Consumers and Health Data in Maine

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Objective

Asked to talk about

• What should the state’s role be in making health care/medical care information available to consumers to help them make informed choices?

• How/why consumers should be involved in the design and governance of health data organizations?
My Background

• Maine Health Data Organization Board
• Maine Health Information Center/Onpoint Board, 2003- 2010
• Maine Data Processing Board 2007-08
• Quality Counts Board, 2004- 2008
• Maine Health Management Coalition Board, 1994-1999
• Several NQF, AHRQ, NCQA and other national committees about health data
• Worked as contractor with
  – Maine Health Management Coalition since 2000
  – Quality Counts since 2008
My Work with Consumers

• Worked with consumers actively since 2002
• Thousands of hours with hundreds of consumers in
  – Focus groups
  – Website testing
  – Various committees and work groups in Maine
  – Various workshops and forums nationally
Start with “Who are Consumers?”

- The general public: (2003)
  - People as citizens of Scotland and consumers who have used or who have the potential to use the services of NHS Scotland, i.e. anyone in Scotland.

- Patients (or users):
  - People who are using services or have recently used services.

- The actively interested public:
  - People who take an active interest in services, particularly carers, and the family and friends of patients. This group may sometimes be integrated with ‘patients’.

- Patient interest groups:
  - People in organisations that can provide information about common and differing perspectives and needs of groups of patients.

- People who may not get involved without particular recognition and a sensitive approach to their individual needs, background and circumstances
  - (For example, people from deprived or remote or rural communities; people with mental health problems; people with learning, physical or sensory disabilities; frail older people; children and young people)
• **Consumers:**
  – individuals who have significant personal experience with the health care system……most lack the ability to influence and communicate with a large network or constituency

• **Consumer Rep:**
  – individuals who work at nonprofit, mission oriented organizations that represent a specific constituency of consumers or patients. …trusted source of information. Unlike individual consumers, they speak from a global perspective and have experience representing the diverse needs and wants of groups of consumers and patients.
  – they typically do not have a financial stake in the health care system.

• **Need Both !!**
History of Consumer Involvement in Health Care Delivery in Maine

- Examples of Consumer Involvement
  - Hospital Board of Directors
  - Hospital Auxiliary
  - FQHC Board of Directors
  - State Employee Health Commission
    - 14 union- 10 management members
    - Winner of first annual Quality Counts QI Award - 2011

- Journey of working with consumers, especially on labor- management groups, over last 10 years
Institute of Medicine Report 1999:

To Err Is Human:
Annual Deaths:

- Medical Mistakes: 44,000 - 98,000
- Motor Vehicle Accidents: 43,458
- Breast Cancer: 42,297
- AIDS: 16,516
- Workplace Accidents: 6,000
• “*Crossing the Quality Chasm:* A New Health System for the 21\textsuperscript{st} Century”
  – “Chasm” not a “Gap”

• Rand: McGlynn 2004
  – Right Care 55% of time
IOM Framework

- Safe
- Timely
- Effective
- Efficient
- Patient Centered
- Equitable
Abdominal Aortic Aneurysm - 2002
Threshold Volume = 30/year
• Has committee looked at variation nationally and in Maine?
Comparative Cost: Large Maine Hospitals 2010

<table>
<thead>
<tr>
<th>Below State Average</th>
<th>Above State Average</th>
</tr>
</thead>
</table>

[Image of a table with two columns: Below State Average and Above State Average.]
Problems With Safety Persist

Don Berwick – November 2007:

• “The chances of being injured by hospital care is greater than one in 10, and accidental death due to mismanaged care is about one in 300.”

• 2007 Maine Discharges:
  – Total Discharges in Maine 163,705
  – Berwick: 1 in 300 result in death 546
  – Berwick: 1 in 10 result in inj./ill. 16,371
• 13.5% of hospitalized Medicare beneficiaries experienced adverse events during their hospital stays that resulted in prolonged hospitalization, required life-sustaining intervention, caused permanent disability, or death.

• An additional 13.5 percent experienced temporary harm events that required treatment.

• Maine in 2010:
  – 61,385 Medicare patients discharged from Maine hospitals
  – 13.5% = 8,287 Medicare beneficiaries
    • 22.7 per day
Not All Preventable

• “Although an adverse or temporary harm event indicates that the care resulted in an undesirable clinical outcome and may involve medical errors, adverse events do not always involve errors, negligence, or poor quality of care and may not always be preventable.”

• We don’t know how many adverse events occur in Maine, but I believe most Maine hospitals work very hard at patient safety.
Maine Hospitals Tops

• CMS
  – Quality in Maine hospitals on averages is highest in country

• Leapfrog
  – Maine hospitals on average are among safest in country
• All sampled hospitals had incident reporting systems to capture events, and administrators we interviewed rely heavily on these systems to identify problems.

• Hospital staff did not report 86 percent of events to incident reporting systems.
Still Crossing The Quality Chasm—Or Suspended Over It?

• Susan Dentzer, Editor Health Affairs, Quality Counts 2010

• Rigorous chart-review methodology pioneered by the IHI disturbingly picked up 10X more confirmed significant adverse events than other methods—and determined that adverse events occurred in one-third of hospital admissions, even in hospitals that had instituted advanced patient safety programs.
• One of the first major national success stories in quality improvement: the campaign to reduce preventable bloodstream infections, which began in Michigan and spread forty-five states.
• Number of patients in US intensive care units suffering a bloodstream infection declined by 63% between 2001 and 2009.
• But it requires doing things differently.
Disturbing Information Continues

- Diagnostic Errors Found in 1 of 4 ICU Patient Deaths
- *HealthLeaders Media, August 28, 2012*

- As many as 40,500 American adults may die in hospital intensive care units each year because their critical care teams didn't accurately diagnose their illnesses, according to a [Johns Hopkins University School of Medicine](https://www.hopkinsmedicine.org) review of 30 international papers that examined autopsy results.

That's more people than die each year of breast cancer in the U.S. or from bloodstream infections acquired in the ICU, the researchers say. And many more patients suffer harm from care provided for the wrong condition.

"The bottom line is that these were misdiagnoses made by the ICU staff," says Bradford Winters, MD, associate professor of anesthesiology and critical care medicine at Johns Hopkins University School of Medicine and lead author of the paper.
• If you are a consumer not connected with the health care system, at this point what are you thinking?
• And how much confidence do you have that health care system will improve on its own?
• And how do you know if it does?
• Only answer is full and credible transparency.
Need More and Deeper Metrics

- on all aspects of the health care system that the state should help fund and produce on all aspects of the IOM framework
  - Safe
  - Effective
  - Timely
  - Patient Centered
  - Equitable
  - Efficient
Consumers Need Trusted Intermediaries
Focused on Delivery System

And the state should work closely with trusted intermediaries to develop and disseminate this information to consumers:

• Multi-stakeholder health improvement collaboratives
  – MHMC Foundation
  – Quality Counts

• Labor – management groups

• Health oriented non-political consumer groups
  – Area Agencies on Aging
  – AARP
  – Others
And We Need to Get Consumers Involved in All Aspects of Health Care System

1. Improve one’s own health / health of family member
   – Wellness offerings
   – Healthy eating
   – Meals on wheels, etc.

2. Get information to make informed choices about care
   – Promote GetBetterMaine
   – Help people access information
   – Articles in newsletters
   – Review at meetings, etc.

3. Work with others to help improve their health
   – Look at numbers Living Well and Matter of Balance are reaching vs. number needed to reach
   – Market to reach desired number
4. Work directly with health care providers to help improve the delivery, quality, experience of care
   – Participate in provider committees (with training)

5. Work with stakeholders to drive system, policy, payment changes to transform care
   – Meetings with local providers
   – Community forums on quality-cost
   – State work groups
Do You Get Quality Health Care?

<table>
<thead>
<tr>
<th>How would you grade each of the following?</th>
<th>A</th>
<th>B</th>
<th>C</th>
<th>D</th>
<th>E</th>
<th>Don’t know/Refused</th>
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<tr>
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<td>6</td>
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Robert Wood Johnson Foundation/Harvard School of Public Health poll from March 9-18, 2011

- As a consumer, there is a fundamental difference between looking out for yourself and looking out for 20,000 people.
Our Quality Is Less.........

U.S. Lags Other Countries: Mortality Amenable to Health Care

Deaths per 100,000 population*

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<tr>
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<td>Italy</td>
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* Countries’ age-standardized death rates before age 75; including ischemic heart disease, diabetes, stroke, and bacterial infections. Analysis of World Health Organization mortality files and CDC mortality data for U.S.

Our Costs Are More

International Comparison of Spending on Health, 1980–2008

Average spending on health per capita ($US PPP)

Total expenditures on health as percent of GDP

Source: OECD Health Data 2010 (June 2010).
Insurance Cost Growth Quadruple the Rate of Wages and Inflation

Cumulative Changes in Health Insurance Premiums, Inflation, and Workers’ Earnings, 1999-2010

What Are We Trying to Achieve?
And what Contributes?

Univ. Wisconsin - RWJF County Health Rankings