# **10-144 MAINE DEPARTMENT OF HEALTH AND HUMAN SERVICES**

 **MAINE CENTER FOR DISEASE CONTROL & PREVENTION**

 **DIVISION OF FAMILY HEALTH**

 **MATERNAL, FETAL & INFANT MORTALITY REVIEW PANEL**

**Chapter 700: RULES AND REGULATIONS RELATING TO THE MATERNAL, FETAL AND INFANT MORTALITY REVIEW PANEL**

**SUMMARY:** These rules establish the responsibilities of the Maine Maternal, Fetal and Infant Mortality Review Panel in regard to collection of data, panel membership, conducting family interviews, confidentiality, the nature of contact between the Maine Maternal, Fetal and Infant Mortality Review Panel with families and access to medical records, and the conduct of reviews of maternal, fetal and infant deaths.

1. **PURPOSE AND STATUTORY AUTHORITY**

These rules implement the Department’s duties and responsibilities in the establishment of a maternal, fetal and infant mortality review panel as enacted by P.L. 2005, c. 467 and P.L. 2009, c. 531, codified at 22 M.R.S.A. §261.

1. **Definitions**

As used in this section, unless the context otherwise indicates, the following terms have the following meanings.

1. “Authorized Representative” means parent, guardian or *guardian ad litem*, or other person authorized by the parent or guardian to act as a representative.
2. "Maine CDC" means the Maine Center for Disease Control and Prevention, Department of Health and Human Services.
3. "Deceased person" means a woman who died during pregnancy or within 42 days of giving birth or a child who died within 1 year of birth.
4. "Director" means the director of the Maine Center for Disease Control and Prevention, Department of Health and Human Services.
5. “Family” means a woman who has experienced a fetal death, or the parent or parents or other authorized representative of a deceased person.
6. "Panel" means the maternal, fetal and infant death review panel established under this section.
7. "Panel Coordinator" means an employee of the Maine Center for Disease Control and Prevention who is appointed by the Director, or a person(s) designated by the Panel
8. The “Panel Coordinator” must be a licensed physician or registered nurse or other health care professional licensed or registered in this State. The Panel Coordinator provides administrative oversight and project management and support for the Maine Maternal and Infant Mortality Review Panel.
9. “Home Interviewer” means a person under the direction and at the discretion of the Panel Coordinator who shall meet the requirements for Panel Coordinator and have professional training or experience in bereavement services.
10. “Hospital” means any facility licensed under the provisions of Title 22 of the Maine Revised Statutes, which provides health careservices.
11. “Specialty Provider” means those persons licensed pursuant to Title 32 of the Maine Revised Statutes who have additional certification by or eligibility for one of the disciplines of the American boards of certification and who are registered and certified by the appropriate specialty boards.
12. The “Medical Director” means an employee of the Maine Center for Disease Control and Prevention who is a licensed physician within the State of Maine who shall oversee Panel operations and Panel appointments.
13. “State Health Officer” means the Director of the Maine Center for Disease Control and Prevention.
14. **RESPONSIBILITies OF MEDICAL director**
	1. The Medical Director shall recommend the size of the Panel; and shall recommend the Panel Coordinator, all members of the Panel, and replacements to the Director of the Maine CDC.
	2. The Medical Director shall provide oversight and guidance in all aspects of Panel development, implementation and operation.
	3. The Medical Director shall appoint the Home Interviewer, who must meet the qualifications of the Panel Coordinator and shall have professional experience or training in bereavement services.
	4. The Medical Director shall have authority to seek funds and authorize disbursements for Panel functions.
	5. The Medical Director shall have authority to recommend removal of Panel members for failure to discharge their duties.
15. **RESPONSIBILITies OF PANEL COORDINATOR**
	1. The Panel Coordinator has the following duties and powers pursuant to 22 M.R.S.A. §261(4):
		1. The Panel Coordinator may appoint suitable persons as Designees to perform or assist with the duties of the Panel Coordinator. Any Designee appointed by the Panel Coordinator shall possess sufficient experience and/or training to conduct the activity and shall operate at all times under the direct supervision of the Panel Coordinator.
		2. The Panel Coordinator or designee(s) shall maintain a central registry of statewide organizations dedicated to improving the health of mothers and infants by preventing birth defects, premature births, and maternal and infant mortality
		3. The Panel Coordinator or designee(s) shall review the deaths of all women, currently residents of Maine, who die during pregnancy or within 42 days of giving birth. Should the Panel Coordinator determine that medical record review is necessary for selected cases, the Panel Coordinator shall first obtain written consent in accordance with state and federal law for that review from the family, no sooner than four months after the date of death.
		4. The Panel Coordinator or designee(s) shall review the majority of cases in which a fetal death occurs after 28 weeks of gestation when not the result of an abortion and in which the mother is currently a resident of Maine. Should the Panel Coordinator determine that medical record review is necessary for selected cases, the Panel Coordinator shall first obtain written consent in accordance with state and federal law for that review from the family, no sooner than four months after the date of death.
		5. The Panel Coordinator or designee(s) shall review a majority of infant deaths and determine the selection of cases based on the need to review particular causes of deaths or to obtain a representative sample of all infant deaths. Should the Panel Coordinator determine that medical record review is necessary for selected cases, the Panel Coordinator shall first obtain written consent in accordance with state and federal law for that review from the family, no sooner than four months after the date of death.
		6. The Panel Coordinator or designee(s) shall prepare a summary of relevant information regarding the case, removing any identifying information prior to case presentation, and shall not release, furnish, disclose, publish, or otherwise disseminate any identifying information.
		7. The Panel Coordinator or designee(s) may conduct voluntary interviews with the of a deceased mother, fetus and/or infant, subject to the requirements of 22 M.R.S.A. §261(4)(D).
		8. The Panel Coordinator or designee(s) shall inform any interested parties of the purpose and function of the Panel.
16. **PANEL MEMBERSHIP**
	1. The Maine CDC Director, upon recommendations from the Medical Director, shall appoint Panel members, who shall serve at his or her pleasure.
	2. The Panel members shall consist of health and social service providers, public health officials, law enforcement officers, and other persons with professional expertise in maternal and infant health and mortality.
17. **Responsibilities of Panel Members**
	1. All members of the Panel shall sign a confidentiality agreement regarding case review conduct and assurances of confidentiality when working with case specific data.
	2. All members of the Panel shall discharge in a timely manner their following duties and powers:
		1. The Panel shall conduct comprehensive multidisciplinary reviews of the case summary presented by the Panel Coordinator.
		2. The Panel shall present an annual report to the Department of Health and Human Services and to the joint standing committee of the Legislature having jurisdiction over health and human services matters. The Department may publish the annual report, or excerpts thereof, at its discretion. The report must identify factors contributing to maternal, fetal and infant death in the State, determine the strengths and weaknesses of the current maternal and infant health care delivery system and make recommendations to the Department to decrease the rate of maternal, fetal and infant deaths.
		3. The Panel shall offer a copy of the annual report to the person or persons that granted permission to the Panel Coordinator for a voluntary interview or medical record review.
		4. The Panel shall share the results of its data reviews and recommendations with the Maine Child Death and Serious Injury Review Panel established pursuant to 22 M.R.S.A. §4004(1)(E). The Panel may request and review data from the Child Death and Serious Injury Review Panel.
18. **Responsibilities of the Home interviewer**
	1. The Home Interviewer shall collect data that is limited for the purposes of the Panel in summary or abstract form without family names or patient identifiers.
	2. The Home Interview shall only take place as long as a valid and written signed consent remains in effect. The consent shall remain in effect unless revoked.
	3. The Home Interviewer may make a referral for bereavement counseling with family consent.
19. **Responsibilities of Those Providing Services**
	1. Any healthcare facility or healthcare provider shall provide access to medical records and other information pursuant to State and Federal Laws.
	2. A health care practitioner, hospital or healthcare facility, or the employee or agent of that person or entity is not subject to civil or criminal liability arising from the disclosure or furnishing of records or information to the Panel pursuant to 22 M.R.S.A. §261(8).
20. **Contact with Families**
	1. The Panel Coordinator shall not contact families prior to 4 months after the date of the death of the mother, fetus or infant.
	2. Initial family contact shall occur through a letter from the State Health Officer on the letterhead of the Maine Center for Disease Control and Prevention and shall include the following information:
		1. An invitation for the family to participate in a home interview and/or medical record review through a voluntary process.
		2. The data gathered will be used to determine and understand the significant social, economic, cultural, safety, and health care delivery system factors that are associated with fetal, infant and maternal mortality.
		3. The information obtained is confidential, and the name of the deceased person and his or her family or other identifying information cannot be released.
		4. A family may decline participation in the home interview, medical record review, or both.
		5. Information on bereavement services shall be offered regardless of status of participation in the interview and/or review process.
	3. The initial family contact shall also include an invitation to participate in a review of the death of the deceased person from a statewide organization dedicated to improving the health of babies by preventing birth defects, premature birth and infant mortality.
	4. Upon family request, referrals shall be made to the Department of Health and Human Services, Public Health Nursing, to provide information on available services.
	5. No family shall be required to accept any services offered.
	6. In the event of documented family objection to participation or indication of unwillingness to participate, the Panel Coordinator shall not collect or gather any confidential medical information relating to death of the infant and/or mother.
	7. In the event the family wishes to revoke the consent, the Panel shall not pursue any further review of the case.
21. **Confidentiality of all individually identifiable health Information**
	1. All data collected or developed by the Panel Coordinator, containing either direct or indirect individually identifiable information, shall be confidential and privileged and will not be considered a public record.
	2. Confidential medical information submitted to or developed by the Panel Coordinator shall only be available to the Panel Coordinator for the purposes of analysis prior to de-identification of such information to the Panel.
	3. In the event a proposed research plan involves contacting family members, written consent of the family of any deceased fetus, infant or mother shall be required for use or release of any information by the Panel Coordinator.
	4. All data will be maintained in a manner consistent with 22 M.R.S.A. §42(5) and §261(7).
	5. Confidentiality provisions which govern the Panel will be reviewed periodically to ensure that public confidence in the ability of the Panel and Maine CDC to safeguard individually identifiable information will be maintained.
22. **LIMITATIONS OF USE OF IDENTIFYING INFORMATION**
	1. The Panel Coordinator shall ensure that any information collected or developed by the Panel is necessary for the conduct of an appropriate maternal or infant death review.
	2. Access to privileged medical information is restricted to the Panel Coordinator or designee(s) and is essential for the conduct of such investigations. Tasks performed by the Panel Coordinator or designee(s) shall include, but not be limited to, the following functions:
		1. Medical record reviews.
		2. Audits and abstractions.
		3. Review of discharge summaries.
		4. Compilation of datasets.
		5. Analysis of vital statistic data with confidential data elements.
	3. Identifying information shall be used only to gain access to medical records and other medical information pertaining to case findings.
	4. Identifying information shall be used to the minimum extent possible to accomplish the purposes of the approved Panel activities.
23. **PURPOSE FOR USE OF IDENTIFYING INFORMATION**
	1. The Panel Coordinator or designee(s) may only use individually identifying information for the following purposes:
		1. Verification and validation of maternal, fetal and infant death oversight, including accuracy of data and document linkage to avoid duplication of occurrence, through contact with hospitals and other institutions regarding data gathering and management.
		2. Full scale epidemiological study of factors contributing to fetal, infant and maternal deaths.

STATUTORY AUTHORITY:

 22 M.R.S.A. §261

EFFECTIVE DATE:

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