine Judicial Branch to expand access to Adult Drug Treatment Courts and Family Treatment Drug Courts.
2. Explore sources of funding to reduce the participation cost of alternative sentencing programs so that all eligible individuals can participate.
3. Assess what law enforcement and other first responder agencies (*e.g.,* fire department, EMS) are doing to address the opioid epidemic in the most vulnerable areas. Work with the agencies to implement programs like the Portland Police Department's Law Enforcement Addiction Advocacy Program (LEAAP), Gloucester, Massachusetts' Angel Project, and Lucas County Ohio's Drug Abuse Response Team.
4. Work with the Somerset and Washington County sheriff's departments to implement MAT in county jails.

Dissemination Plan

In collaboration with the stakeholder group, PCG identified several strategies for disseminating the findings. The primary dissemination method is distribution of the fact sheet and executive summary to a diverse set of organizations throughout the state. Secondary dissemination methods, which are more time-intensive, include presenting findings at local meetings in the most vulnerable areas and at conferences. This section outlines the proposed groups to target.

Healthcare and Substance Use Treatment Providers

- Provide the fact sheet and executive summary to hospitals, Federally Qualified Health Centers, primary care practices, and substance use treatment providers in the most vulnerable counties.

Law Enforcement and Criminal Justice Agencies

- Provide the fact sheet and the executive summary to county sheriff's departments, town/city police departments, district attorney's offices, state prisons, and county jails.

Local Social Service Organizations

- Provide the fact sheet and executive summary to local organizations providing social services related to employment, housing, substance use prevention (*e.g.,* Drug Free Communities), and child welfare.

Local Government Leadership

- Present findings at city/town council meetings and school board meetings in the most vulnerable areas.
- Provide the fact sheet and executive summary to town and city governments throughout the state.

Maine CDC Division of Disease Prevention

- Present findings at the bi-monthly Tobacco and Substance Use Prevention Advisory Board meeting.

Maine Director of Opioid Response

- Meet with Gordon Smith, the Director of Opioid Response, to discuss findings.

Professional Associations and Conferences

- Provide the fact sheet and executive summary to a variety health-related, law enforcement, and criminal justice professional associations such as the

Maine Medical Association, Maine Hospital Association, Maine Association of Police, and Maine State Bar Association.

- Present findings at conferences, including the 2019 Northeast Epidemiology Conference and 2019 Maine Prevention Professionals Conference.

Public Health District Coordinating Councils (DCC)

- Provide the fact sheet and executive summary to the nine DCCs in the state.
- Present findings at DCC meetings in the most vulnerable counties: District 2 (Cumberland), District 5 (Somerset and Kennebec), District 6 (Penobscot), and District 7 (Washington).

Statewide Epidemiology Outcomes Workgroup

- Present findings at the quarterly SEOW opioid data meeting.

References

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Appendix A. County and Subcounty Maps and Rates

Figure A-1. Counties

Figure A-2. Subcounty Areas

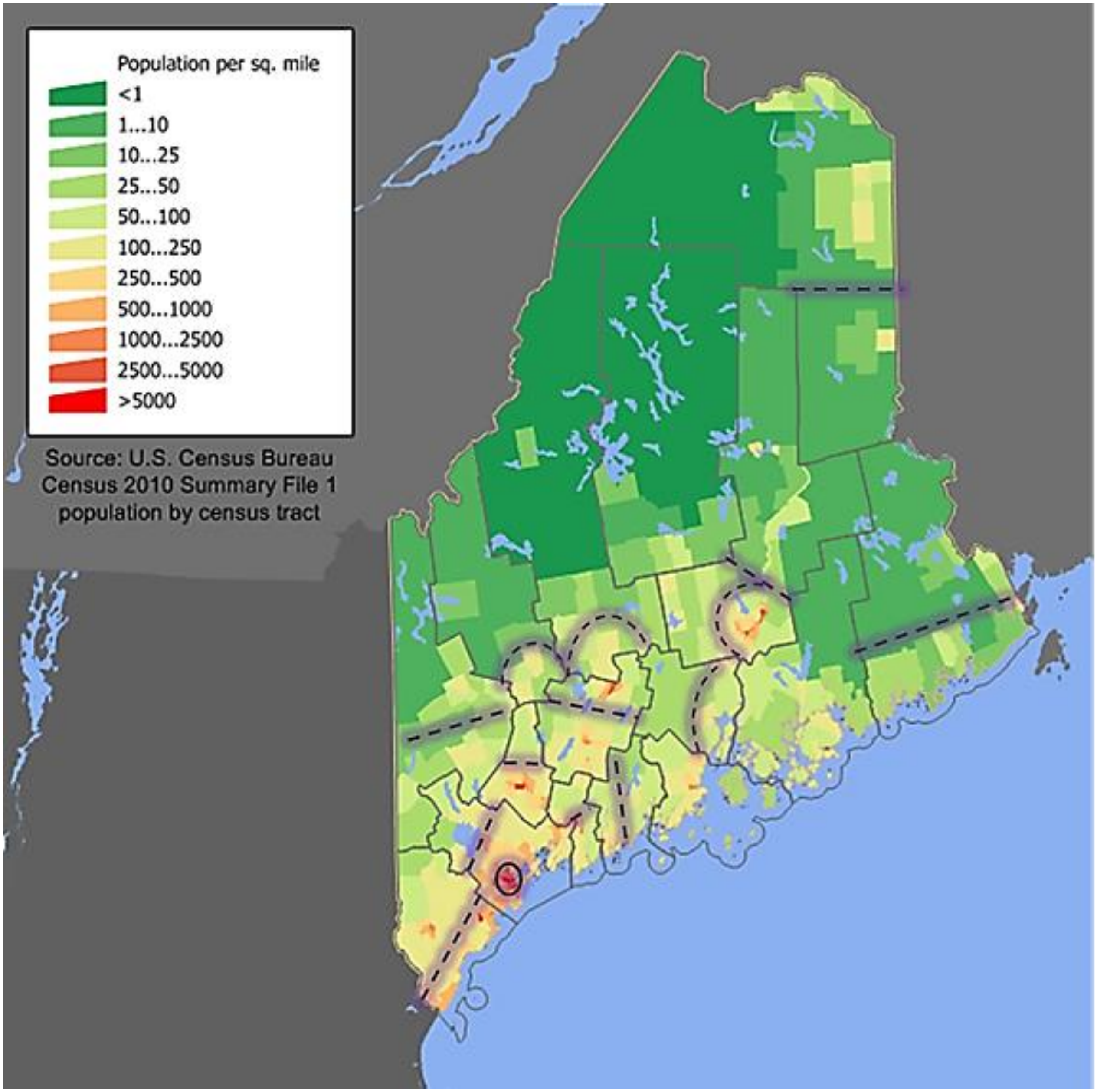
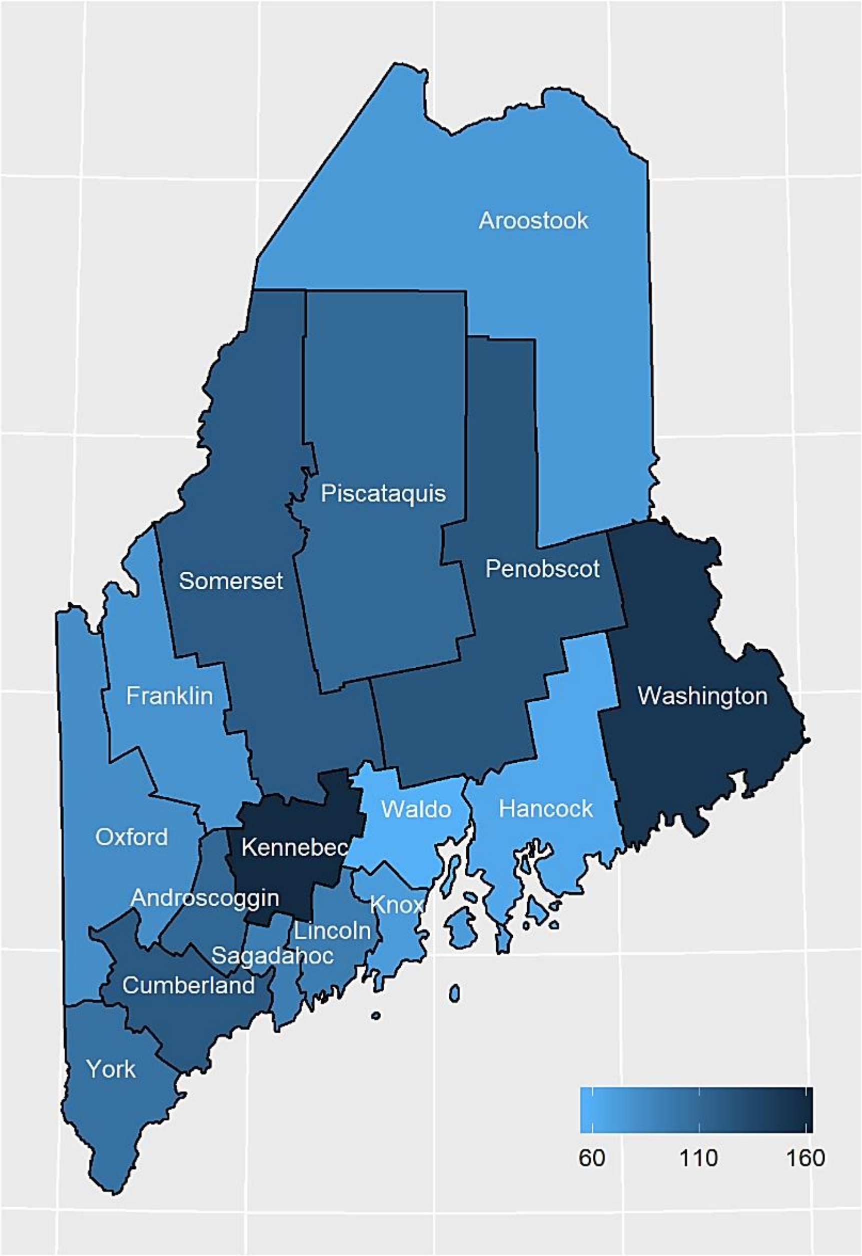


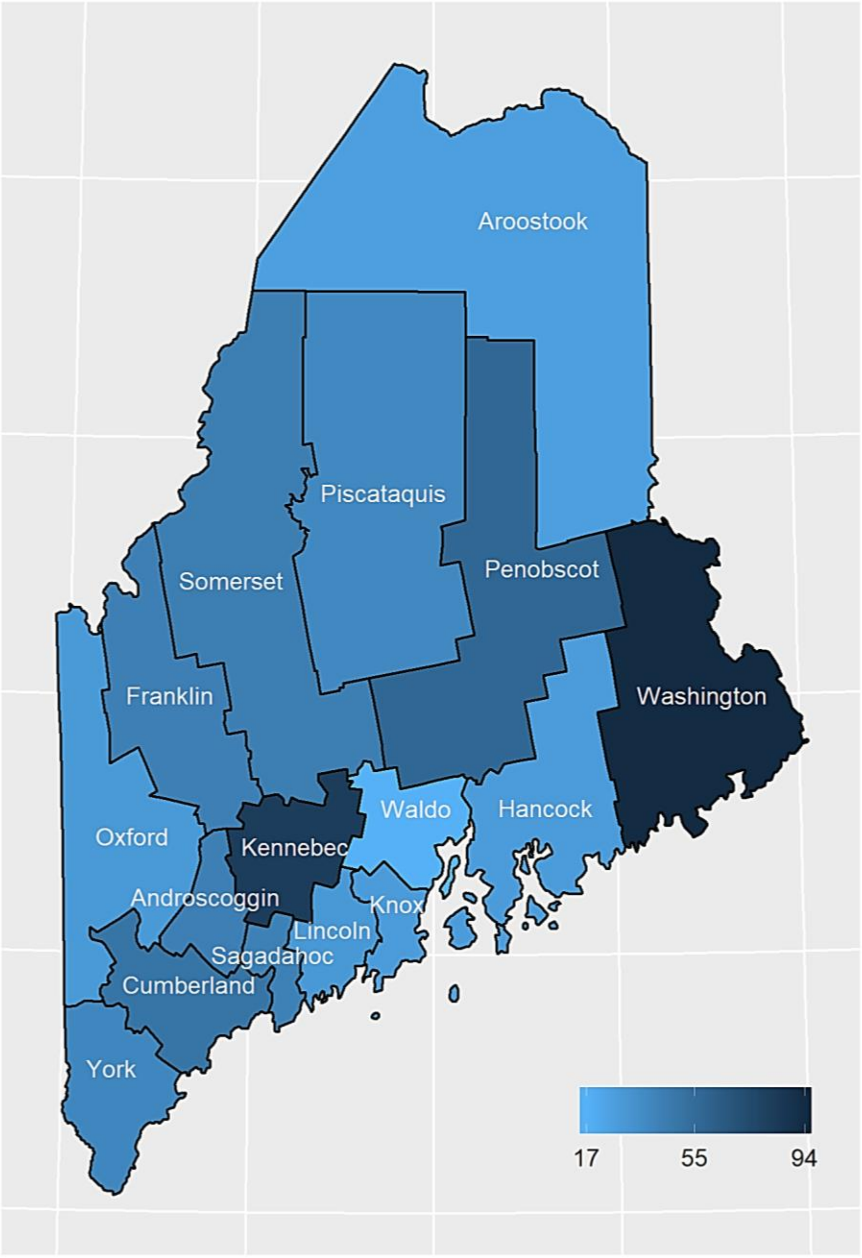
Figure A-3. Non-Fatal Opioid Overdose *Per Capita* Rates



County	Rate
Waldo	57.3
Hancock	63.3
Knox	71.8
Aroostook	73.4
Franklin	77.9
Oxford	82.1
Sagadahoc	93.9
Lincoln	94.1
York	102.5
Piscataquis	109.1
Androscoggin	110.4
Somerset	119.6
Cumberland	121.7
Penobscot	123.8
Washington	150.8
Kennebec	160.4

Counties with higher rates are shown in darker colors.

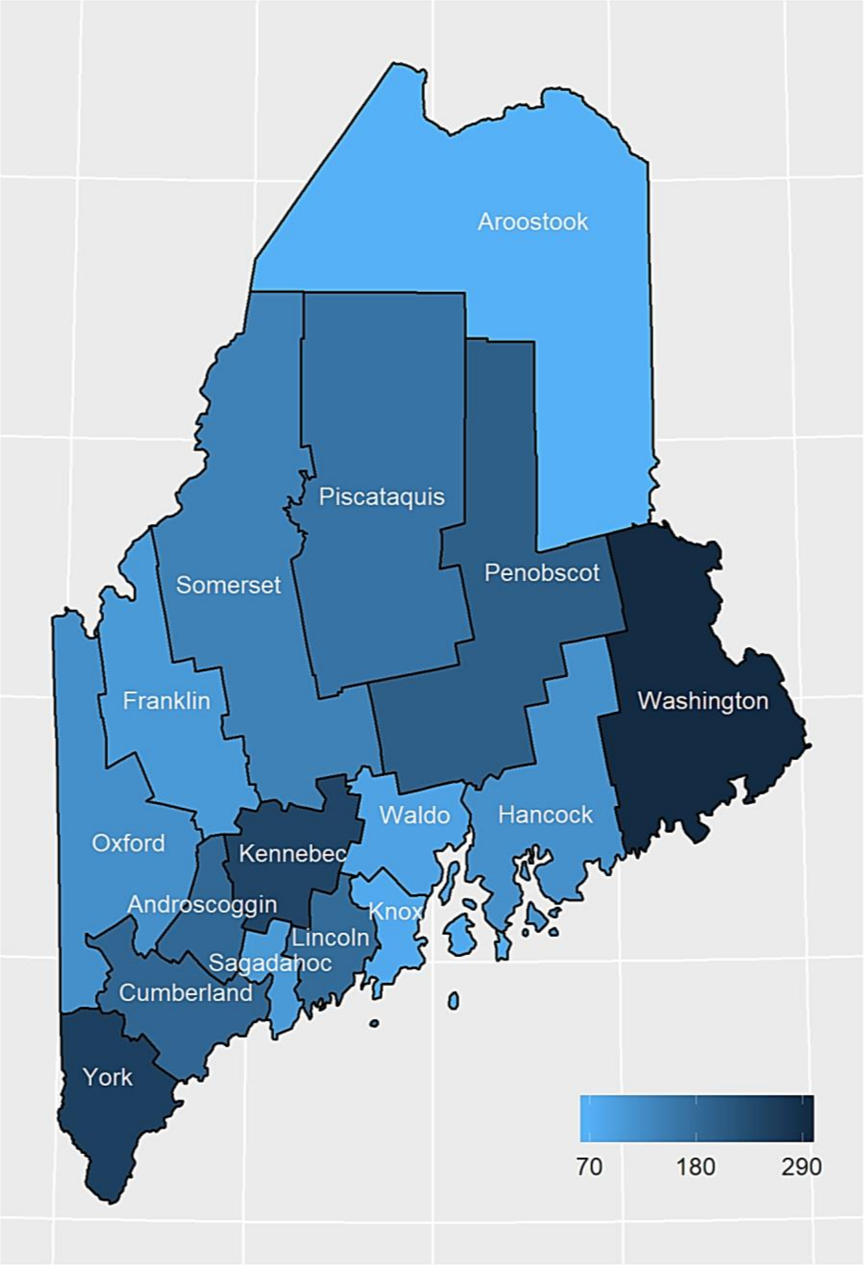
Figure A-4. Non-Fatal Heroin Overdose *Per Capita* Rates



County	Rate
Waldo	16.5
Aroostook	26.1
Hancock	27.5
Knox	27.7
Oxford	28.8
Lincoln	29.4
Piscataquis	38.3
York	39.2
Sagadahoc	42.7
Androscoggin	42.9
Franklin	43.1
Somerset	44.1
Cumberland	49.1
Penobscot	57.1
Kennebec	82.45
Washington	94.27

Counties with higher rates are shown in darker colors.

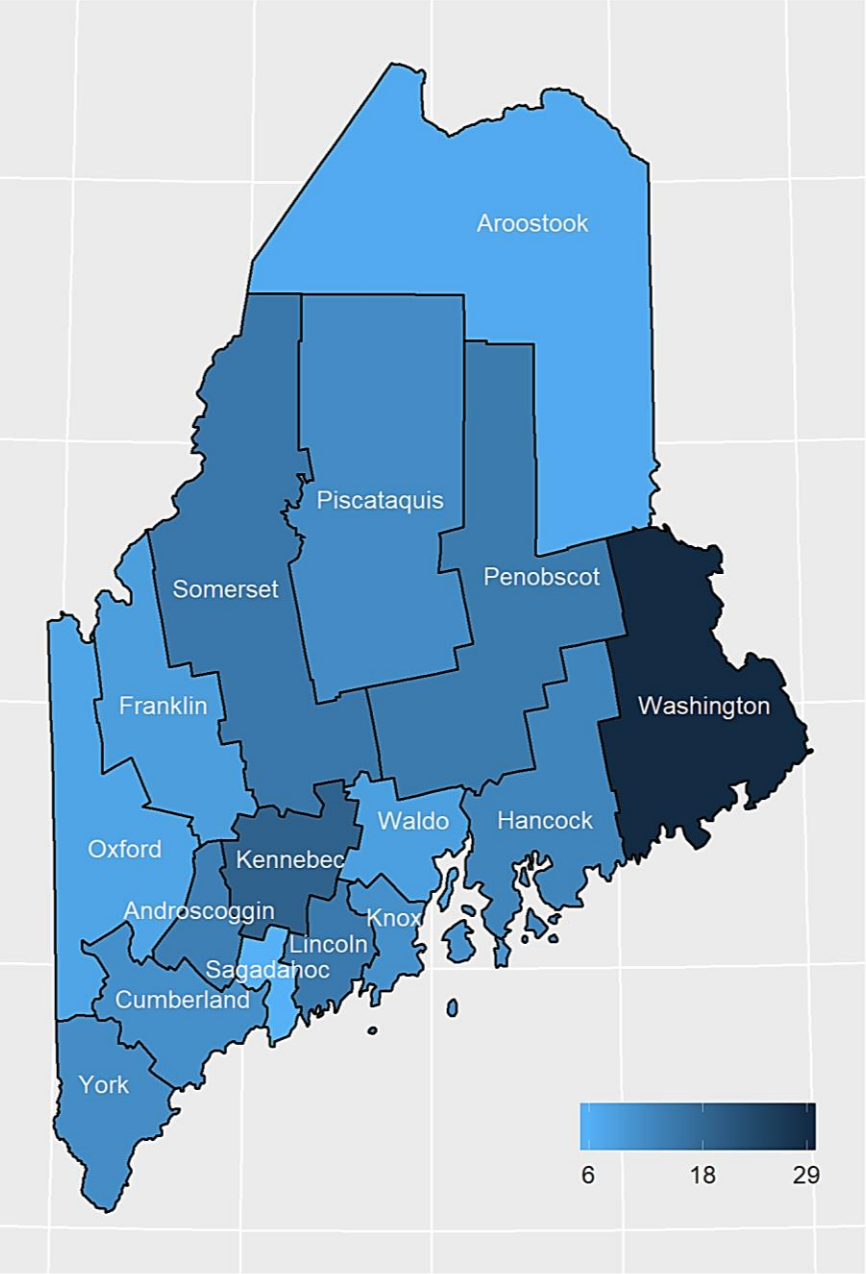
Figure A-5. Naloxone Administration Incident *Per Capita* Rates



County	Rate
Aroostook	66.1
Knox	78.1
Waldo	89.1
Sagadahoc	102.4
Franklin	102.7
Hancock	118.4
Oxford	118.8
Somerset	141.2
Piscataquis	165.1
Lincoln	177.8
Androscoggin	184.0
Cumberland	188.5
Penobscot	200.3
Kennebec	246.5
York	254.6
Washington	295.4

Counties with higher rates are shown in darker colors.

Figure A-6. Opioid-Related Mortality *Per Capita* Rates



County	Rate
Sagadahoc	5.7
Aroostook	6.8
Oxford	7.6
Waldo	8.5
Franklin	8.8
Knox	10.9
Cumberland	11.2
York	11.6
Piscataquis	11.8
Hancock	12.9
Androscoggin	13.7
Penobscot	14.7
Lincoln	14.7
Somerset	15.0
Kennebec	19.0
Washington	29.3

Counties with higher rates are shown in darker colors.

Table A-1. Subcounty Non-Fatal Opioid Overdose *Per Capita* Rates

Subcounty Area	Rate
Franklin_North	32.9
Waldo_East	49.4
Hancock	64.3
Aroostook_South	65.1
Waldo_West	65.5
Oxford_South	65.7
Knox	71.8
Aroostook_North	76.2
Cumberland_East	82.2
Sagadahoc_West	82.7
Penobscot_West	88.0
Androscoggin_North	88.0
Lincoln_East	89.4
Franklin_South	95.9
Lincoln_West	98.3
York_East	100.5
Cumberland_West	103.3
York_West	104.6
Sagadahoc_East	106.0
Somerset_North	109.3
Penobscot_North	109.7
Oxford_North	111.0
Piscataquis	111.6
Androscoggin_South	114.8
Somerset_South	122.5
Penobscot_Bangor	130.1
Kennebec_North	139.7
Washington_North	143.6
Washington_South	154.9
Kennebec_South	174.1
Cumberland_Portland	198.9

Table A-2. Subcounty Non-Fatal Heroin/Fentanyl Overdose *Per Capita* Rates

Subcounty Area	Rate
Franklin_North	13.2
Waldo_East	14.8
Aroostook_South	15.5
Waldo_West	18.3
Lincoln_East	24.7
Knox	27.7
Oxford_North	27.7
Hancock	28.4
Oxford_South	28.9
Aroostook_North	29.5
Androscoggin_North	31.2
Lincoln_West	33.7
Cumberland_East	34.5
Penobscot_East	36.1
York_West	36.4
Sagadahoc_West	38.6
Piscataquis	39.2
Cumberland_West	40.7
York_East	41.8
Somerset_South	43.7
Androscoggin_South	45.1
Somerset_North	46.8
Sagadahoc_East	47.1
Penobscot_North	53.9
Franklin_South	54.8
Kennebec_North	57.9
Penobscot_Bangor	60.1
Washington_North	75.6
Cumberland_Portland	78.1
Kennebec_South	98.7
Washington_South	106.8

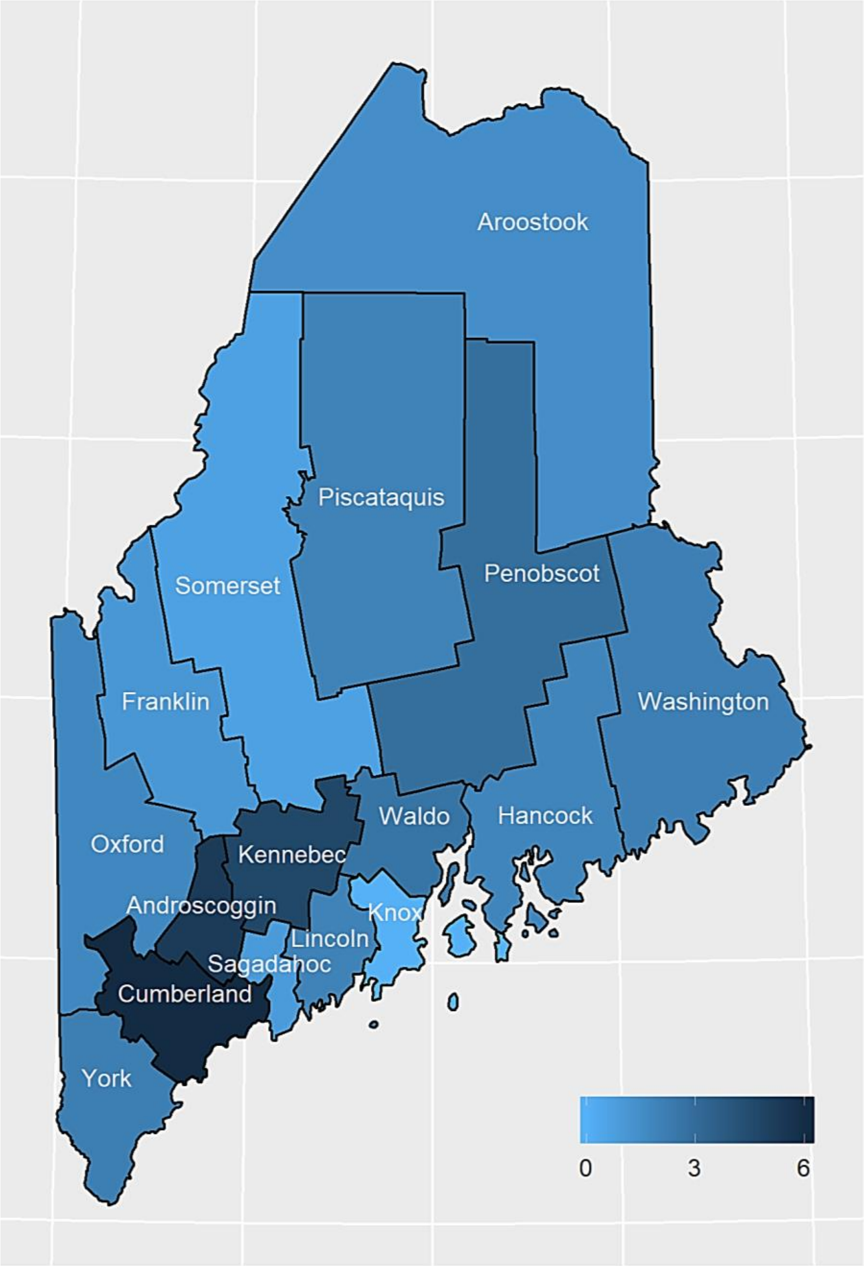
Table A-3. Subcounty Naloxone Administration Incident *Per Capita* Rates

Subcounty Area	Rate
Aroostook_South	41.7
Waldo_West	69.6
Aroostook_North	73.9
Androscoggin_North	76.2
Knox	78.1
Sagadahoc_West	80.0
Penobscot_North	96.1
Lincoln_East	96.6
Franklin_North	98.7
Franklin_South	107.3
Waldo_East	107.4
Oxford_South	108.2
Cumberland_West	117.8
Hancock	121.9
Sagadahoc_East	126.6
Oxford_North	135.4
Cumberland_East	137.3
Somerset_North	141.2
Somerset_South	141.8
Lincoln_West	161.9
Penobscot_West	166.5
Piscataquis	168.9
Kennebec_North	204.6
Androscoggin_South	205.2
York_West	216.4
Penobscot_Bangor	227.5
Washington_South	260.8
Kennebec_South	274.3
York_East	290.5
Cumberland_Portland	305.9
Washington_North	341.5

Table A-4. Subcounty Opioid-Related Mortality *Per Capita* Rates

Subcounty Area	Rate
Sagadahoc_West	3.7
Lincoln_East	4.1
Oxford_South	5.3
Aroostook_North	6.4
Somerset_North	6.9
Cumberland_East	7.5
Androscoggin_North	7.6
Franklin_South	7.6
Sagadahoc_East	7.9
Waldo_East	8.2
Aroostook_South	8.3
York_West	8.5
Cumberland_West	8.7
Waldo_West	8.7
Franklin_North	8.8
Knox	10.9
Oxford_North	11.8
Hancock	13.2
Penobscot_North	13.3
Penobscot_Bangor	14.0
Piscataquis	14.1
York_East	14.4
Androscoggin_South	14.9
Penobscot_West	15.0
Kennebec_North	15.2
Somerset_South	17.8
Cumberland_Portland	17.9
Kennebec_South	21.5
Lincoln_West	24.3
Washington_South	28.5
Washington_North	30.2

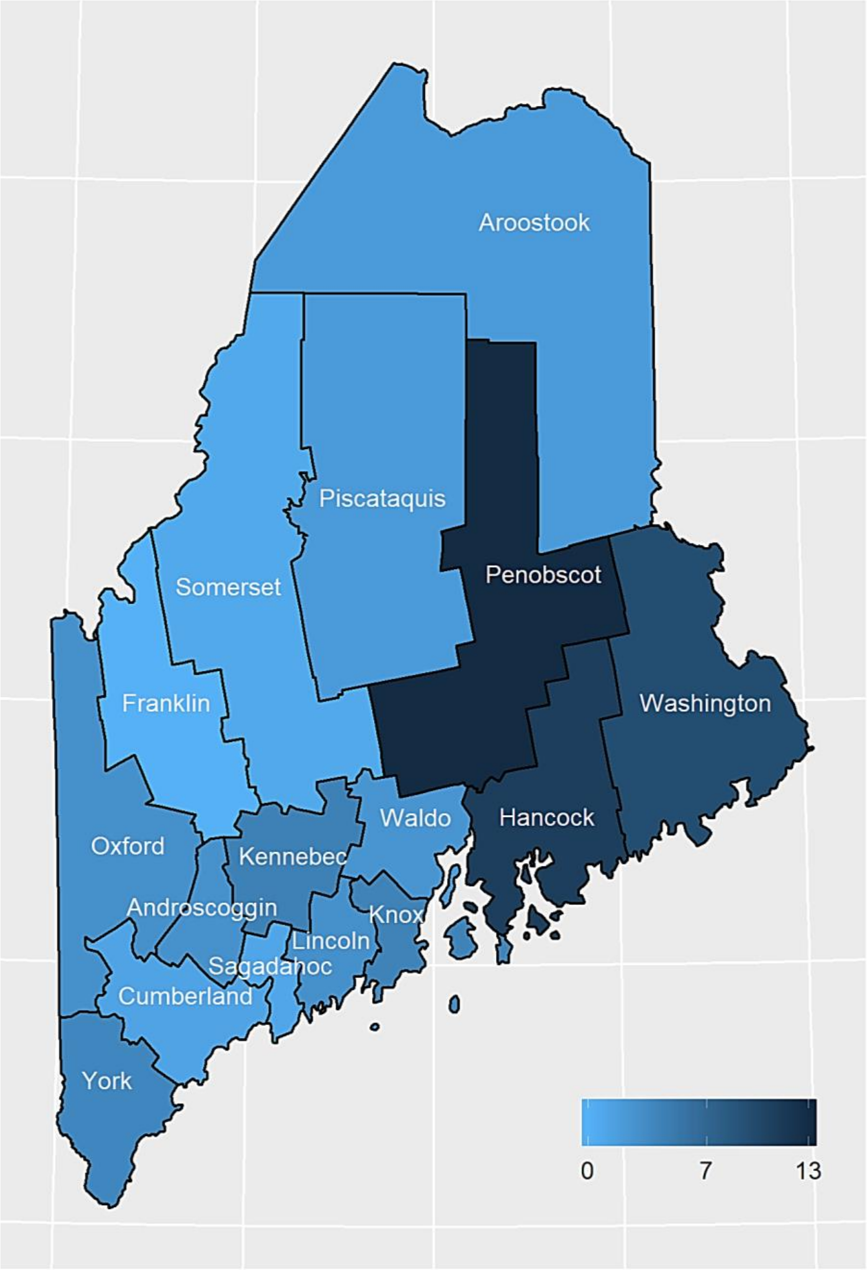
Figure A-7. HIV *Per Capita* Rates



County	Rate
Knox	0.0
Somerset	0.7
Sagadahoc	0.9
Franklin	1.1
Aroostook	1.5
Oxford	1.7
Hancock	1.8
Lincoln	2.0
Piscataquis	2.0
Washington	2.1
York	2.2
Waldo	2.5
Penobscot	2.8
Kennebec	4.7
Androscoggin	5.3
Cumberland	6.1

Counties with higher rates are shown in darker colors.

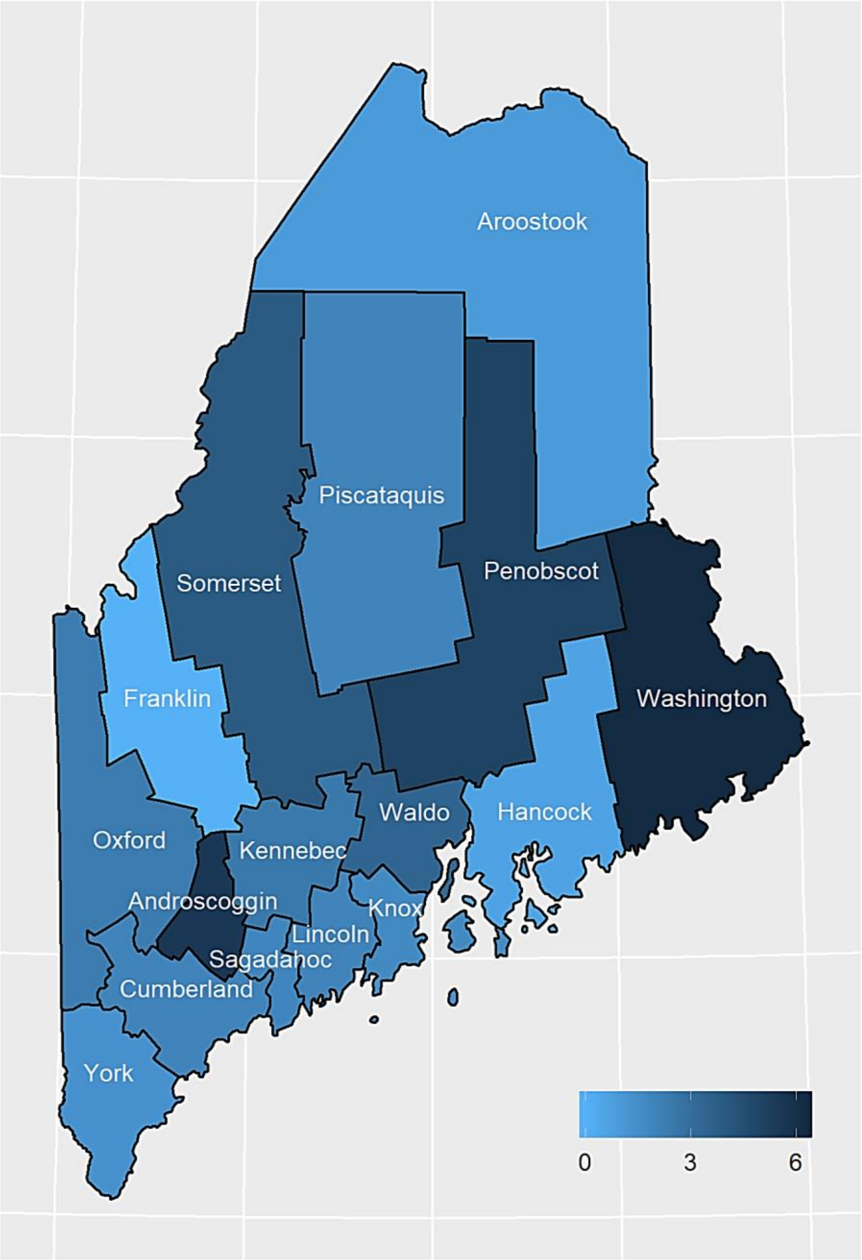
Figure A-8. Acute Hepatitis B *Per Capita* Rates



County	Rate
Franklin	0.0
Somerset	0.7
Sagadahoc	0.9
Cumberland	1.2
Aroostook	1.9
Piscataquis	2.0
Waldo	2.5
Androscoggin	2.8
Oxford	2.9
Lincoln	2.9
York	3.8
Knox	4.2
Kennebec	4.4
Washington	9.4
Hancock	11.0
Penobscot	13.1

Counties with higher rates are shown in darker colors.

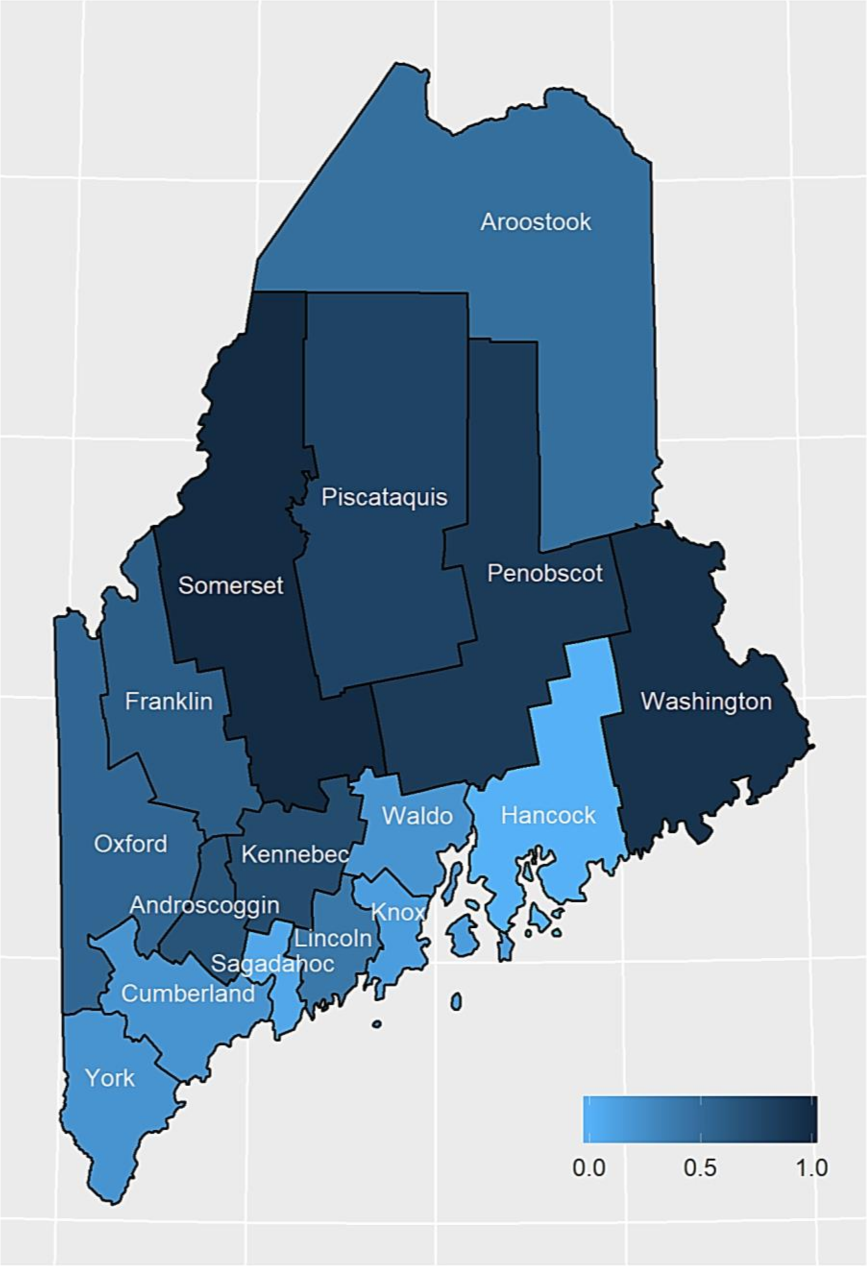
Figure A-9. Acute Hepatitis C *Per Capita* Rates



County	Rate
Franklin	0.0
Hancock	0.6
Aroostook	1.0
York	1.3
Knox	1.7
Sagadahoc	1.9
Lincoln	2.0
Cumberland	2.0
Piscataquis	2.0
Oxford	2.3
Kennebec	2.5
Waldo	3.4
Somerset	3.9
Penobscot	5.0
Androscoggin	5.6
Washington	6.3

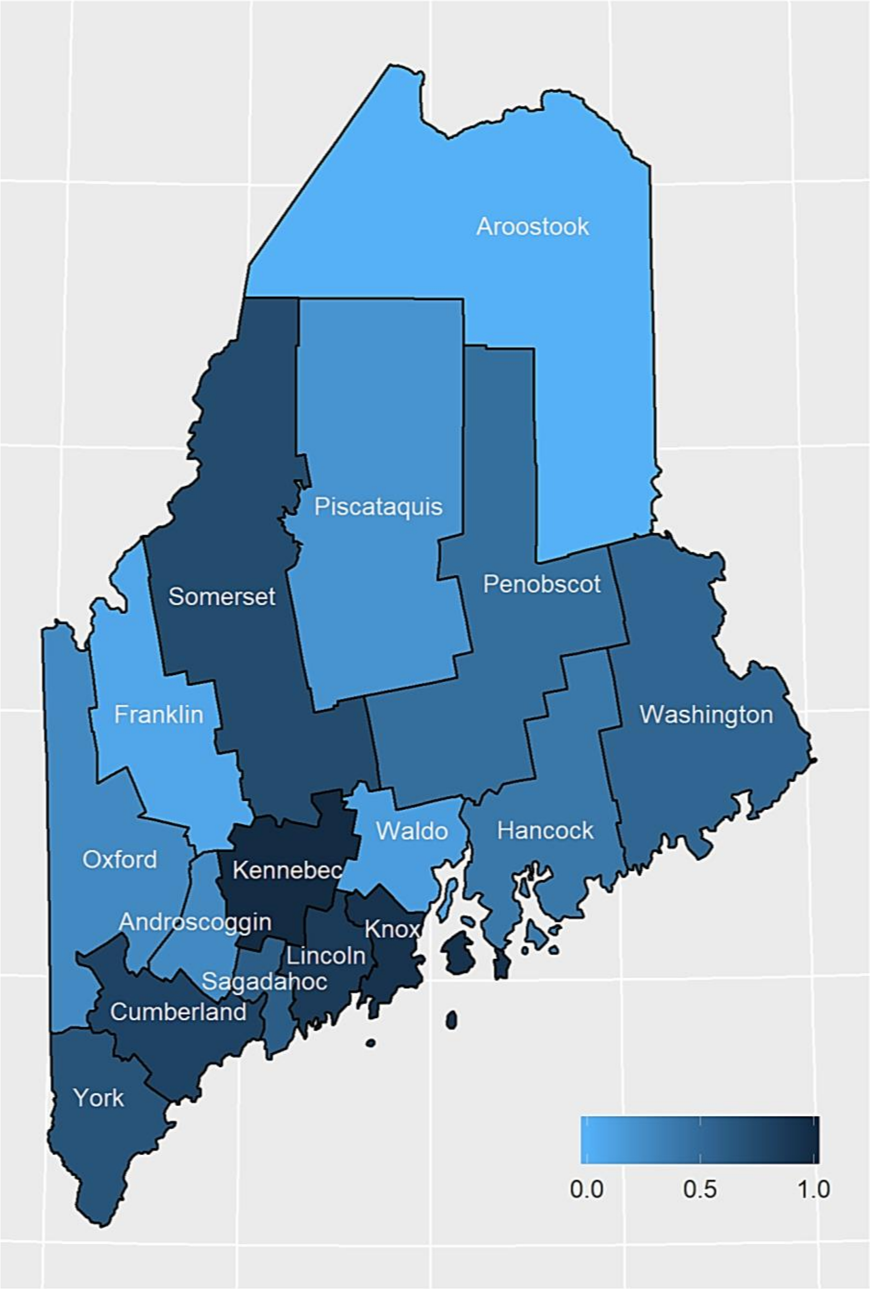
Counties with higher rates are shown in darker colors.

Figure A-10. Overall Social Vulnerability Index Map



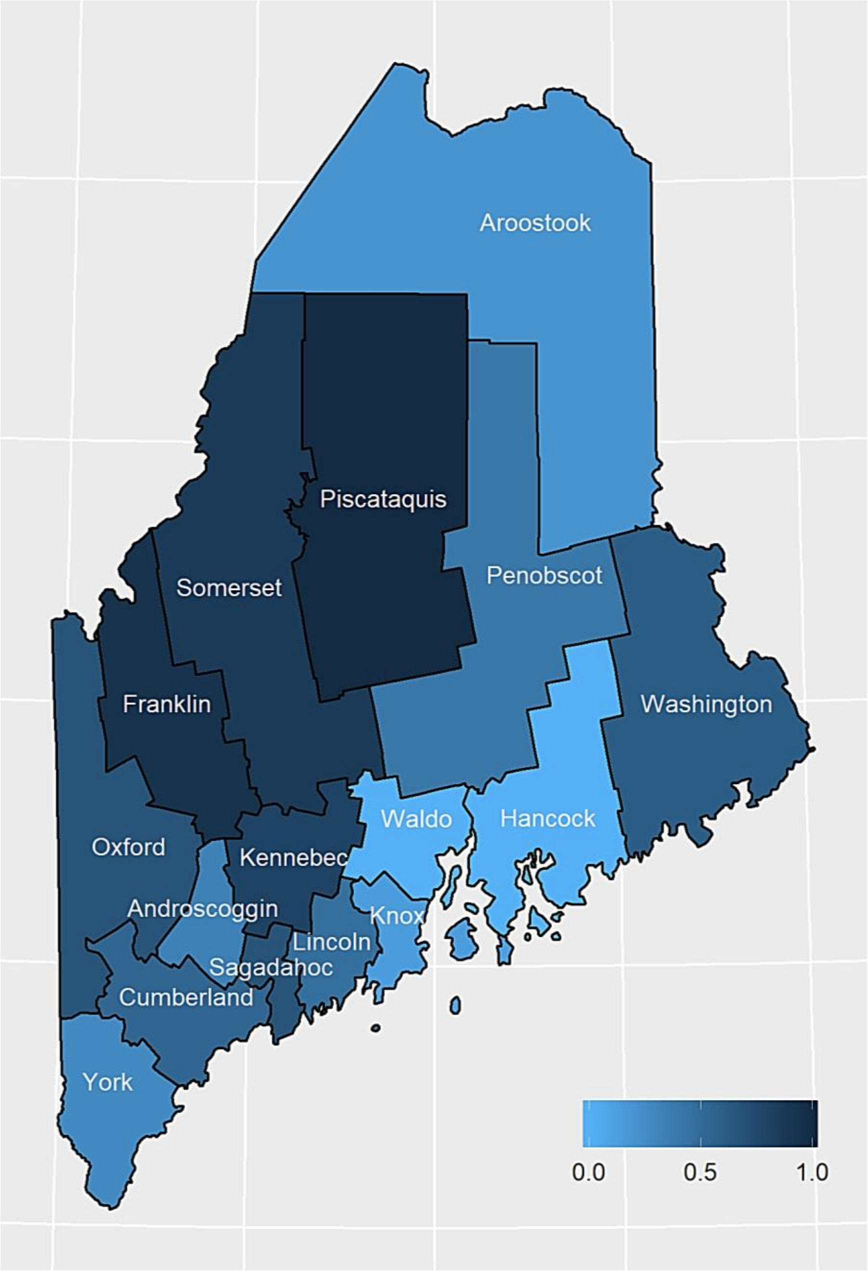
Counties with higher rates are shown in darker colors.

Figure A-11. Social Vulnerability Index: Substance Use Domain Map



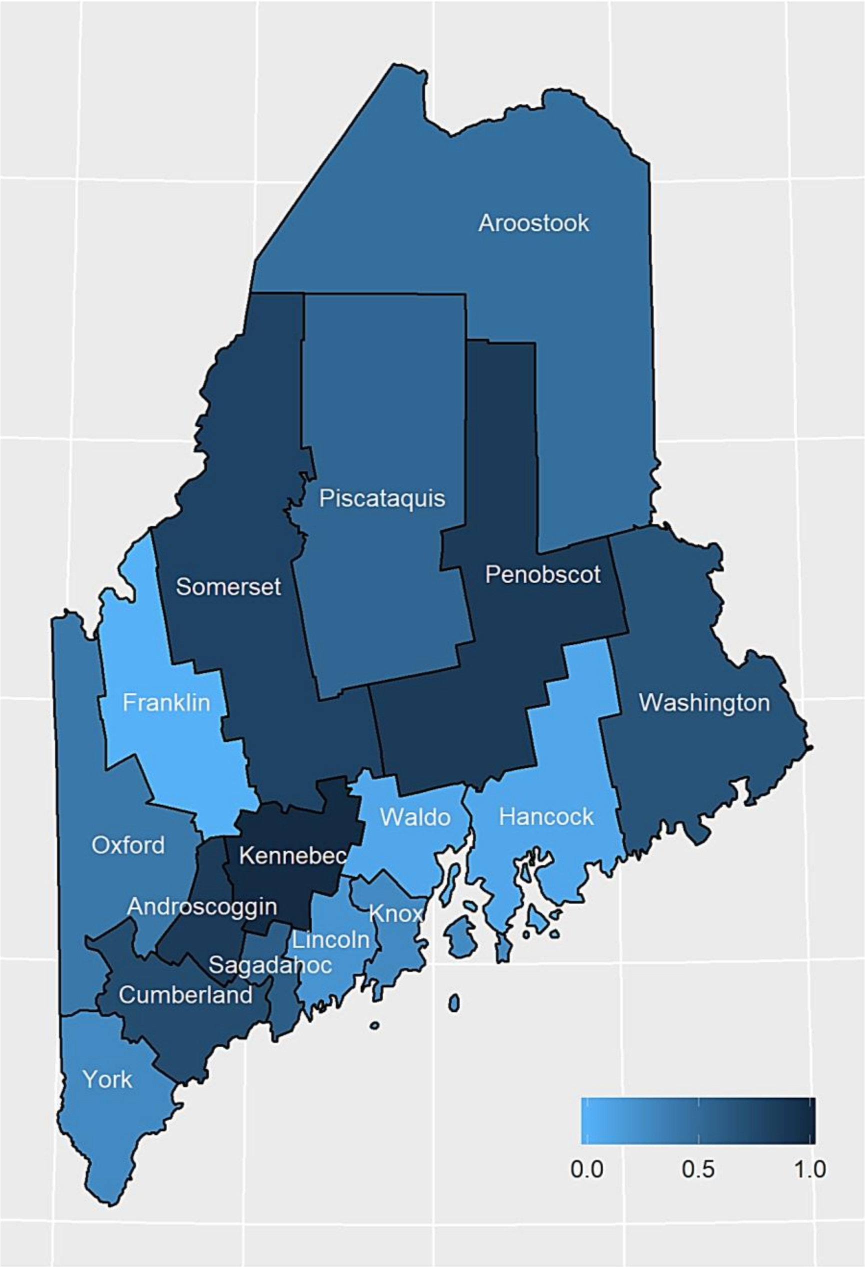
Counties with higher rates are shown in darker colors.

Figure A-12. Social Vulnerability Index: Law Enforcement Domain Map



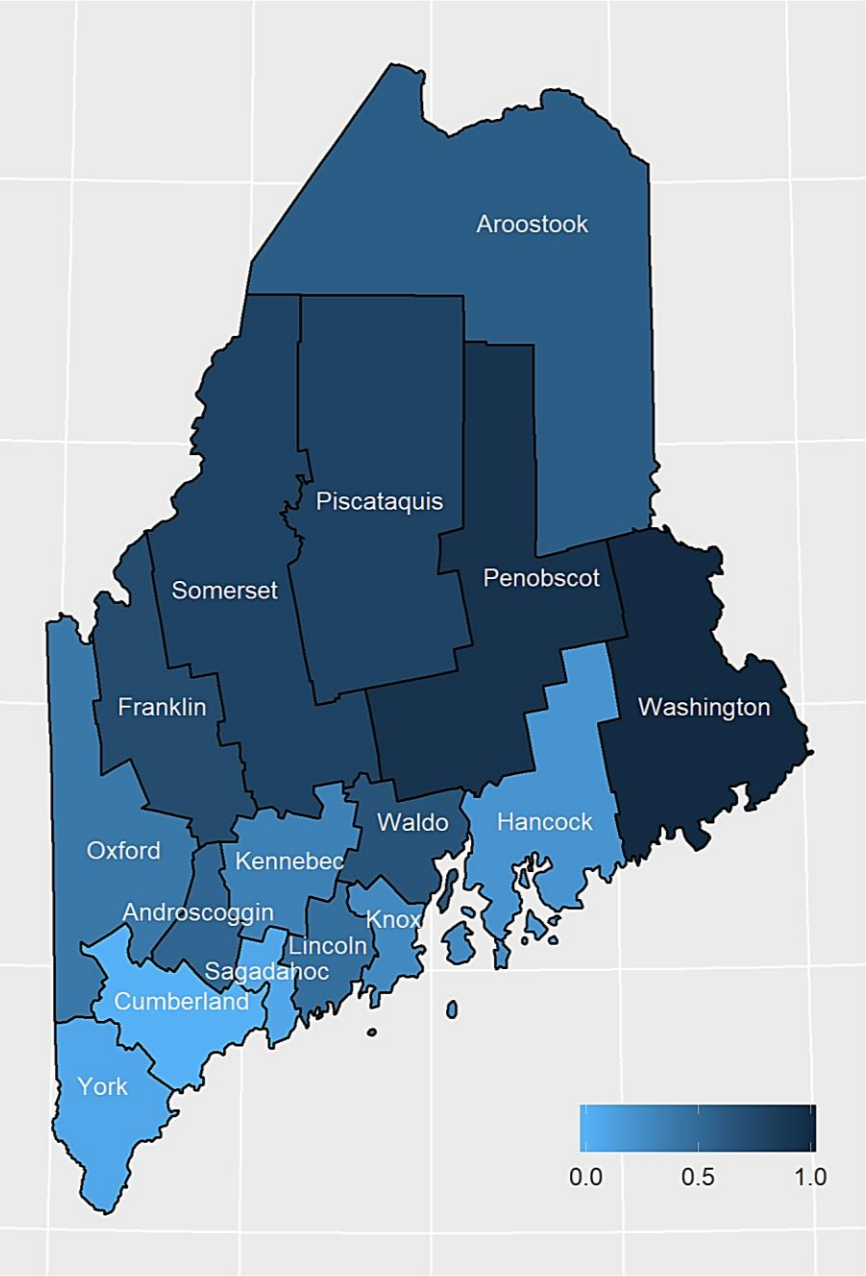
Counties with higher rates are shown in darker colors.

Figure A-13. Social Vulnerability Index: Mental Health Domain Map



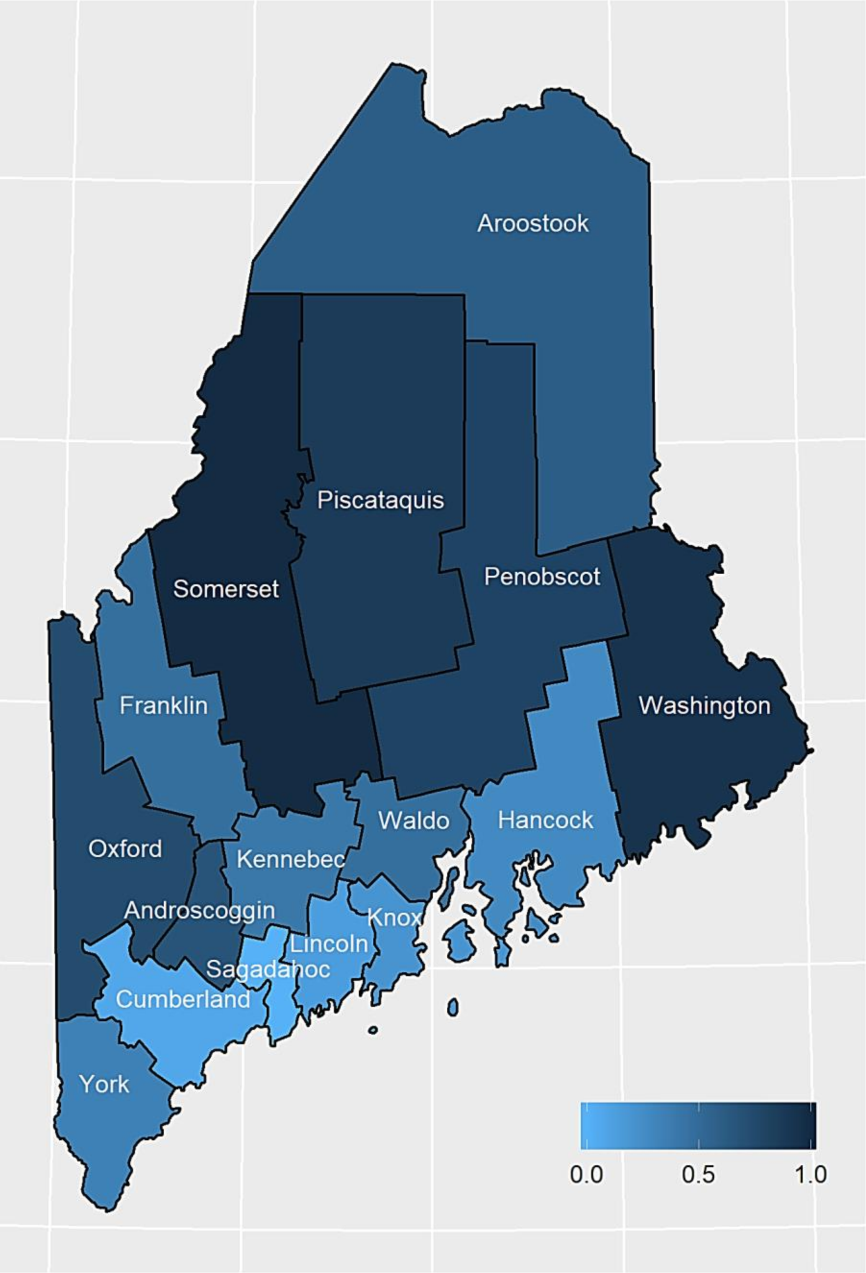
Counties with higher rates are shown in darker colors.

Figure A-14. Social Vulnerability Index: Physical Health Domain Map



Counties with higher rates are shown in darker colors.

Figure A-15. Social Vulnerability Index: Socioeconomic Status Domain Map



Counties with higher rates are shown in darker colors.

Appendix B. Maps of Services in Maine

Figure B-1. Drug Free Communities

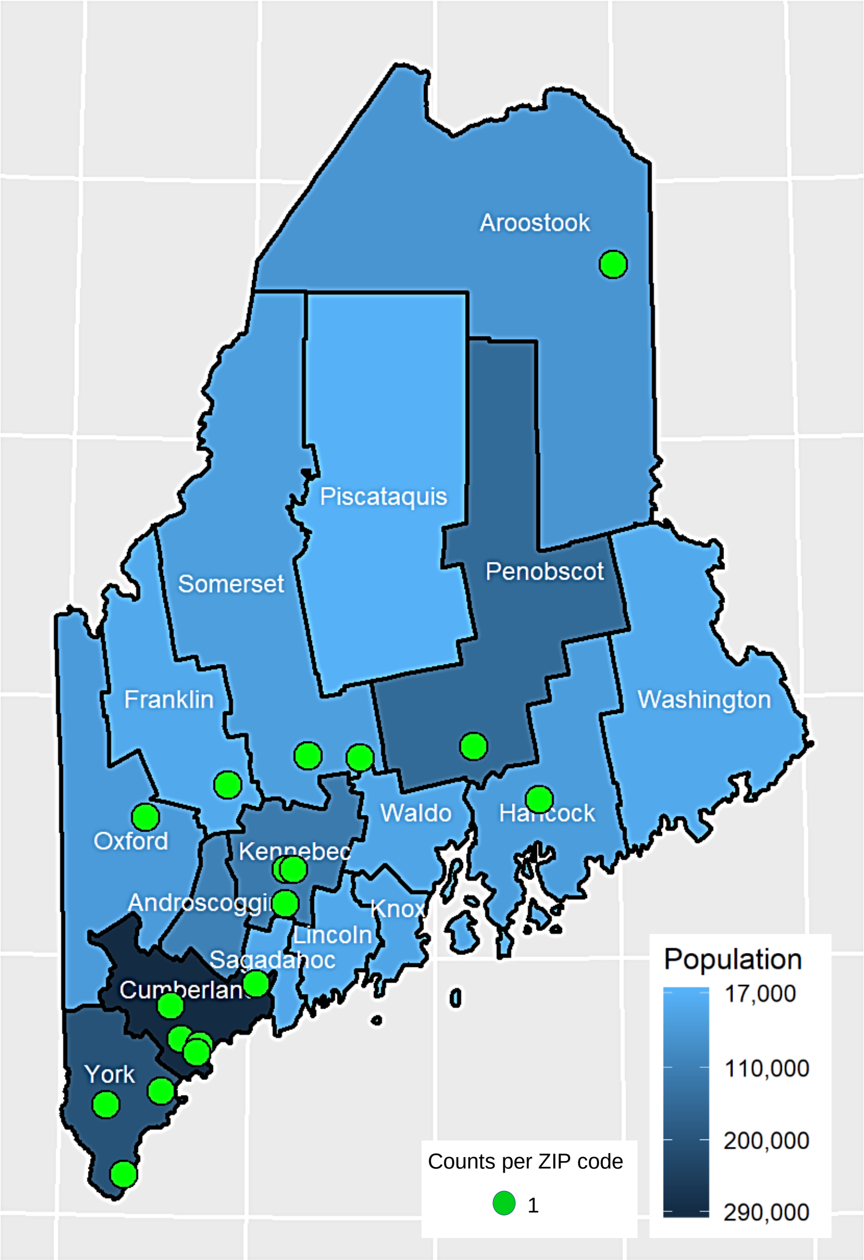


Figure B-2. Community Prevention Organizations

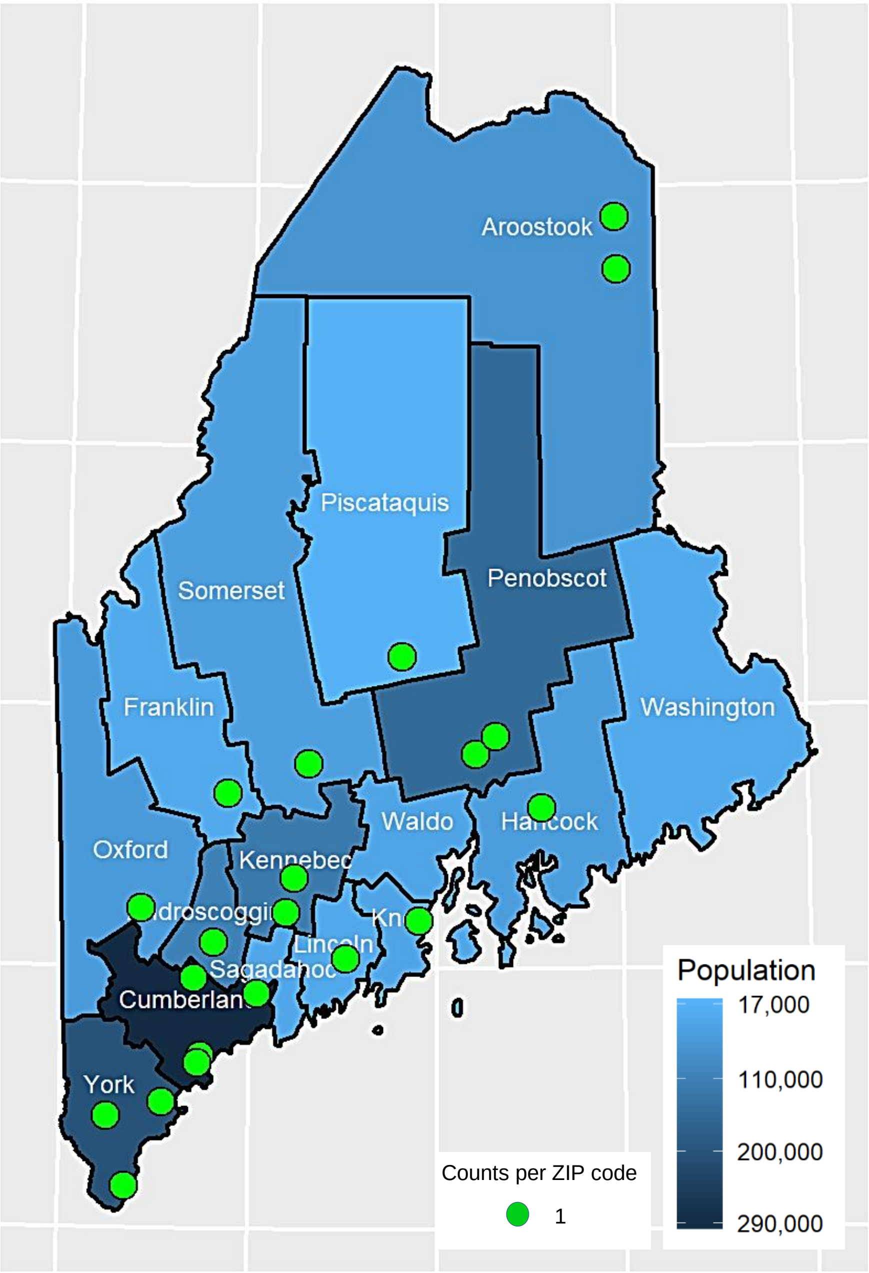


Figure B-3. Syringe Exchanges Programs

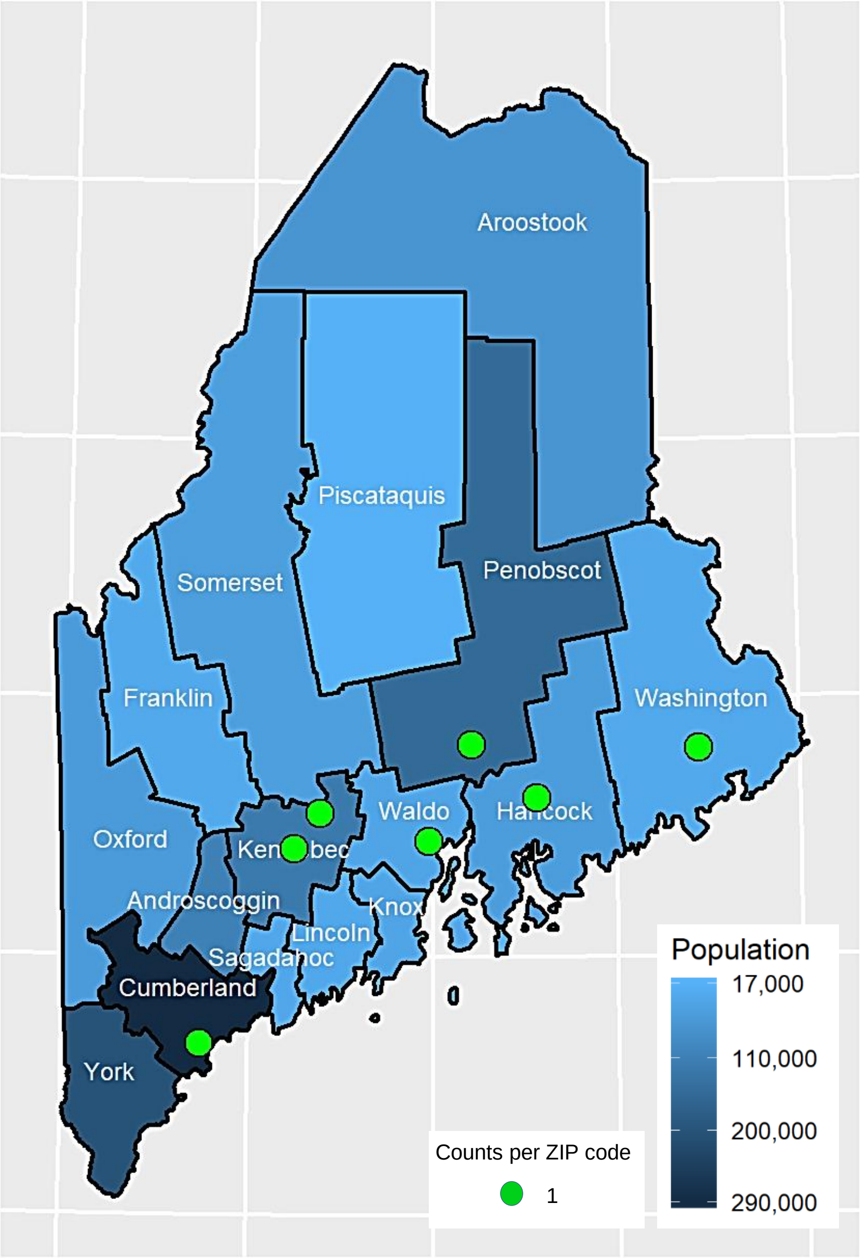


Figure B-4. Substance Use Treatment Providers

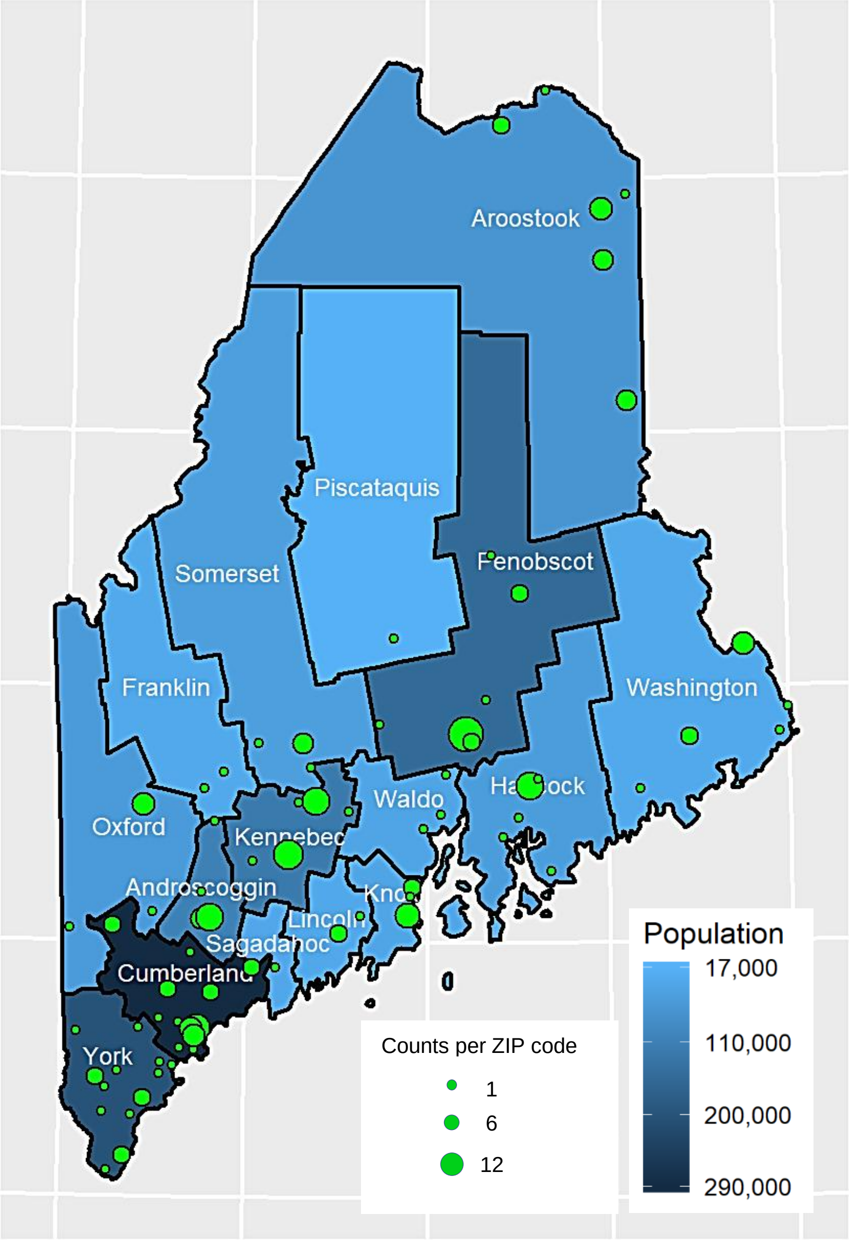


Figure B-5. Opioid Health Homes

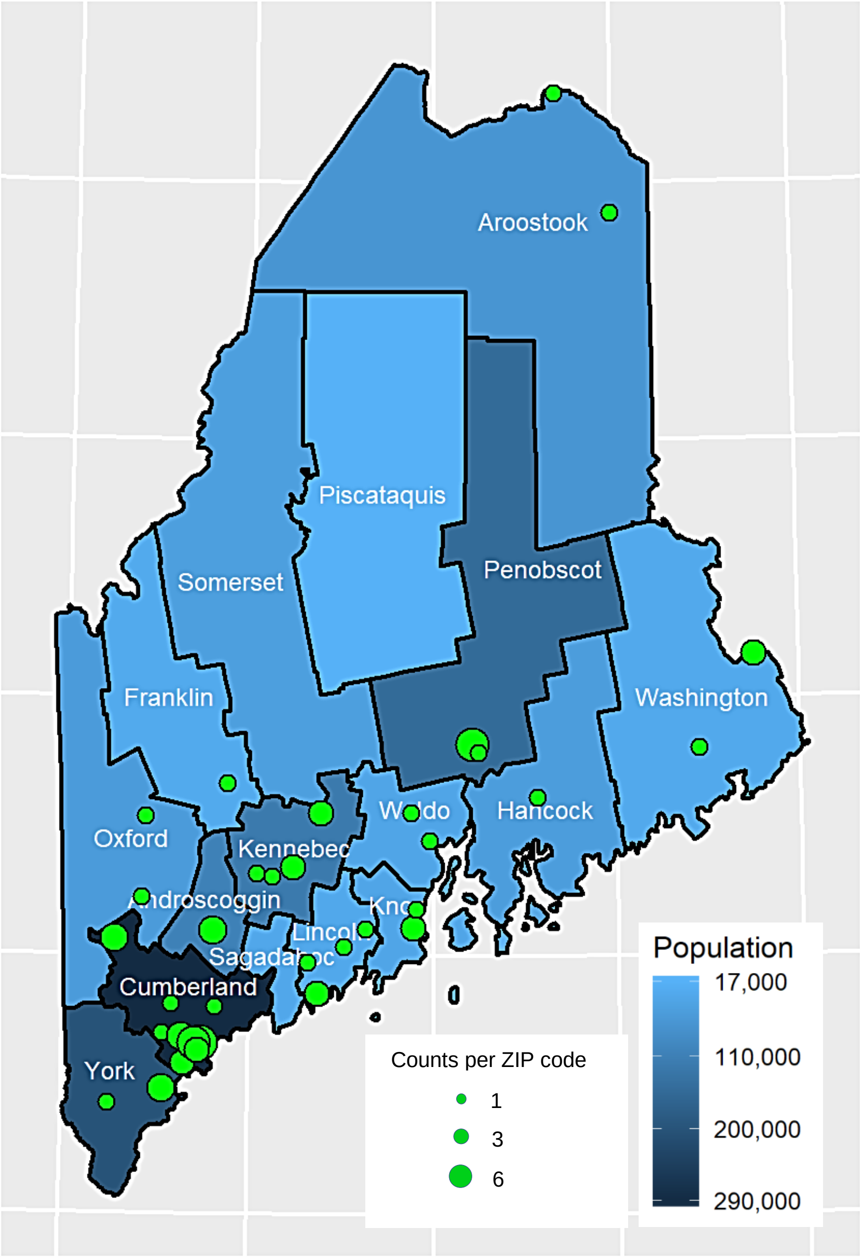


Figure B-6. Recovery Community Centers

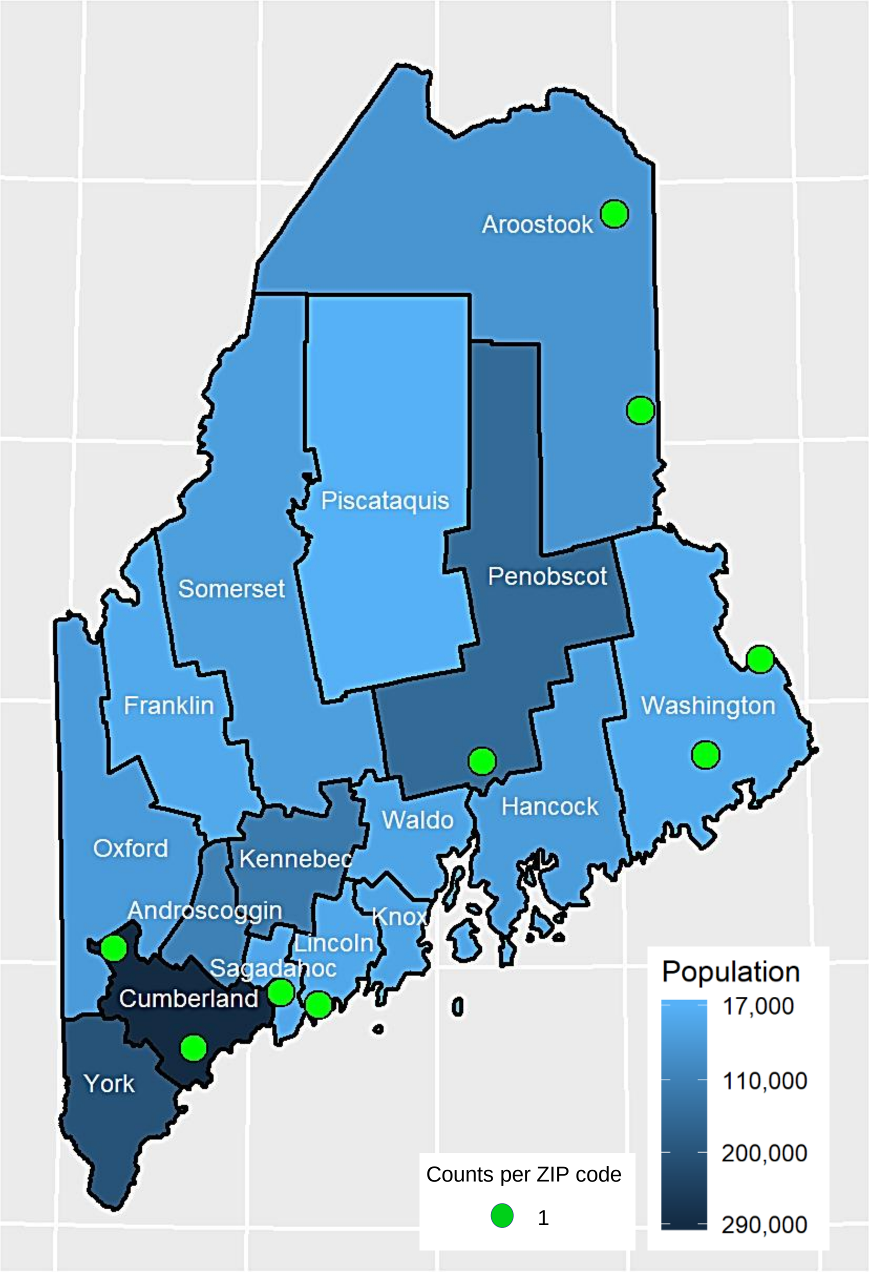


Figure B-7. Recovery Residences

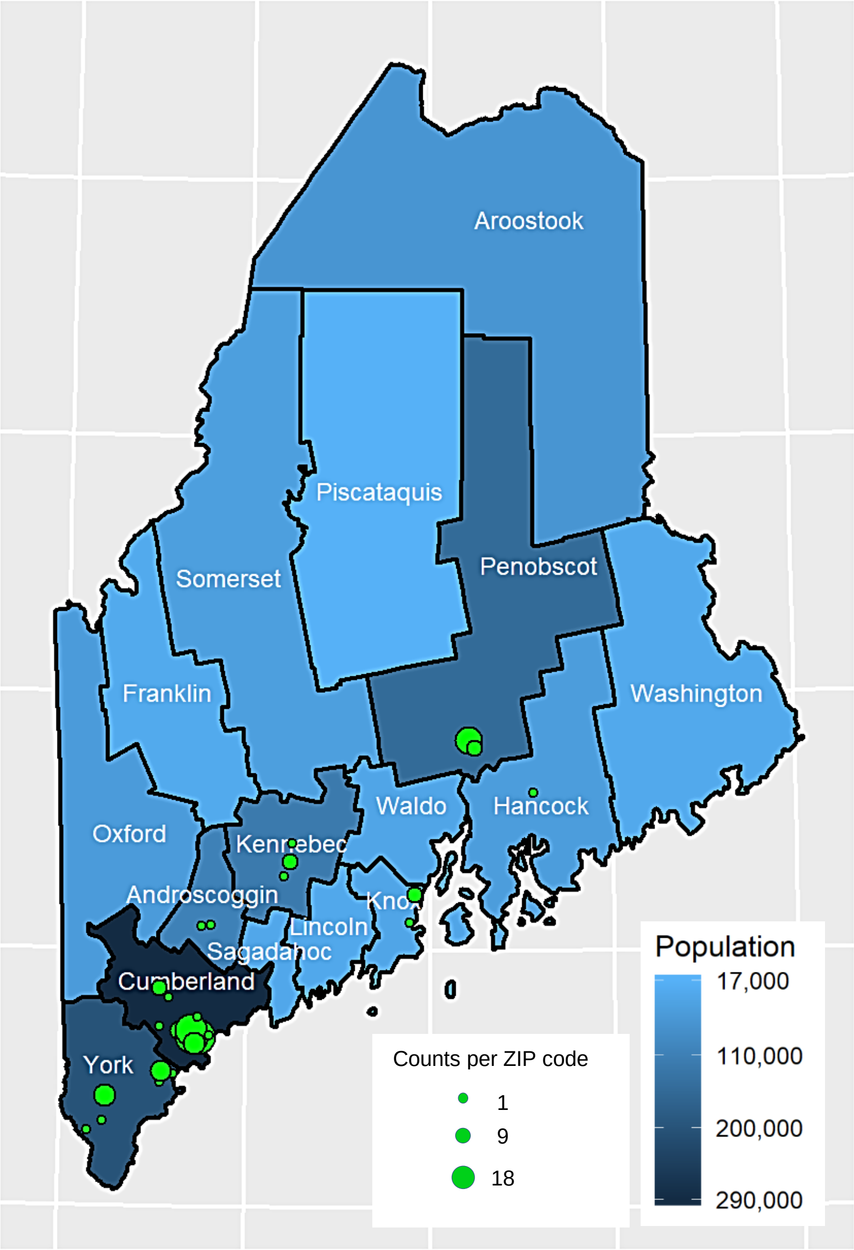


Figure B-8. Recovery Residences Allowing Medication Assisted Treatment

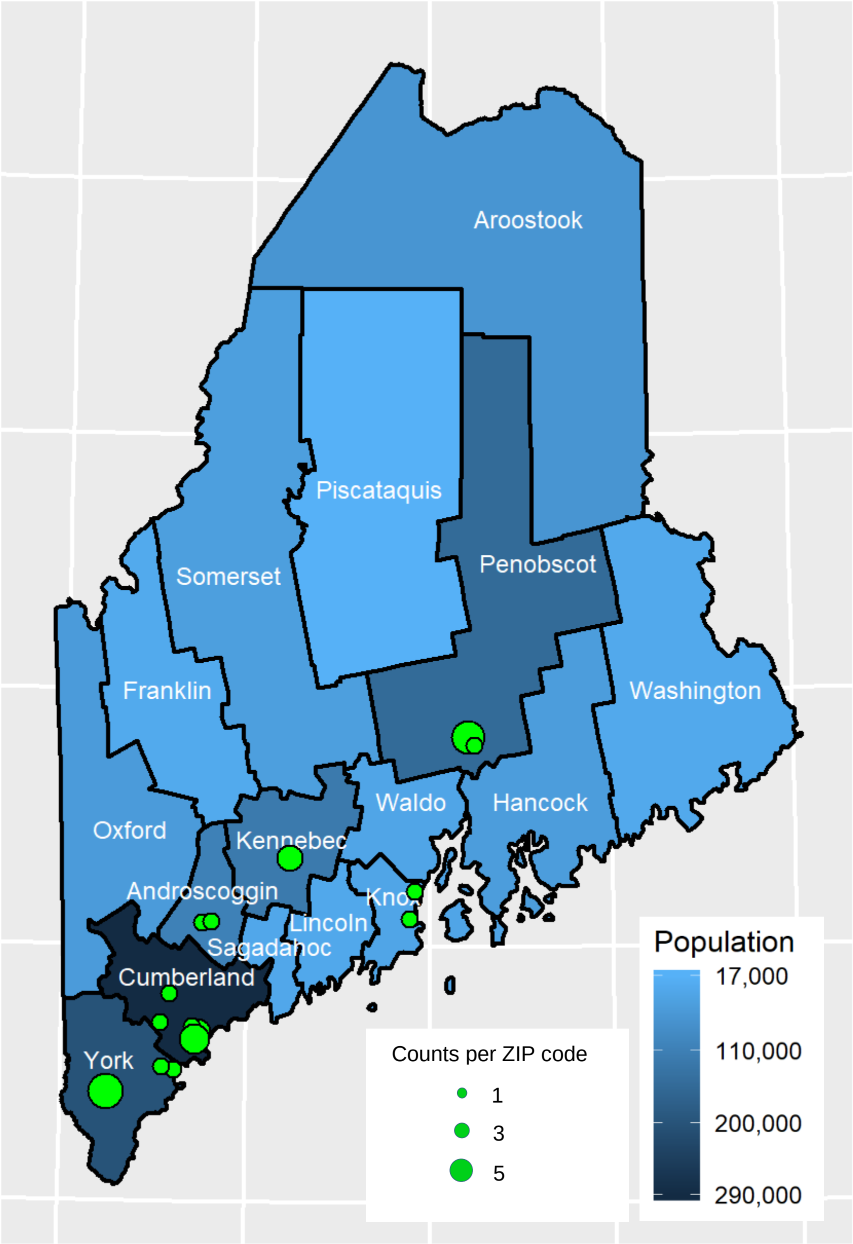


Figure B-9. Acute Care, Psychiatric, and Veterans Administration Hospitals

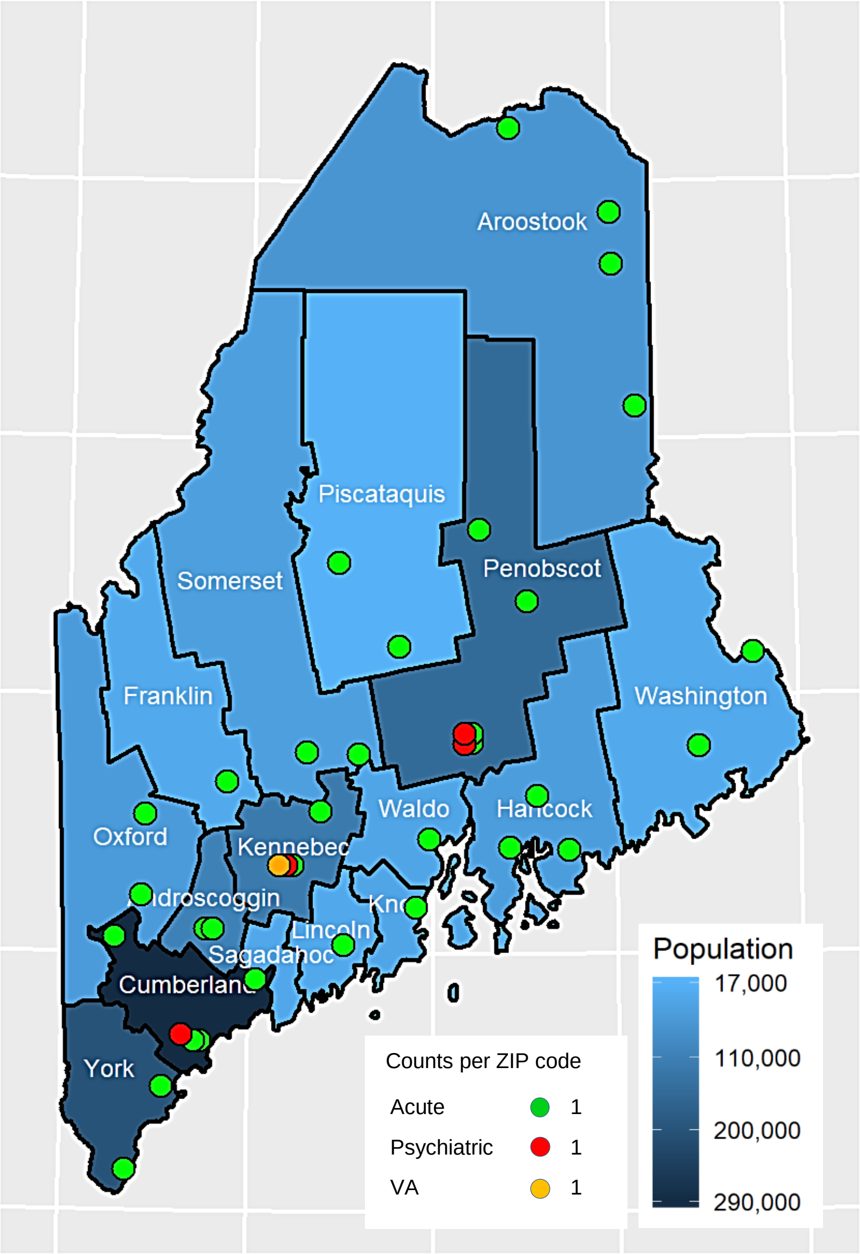


Figure B-10. Rural Health Clinics

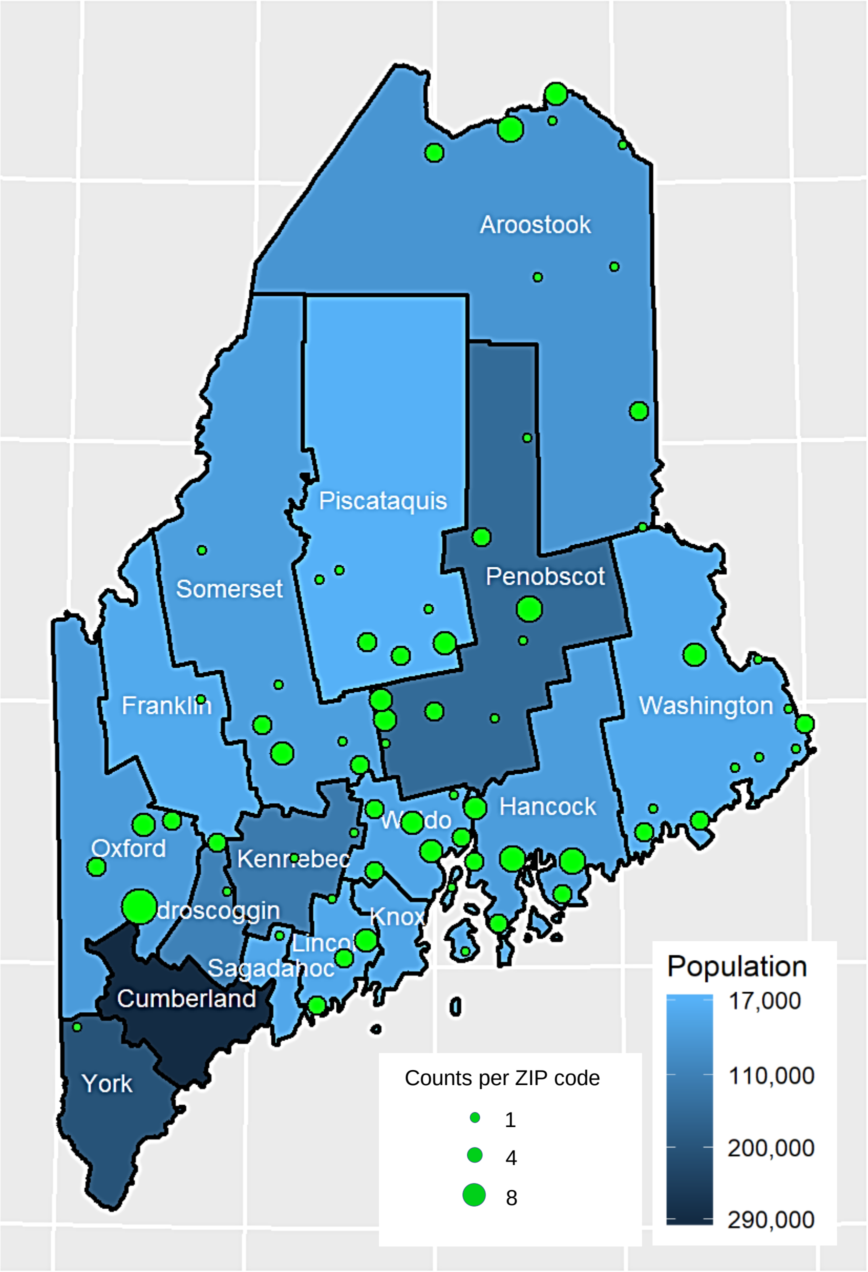


Figure B-11. Federally Qualified Health Centers

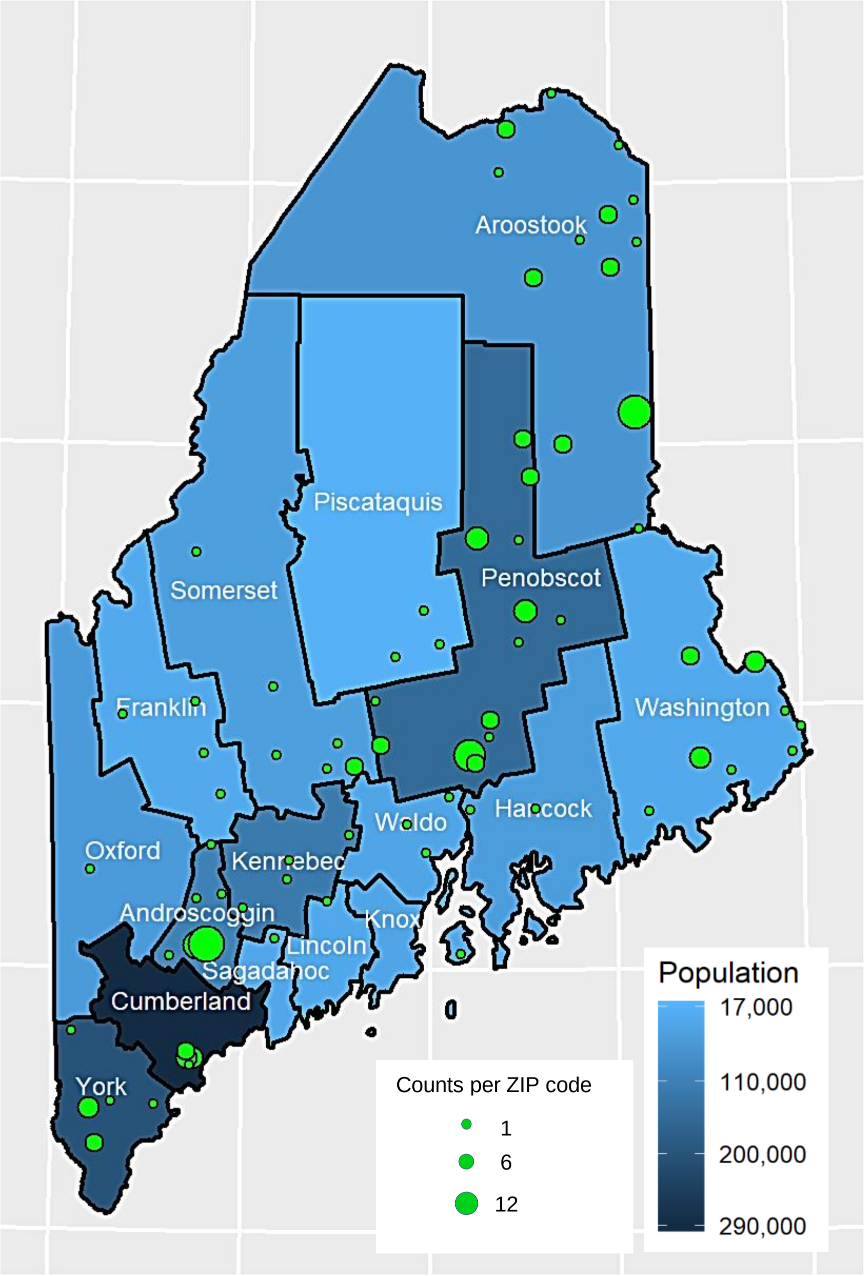


Figure B-12. Mental Health Providers

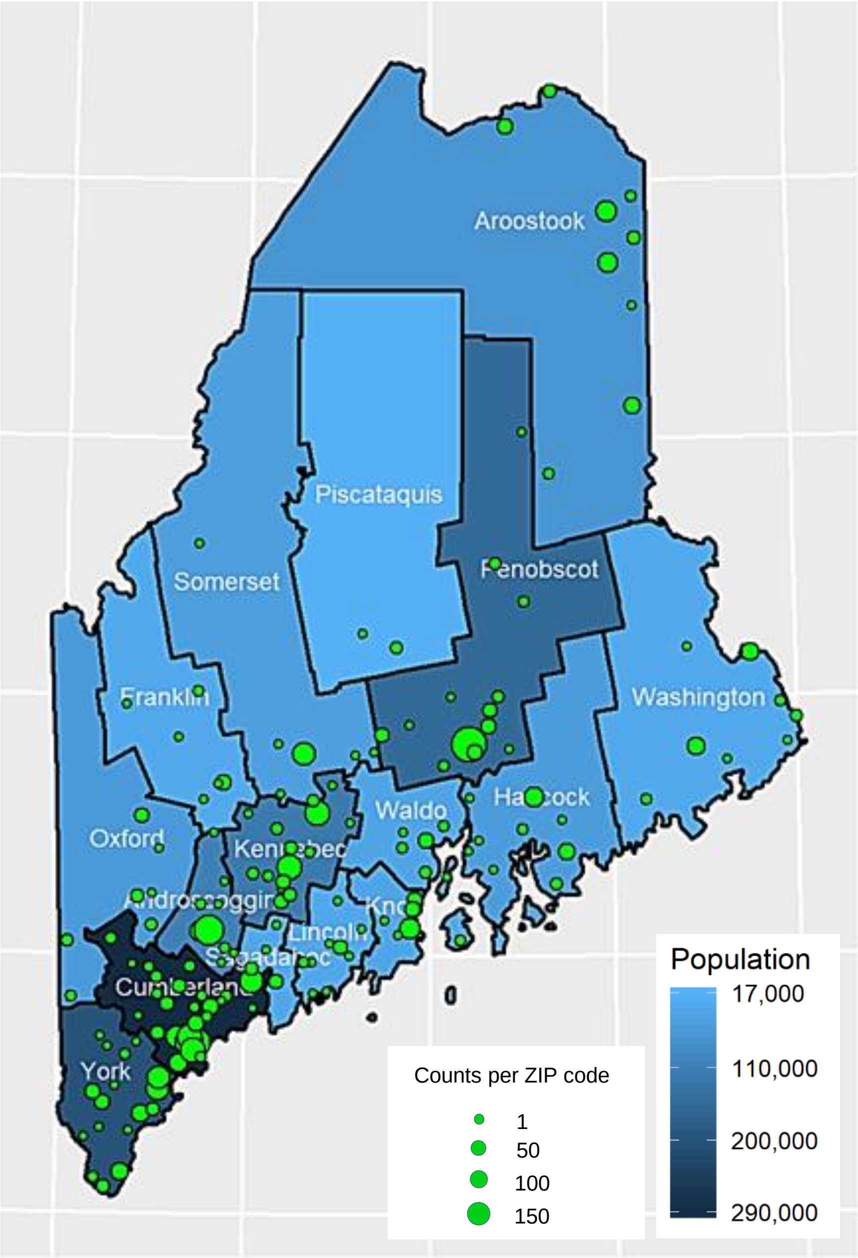


Figure B-13. Adult Drug Treatment Courts and Family Treatment Drug Courts

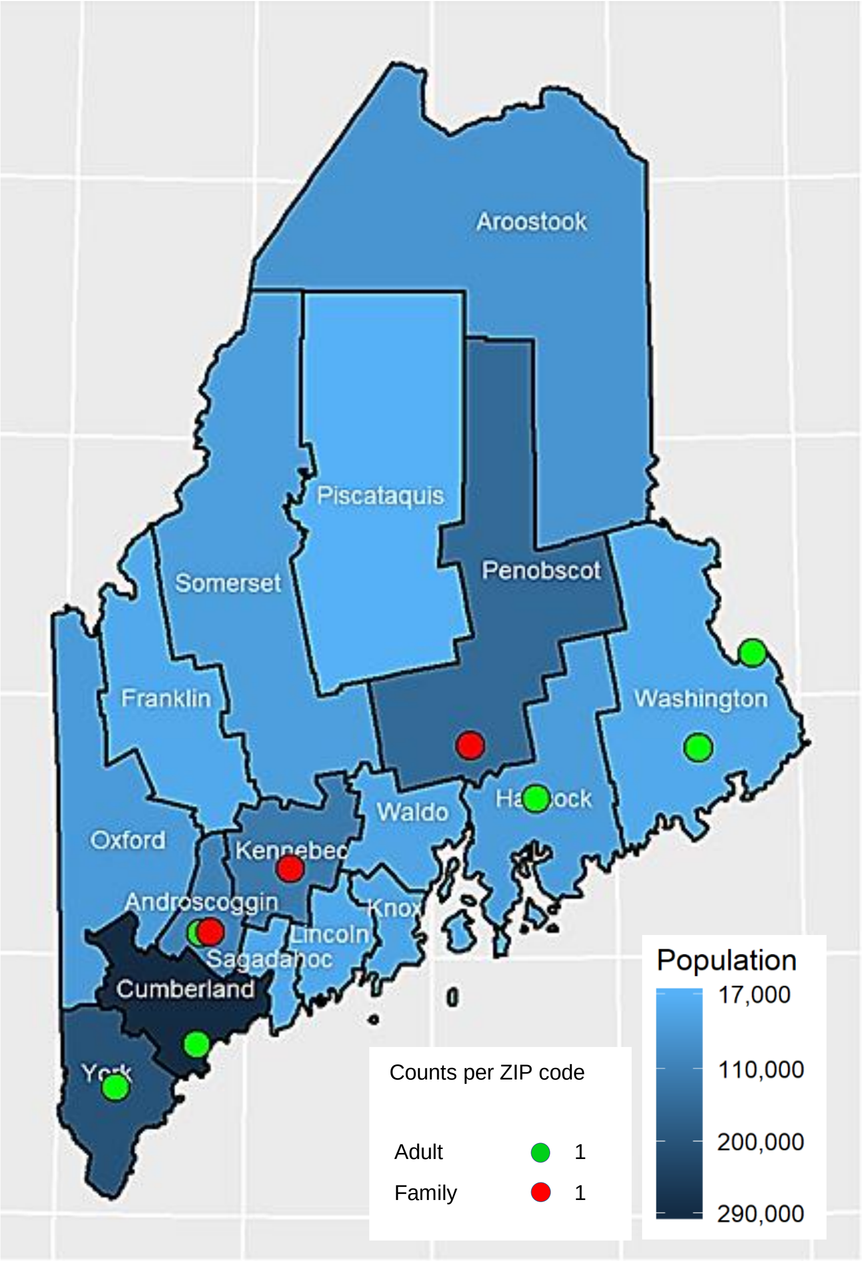
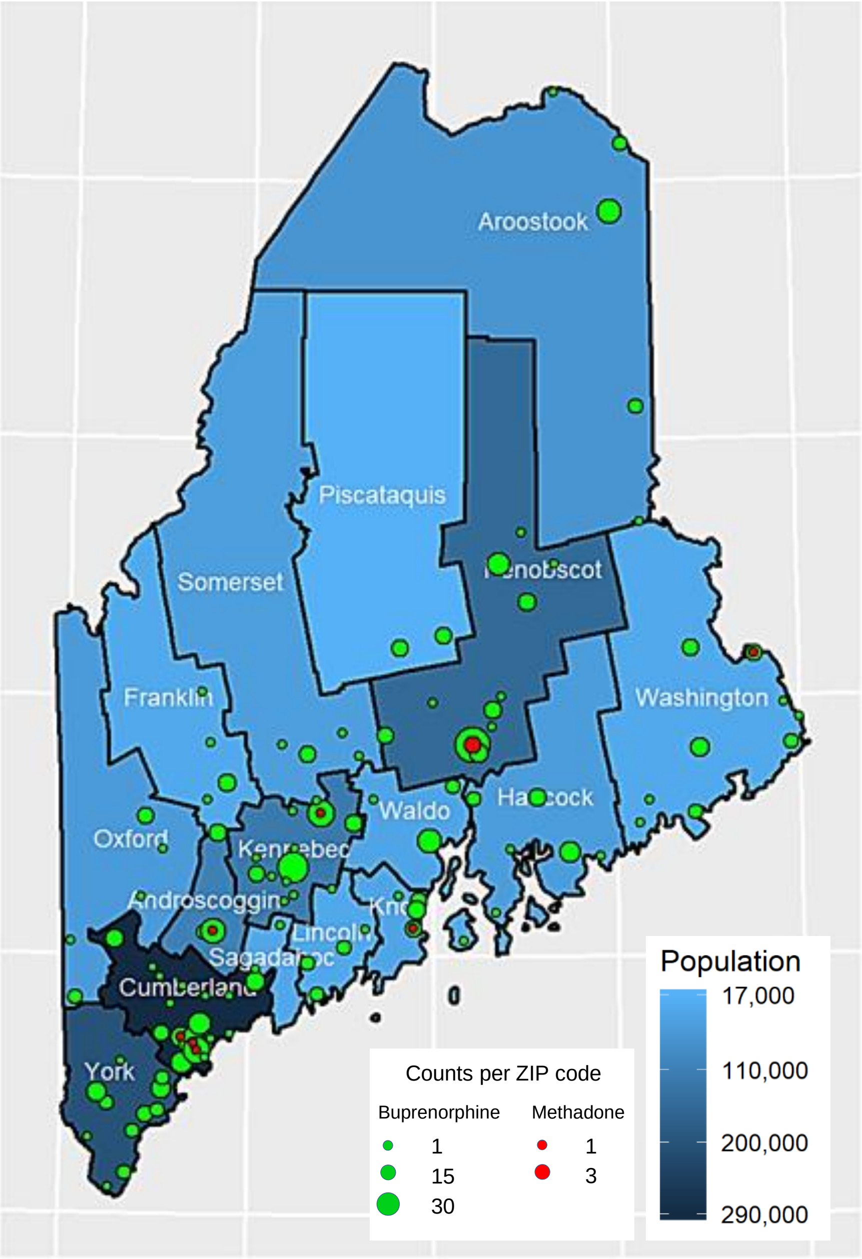


Figure B-14. Buprenorphine Providers and Methadone Clinics



Maine Opioid Response: 2021 Strategic Action Plan

Introduction

Maine has been hit hard by the opioid epidemic. Between 2010 and 2019, almost 2,700 individuals died from an opioid-related overdose. These are our neighbors, our colleagues, our friends, and our family members. We owe it to each of them, and to the tens of thousands of Mainers currently living with the chronic illness of addiction, to do more to break this deadly cycle.

Too many Maine youth are experiencing traumatic events, and too many are experimenting with substances that increase their risk of addiction. For people with an opioid use disorder, finding treatment that is local, immediate, and affordable must improve. Many people in recovery face stigma, along with employment, housing, and transportation shortages faced by the general population – shortages that have been exacerbated by the pandemic. The pandemic has made recovery from substance use disorder much more difficult, and the number of overdoses and deaths has escalated. Our work is more critical than ever.

Accomplishments

Maine's annual Strategic Action Plan is designed to confront the epidemic of substance use disorder (SUD), emphasizing opioid use disorder (OUD), with evidence-based strategies that are targeted and tailored for maximum impact in Maine. Since Executive Order 2, issued two years ago, the Mills administration has taken the following steps:

- Purchased and distributed 55,788 doses of naloxone through public health and harm reduction organizations (through November 2020), resulting in 1,136 opioid overdose reversals during the period January – November 2020.
- Recruited and trained 534 recovery coaches (more than double the original objective), of whom 133 are actively coaching individuals in recovery.
- Provided Medication Assisted Treatment (MAT) to over 500 inmates within the Department of Corrections, while they were incarcerated or linked to community providers upon release, in addition to approximately 200 individuals in current treatment.
- Provided MAT to over 250 individuals with a diagnosis of SUD in county jails.
- Despite the challenges of the global pandemic, supported 22 emergency departments in standing up low-barrier MAT through which over 500 patients received their first dose of medication in the hospital.
- Increased the prescribing of buprenorphine for MAT by 43% in the past three years.
- Increased the number of recovery residences from 101 to 120 in two years, including certified residences growing from 23 to 51, with 42% of all residences currently welcoming individuals using MAT in their recovery.
- Increased Syringe Service Provider sites from 7 to 12, with 3 additional applications pending.
- Increased Recovery Community Centers from 9 to 13 locations, with an additional 2 centers planned for York County and the community of Lincoln.
- Enhanced prevention efforts, including the Department of Education making available to every school in the state a pre-K through grade 12 social and emotional learning (SEL) curriculum known as SEL4ME. In its first three months of use, SEL4ME has registered 3665 users and on-line modules have been accessed over 12,000 times.
- Served 295 individuals in Maine's Adult Drug Courts, Co-Occurring Court and Veterans Courts in 2019, an increase of 11.3% over the previous year.

2021 STRATEGIC ACTION PLAN

1 GOAL → 5 FOCUS AREAS → 10 PRIORITIES → 33 STRATEGIES

OUR GOAL Reduce the negative health and economic impacts of opioid and other substance use disorders (SUD/OUD) on individuals, families, and communities in Maine and, in so doing, give hope to all persons with a substance use disorder that recovery is not just possible, but probable.

OUR SHARED VALUES This plan includes five cross-cutting values that are foundational to each area of focus. All actions called for in this plan shall be undertaken through the lens of these shared values: 1) reducing the stigma associated with substance use disorder and identifying it as a chronic medical condition; 2) building resilience in individuals across the lifespan; 3) improving data collection, analysis, and timely communication; 4) building and maintaining a robust infrastructure capable of supporting the priority activities; 5) implementing all activities subject to available funding from federal, state, community, and philanthropic sources.

Governor's Office of Policy Innovation and the Future *January 2021*

Focus Areas, Priorities, Strategies

LEADERSHIP

Priority A: Take decisive, evidence-based and community focused actions in response to Maine's opioid crisis

Strategy #1: *Provide strong state-level leadership and coordination among prevention, harm reduction, treatment, and recovery strategies*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Continue to make SUD/OUD response a top priority of the Mills administration with leadership from the Director of Opioid Response, the Prevention and Recovery Cabinet, the Opioid Coordinating Council, Clinical Advisory Committee, and the Opioid Data Sharing Committee **b.** Assess and update the SUD/OUD Strategic Action Plan **c.** Ensure dedicated staff to support the implementation of the Strategic Action Plan **d.** Enhance the Governor's Office of Policy Innovation and the Future (GOPIF) web page for SUD/OUD **e.** Inventory all SUD/OUD programs and, including state, federal (HRSA, SAMHSA, etc) and private philanthropy. **f.** Host an annual Opioid Response Summit, enhanced with monthly educational webinars **g.** Build collaborative relationships with local, state, and national stakeholders and philanthropic organizations **h.** Support, and implement if enacted, legislation establishing an overdose fatality review panel	**i.** Regularly review and enhance the Opioid Response Strategic Action Plan **j.** Secure and publicly promote leadership commitments from key stakeholders **k.** Expand the Opioid Response Summit to include an additional half-day of workshops and an evening reception **l.** Support additional recovery events in local communities **m.** Hold manufacturers and distributors accountable

Strategy #2: *Develop a treatment and prevention workforce sufficient to meet the needs of Maine's population*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support the development and growth of new and emerging workforce models for addressing SUD/OUD, including Community Health Workers, Recovery Coaches, and Community Paramedicine **b.** Implement a Substance Use Disorders Learning Community **c.** Through the Support for ME initiative and MaineCare's Comprehensive Rate System Evaluation, examine rates to ensure adequate payment to support recruitment and retention of workforce	**d.** Support universities and community colleges in developing curriculum **e.** Assess workforce supply and demand, including a review of licensing categories **f.** Continue to evaluate and promote expansion of MAT prescriber capacity in geographic areas of need

Strategy #3: *Support local and regional community engagement efforts*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support the growth and sustainability of Recovery Community Centers **b.** Engage and showcase communities in statewide events, including the annual Opioid Response Summit **c.** Support the use of film and storytelling to engage communities **d.** Promote Recovery Friendly Communities **e.** Support public, private, and philanthropic funding of communities implementing prevention initiatives	f. Evaluate and fund as resources allow, promising local community engagement efforts

Strategy #4: *Promote changes in public understanding, beliefs and behaviors regarding substance use disorder and opioid use disorder (SUD/OUD)*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Develop and implement evidence-based public messaging campaigns **b.** Conduct outreach and education opportunities for health care providers **c.** Implement an education module for law enforcement professionals and Maine Criminal Justice Academy recruits **d.** Host and participate in forums, presentations, and recovery events in local communities and key sectors **e.** Create more opportunities for individuals, families, and others affected by SUD/OUD to tell their personal stories of addiction or recovery **f.** Educate employers and support efforts that promote recovery-friendly workplaces, including the new Youth Employment Assistance Program (YEAP)	**g.** Disseminate a stigma and discrimination reduction curriculum, including continuing education credits, to all health care providers, first responders, and frontline support staff **h.** Continue to work with employers to promote treatment and recovery-friendly worksites **i.** Engage municipal governments, business associations, and community service organizations in taking supportive actions **j.** Evaluate stigma and discrimination reduction efforts for possible replication

Strategy #5: *Maximize the collection of actionable data and evaluate the impact of interventions*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Establish an Opioid Data Sharing Committee (ODSC), replacing the Statewide Epidemiology Outcomes Workgroup (SEOW) Opioid Sub-Committee **b.** Continue to support the SEOW in its prevention work, including the engagement and education of multi-sector partnerships **c.** Develop a strategic data plan, including clearly defined roles and purposes for the data currently available, including automation of population-based surveillance data **d.** Conduct an economic study and report on the cost of SUD/OUD to Maine families and businesses **e.** Create an online data hub to increase public transparency **f.** Share key data to inform policy and program design **g.** Conduct ongoing data analysis and interpretation to improve understanding of program performance **h.** Promote the use of ODMAP (overdose mapping tool) i. Share overdose spike data with clinicians and community partners, promoting appropriate response	**j.** Compile stories that add context and texture to communications of data and outcomes **k.** Communicate the results of data analysis and interpretation to policymakers and the public **l.** Support efforts to align state and federal guidelines on SUD data-sharing

Priority B: Prevent the early use of addictive substances by children, youth, and young adults

Strategy #6: *Support healthy early childhood development*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support the activities of the Children's Cabinet which benefit and improve early childhood development and prevent early use **b.** Support the implementation of early childhood education and social and emotional learning skills for children and youth **c.** Support access to contraception. **d.** Support efforts to thoroughly review infant and child mortality data **e.** Continue to implement the Safe Sleep campaign	**f.** Expand the availability of Home Visiting and Public Health Nurses **g.** Promote educational information and skill-building for parents and families, including evidence-based programs to develop effective parenting skills **h.** Provide education and training opportunities for child care providers **i.** Implement social and emotional learning curriculum in all schools **j.** Identify and implement out-of-school social and emotional learning programs **k.** Evaluate social and emotional learning programs for efficacy and potential expansion

Strategy #7: *Reduce adverse childhood experiences (ACEs)*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Promote awareness and education on the prevention of ACEs **b.** Support parents with SUD/OUD in maintaining custody or achieving reunification **c.** Provide parent education, coaching and case management **d.** Explore the evidence base and potential target audiences for trainings on childhood brain development, ACEs, and SUD prevention **e.** Promote ACEs education and training for high-risk communities and/or families	**f.** Explore the creation of ACEs Response Teams to support children exposed to violence **g.** Reduce arrests and incarceration through the OPTIONS program, pre-booking diversion and Drug Courts **h.** Participate in a comprehensive, cross-departmental plan to address ACE's and trauma informed interventions

Strategy #8: *Promote life skills and resilience-building for all youth*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support and participate in the Maine Resilience Building Network's "Youth Matters" Initiative **b.** Support the Maine Youth Action Network's efforts to engage youth and create more resources to address students' mental health and emotional needs **c.** Support Positive Action Teams in Piscataquis County **d.** Support the Department of Education and Maine Center for Disease Control and Prevention, Office of Behavioral Health, Office of Child and Family Services, and others in promoting and disseminating social and emotional learning (SEL) curriculum and programs, including Sources of Strength, Primed for Life, Second Steps, and Maine Department of Education's curriculum developed in collaboration with EVOLUTION LAB **e.** Support the StrengthenME resilience and wellness initiative	**f.** Assess potential partnerships with School Based Health Centers **g.** Continue to support the promotion and dissemination of SEL curriculum, subject to ongoing evaluation of efficacy and successful outcomes

Strategy #9: *Identify and support youth and young adults at risk of developing a substance use disorder*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Provide trauma-informed, evidence-based education and trainings to high-risk youth **b.** Include information on SUD treatment for adolescents in online content **c.** Strengthen school and community-based approaches to SUD/OUD prevention **d.** Provide support for Teen Centers **e.** Support restorative justice practices **f.** Develop and distribute Maine-specific and trauma-informed programs and curricula at no cost to all public schools **g.** Continue to implement the Maine Youth Leadership Institute SEALFIT program **h.** Implement and increase referrals to the Student Intervention Reintegration Program (SIRP) **i.** Identify and assess for potential implementation evidence based practices for reaching the young adult population **j.** Support federally funded (HRSA) Pediatric and Behavioral Health Partnership (MPBHP)- tele consult line for providers to access child psychiatrists for behavioral health issues, including polysubstance issues	**k.** Increase the number of children's behavioral health counselors, especially in rural areas **l.** Increase the number of mental health/behavioral health (MH/BH) counselors and/or social workers in schools **m.** Increase restorative justice practices in schools **n.** Promote the use of SBIRT (Screening, Brief Intervention & Referral for Treatment) for early use of addictive substances in primary care, school-based health centers and other youth settings **o.** Expand SIRP through virtual offerings and outreach to primary care physicians and Department of Corrections as new referral resources **p.** Identify new partners and strategies to reach the young adult population through secondary education and workplaces.

Strategy #10: *Support and expand community partnerships to educate and engage youth, families, and communities*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Promote community-based efforts to educate and engage parents and youth on the risks of early use of addictive substances **b.** Promote opportunities to engage youth in healthy activities **c.** Support community youth organizations **d.** Provide interdepartmental support and participation in efforts among partners to understand and build upon evidence-informed rural community prevention models **e.** Promote education for parents and providers on the impact of the early use of addictive substances and how to reduce early use among children and youth **f.** Support the development and implementation of a networked campaign of messaging and materials to reduce early use of addictive substances and vaping devices **g.** Engage communities in efforts to address social norms and policies that increase protective factors, such as the Youth Matters initiative of the Maine Resilience Building Network	**h.** Promote healthy outdoor after-school programs/activities, such as the Icelandic Model **i.** Explore federal funding and private philanthropic opportunities to sustain local prevention efforts and build capacity.

Strategy #11: *Implement and sustain COVID response, recovery and resiliency strategies*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Adapt school and community based prevention strategies to virtual learning environments. **b.** Design and implement the StrengthenME Initiative to provide free tools, support, and connections to Community Health Workers to reduce stress and promote wellness, resilience, and recovery **c.** Continue to assess, learn, and sustain innovations that improve quality, access, and effectiveness of programs and services, including telemedicine enhancements	**d.** Assess and maintain the most effective COVID innovations to expand the access and reach of prevention strategies. **e.** Working with the Children's Cabinet and other aligned organizations, research and develop messaging and interventions that promote healthy coping skills to prevent increased substance use during times of stress.

Priority C: Reduce the number of prescribed and illicitly obtained opioids

Strategy #12: *Improve the safety of opioid prescribing*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support clinician adherence to evidence-based guidelines for opioid prescribing through the SUD Learning Community and other online trainings **b.** Offer the Controlled Substances Stewardship Program to practices & providers to assist with tapering opioids **c.** Enhance reporting from the prescription monitoring program (PMP) **d.** Support drug take-back days **e.** Provide clinical training opportunities to address safe prescribing practices	**f.** Use PMP data to identify and engage high prescribing outliers **g.** Evaluate expansion of the Controlled Substances Stewardship Program **h.** Add additional academic detailing programs

Strategy #13: *Strengthen law enforcement efforts to intercept and reduce illicit opioid supply*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Continue to aggressively prosecute drug traffickers **b.** Continue to assist law enforcement in coordinating, cooperating, and collaboratively aligning data, programs, technology, and resources **c.** Explore alternative funding sources, systems, and technology, including statutory changes, so that drug testing is not a barrier to successful prosecution of drug traffickers	**d.** Implement alternative options to reduce barriers to drug testing, subject to available resources **e.** Maximize the use of seized assets to support enforcement efforts

HARM REDUCTION

Priority D: Reduce the number of fatal and non-fatal overdoses

Strategy #14: *Ensure the availability of naloxone for high-risk individuals via targeted distribution*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Deploy mobile response teams in every Maine county as part of the OPTIONS (Overdose Prevention Through Intensive Outreach, Naloxone and Safety) initiative to educate and engage high risk individuals in harm reduction strategies, including the distribution and use of naloxone and to offer treatment/recovery services, including MAT **b.** Support legislation permitting Emergency Medical Technicians (EMTs) to distribute as well as administer naloxone **c.** Support MeHAF funded pilot harm reduction education for pregnant patients, OB staff, and providers and naloxone distribution to post-partum patients	**d.** Continue to mobilize response teams in collaboration with local law enforcement, emergency responders, recovery coaches and harm reduction professionals as part of the OPTIONS Initiative **e.** Continue to support quality improvement initiatives for pregnant women

Strategy #15: *Ensure widespread distribution and ease of access to naloxone by the general public*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Continue to support the purchase and distribution of sufficient doses of naloxone to supply Tier 1 and Tier 2 distributors as designated by the Naloxone Steering Committee	**b.** Educate health care providers about the opportunities and importance of prescribing naloxone, including co-prescribing naloxone with opioids **c.** Collaborate with the State Board of Pharmacy and other health professional boards on stigma reduction, naloxone distribution, and co-prescribing initiatives

Strategy #16: *Increase public awareness of overdose prevention and the use of naloxone*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Update and resume the "Have it On Hand" and related public messaging campaigns as part of the OPTIONS campaign **b.** Update and launch Eyes Open overdose prevention campaign.	**c.** Evaluate the effectiveness of the public education campaigns **d.** Broaden public education efforts where found to be effective

Priority E: Engage active users and the recovery community in harm reduction

Strategy #17: *Increase awareness, understanding, and utilization of harm reduction strategies and resources*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Train and deploy "co-responders" –licensed behavioral health specialists embedded in emergency response units - in every Maine county as part of OPTIONS program **b.** Provide education on overdose prevention and treatment resources at naloxone distribution sites and syringe service programs through the OPTIONS program **c.** Educate and promote the "Good Samaritan" law through the OPTIONS program, and assess its current effectiveness **d.** Implement public health education and intervention campaign as part of the OPTIONS program **e.** Expand sterile syringe access **f.** Expand drug testing resources (e.g. fentanyl test strips)	g. Evaluate safe supply programs and consider implementation of effective harm reduction programs that meet the requirements of state and federal law

Strategy #18: *Provide resources and supports for people experiencing homelessness*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Engage and educate people experiencing homelessness in harm reduction strategies and options for treatment and recovery through the OPTIONS and StrengthenME initiatives **b.** Implement the Housing for Opioid Users Service Engagement (HOUSE) pilot to engage individuals experiencing homelessness in treatment and housing	

Priority F: Engage providers, law enforcement, and the public in harm reduction strategies

Strategy #19: *Support the design and statewide replication of promising practices to reduce public opposition to effective harm reduction strategies*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Convene community conversations to listen and share information and educational materials on harm reduction strategies	b. Contract with organizations with content expertise to provide education and training on harm reduction strategies

Strategy #20: *Promote a comprehensive system of care and referrals among health care and harm reduction services*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Promote bidirectional referrals between syringe exchange programs, primary care, MAT, and other health services, including the diagnosis and treatment of hepatitis C and HIV **b.** Decriminalize the possession of needles	c. Evaluate models of interconnected systems of care and referrals

TREATMENT

Priority G: Ensure the availability of treatment that is local, immediate, affordable, and best fit

Strategy #21: *Dedicate staff and funding to support the screening, treatment, and recovery of pregnant women with substance use disorder and support substance-exposed infants*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support, enhance, and align all efforts to ensure high quality treatment for pregnant and parenting women among departments, offices, and programs, including working with the Perinatal Quality Collaborative to join the Alliance for Innovation on Maternal (AIM) Health **b.** Implement integrated models of care for pregnant and parenting women, such as the Maternal Opioid Misuse (MOM) initiative **c.** Maintain a Maternal SUD and Substance-Exposed Infant (SEI) Task Force **d.** Support the annual SEI conference **e.** Promote evidence-based approaches to supporting substance-affected infants during the newborn hospitalization, including use of Eat, Sleep, Console and Snuggle ME guidelines **f.** Ensure that all substance-exposed infants have a Plan of Safe Care (POSC)	**g.** Develop a statewide strategic workplan for addressing the prevention and treatment of substance exposed infants in Maine. **h.** Enhance the Cradle ME referral system to include Public Health Nursing, Home Visiting and WIC **i.** Implement the federal Medicaid 1115 Waiver for SUD services **j.** Increase access to SUD treatment for parents with children in foster care **k.** Support the development of systems to ensure SEI newborns get appropriate preventive services, developmental screening, and follow-up Hepatitis C screening **l.** Review and update the birth certificate worksheet to reduce stigmatizing language and collect surveillance data around SEI, POSC, and maternal SUD

Strategy #22: *Improve patient access to Medication Assisted Treatment (MAT), with special efforts to reach populations most at risk*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Strengthen Maine's system for treatment and recovery **b.** Implement the federal Medicaid 1115 IMD Waiver to enhance access to residential SUD treatment **c.** Continue supporting emergency departments in adding rapid induction MAT **d.** Continue supporting county jails and Department of Corrections in adding MAT **e.** Support the Wabanaki nations in creating a Maine-based treatment and recovery center	**f.** Work with the Department of Corrections and county jails to identify sustainable funding to provide MAT universally to all incarcerated individuals with a diagnosis of SUD **g.** Assess need and fill gaps in treatment capacity for adolescents, including medically supervised withdrawal **h.** Pilot and evaluate mobile MAT services **i.** Support expansion of MAT programs in county jails and DOC by including all forms of MAT **j.** Improve referrals with and within specialty courts

Strategy #23: *Increase MAT provider capacity for providing low barrier, rapid access to treatment*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support Federally Qualified Health Centers (FQHCs) in piloting low barrier MAT, including rapid induction and bridging capacity, especially in rural areas **b.** Build upon existing MaineCare payment and benefits models, including the Opioid Health Homes (OHH) program **c.** Assess and update reimbursement systems, including commercial insurance, to maximize counseling capacity	**d.** Implement a statewide system for providing education and technical assistance support for MAT providers, including an SUD Learning Community **e.** Secure leadership commitments from health systems and provider groups to increase their number and capacity of MAT (X-waivered) clinicians **f.** Allocate resources to ensure adequate reimbursement to treatment providers across the range of services **g.** Assess transportation needs to ensure access to MAT appointments **h.** Support additional capacity for "bridging" from MAT induction to maintenance treatment and recovery **i.** Provide education and training on the Contingency Management & Community Reinforcement approach for stimulant use disorder

Strategy #24: *Implement innovative treatment strategies in response to the COVID-19 pandemic*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Expand the allowable credentials for preparation of take-home doses of methadone by Opioid Treatment Programs **b.** Implement the StrengthenME Initiative to provide proactive outreach from Recovery Community Centers and Recovery Coaches to reduce stress and improve connectivity and Community Health Workers to engage communities disproportionately affected by COVID- **c.** Maintain the use of digital technology, including telehealth, to deliver MAT and support patient monitoring **d.** Implement active outreach as part of "OPTIONS" program to increase referrals to treatment	e. Assess and maintain the most effective innovations to build resiliency and preparedness

Strategy #25: *Implement the most promising practices in response to increased use of stimulants and polysubstances*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Design a Contingency Management pilot	**b.** Assess and update reimbursement systems and insurance coverage for stimulants and polysubstance use disorders **c.** Implement the Contingency Management pilot

Priority H: Increase the proportion of persons with SUD/OUD who seek or are in treatment

Strategy #26: *Provide clear public information about real time availability of treatment options and how to access treatment and referrals, including telehealth options*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Implement the Map & Match initiative to identify gaps in the treatment service continuum and geographic access shortages with real time capacity data **b.** Implement the treatment and recovery services locator tool, including education of providers and the public **c.** Pilot an SUD telephonic helpline in Washington County **d.** Implement the Office of Medicaid Service's "Health Care Happens Here" campaign to provide a digital health option during the COVID-19 pandemic **e.** Improve the 211 database and maintain the 211 Opioid Helpline **f.** Use Opioid Data Sharing Committee results to determine gaps in treatment and recovery	g. Refine efforts to match people seeking treatment with options that offer the best fit for their needs

Strategy #27: *Reduce structural and systemic barriers to treatment*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Collaborate with Maine's CAP Agencies and other partners to provide transportation and child care for people seeking treatment **b.** Improve access to public and private health insurance coverage **c.** Examine compliance with federal and state parity laws by commercial health insurance companies	

RECOVERY SUPPORTS

Priority I: Support individuals in recovery

Strategy #28: *Support recovery for youth and adults with SUD/OUD*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Provide recovery supports for youth with SUD/OUD through support for Young People in Recovery and other youth-led and youth-serving organizations **b.** Provide employment support through the Department of Labor's "Connecting with Opportunities" and "Maine Works" initiatives **c.** Provide more supports, including case management and recovery support specialists, to assist individuals coming out of incarceration in maintaining their recovery	**d.** Continue supporting youth-led and youth-serving organizations and activities **e.** Support secondary prevention projects within Maine Center for Disease Control and Prevention and the Department of Education **f.** Identify and pilot new/innovative models of recovery

Strategy #29: *Support individuals involved in the criminal justice and juvenile justice systems*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Promote and expand pre-arrest diversion programs and treatment alternatives to incarceration, including Treatment and Recovery Courts for individuals with SUD or co- occurring mental health disorders **b.** Support the law enforcement Co-Responder and SUD Liaison/Navigator programs **c.** Support innovative pre-arrest and post arrest diversion programming pilots, such as law enforcement assisted diversion (LEAD) and the Sequential Intercept Model in order to provide care coordination, improve communication, reduce recidivism, and support recovery **d.** Support the peer-to-peer mentoring program for participants in Treatment and Recovery Courts	**e.** Review recommendations from the 2020 evaluation of Maine's Treatment and Recovery Courts for potential implementation **f.** Evaluate the Southern Kennebec County Diversion and Support Program for potential replication **g.** Evaluate the Waldo-Knox Drug Offense Diversion and Deflection Program **h.** Assess and support evidence-based re-entry programs, such as those operated by the Maine Prisoner Re-Entry Program **i.** Expand the training for prosecutors, defense attorneys, and participants in Treatment and Recovery Courts

Strategy #30: *Increase the availability of recovery coaching services*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Support peer recovery coach trainings **b.** Continue to expand peer recovery coaches in emergency departments initiating MAT **c.** Continue to expand peer recovery coach capacity through community recovery centers and improve the monitoring and supervision of recovery coaching **d.** Create a comprehensive list of all certified (CCAR) recovery coaches in the state, regardless of their source of training	**e.** Host an education and coordination conference for recovery coaches, including recovery coaches who are incarcerated **f.** Establish a second level, state certification for Recovery Coaches who meet the requirements **g.** Evaluate cost and establish payment codes for recovery coaching **h.** Connect recovery coaches who have graduated from a Treatment and Recovery Court to current and potential Court participants

Strategy #31: *Provide resilience-building programs and services for people in recovery*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Implement the StrengthenME Initiative to help people cope with the stress of the COVID pandemic	b. Assess resilience-building programs and strategies for adults, and make recommendations for potential implementation

Strategy #32: *Expand safe and secure housing options for people in recovery*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Partner with the Maine State Housing Authority (MSHA) to implement Public Law Chapter 524, "An Act to Ensure the Quality of and Increase Access to Recovery Residences" **b.** Partner with the Maine Association of Recovery Residences (MARR) to encourage certification of residences and reduce discrimination against residences allowing MAT **c.** Work with housing providers to support individuals with SUD in successfully maintaining permanent housing, including through a permanent supportive housing (PSH) initiative utilizing a Health Home model program to serve those who are at risk for, or are chronically homeless	d. Continue the MSHA pilot and increase the number of certified residences in the pilot

Priority J: Build and support recovery-ready communities

Strategy #33: *Increase community-based recovery supports*

CURRENTLY PLANNED/FUNDED ACTIVITIES (FY21)	PRIORITY FUTURE ACTIVITIES (FY22 - FY23)
a. Develop an initiative around recovery ready communities, including recovery ready campuses **b.** Fund and support additional SUD/OUD community coalitions/partnerships	**c.** Evaluate the Youth Employment Assistance Program for possible replication statewide **d.** Fund and support additional SUD/OUD community coalitions/partnerships **e.** Implement recovery ready initiative

Join Us!

Maine's HIV/AIDS Advisory Board (MeHAAB) is looking for new members!

WHAT: MeHAAB is group of people who offer information, advice, and experience to develop Maine's next five-year, statewide Integrated HIV Prevention and Care Plan. The plan is to guide services for people living with or at risk of HIV.

WHO: You! MeHAAB is open to anyone who has relevant life or work experience related to HIV/STD/Hepatitis prevention or care can participate.

WHEN: Meetings will typically be held the 2nd Tuesday of every month in 2022 on Zoom and by phone.

HOW: If you would like join, send an email to RyanWhitePartB@maine.gov with the subject "MeHAAB". If you can't attend all the meetings, that's ok!

As a thank you, clients will receive giftcards for their time. If you have any additional questions, please call 207-287-3747.

Department of Health and Human Services

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State of Maine
Infectious Disease Prevention Program
2022 Interview Summary Report

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Introduction

The Maine HIV/AIDS Advisory Board (MeHAAB) wanted to gain qualitative information about Mainers to address programmatic needs in greater depth as part of the process to develop the Integrated HIV Prevention and Care Plan. The internal goal was to conduct five to ten interviews. Twenty-two interviews were conducted.

Two representatives, one from the State's HIV care team and one from the State's prevention team, took the following actions to recruit interviewees:

- Handed out flyers at five tabling events in four cities
- Reached out to all Case Managers in the state asking for referrals
- Posted on social media via a case management organization
- Reached out directly to specific Ryan White Part B clients
- Distributed flyers and asked organizational staff to recruit participants at SSPs, case management organizations, and local STD clinics

The interviews lasted around 90 minutes on average and were recorded and transcribed when consent from interviewee was granted.

Of the 22 interviews, five took place via Zoom, five were conducted on the phone, three were in-person in the Maine CDC office, and nine were in the county of residence of the interviewee.

Twenty-one interviews were held in English, and one interview was held in Lingala via a phone interpreter from Maryland.

Seventeen interviews were held with people living with HIV/AIDS, 15 of whom were enrolled in the State's Ryan White Part B Program. Five interviews were held with people not living with HIV/AIDS who are members of at-risk priority populations.

Interviewees received a $50 Hannaford food card for their participation.

The interview proved lasted about eight weeks and took place in May and June of 2022.

Interviewee Demographics

Gender	Number of Interviewees
Transgender	1
Female	7
Male	14

Age Range	Number of Interviewees
0-30	4
31-50	6
50+	12

Race/Ethnicity	Number of Interviewees
BIPOC	4
White	18

County of Residence	Number of Interviewees	County of Residence	Number of Interviewees
Androscoggin	4	Oxford	0
Aroostook	0	Penobscot	2
Cumberland	6	Piscataquis	1
Franklin	0	Sagadahoc	2
Hancock	2	Somerset	0
Kennebec	1	Waldo	0
Knox	0	Washington	2
Lincoln	2	York	0

Summary of Major Themes

People Living with HIV

- There are high satisfaction levels with medical care.
- There are high satisfaction levels with ADAP/ RWHAP Part B services.
- There are common complaints of too much paperwork and bureaucracy accessing care across the board.
- RWB/ADAP clients have a high utilization rate of Case Managers to navigate paperwork and bureaucracy. Overall, people have had very good experiences with their Case Managers over the years.
- There is an unhelpful medical referral cycle for PLWHA when it comes to issues not related to HIV (like a flu, COVID-19, etc.). When seeking care for these unrelated illnesses, PLWHA will often first see their Primary Care Physician (PCP). However, PCPs would commonly refer out to the patient's Infectious Disease Physician (IDP). The IDP would then refer the client *back* to their PCP because these health concerns did not fall within their specialty. This created cyclical ineffective care.
- There is a need for better transportation to get to services; telehealth is beneficial, but patients wanted to see their providers in person as well.
- There is a desire for financial support when it comes to alternative therapies (acupuncture, vitamins, etc.). Clients are looking to the RWHAP Part B Program for coverage.
- Maine's immigrant population living with HIV expressed a desire for free or reduced cost legal help and individual lessons on American cultural norms. Doing so on an individual basis was important due to stigma in small communities. Group education was not advised.
- There is a desire for health care providers to be better at taking/discussing sexual history. Men who have sex with men also wanted providers to be more culturally competent surrounding common sexual practices (like non-monogamy).

Individuals at Higher Risk Contracting HIV

- There is low knowledge of free or low-cost HIV and STD testing services.
- There is low knowledge of rapid HIV tests.
- There is low knowledge that rapid tests are available in non-clinical settings.
- There is a desire for more easily accessible syringe service program (SSP) locations and more locations around the state. Those who need SSP access often do not have reliable transition and are unable to effectively utilize services.
- There is a high satisfaction with SSP services.
- There is dissatisfaction with one-for-one needle exchange regulations. This system makes it difficult for people to get clean syringes after they are confiscated (by police or after rehab programs). Need-based models were referred as most effective.
- There is a desire for health care providers to be better at taking/discussing sexual history, drug use, harm reduction practices, and HIV/STD prevention and testing options.

Interview Questions

The following questions were used as a general guide for the interviews. If interviewees wanted to talk about additional topics or not discuss a topic, the interviewers adjusted the questions to accommodate their comfort, time, and interest.

Interview questions were developed then refined after considering:

- Emerging issues identified during the Integrated Planning process kickoff meeting
- Interview guidance from other states
- Gaps in our knowledge at the State level
- Edits from various stakeholders, including PLWHA

Interview Questions for People Living with HIV

Background

1. Tell us about yourself. What are some memories you have related to learning about learning or living with HIV?
    a. What are some memories you have related to learning about learning or living with HIV?
2. Can you tell me about your HIV journey? What has it been like to live with HIV?
    a. What are some memories related to learning about HIV, your diagnosis, or realities of living with HIV that really stood out to you? Especially when it comes to living in the State of Maine.
    b. What was your understanding of HIV before your diagnosis?
    c. When were you diagnosed with HIV?
    d. Why did you decide to get tested?
    e. Did you know that you were at risk for HIV?

Services

3. Do you receive any Ryan White Part B services?
    a. What are they?
    b. Do you feel like they meet your needs?
4. Do you receive any other social support services (Case Managers, housing help, etc.)?
    a. If so, what are they?
    b. Do you feel like they meet your needs?
5. Thinking about the services you receive, what makes them helpful?
6. What are your biggest challenges you face with accessing HIV services?
7. What could Maine do to make it easier to access services?
    a. Possible follow-up question if participant is coming up blank:
        i. Do you find program requirements easy to understand?
        ii. Do you find services easy to use?
        iii. What are your favorite and least favorite parts of the services you receive?
        iv. What do you think is your biggest unmet need in the HIV services you receive?

        v. What do you want to be different about the services you receive?
        vi. How well are the services working for you?
    b. So, what do you think HIV support workers in Maine could do to help people become or stay virally suppressed?
    c. Is there anything that you think HIV support workers in Maine could do to help prevent new HIV infections?
    d. What are your experiences (as they relate to HIV) HIV support workers? Have they changed over the years?
    e. Are there things that you want health care providers specifically to know or do that would make it easier/better to work with them?
    f. Are there things that you want case managers or support workers (like us) to know or to do that would make it easier/better to work with them?
    g. Was there ever a time that you felt your doctor did not listen to you or your needs?
    h. Was there ever a time when you felt that you did not get the care you needed because of your HIV status?
    i. If you have a case manager, in what ways does your case manager help you connect to or stay connected to your medical care services?
        i. How could they help you more with this?
    j. Do you feel like you have access to all the medical care you need, including specialists?
        i. What challenges have you had?
    k. What kind of doctor are you seeing to get most of your healthcare?
        i. Do you go to one doctor for general issues and another for HIV-related care?
        ii. Are you getting all the healthcare you feel like you need or want?

Medical Questions

8. How often do you access STD testing services? We're talking about testing for diseases like Hepatitis, Chlamydia, Gonorrhea, Syphilis, Herpes, HCV, etc.
    a. If yes: where do you most often go to get tested?
    b. Do you feel like you can easily keep up with routine testing?
9. How frequently do you receive labs to monitor your HIV (viral load, CD4)?
    a. (If they get tested): Do you feel like you can easily keep up with routine testing?

Final Question

Imagine if Maine gave you exactly what you needed to live you best life with HIV. What would that look like? Where would our money go? Where do you not want our money to go? What kind of services would we provide? Not just the State, but Case Managers, doctors, prisons, etc. We want you to dream big. Would you like an example of what I think this would look like?

Interviews for People at Higher Risk Contracting HIV

Demographics

- How old are you?
- What is your race?
- Do you have kids?

Drug Use

- Can you tell me how you started using drugs?
- What drugs do you use?
- What do you think about sharing needles?
- Do you reuse needles? How often do you reuse needles?
- Do you clean your skin before injecting?
- If you do share needles, are you worried about getting diseases?
- Do you have supplies to clean your skin before injecting?
- Do you have supplies to clean needles in between uses?
- Would you clean your skin or needles before use if you had supplies available?

Services

- What help do you get from Green Street?
- Do you access any form of health care?
- If so, what types of care do you receive?
- Where do you go to get care?

Sexual Activities

- Do you have sex?
- When are you most likely to use a condom? When are you most likely to not use a condom?
- How do you meet the people you are having sex with?
- What type of people do you have sex with? Mostly men, women, transgender people?
- What types of sexual activities do you engage in? Vaginal, anal, oral
- Do your sexual practices change when you use drugs?
- Have you ever exchanged sex for drugs, housing, food?
- When you do not use a condom, what makes you not use them? Availability, comfort, cost, just to prevent pregnancy

STD Knowledge

- What do you know about HIV?
- What do you know about HCV?
- What STDs do you know about?
- Are you concerned about any of these in your own life?
- Do you think about safer sex practices? What do you do to stay safe from STDs?
- Do you get tested for STDs?

- If so, how often do you get tested?
- What types of birth control do you use?

Visioning

- What could we do at the State to make you feel safer?

September 29, 2022

Kerry Hill, MSW; Public Health Analyst
Health Resources and Services Administration
5600 Fishers Lane
Mail Stop 09SWH03
Rockville, MD 20857

David Block, PDIB, DHP, CDC; Public Health Advisor/Project Officer

Dear Mr. Hill and Mr. Block:

The Maine Integrated HIV Planning Body ***concurs*** with the following submission by the Maine Center for Disease Control and Prevention in response to the guidance set forth for health departments and HIV planning groups funded by the U.S. CDC's Division of HIV/AIDS Prevention (DHAP) and HRSA's HIV/AIDS Bureau (HAB) for the development of an Integrated HIV Prevention and Care Plan.

The Maine Integrated HIV Planning Body has reviewed the Integrated HIV Prevention and Care Plan submission to the CDC and HRSA to verify that it describes how programmatic activities and resources are being allocated to the most disproportionately affected populations and geographical areas that bear the greatest burden of HIV disease. The planning body ***concurs*** that the Integrated HIV Prevention and Care Plan submission fulfills the requirements put forth by the Funding Opportunity Announcement PS12-1201 and the Ryan White HIV/AIDS Program legislation and program guidance.

Maine's Integrated HIV Prevention and Care Plan was developed through a collaborative process between the Integrated HIV Planning Body and Maine CDC. The Planning Body contributed its experience and perspective at every stage of development by participating needs assessments and providing feedback on findings included in the Statewide Coordinated Statement of Need (SCSN), participating in bi-weekly meetings throughout the planning process, discussing SCSN findings and their relationship to the goals in the National HIV/AIDS Strategy and assisting with the development of the final Integrated HIV Prevention and Care Plan. The Planning Body reviewed each section of the Integrated HIV Prevention and Care Plan as it was drafted and participated in a final review of the complete document before submission.

The signature(s) below confirms the ***concurrence*** of the planning body with the Integrated HIV Prevention and Care Plan.

Signature: Wayne A Griffeth-Hurst Date:

Planning Body Chair(s): November 10, 2022