



Franklin Pierce School of Law
Institute for Health Policy & Practice
Health Law & Policy

Maternal Mortality Review Committee Cross-Border Information Sharing

REGULATORY BARRIERS AND RECOMMENDATIONS

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HEALTH LAW AND POLICY PROGRAMS, UNH FRANKLIN PIERCE SCHOOL OF LAW AND THE
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Executive Summary

The rising rate of maternal mortality in the United States has received considerable federal and state attention in recent years.² In response, the federal government has supported funding and frameworks for state-created maternal mortality review committees (MMRCs). Currently, almost every state in the union has a committee that to some extent investigates and reviews maternal deaths.

The Centers for Disease Control and Prevention and Review to Action (a partnership between the Association of Maternal and Child Health Programs (AMCHP) and the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) administered by the CDC) promote the state-based maternal mortality review process and support and assist states with extensive resources and guidance around best practices in abstracting and review.³ Yet in practice, collecting complete records and data related to a decedent's care and/or death in order to fully inform the review of the maternal death remains an identified barrier to MMRCs, especially if the death or care occurred outside of the state in which the case is being reviewed.⁴ Many states are challenged by this issue as well as by data collection in general. The barriers to sharing records related to maternal deaths across state lines arise, at least in part, because maternal mortality review and data collection is governed by state statute and each state has its own regulatory structure. The smaller New England states also have relatively few maternal deaths as compared to more populated states, and therefore the pathways for collection are not as familiar. Regardless, the inability of a state to obtain and abstract comprehensive information can render a maternal mortality case unreviewable.

This report highlights barriers and strategies to records collection to support the critical Maternal Mortality Review process.

This report is based on an extensive review of the federal regulatory landscape governing information sharing, analysis of the Maternal Mortality Review Committee (MMRC) statutory provisions in the New England states (ME, VT, NH, MA, RI, CT) and investigation into what might optimize one state's efforts to ensure reviews are not duplicated and data collection is facilitated. The investigation included interviewing MMRC abstractors in the New England region and in select other states where statutes appeared to allow for improved data sharing. Reviewers were asked a key set of questions about their practices, commonly encountered barriers to data sharing, and ways in which data sharing was facilitated either through established technique or statutory pathways. The information was compiled, reviewed and recommendations developed. While some states have statutes that could serve as models for data exchange, an equally important component of data exchange is the practiced techniques that allow for more consistent and collaborative data sharing within the existing authority of each state statute.

Based on the investigation, the authors developed the following key recommendations to facilitate record sharing:

- Developing model legislative language to enhance data sharing between and among state MMRC abstractors;

- Entering into interstate compacts and/or executing memoranda of understanding (MOUs) between New England states that experience barriers to sharing relevant records with one another; and
- Establishing a New England Regional Collaborative in order to engage in learning sessions among state abstractors to support consistent strategies and facilitate mentoring and resource development.

More detailed recommendations are included in the report.

Introduction

The rising rate of maternal mortality in the United States has received considerable federal and state attention in recent years.⁵ “Maternal mortality”, as defined by the Centers for Disease Control and Prevention (CDC), is the broad definition that encompasses the death of a woman during pregnancy, childbirth, and the postpartum period up to a year from the end of pregnancy.⁶ MMRCs focus review and recommendations on deaths that are pregnancy-related. The Centers for Disease Control has defined pregnancy associated deaths as follows:

“...Pregnancy-Associated Death. A death during or within one year of pregnancy, regardless of the cause. These deaths make up the universe of maternal mortality; within that universe are pregnancy-related deaths and pregnancy-associated, but not related deaths.

Pregnancy-Related Death. A death during or within one year of pregnancy, from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.

Pregnancy-Associated, but Not Related Death. A death during or within one year of pregnancy, from a cause that is not related to pregnancy.”⁷

Recognizing that standardized data collection and review is critical to better understanding the causes of maternal mortality and eliminating preventable maternal deaths, the federal government has supported funding and frameworks for state-created maternal mortality review committees (MMRCs). Currently, almost every state has a committee that to some extent investigates and reviews maternal deaths.⁸

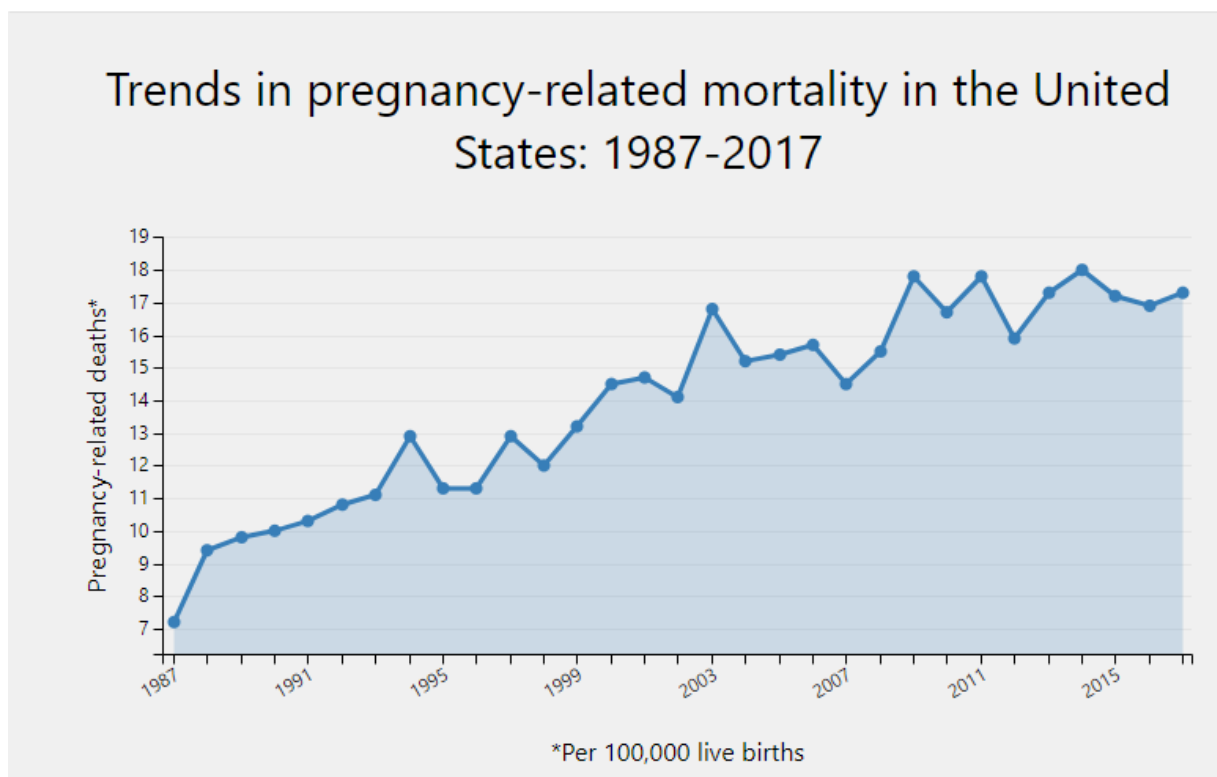
Where a death occurs does not necessarily correspond with where the decedent lived or received medical care.⁹ MMRCs are guided by the CDC Maternal Mortality Prevention Team to review if the state is the deceased individual’s state of residence as listed on the death certificate. Notwithstanding, the process of comprehensive review to better understand maternal mortality necessitates collecting complete records and data related to the decedent’s life, care and death, which process can be complicated if any occurred outside of the state completing the review. Many states are challenged by cross-border information sharing at least in part because maternal mortality review and data collection is governed by state statute – and each state has its own regulatory structure and review practices. The inability of a state to obtain and abstract comprehensive information can render a maternal mortality case unreviewable.

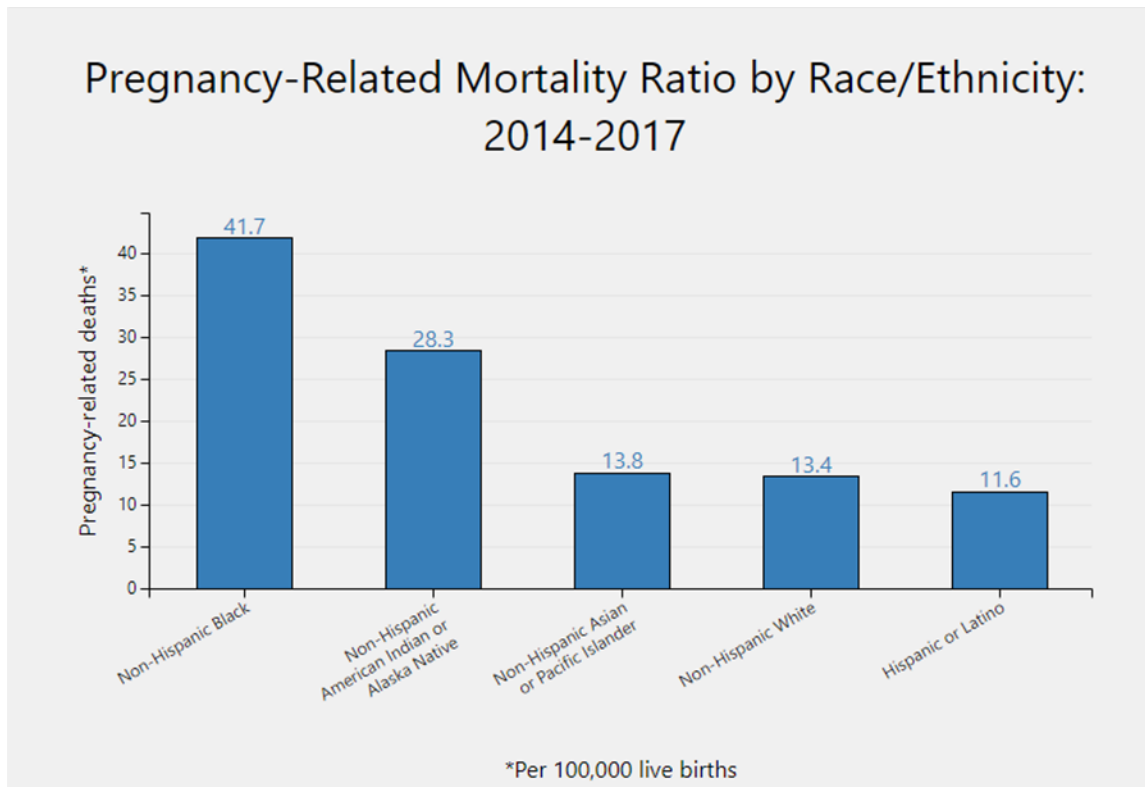
In search of strategies for effective interstate data sharing to support meaningful maternal mortality review, the New Hampshire Maternal Mortality Team contracted with the Health Law and Policy group at the Institute for Health Policy and Practice (IHPP). Specifically, IHPP was asked to examine legal barriers to sharing information across state borders and identify options to reduce barriers or leverage collaboration with other states to obtain complete records for review of all maternal death cases.

Maternal Mortality: The Scope of a Persistent Problem

The U.S. maternal mortality rate is one of the highest among industrialized countries and has remained high over the last two decades.¹⁰ In 2008, the maternal mortality rate was 7.4 deaths per 100,000 live births; by 2018, the rate had accelerated to 17.4 deaths per 100,000 live births.¹¹ More than half of recorded maternal deaths occur after the day of birth.¹² Below is a chart showing trends in pregnancy-related mortality in the United States between 1987 – 2017. See Trends in Pregnancy-Related Deaths – CDC Pregnancy Mortality Surveillance System.¹³

There are deep racial and ethnic disparities in maternal health outcomes and gaps in services, particularly in rural areas. Pregnancy-related mortality ratios for black and American Indian/Alaska Native women are two to three times higher than for white, Hispanic, and Asian/Pacific Islander women.¹⁴ Additionally, women in rural areas experience higher rates of delayed prenatal care initiation, which increases the risk of adverse outcomes.¹⁵ Researchers estimate that about 66% of maternal deaths are preventable.¹⁶





See Trends in Pregnancy-Related Deaths – CDC Pregnancy Mortality Surveillance System, n.10.

Based on interviews with Maternal Mortality Review Committee staff, an increasing number of maternal deaths investigated involve substance use.

NH has been experiencing approximately 10 pregnancy-associated deaths per year for the last several years. Of these, 1 or 2 are typically categorized as pregnancy-related. While NH does report these counts annually, the small numbers prohibit the calculation of a reliable pregnancy-related mortality ratio. For a full analysis of New Hampshire’s maternal mortality reviews, please see *New Hampshire’s Annual Report on Maternal Mortality to NH Health and Human Services Legislative Oversight Committee, October 23, 2020*.¹⁷

Various legislation, collaboratives, systems, and reports at the state and federal level underscore the significance of maternal mortality in the United States and the consensus that action needs to be taken to reverse the trend.¹⁸ There are federal and state legislative and administrative vehicles for supporting state efforts to review and identify causes of maternal mortality. They are examined in the next section.

Federal Legislative and Regulatory Initiatives Related to Maternal Mortality

Federal Law: The Preventing Maternal Deaths Act

Congress passed the Preventing Maternal Deaths Act (the Act) at the end of 2018, which created a federal infrastructure to support states in gathering and reviewing information about maternal deaths.¹⁹ The Act authorizes access to federal resources and funds for jurisdictions to

establish new and support existing maternal mortality review committees (MMRCs). At the time of its enactment, only thirty-six states had MMRCs and many of these were not operating fully or optimally.²⁰ The Preventing Maternal Deaths Act also sets forth reporting standards and guidance for state departments of health with respect to operating a MMRC.

According to the Act, the Secretary of the Department of Health and Human Services and States, Indian tribes, and tribal organizations (collectively “jurisdictions”) may work together to establish a program to support the establishment or operation of MMRCs. The Act identifies the data to be collected and the process for review. The jurisdictions participating in the program must “annually identify pregnancy-associated deaths and pregnancy-related deaths through the appropriate vital statistics unit.” Doing so requires:

- (I) matching each death record related to a pregnancy-associated death or pregnancy-related death in the State or tribal area in the applicable year to a birth certificate of an infant or fetal death record, as applicable;
- (II) to the extent practicable, identifying an underlying or contributing cause of each pregnancy-associated death and each pregnancy-related death in the State or tribal area in the applicable year; and
- (III) collecting data from medical examiner and coroner reports, as appropriate[.]”

Alternatively, pregnancy-associated and pregnancy-related deaths may be identified using other appropriate methods or information.²¹

ERASE MM Grant Program and Maternal Mortality Review Information Application (MMRIA)

In 2019, the CDC announced the award of more than \$45 million over the course of five years to support the work of Maternal Mortality Review Committees (MMRC) through the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) initiative.²²

Approximately thirty-one states, including New Hampshire, are being supported through the ERASE MM initiative.²³ As part of ERASE MM, grant awardees engage in standardized data collection. De-identified information is then entered into the Maternal Mortality Review Information Application (MMRIA) within two years.

MMRIA is a data system designed to facilitate MMRC functions through a common data language and is available to all MMRCs. Standardized data collection is a critical component of fully understanding the causes of maternal mortality and eliminating preventable maternal deaths. MMRIA helps MMRCs organize available data and begin to comprehensively identify and assess maternal mortality cases. MMRIA provides the following:

- A repository for the collection of clinical and non-clinical information surrounding a woman’s life and death, which can help facilitate review by a jurisdiction-based maternal mortality review committee.
- A repository for documentation of committee deliberations on:
 - whether the death was related to pregnancy;
 - if it could have been prevented;
 - factors that contributed to the death; and
 - recommendations to prevent future deaths.

- Standardized indicators, common to most pregnancy-related deaths that can be used for surveillance, monitoring, and examining maternal mortality.²⁴

MMRIA provides an opportunity for MMRCs to achieve process requirements such as collecting data, producing case summaries, and providing reports using robust data.²⁵ However, MMRIA does not facilitate sharing of identifiable information between states.²⁶ Cases shared on MMRIA are de-identified. A MMRIA data abstractor enters complete information onto MMRIA, to be de-identified when shared.²⁷

MMRIA provides a shared data framework that empowers MMRC prevention activities. As more MMRCs use MMRIA and are able to share de-identified data, it may be possible to:

- examine the most current and the overall data;
- Monitor and identify inconsistencies in decisions about pregnancy-related care to improve or develop support tools;
- Identify specific actions for prevention among all of the leading causes of pregnancy-related death; and
- Increase understanding and specificity of potential high-impact recommendations.²⁸

Federal Surveillance Data Systems Related to Maternal Mortality

In addition to ERASE MM, there are federal surveillance data efforts that also support monitoring maternal deaths. The CDC has two systems that collect data on maternal mortality: Pregnancy Mortality Surveillance System (PMSS) and the National Vital Statistics System (NVSS). Both of these systems rely heavily on death certificates. Death certificates provide the reasons for a death through the International Classification of Diseases codes. However, there are limits to the usefulness of this data: a death certificate does not include “diagnostic nuance,” nor can it “communicate the interconnected stressors and system failures, often community-specific, that contributed to a particular maternal death.”²⁹ The information on death certificates is too limited to explain why an individual death occurred, preventing these national surveillance systems from being able to answer what could be done to prevent the death in question. The data does, however, help expose the extent of the maternal mortality problem in the United States. Epidemiologists often can identify pregnancy-related deaths from death certificates because states have included a “pregnancy checkbox” that allows a physician, coroner, or medical examiner to identify that the deceased was recently pregnant.

Centers for Disease Control – Pregnancy Mortality Surveillance System

The CDC conducts national pregnancy-related death surveillance through the Pregnancy Mortality Surveillance System (PMSS).³⁰ PMSS defines pregnancy-related death as “the death of a woman while pregnant or within one year of the end of pregnancy from any cause related to or aggravated by the pregnancy.” To collect relevant data, the CDC requests that all fifty states, New York City, and Washington DC voluntarily send copies of death records for all pregnancy-related deaths, linked live birth or fetal death records, and additional data when available. Medical epidemiologists determine the cause of death and whether the death was pregnancy-related.

Centers for Disease Control – National Center for Health Statistics

The CDC National Center for Health Statistics maintains the National Vital Statistics System (NVSS), which collects data on maternal deaths that occur while the woman is pregnant or within forty-two days of the end of pregnancy, from any cause related to or aggravated by the pregnancy or its management.³¹ By 2017, all states had added a standardized checkbox to their death certificates to identify these maternal deaths, which are reported into the NVSS.

Other Federal Maternal Mortality Supports

Postpartum Medicaid Coverage

Federal law mandates that Medicaid must provide coverage to pregnant women with incomes up to 138% of the federal poverty level; that coverage must last until 60 days postpartum. This requirement gives Medicaid a significant role in covering births in the U.S. Medicaid covers more than four in ten births nationally. Both Congress and state legislatures are focusing on leveraging Medicaid's significant role in paying for maternal care to improve it.³²

Efforts to expand insurance coverage options for prenatal and postpartum women is most recently evident in the American Rescue Plan Act of 2021, which includes an option for states to extend an additional 12 months of Medicaid coverage to women it covered through its pregnancy eligibility category. This option, to provide an additional year of health insurance coverage to new mothers, is viewed as a key support to mitigating risks of maternal mortality. This option becomes effective April 2022 and is available to states through April 2027.

Medicaid does offer other pathways to coverage for low-income mothers, but the application of them is not universal. In states that have expanded Medicaid, women with incomes up to 138% FPL have a continued pathway to coverage. In the 12 states that have not adopted the ACA's Medicaid expansion, postpartum women could qualify for Medicaid as parents, however the income eligibility for the parent category is generally much lower than the income eligibility threshold for pregnant women in all of the states. Subsequently, the parent category cannot provide coverage to all women who had pregnancy coverage without action by the state to expand the income threshold of that eligibility group.

HHS Initiatives

In late 2020, the Department of Health and Human Services and the Surgeon General announced a Call to Action and HHS Action plan to combat the high rates of pregnancy-related complications and deaths. Concomitant to the increasing rates of pregnancy related complications and deaths, is the disproportionate racial and ethnic disparities apparent in maternal mortality data. Both the federal government and many states recognize the benefits of maternal mortality review committees.

State Maternal Mortality Review Committees

The Preventing Maternal Deaths Act (the Act) further encouraged and supported state Maternal Mortality Review Committees although some states and cities have had Maternal Mortality Review Committees (MMRCs) for close to 100 years. MMRCs are interdisciplinary committees that conduct reviews of maternal deaths generally occurring within one year of the end of pregnancy.³³ Most have statewide jurisdiction, although a few cities have their own city-

specific MMRC. MMRCs examine the circumstances of women’s deaths that occur during or within one year of pregnancy, investigate why the death occurred, and identify recommendations for preventing future deaths.

Currently more than forty states and a few cities have a formal process and committee to review maternal deaths. These MMRCs, which are mostly created by state statute, vary in their organizational structure and practices. There are also varying requirements for what next steps or actions must be taken following committee review of the deaths.³⁴ Common locations for MMRCs generally are in Maternal and Child Health divisions of Public Health Departments or within a Medical Examiner’s Office. States vary as to what their MMRCs investigate and review, including whether they review all maternal deaths that occur within the state or maternal deaths of all residents regardless of the location of the death. [See the](#) Section on MMRC Statutory Authorities and Appendix A for additional details on how MMRCs in New England function.

Health Information Privacy

Federal and state requirements around maintaining privacy and confidentiality of health information may also contribute barriers to sharing relevant maternal mortality information across state lines. Federal privacy restrictions prohibit medical providers and certain other entities from the unauthorized release of a patient’s medical records and health information. Generally, the minimum protections for this information are established by the Health Information Portability and Accountability Act (HIPAA).³⁵ Other federal regulations establish greater privacy protections for certain types of records, including 42 C.F.R. Part 2 for certain substance use disorder treatment records. States may also create more stringent protections for individual health information.³⁶ To counterbalance these patient protections, privacy laws generally include mechanisms to “allow[] the flow of health information needed to provide and promote high quality health care and to protect the public’s health.”³⁷

There are laws governing every aspect of health data: collection, use, sharing, and protection. Every transfer of health information corresponds with a decision point about what law applies and what the law permits. These legal determinations pivot on who has the information, who is requesting it, the nature of the information, why it was originally collected, and the information’s intended use or purpose. An overview of relevant privacy laws can be found below.

Understanding the federal privacy rules help to eliminate information blocking during the MMRC abstracting process and clarification can support legal information sharing for purposes of confidential MMRC review.

Federal Confidentiality Laws

HIPAA

The HIPAA Privacy Rule, issued by the U.S. Department of Health and Human Services to implement the requirements of the HIPAA statute, establishes national standards for the protection of individual health information. The Privacy Rule regulates the use and disclosure of protected health information (PHI) by covered entities, which are organizations subject to

the Privacy rule. It also sets standards for the right of individuals to understand and control how their health information is used.³⁸ Under HIPAA, the general rule is that “[a] covered entity or business associate may not use or disclose PHI except as permitted or required by [the HIPAA Privacy Rule].”³⁹ The Privacy Rule lists the specific, permitted uses of PHI. Other uses ordinarily require HIPAA-compliant authorization from the patient or the patient’s personal representative.

As part of HIPAA, Congress deliberately prohibited patient privacy protections from impeding public health activities, stating “Nothing in this part shall be construed to invalidate or limit the authority, power, or procedures established under any law providing for the reporting of disease or injury, child abuse, birth, or death, public health surveillance or public health investigation or intervention.”⁴⁰

Under the Health Insurance Portability and Accountability Act (HIPAA), the Department of Health and Human Services (HHS) has enacted regulations protecting a category of medical information called “protected health information” (PHI). These regulations apply to health care providers, health plans, and health care clearinghouses (covered entities), as well as certain “business associates” of such entities.⁴¹ The HIPAA regulations generally speak to covered entities’: (1) use or sharing of PHI, (2) disclosure of information to consumers, (3) safeguards for securing PHI, and (4) notification of consumers following a breach of PHI. First, with respect to sharing, HIPAA’s privacy regulations generally prohibit covered entities from using PHI or sharing it with third parties without patient consent unless such information is being used or shared for treatment, payment, or “health care operations” purposes, or unless another exception applies.⁴²

Reviewing the requests for information by MMRC abstractors in the context of various HIPAA exceptions, including the public health exception, may help eliminate actual or perceived barriers to information sharing. In addition, HIPAA does not cover de-identified information as is generally described below.

Protected Health Information

The designation “protected health information” or “PHI” applies to all “individually identifiable health information” held or transmitted by a covered entity or its business associate, in any form or media including electronic, paper, or oral. “Individually identifiable health information” includes demographic data and other information that:

- is created or received by a health care provider, health plan, employer, or health care clearing house; and
- relates to the past, present, or future physical or mental health or condition of an individual; the provision of health care to an individual; or the past, present, or future payment for the provision of health care to an individual; and
- that identifies the individual or can be used to identify the individual.

Various common identifiers constitute individually identifiable health information, including name, address, birth date, and Social Security Number.

For individuals who are deceased, HIPAA continues to protect their PHI for up to 50-years post death. Covered entities may disclose the protected health information of a deceased patient to

family members and others who were involved in the care or payment for care of the decedent prior to death, unless the covered entity is aware that doing so is inconsistent with a prior expressed preference of the individual.

Once health information has been de-identified, HIPAA does not restrict its use or disclosure. To be considered de-identified, the information must not identify or provide a reasonable basis to identify an individual.⁴³ This exception is often relied upon for reporting out on maternal deaths and can be a helpful exception for MMRC review.

[HIPAA Covered Entities, Business Associates and Hybrid Entities⁴⁴](#)

Most health care providers, whether institutions, organizations, or individuals, meet the criteria to be classified as a covered entity. A health care provider that bills or receives payment for health care in the normal course of business and sends covered transactions electronically is a covered entity. Health plans and health care clearinghouses are also covered entities.

Businesses or persons that support a covered entity and access the entity's PHI are business associates. Like covered entities, business associates must comply with HIPAA for the PHI that it collects, creates, uses, discloses, retains, and destroys.

Some entities that perform both covered and non-covered functions, including many state public health departments, elect to become a hybrid entity to limit HIPAA's application.⁴⁵ A hybrid entity must designate its "health care components," which include "any components that would meet the definition of a covered entity or business associate if it were a separate legal entity." These health care components of the hybrid are subject to HIPAA. Other "non-covered traditional public health activities, such as registries, surveillance programs and inspection programs" are carved out from HIPAA disclosure restrictions, permitting important data sharing to continue subject to state law.⁴⁶

[HIPAA Preemption](#)

In creating HIPAA, Congress sought to establish a national framework for patient privacy that sets a "floor" or a minimum set of individual privacy protections.⁴⁷ For this reason, the Privacy Rule preempts only those contrary state laws relating to the privacy of individually identifiable health information that have less stringent requirements or standards than the Privacy Rule (i.e., more stringent laws remain in effect). In this context, "contrary" means that it is impossible to comply with both laws or complying with the state law stands as an obstacle to the accomplishment and execution of the Privacy Rule. "More stringent" means that the state law provides the individual with greater rights or amounts of information or increases the privacy protections afforded the individual.

State public health laws that permit use and disclosure of PHI for public health reasons cannot be categorized as more stringent than HIPAA. To protect these important laws from preemption, the Privacy Rule specifically does not preempt contrary state public health laws that provide for the reporting of disease or injury, child abuse, birth or death, or for the conduct of public health surveillance, investigation, or intervention."⁴⁸ Thus, HHS may, upon specific request from a State, determine that a provision of State law which is "contrary" to the federal requirements, will not be preempted. Given HIPAA's broad permission around public health disclosures, the savings clause of the Privacy Rule will protect public health activities

authorized by state law. This means that states should look carefully at what they need to allow for disclosure of information for purposes of MMRC review.

Permitted Uses and Disclosures

A covered entity is permitted, but not required, to use and disclose protected health information, without an individual's authorization, for the following purposes or situations: (1) to the individual (unless required for access or accounting of disclosures); (2) treatment, payment, and health care operations; (3) opportunity to agree or object; (4) incident to an otherwise permitted use and disclosure; (5) public interest and benefit activities; and (6) limited data set for the purposes of research, public health or health care operations.⁴⁹ Covered entities may rely on professional ethics and best judgments in deciding which of these permissive uses and disclosures to make.⁵⁰

The Privacy Rule generally requires covered entities to take reasonable steps to limit the use or disclosure of, and requests for, protected health information to the minimum necessary to accomplish the intended purpose. The minimum necessary standard does not apply to certain disclosures, however, including disclosures to a health care provider for treatment purposes, disclosures to the individual who is the subject of the information, and disclosures that are required by law.

The exceptions to HIPAA allow for uses and disclosures of PHI that are broader than allowed by the savings clause.⁵¹ In light of the goals of this project to better understand how cross-border information sharing may be improved for purposes of maternal mortality case reviews, the forthcoming sections focus on permitted uses and disclosures for public interest and benefit activities and the limited data set.

Public Interest and Benefit Activities Required by Law⁵²

The Privacy Rule permits a covered entity to disclose PHI without the authorization of the individual when the disclosure is required by law and the disclosure complies with the requirements of that law. When a disclosure is required by law, the Privacy Rule's minimum necessary standard does not apply. The law requiring the disclosure will establish limitations around what should be disclosed. A covered entity cannot point to the Privacy Rule as a basis for not complying with a disclosure that is required by law.⁵³

Public Health Activity

HIPAA recognizes that public health authorities and others responsible for ensuring public health and safety have a legitimate need to access protected health information. To protect this legitimate need, the Privacy Rule permits covered entities to disclose PHI without authorization to a public health authority that is authorized by law to receive such reports for the purpose of preventing or controlling disease, injury, or disability. This includes the reporting of a disease or injury, reporting vital events such as births or deaths, and conducting public health surveillance, investigations, or interventions.⁵⁴

A public health authority is defined as an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe. The definition also extends to a person or entity acting under a grant of authority from or contract with such public agency.⁵⁵ In addition to being a public health authority, the entity seeking the information must

also be “authorized by law” to receive it. This requirement is satisfied when there is a legal basis for the activity; it does not require a specific law authorizing the collection of the information requested.⁵⁶ Covered entities are not required to make a minimum necessary determination for public health disclosures that are required by other law. Covered entities that are also a public health authority may use, and disclose, protected health information consistent with laws, regulations, and policies applicable to the public health authority.⁵⁷

In most states queried for this report, the barriers to disclosure of individually identifiable health information were not due to HIPAA privacy rules, but to more restrictive state laws governing confidentiality of such information, or, in some cases, a perception that such restrictions would apply. The HIPAA privacy rule preempts contrary state laws, but not if the state law provides greater privacy protections to such information, making the potential HIPAA public health exception pathway unavailable in some states.

Limited Data Sets

A limited data set is PHI with most, but not all, identifiers removed. The Privacy Rule lists sixteen direct identifiers that may not be included in a limited data set, but permits the inclusion of dates of admission, discharge and service; dates of birth and death; and geographic information (except street address), among others. Limited data sets may be disclosed for research, public health, or health care operations purposes and must be accompanied by a data use agreement.

Research on Decedents

To use or disclose PHI of the deceased for research, covered entities are not required to obtain authorizations from the personal representative or next of kin, a waiver or an alteration of the authorization, or a data use agreement. However, the covered entity must obtain from the researcher who is seeking access to decedents' PHI (1) oral or written representations that the use and disclosure is sought solely for research on the PHI of decedents, (2) oral or written representations that the PHI for which use or disclosure is sought is necessary for the research purposes, and (3) documentation, at the request of the covered entity, of the death of the individuals whose PHI is sought by the researchers.

Substance Use Disorder Treatment Records (42 CFR Part 2)

Federal law, regulated by SAMHSA and 42 CFR Part 2 (“Part 2”) also protects the privacy of those who seek evaluation or treatment for substance use disorders from federally assisted programs, known as “Part 2 programs.” Generally, Part 2 requires a patient’s written consent before disclosing the identity of the patient and any protected treatment records. Part 2 also recognizes a few limited exceptions when providers can make disclosures without a patient’s written consent, such as for government program audit, research or in an emergency. Unlike HIPAA, Part 2 does not include an exception for disclosures to a public health authority or disclosures required by law. Providing information to a maternal mortality review commission does not appear to fall squarely within one of the exceptions, as described in further detail below, but upcoming changes to Part 2 implemented by the Coronavirus Aid, Relief, and Economic Security Act (CARES Act) may change this.⁵⁸

Audits and Evaluations

A Part 2 program may disclose Part 2 data for activities undertaken by a federal, state, or local governmental agency or third-party payer to identify needed actions to improve the delivery of care, to manage resources effectively to care for patients, or to determine the need for adjustments to payment policies to enhance care or coverage for patients with SUD. The final rule clarifies that governmental agencies and third-party payers may conduct audits and evaluations to identify necessary actions at the agency or payer level to improve care. This includes reviews of appropriateness of medical care, medical necessity and utilization of services by auditors that may include quality assurance organizations as well as entities with direct administrative control over a Part 2 program. The final rule removes the word “periodic” so as not to indicate the frequency with which audit and evaluation activities should occur.

Research

The final rule permits disclosure of SUD Records by a Health Insurance Portability and Accountability Act (HIPAA) covered entity or business associate to individuals/organizations who are not subject to HIPAA’s privacy rule or the HHS regulations regarding the protection of human subjects, known as the Common Rule, for the purpose of conducting scientific research. The final rule seeks to align Part 2, the Common Rule and the Privacy Rule for the conduct of research on human subjects, and to streamline duplicative requirements for research disclosures under Part 2 and the privacy rule. It also permits research disclosures to recipients covered by FDA regulations for the protection of human subjects in clinical investigations.

Preventing Maternal Deaths Act⁵⁹

As noted previously, the Preventing Maternal Deaths Act of 2018 (HR 1318), signed into law December 21, 2018, established a system for assessing maternal deaths by setting up a federal infrastructure and allocating resources to collect and analyze data on every maternal death in every state. The Act supports MMRCs through federal funding and reporting of standardized data.

The Act requires that Maternal Mortality Review Committees established by participating states use best practices in their methods and processes for data collection and review of all pregnancy-associated deaths and pregnancy-related deaths, regardless of the outcome of the pregnancy. *Id.*

More specifically, in addition to prescribing conditions for participation as a Maternal Mortality Review Committee, the Act establishes a process for confidential reporting and data collection:

(Section 317K of the Public Health Service Act (42 U.S.C. 247b– 12) (d)(2))

Process for confidential reporting.--States, Indian tribes, and tribal organizations that participate in the program described in this subsection shall, through the State maternal mortality review committee, develop a process that—

(A) provides for confidential case reporting of pregnancy-associated and pregnancy-related deaths to the appropriate State or tribal health agency, including such reporting by—(i) health care professionals;(ii) health care facilities; (iii) any individual responsible for completing death records, including medical examiners and medical coroners; and (iv) other appropriate individuals or entities; and

(B) provides for voluntary and confidential case reporting of pregnancy-associated deaths and pregnancy-related deaths to the appropriate State or tribal health agency by family members of the deceased, and other appropriate individuals, for purposes of review by the applicable maternal mortality review committee; and

(C) shall include—(i) ... making publicly available contact information of the committee for use in such reporting; and (ii) conducting outreach to local professional organizations, community organizations, and social services agencies regarding the availability of the review committee.

(3) Data collection and review.--States, Indian tribes, and tribal organizations that participate in the program described in this subsection shall--

(A) annually identify pregnancy-associated deaths and pregnancy-related deaths-- (i) through the appropriate vital statistics unit by-- (I) matching each death record related to a pregnancy-associated death or pregnancy-related death in the State or tribal area in the applicable year to a birth certificate of an infant or fetal death record, as applicable; (II) to the extent practicable, identifying an underlying or contributing cause of each pregnancy-associated death and each pregnancy-related death in the State or tribal area in the applicable year; and (III) collecting data from medical examiner and coroner reports, as appropriate; (ii) using other appropriate methods or information to identify pregnancy-associated deaths and pregnancy-related deaths, including deaths from pregnancy outcomes not identified through clause (i)(I);

The Preventing Maternal Deaths Act requires jurisdictions participating in the program to establish minimum confidentiality protections prohibiting disclosure, including to any government official, of any identifying information about any specific maternal mortality case by the maternal mortality review committee. The protections also forbid making public any information from committee proceedings, including deliberation or records, unless specifically authorized by state or federal law.

State Law Confidentiality: MMRC Statutory Authorities

States vary significantly in their MMRC processes and approaches to maintaining the confidentiality of personal health information. An overview of the MMRC legal authorities of the New England states, with a focus on their authorities and practices to obtain relevant records is described below and set forth in greater detail in Appendix A. Most New England states' MMRCs are created and defined by state statute.

New Hampshire

New Hampshire's maternal mortality review panel conducts comprehensive, multidisciplinary reviews of "maternal deaths in New Hampshire for the purpose of identifying factors associated with the deaths and to make recommendations for system changes to improve services" for New Hampshire women.⁶⁰ Health care providers, health care facilities, and state agencies are among those required to report maternal mortality deaths.

Before the panel receives information to complete its review, records are deidentified. Either New Hampshire's Department of Health and Human Services or, at the direction of the Commissioner, the Northern New England Perinatal Quality Improvement Network (NNEPQIN) will collect and analyze records.⁶¹ By statute, the types of case information that may be

collected include vital records; hospital discharge data; prenatal, fetal, pediatric, or infant medical records; hospital or clinic records; laboratory reports; records of fetal deaths or induced terminations of pregnancies; and autopsy reports.⁶² This same case information may be acquired from health care facilities, maternal mortality review programs, and other sources in other states as needed for accurate and complete information. The family of the deceased woman may also be contacted for a discussion of the events surrounding the death.

Each year the Commissioner must issue a report describing the adverse events reviewed by the panel, outlining corrective action plans, and making recommendations for system change and legislation. Each member of the multidisciplinary panel is required to disseminate panel recommendations to his or her respective institutions and professional organizations through the quality assurance programs to protect confidentiality.

All proceedings, records, and opinions of the panel are confidential and not subject to RSA 91-A, which means the public cannot make a public records request or access the information collected by or shared from the MMRC even through discovery in civil or criminal proceedings. In addition, members can't be questioned in any civil or criminal proceeding regarding information presented or opinions formed as a result of a meeting of the MMRC team.

Massachusetts

Massachusetts has in place a general statute permitting the Commissioner of the Department of Public Health (DPH) to “authorize or cause to be made scientific studies and research which have for their purpose the reduction of morbidity and mortality within the commonwealth.” Under this statute’s legal authority, the Commissioner of Public Health has approved the Maternal Mortality and Morbidity Review Committee to proceed using confidential Massachusetts DPH state-wide data.

The Massachusetts MMRC committee has been approved, essentially, to conduct a research study into maternal deaths, with strict confidentiality guidelines and limitations on use.

“The Research and Data Access Review (RaDAR) Committee has approved [249885-1] the Pregnancy-associated Mortality and Morbidity Review Study, and authorizes you to conduct that study using confidential Massachusetts Department of Public Health (MDPH) data in accordance with M.G.L. c. 111, §24A. Please note that any research study to be conducted as a result of the Maternal Mortality and Morbidity Review Committee's work and the use of MDPH confidential information will require MDPH IRB review and approval prior to proceeding.”⁶³

All information obtained in connection with the Committee “shall be confidential and shall be used solely for the purposes of medical or scientific research.” No one participating in an authorized study or research project may disclose any information obtained, except in strict conformity with the research project.⁶⁴ Historically, Massachusetts has been able to collaborate with outside institutions on research studies, but not investigations.

In January 2021, Massachusetts’ Governor Baker signed An Act to Reduce Racial Inequities in Maternal Health, which created a special legislative commission to investigate and study methods to reduce racial inequities in maternal health. Part of the commission’s mandate will be to investigate and study “the availability of data collected by the commonwealth and the

Massachusetts Maternal Mortality and Morbidity Review Committee, including outpatient data and what additional data may be needed.”⁶⁵ Massachusetts hospitals are required to report the death of a pregnant woman during pregnancy or within 90 days of delivery or termination of pregnancy.⁶⁶

Vermont

The Vermont Maternal Mortality Review Panel reviews maternal deaths in Vermont to identify factors associated with the deaths and make recommendations for system changes to improve health care services for women in Vermont.

As in New Hampshire, the Vermont Commissioner of Health may delegate the functions of collecting, analyzing, and disseminating maternal mortality information to NNEPQIN. Vermont’s statute was recently amended to expressly reference cross-border information sharing as part of its maternal mortality review process. Pursuant to the new language, Vermont “may enter into reciprocal agreements with other states that have maternal mortality review panels provided access under such agreements is consistent with privacy, security, and disclosure protections in this chapter.”⁶⁷ It may also acquire records from “health care facilities, maternal mortality review programs, and other sources in other states to ensure that the Panel’s records of Vermont maternal mortality cases are accurate and complete.”⁶⁸

Vermont’s reciprocity language may be worth considering as a model. In practice, Vermont has not relied yet on the reciprocity provisions partly because Vermont has very few maternal deaths to investigate.

Maine

In 2020, Maine’s Maternal, Fetal and Infant Mortality Review (MFIMR) Panel expanded the scope of maternal deaths it reviews, changing from “a woman who died during pregnancy or within 42 days of giving birth” to one “who died during pregnancy or within one year of giving birth.”⁶⁹ The statutory change also removed the requirement that the investigator proceed with the investigation only after a four-month waiting period from the date of the death together with obtaining the permission of the decedent’s family to investigate.

The new statute grants the panel coordinator authority to access the health care information of the deceased and permits the panel to request and review data from another state review panel. The panel must create an annual report identifying factors contributing to maternal, fetal and infant mortality in the state, determine the strengths and weaknesses of the maternal and infant health care delivery system and make recommendations to decrease the rate of maternal, fetal and infant mortality.

MFIMR reviews maternal deaths that occur in Maine, together with fetal and infant deaths. It gathers health care records by submitting a written request to the provider together with a copy of the state statute that outlines its legal authority to seek information and conduct investigations. Maine relies on vital records and health care records of the decedent to identify healthcare providers of the decedent. The linked birth records, which includes birth hospital and location of parent, is helpful. The panel reviews ten or fewer maternal deaths annually and could not identify an instance in which out-of-state care was provided and subsequently, no out-of-state records were needed.

Connecticut

Connecticut has a maternal mortality review committee within the Department of Public Health to “conduct a comprehensive, multidisciplinary review of maternal deaths for purposes of identifying factors associated with maternal death and making recommendations to reduce maternal deaths.”⁷⁰ The statute outlines that the committee is responsible for identifying maternal deaths in Connecticut and reviewing medical records and other relevant data.⁷¹ The information reviewed may be used “solely for the purpose of medical or scientific research,” and may be exchanged for this purpose with “any other governmental agency or private research organization.”⁷²

Connecticut’s MMRC investigates maternal deaths of Connecticut residents regardless of the location of the death. To obtain relevant records, similar to Rhode Island and Maine, the investigator sends the request for records together with a copy of the statute that outlines its legal authority to seek information and conduct investigations. Similar to Maine, Connecticut relies heavily on vital records – including death certificates and medical examiners reports - together with health care records. Linked birth records - including the name of the birth hospital – are frequently included with the other vital records information and offers another avenue for locating additional health care provider of the decedent.

Connecticut is able to share its vital records information with other states, but not all states have reciprocal authority. Connecticut’s MMRC panel reviews 15-20 maternal deaths annually. To the extent Connecticut identifies an out-of-state maternal death or out-of-state care provided to a relevant decedent, it relies on calling the provider and explaining the circumstances in order to obtain the relevant records. Connecticut staff reflected that its state statute likely would not be binding on another jurisdiction. Subsequently, it prioritized relationships and telephone contact as a way to obtain records in a context in which no legal obligation to produce the record existed.

Rhode Island

Rhode Island codified its maternal mortality review committee as its Pregnancy and Postpartum Death Review Committee (PPDRC) in 2019, making the office of the state medical examiner responsible for a “multidisciplinary maternal mortality review committee for review of maternal deaths.” The committee has the authority to request and receive data from vital records, healthcare providers, healthcare facilities, pharmacy records, and other agencies or officials having information that is necessary for the committee to carry out its duties. The committee must develop recommendations for the prevention of maternal deaths and disseminate findings and recommendations to policy makers, healthcare providers, healthcare facilities, and the general public.⁷³

Rhode Island, similar to Connecticut and Maine, obtains relevant records by sending a request form from the Medical Examiners’ Office citing the statutory language that authorizes PPDRCs to seek records for investigation of maternal deaths.

Rhode Island also frequently links the name of the birth hospital to the vital records of the decedent, providing another route for identifying relevant health care providers. To the extent Rhode Island identifies an out-of-state maternal death or out-of-state care provided to a

relevant decedent, it relies on calling the provider and explaining the circumstances in order to receive the relevant records.

Rhode Island staff reflected that being persistent and friendly were among the most effective tools for obtaining health care records from all providers. Staff also reflected that the most time-consuming component of investigations was combing through records to identify relevant providers. Rhode Island anticipates there will be 10-15 annual deaths for the PPDRC to review.

Barriers to Cross-Border Information Sharing

There are barriers and common challenges to cross border sharing of maternal death records and to data collection in general. Some of the key barriers include:

- Lack of explicit statutory authority authorizing one state to share vital records with other states even on behalf of MMRC or a lack of awareness of pathways such as interjurisdictional agreements (*e.g.*, State and Territorial Exchange of Vital Records or STEVE);
- Lack of explicit statutory or other authority for one state MMRC to share protected health or other private information with a cross-border state MMRC;
- Lack of explicit requirement for providers to share records following any MMRC request or maternal death;
- Small number of maternal deaths in New England states and inconsistent treatment of SUD, traffic accidents, mental health conditions as relevant to MMRC activities.
- Under-developed process for requesting and obtaining records directly from providers; and
- Lack of familiarity with other regional MMRC abstractors to share contacts and “tips” regarding their state’s information and access;
- Varying experience/background of abstractors;
- Uncertainty about legal authority to ask for or share information.

The multiple federal and state laws protecting certain types of information from disclosure or that govern access create actual or perceived barriers to data sharing for purposes of maternal mortality review. Consistent barriers to cross-border information sharing include narrowly tailored statutes lacking explicit clarity around data sharing, small numbers of maternal mortality cases in New England states, inconsistent treatment of pregnancy-associated deaths, relatively new MMRC programs and abstractors and under-developed processes for requesting and obtaining records. The information and learning opportunities made available through the CDC have helped to make the review process more consistent amongst states, however, more regional learning collaboratives focused on information access could help to alleviate barriers.

Lack of Statutory Authority

In assessing the barriers within the MMRC statutes, it’s important to review whether the statute allows the states MMRC authority to collect any and all information necessary to conduct the review.

Narrowly tailored MMRC statutes limit the ability of MMRCs to collect important information. While most MMRC statutes authorize collection in the home state, there are few statutes that explicitly authorize one MMRC to share information with a review committee in another state or engage directly in records exchanges. That said, the state MMRC statutes do not typically bind providers or prohibit a provider from making records available to a cross-border MMRC.

The MMRC statutes in New England, with the exception of the Massachusetts statute, provide clear authority to conduct maternal mortality review activities for public health purposes, which technically may be sufficient to satisfy the public health exception to the HIPAA privacy rule and support improved information access.⁷⁴ However, state entities are often reluctant to act without explicit state statutory authority to do so and many may be unfamiliar with the public health exception to the HIPAA privacy rule. This may inhibit MMRCs from relying on the HIPAA public health exception to disclose records across state lines with other state MMRCs. This same dynamic may inhibit individual providers from sharing records across states, although, as noted above, while the MMRC may be limited, the provider, as a HIPAA entity, should provide records upon request to MMRCs.

While the MMRC statutes in New England provide authority for MMRCs to obtain records from providers within their home states, the statutes do not extend the requirement that providers share requested relevant records or data to MMRCs outside of the state. That said, providers are authorized under HIPAA to provide to a public health authority and for purposes of MMRC activities

More importantly, most New England states do not generally have language explicitly allowing states MMRCs or other state entities to share identifiable health data for public health purposes, therefore limiting what an abstractor in one state could share with an abstractor in another state, or what an abstractor in one state could obtain from state entities. Only Connecticut has a statute that explicitly permits the state to share identifiable health data with other states upon request for public health purposes. This provision enables Connecticut to share its vital records, including birth and death certificates, which are often central to the MMRC abstractor identifying where and what type of care the decedent received.

Vermont's MMRC statute permits the MMRC to enter into a reciprocal data sharing agreement with another MMRC. However, no other New England state has explicit language permitting it to enter into an MMRC data sharing reciprocal agreement, which leaves Vermont without a data sharing partner.

Small Numbers of Maternal Mortality Cases in the Region

The small number of maternal mortality cases impacts the information sharing. State MMRCs report inconsistent treatment of pregnancy-associated deaths, lack of funding and resources to support thorough reviews, and relatively new MMRC programs.

The estimated number of maternal deaths to be annually reviewed by the New England states were very low, ranging from 2 to 20 per state. While anecdotal, some abstractors noted that the involvement of opioids or other substances in the deaths makes the abstracting more difficult.

Some states did not expect to pursue comprehensive reviews of maternal deaths associated with traffic accidents or complications from addiction, as those incidents were construed as being outside of the intended focus of the review. This narrower focus likely further reduces the number of maternal mortality reviews. The low number of cases to review ultimately results in less need to request and obtain relevant records, both in state and out of state. At the time of the state interviews, many of the MMRC programs and staff were relatively new and still learning how to define the scope of their review, conduct an investigation, develop an abstract, effectively request and obtain needed records, and prepare the cases for the committee review.

While states have had issues collecting cross-border information, the barriers presented by cross-border sharing do not overwhelm other immediate barriers to review, such as staffing, resources and experience. Whether or not a state prioritizes review is also a key indicator of success.

Recommendations for Improved Cross-Border Information Sharing

To be effective, any information sharing approach adopted should be minimally burdensome, flexible, and have clear guidelines. Clear communication identifying the legal authority to share the information, together with persistent follow up, may help facilitate information sharing in the absence of changes to statutory language. All states, including New Hampshire, have multiple panels, commissions, and committees with the authority to investigate and review information on death, disease or other public health concerns. For example, these various panels are tasked with investigating child fatality, domestic abuse, drug overdose, incapacitated adults, birth defects, and rare disease. Follow up with some of these entities may be useful for identifying additional potential solutions to cross-border information sharing beyond those shared below.

Consistent Authorizing Legislation to Preserve Confidentiality While Allowing for Cross-Border Exchange for MMRC:

- MMRC legislation should clarify that MMRC has access to vital records both within the state and for deaths outside the state to ensure no barriers to vital records access exist;
- MMRC legislation should specify all state health care providers must share requested records with any maternal mortality review committee request from any state, for public health purposes;
- MMRC legislation should clarify that MMRC abstractor may request and obtain information from other jurisdictions in order to have complete information about maternal mortality in home state;
- MMRC legislation should specify that MMRC may enter into memoranda of understanding with other MMRCs to facilitate comprehensive data collection;
- MMRC legislation should state that the maternal mortality review committee is a public health authority conducting public health activities pursuant to the federal Health Insurance Portability and Accountability Act (HIPAA) ([42 U.S.C. § 1320d et seq.](#));

- Create interstate compacts around data collection for MMRCs to set forth common practices, agreements and protocols for confidential cross-border data sharing for MMRC purposes.

Statutory Changes: Model Legislation/Uniform Laws

While many of the state statutes authorizing the MMRCs may be sufficient to satisfy the HIPAA public health exception to the privacy rule, state entities may be reluctant to share information without explicit legal authority to do so in state statute. Having the following provisions explicitly in statute will facilitate sharing relevant MMRC data and records across state lines:

- authorize the state to share identifiable health information, including births and deaths, upon request with other states for public health purposes including reducing mortality and morbidity from all causes;
- direct all health care providers to share requested records with regional maternal mortality review committee requests for public health purposes;
- specify that the maternal mortality review committee may request, obtain and review information from other jurisdictions in order to have complete maternal mortality data;
- specify that the MMRC may enter into memoranda of understanding with other MMRCs to facilitate comprehensive data collection;
- amplify that the maternal mortality review committee and its staff is a public health authority conducting public health activities pursuant to the federal Health Insurance Portability and Accountability Act (HIPAA) (42 U.S.C. § 1320d et seq.)

Interstate Compact

Interstate compacts or memoranda of understanding are a tool used by state governments regionally or nationally to promote and insure cooperative action among the states. They are state-developed and act as a formal agreement between states. Compacts have the characteristics of both a statute and a contract. Typically, each state legislature will adopt identical statutory language, using the interstate compact to:

- Establish a formal, legal relationship among states to address common problems or promote a common agenda;
- Create independent, multistate governmental authorities (e.g., commissions) that can address issues more effectively than a state agency acting independently, or when no state has the authority to act unilaterally;
- Establish uniform guidelines, standards, or procedures for agencies in the compact's member states;
- Create economies of scale to reduce administrative and other costs;
- Respond to national priorities in consultation or partnership with the federal government;
- Retain state sovereignty in matters traditionally reserved for the states; and
- Settle interstate disputes.⁷⁵

Interstate compact negotiation is usually done at the direction of the governor by the governor's appointee. Once an initial agreement is reached, it must be enacted by the legislature. Certain interstate compacts, those that are "directed to the formation of any

combination tending to the increase of political power in the States, which may encroach upon or interfere with the just supremacy of the United States” must receive the consent of Congress.⁷⁶ Compacts that are approved by Congress also become federal law.

New Hampshire is a member of several compacts, including the Nurse Licensure Compact, National Crime Prevention and Privacy Compact, the Interstate Compact for the Supervision of Adult Offenders, among others.⁷⁷ The Nurse Licensure Compact allows a nurse to practice in states that are part of the compact without obtaining a separate nursing license in each state. The Nurse Licensure Compact has purposes other than data sharing, but it is one example of a compact that facilitates the transmission of confidential data between states. As part of the Nurse Licensure Compact, states can share information about confidential complaint investigations. Typically, the nurse’s state of residence (“home state”) and the state where the incident forming the basis of the complaint occurred, also known as the remote state, will communicate, with the remote state taking the lead in conducting the investigation because it will have easier access to investigative records and witnesses. Once the investigation is complete, the investigative information is transmitted to the home state for consideration of disciplinary action against the nurse’s license, which will affect the nurse’s practice in all compact states. A remote state may, based on the same complaint investigation, impose other restrictions on the privilege to practice in the remote state. Licensure, discipline, and practice privileges are recorded in Nursys, a national database.⁷⁸ An MMRC interstate compact could work in the same manner, allowing all participating MMRCs to transmit information relevant to MMRC investigations to other states without additional legal authority.

As an alternative to the more formal “compact”, states could enter into Memoranda of Understanding regarding shared protocols and practices for enhanced information sharing consistent with each state’s statutory authority.

Establish a New England Regional MMRC Collaborative

The New England states (Maine, Vermont, New Hampshire, Massachusetts, Rhode Island and Connecticut) should establish a robust New England Regional MMRC Collaborative. Beyond explicit statutory changes, the New England state MMRCs could enhance cross-border data sharing by cultivating best practices and protocols amongst the states and the state MMRC abstractors in order to:

- Meet consistently to share best practices and common barriers;
- Develop roster of Abstractors and list serve amongst NE states;
- Pursue Interstate Compacts or Memoranda of Understanding to facilitate data exchange;
- Leverage relationship with other MMRC abstractor to facilitate relationship /requests with out of state providers or out of state vital records holders;
- Share information about evidenced based indicators impacting maternal mortality and policy options to address.

A New England MMRC would require the 6 new England states MMRC staff meeting regularly to share best practices, common barriers and potential opportunities to formally allow record or data sharing. MMRC staff in other regions of the country noted that they know their MMRC

counterparts in border states and that relationship can be useful in obtaining needed records. One abstractor provided an example in which she indirectly facilitated obtaining out-of-state records from an out-of-state provider because her MMRC border state counterpart made a provider aware of her relationship with the in-state MMRC abstractor. Establishing a common connection and purpose provided context for the provider, who was familiar with the in-state MMRC abstractor and understood the need for the request. This aided in an expedited receipt of records for the out-of-state MMRC abstractor.

Develop Consistent Record Request Pathways and Learning Collaborative/Tools to Support Protocols

Summary

Interviews with MMRC abstractors highlighted the need for a more robust learning opportunity amongst the states to allow for refined and evidenced based processes and practices for obtaining records directly from providers and agencies both in-state and cross-borders. Some of the recommendations that manifest from the detailed conversations with the state abstractors include the following:

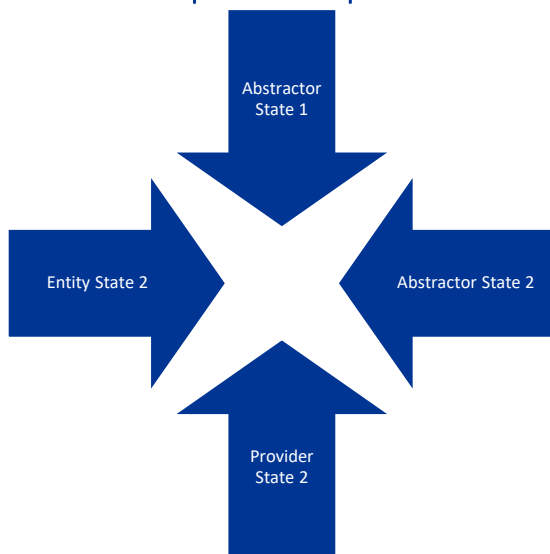
- Consistent written requests, citing statutory authority of MMRC together with request for specific records (form letters are available from states);
- Share written request templates with cross-border abstractors and include reference to cross-border state MMRC or other helpful authority;
- Seek assistance from cross-border state abstractor around difficulties presented by cross-border state providers or regulators;
- Amplify exceptions of “required by law” and “public health activity” to HIPAA privacy rule;
- Plan and prepare to follow-up written requests with multiple phone calls;
- Create familiarity of MMRC purpose and process with providers, labs, vital records, any holder of relevant records;
- Use Abstractor Manual to explain different processes for requesting required records; and
- Develop inserts or updates to Abstractor Manual on case studies and other experienced based strategies.

The concept of creating or using MMRIA as a type of health information exchange is worth pursuing, however, it would only be as good as the inputs. There are many circumstances where technology might not solve the information barriers. During the research for this report, abstractors in states where information is effectively exchanged across-borders reported they were most successful at completing their abstracts when they relied on a variety of techniques to investigate the mother’s history and contacts, both clinical and social. After investigating the clinical and social history, the abstractors targeted the providers or entities with records requests and follow-up either in-state or out-of-state using channels of communication often already established (e.g., familiarity with medical records staff at large hospital system). The abstractors often found that the in-state providers had out-of-state records in their files already. More importantly, the abstractors mapped out what records they needed, and who

they needed to request them from, often seeking the help of out-of-state abstractors to trouble shoot best strategies.

Much of the information obtained by abstractors from other states came directly from sources, and not through the out-of-state abstractors. Technology that enabled abstractors to access records through a Health Information Exchange from states who host them, or communicate more effectively with other abstractors through a MMRIA messaging system, might be productive.

Abstractor Techniques and Experiences



The abstractors who shared their history and successful experiences, recounted a number of different strategies and techniques to obtain records. MMRC abstractors frequently utilize a common process. They send a form letter requesting particular records to a provider or entity, attaching a reference to and specific language from the enabling state statute providing the MMRC's authority to seek and obtain records. MMRC staff acknowledged that while out-of-state providers aren't subject to in-state laws, they felt it was helpful to share their

legal authority and responsibilities with the out of state provider and they often complied. MMRC staff plan for and follow up on the written request with phone calls.

The success of the MMRC abstractors seemed to depend upon their clinical experience and familiarity with key staff at organizations who typically provide necessary records. Many of the abstractors rely on long established lines of communication developed by prior abstractors. Many were able to use the credibility and purpose of the MMRC process as well as education to assist.

Educating providers and other entities about the MMRC process and familiarizing key staff with the MMRC abstractor and purpose of the program facilitated receiving requested records. Certainly, the abstractors who are required to promptly perform the abstract are able to streamline the process, especially in states with higher mortality rates. Even if an abstractor initially had difficulty obtaining out-of-state records, once providers and medical record keepers became familiar with the MMRC purpose and staff, they generally willingly complied with records requests. MMRC staff may want to consider a mechanism to formally introduce the MMRC program and staff to providers and state agencies in order to facilitate sharing of records.

Highlighting the authority the state has vested in the MMRC to investigate maternal deaths together with building familiarity and relationships with those who hold relevant records can be

an effective combination to facilitate information sharing. More importantly, each abstractor has, over time and with practice, developed strategies to facilitate the collection of necessary information all of which would be helpful to share in order to map out best practices in action for other abstractors.

Enhanced Abstractor Manual

The Review to Action framework has produced a Maternal Mortality Review Committee Abstractor Manual for use by abstractors to help them with both a clinical understanding of issues as well as processes for identifying necessary data and information.⁷⁹ The Manual is helpful and highlights what type of records provide important sources of data and information:

- Vital statistics: death certificates, birth certificates, fetal death records
 - Information on death certificate provides demographic information and descriptive information on cause, place, and time of death.
 - Examples of information on a standard infant birth certificate include: demographic information on mother and father, prenatal care entry, number of visits, birth weight, Apgar scores, gestational age, complications, and name of birth hospital.
- Prenatal records:
 - These records are typically sent by 36 weeks to the delivery facility; therefore, end of pregnancy visits may be missing.
 - You may need to request full records or make an on-site visit to the prenatal clinic.
- Hospital records: including all outpatient and inpatient stays during terminal pregnancy/postpartum period, and notes on social services
- Outpatient clinic records: preconception/family planning clinics, primary care, abortion centers
- Autopsy reports and case findings from hospital, coroner, or other medical examiner
- Police/investigative reports
- Medical transport records including timing, notes, vitals, treatments
- Personal interviews with providers, family, or friends

The Manual also provides brief tips on ensuring the MMRC and abstractor know their responsibilities and authorities, drafting appropriate letters to providers and entities in order to collect necessary data, making contact with entities who have important information, being a “squeaky wheel” to get the abstraction done (for example, placing follow up calls, getting names and phone numbers, using contacts of members of the MMRC, patients, sensitivity, persistence, and documentation of unsuccessful attempts in order to problem solve solutions with MMRC. Id. at pp. 15-18.

Despite these tips, there is significant anecdotal information from the many New England abstractors that demonstrates the “how to” information, guidance, and “work shop” could include significant addition ideas, methodologies and case studies to allow for true consistency and success. In addition, each state, each agency, each provider present special barriers, which in-person learning could help to solve and resolve.

Conclusion

A widely recognized and critical barrier to identifying and investigating maternal deaths is the collection of complete data when care for the mother was provided outside of the state in which the maternal death occurred or in the instance in which the mother's death occurred outside her state of residence. Many states are challenged by this issue, including those in New England. Maternal mortality review and data collection is governed by state statute, which results in different governance structures, priorities and regulations amongst the states, creating barriers to sharing records between them. The inability of an abstractor in one state to obtain and abstract relevant information from another state or from within can render a maternal mortality case unreviewable.

This report is based on an extensive review of the federal regulatory landscape, analysis of the Maternal Mortality Review Committee (MMRC) statutory provisions in the New England states (ME, VT, NH, MA, RI, CT) and investigation into what might optimize one state's efforts to ensure reviews are not duplicated and data collection is facilitated. The investigation included interviewing MMRC abstractors in the New England region and in select other states where statutes appeared to allow for improved data sharing. Reviewers were asked a key set of questions about their practices, commonly encountered barriers to data sharing, and ways in which data sharing was facilitated either through technique or statutory pathways. The information was compiled, reviewed and recommendations developed.

The abstractor interviews provided a detailed view into the barriers and revealed the need to ensure consistent learning opportunities to share best practices amongst abstractors. Many abstractors who performed numerous abstracts over time developed innovative and practiced ways to ensure data could be secured both from in-state and from out-of-state providers. While some states have statutes that could serve as models for data exchange and authority, an equally important component is the practiced techniques to allow for more consistent and collaborative data sharing within the authority of each state statute.

Based on the investigation, recommendations were developed to facilitated information sharing and communicated during presentations and as set forth herein. The recommendations can be summarized as follows:

- Develop model legislative language to enhance data sharing between and among state MMRC abstractors;
- Execute memoranda of understanding (MOUs) between states that experience barriers to sharing relevant records with one another; and
- Enhance a learning collaborative amongst the states to provide learning sessions among state abstractors in order to:
 - Support consistent strategies for abstracting;
 - Share contact information and develop other forms of direct communication between abstractors;
 - Facilitate mentoring and resource development for abstractors in states where relatively few maternal deaths may lead to inconsistent cases and practices.

- Update the Abstractor Manual to include more case specific examples of abstracting strategies and learning modules for abstracting practice.

While one abstractor may not be able to help secure and produce the needed information for a cross-border state, there are opportunities for support through provider education, contact information, facilitated communication or even MOUs regarding action steps so that one state can better help another even if confidential information sharing is not authorized from state to state.

Exhibit A: New England States' Maternal Mortality Statute Comparison Grid: 2021

State	Cases Reviewed	Purpose	Notification	Records Reviewed	Process for Obtaining Records	Confidentiality	Requesting Records from other Jurisdictions	Sharing Records with Other Jurisdictions
New Hampshire	Maternal mortality deaths in NH. RSA 132:30(I)	Identify factors associated with the deaths and recommend system changes to improve services. RSA 132:30(I)	Maternal mortality deaths must be reported by: health care providers, health care facilities, clinics, laboratories, medical records departments, state offices, agencies and departments. RSA 132:31(II)	Includes, but is not limited to: vital records; hospital discharge data; prenatal, fetal, pediatric, or infant medical records, hospital or clinic records, laboratory reports, records of fetal deaths or induced pregnancy terminations, and autopsy reports. RSA 132:31(II)		The panel's proceedings, records, and opinions are confidential and not subject to RSA 91-A, discovery, subpoena, or introduction into evidence. RSA 132:30(VI)(d) The commissioner / designee may retain identifiable information regarding facilities where maternal deaths occur and geographical information on each case solely for the purposes of trending and analysis over time. Identifiable information on individuals and facilities shall be removed prior to panel case review. RSA 132:31(III)	The same case information may be acquired from health care facilities, maternal mortality review programs, and other sources in other states to ensure that its records of New Hampshire maternal mortality cases are accurate and complete. RSA 132:31(II)	N/A

State	Cases Reviewed	Purpose	Notification	Records Reviewed	Process for Obtaining Records	Confidentiality	Requesting Records from other Jurisdictions	Sharing Records with Other Jurisdictions
Massachusetts	<p>The commissioner may authorize or cause to be made scientific studies and research for the purpose of the reduction of morbidity and mortality within the commonwealth.</p> <p>MGL 111 § 24A</p> <p>All pregnancy-associated deaths in MA.</p> <p>2009 Application, "Purpose and Rationale"</p>	<p>Reduce pregnancy-associated mortality and morbidity.</p> <p>2009 Application, "Purpose and Rationale"</p>	<p>The Registry of Vital Records and Statistics is responsible for reporting all pregnancy-associated deaths to the CDC.</p> <p>2009 Application, "Study Design & Analysis Plan"</p>	<p>Copies of hospital medical records (limited to hospital use during pregnancy and postpartum); copies of original death certificates and fetal death certificates, along with the one page generated birth certificate; incident reports from the Div. of Health Care Quality; case information provided by the ME's office; autopsy reports; hospital inpatient discharge, emergency department and observations stay data from the Div. of Health Care Finance & Policy</p> <p>2009 Application, "Study Design & Analysis Plan" & "Other Data Sources"</p>	N/A	<p>All information, records of interviews, written reports, statements, notes, memoranda, or other data procured in connection with such scientific studies and research conducted by the department or others so authorized by the commissioner shall be confidential and shall be used solely for the purposes of medical or scientific research.</p> <p>Such information, records, reports, statements, notes, memoranda, or other data shall not be exhibited nor their contents disclosed in any way, in whole or in part, by any officer or representative of the department, nor by any other person, except as may be necessary for the purpose of furthering the study or research project to which they related. No person participating in such an authorized study or research project shall disclose, in any manner, such information so obtained except in strict conformity with such research project.</p> <p>MGL 111 §24A</p> <p>Identifying information will not be released.</p>	N/A	N/A

State	Cases Reviewed	Purpose	Notification	Records Reviewed	Process for Obtaining Records	Confidentiality	Requesting Records from other Jurisdictions	Sharing Records with Other Jurisdictions
Vermont	Maternal deaths in Vermont 18 VSA § 1552(a)	Identify factors associated with maternal deaths and make recommendations for system changes to improve health care services for women in this State. 18 VSA § 1552(a)	Health care providers, health care facilities, laboratories, medical records departments, and State offices, agencies and departments shall report all maternal mortality deaths to the Chair of the Maternal Mortality Review Panel and to the Commissioner of Health / designee. 18 VSA § 1555(a)(1)	Information and records that are necessary and relevant to the review of maternal mortality. 18 VSA § 1555(b)	In any case under review by the Panel, upon written request of the Commissioner or designee, a person who possesses information or records that are necessary and relevant to the review of a maternal mortality shall, as soon as practicable, provide the Panel with the information and records. All requests for information or records by the Commissioner or designee related to a case under review shall be provided by the person possessing the information or records to the Panel at no cost. 18 VSA § 1555(b)(1)	The Panel's meetings are confidential and shall be exempt from the Open Meeting Law, 1 V.S.A. chapter 5, subchapter 2. The records produced or acquired by the Panel are exempt from public inspection and copying under the Public Records Act and shall be kept confidential. The records of the Panel are not subject to discovery, subpoena, or introduction into evidence in any civil or criminal proceeding. 18 VSA § 1554(a)	The Commissioner and the Chair may acquire the information described in subdivision (1) of this subsection from health care facilities, maternal mortality review programs, and other sources in other states to ensure that the Panel's records of Vermont maternal mortality cases are accurate and complete. 18 VSA § 1555	The Department may enter into reciprocal agreements with other states that have maternal mortality review panels provided access under such agreements is consistent with privacy, security, and disclosure protections in this chapter. 18 VSA § 1552(e)

State	Cases Reviewed	Purpose	Notification	Records Reviewed	Process for Obtaining Records	Confidentiality	Requesting Records from other Jurisdictions	Sharing Records with Other Jurisdictions
Maine	Maternal, fetal and infant deaths. ME ST T. 22 § 261	Review the deaths of all women during pregnancy or within one year of giving birth, the majority of cases in which a fetal death occurs after 28 weeks of gestation and the majority of deaths of infants. under one year of age. ME ST T. 22 § 261	A health care practitioner or facility may disclose, or when required by law must disclose, health care information without authorization to disclose under the circumstances stated in this subsection. Disclosure may be made without authorization as follows: To a panel coordinator of the maternal, fetal and infant mortality review panel pursuant to section 261, subsection 4, paragraph B-1 for the purposes of reviewing health care information of a deceased person and a mother of a child who died within one year of birth, including fetal deaths after 28 weeks of gestation. 22 M.R.S.A. § 1711-C	The panel coordinator may have access to the death certificates of deceased persons and to fetal death certificates of fetal deaths occurring after 28 weeks of gestation. The panel coordinator may have access to health care information of a deceased person and a mother of a child who died within one year of birth, including fetal deaths after 28 weeks of gestation. ME ST T. 22 § 261	N/A	All records created or maintained pursuant to this section, other than reports provided under subsection 5, paragraph B, are protected as provided in this subsection. The records are confidential under section 42, subsection 5. The records are not open to public inspection, are not public records for the purposes of Title 1, chapter 13, subchapter 1 and are not subject to subpoena or civil process nor admissible in evidence in connection with any judicial, executive, legislative or other proceeding. ME ST T. 22 § 261	N/A	N/A

State	Cases Reviewed	Purpose	Notification	Records Reviewed	Process for Obtaining Records	Confidentiality	Requesting Records from other Jurisdictions	Sharing Records with Other Jurisdictions
Connecticut	<p>There is established, within the department, a maternal mortality review program.</p> <p>C.G.S.A. § 19a-59h</p> <p>There is established a maternal mortality review committee within the department to conduct a comprehensive, multidisciplinary review of maternal deaths for purposes of identifying factors associated with maternal death and making recommendations to reduce maternal deaths.</p> <p>C.G.S.A. § 19a-59i</p>	<p>The program shall be responsible for identifying maternal death cases in Connecticut and reviewing medical records and other relevant data related to each maternal death case, including, but not limited to, information collected from death and birth records, files from the Office of the Chief Medical Examiner, and physician office and hospital records.</p> <p>C.G.S.A. § 19a-59h</p> <p>To conduct a comprehensive, multidisciplinary review of maternal deaths for purposes of identifying factors associated with maternal death and making recommendations to reduce maternal deaths.</p>	<p>Licensed health care providers, health care facilities and pharmacies shall provide the maternal mortality review program, established under this section with reasonable access to all relevant medical records associated with a maternal death case under review by the program.</p> <p>C.G.S.A. § 19a-59h</p>	<p>All relevant medical records associated with a maternal death case under review...</p> <p>including, but not limited to, information collected from death and birth records, files from the Office of the Chief Medical Examiner, and physician office and hospital records.</p> <p>C.G.S.A. § 19a-59h</p>		<p>All information, records of interviews, written reports, statements, notes, memoranda or other data, including... the maternity mortality review committee, established pursuant to section 19a-59i, in connection with studies of morbidity and mortality conducted by the Department of Public Health, such staff committees or the maternal mortality review committee, or carried on by said department, such staff committees or the maternal mortality review committee jointly with other persons, agencies or organizations, or procured by the directors of health of towns, cities or boroughs or the Department of Public Health pursuant to section 19a-215, or procured by such other persons, agencies or organizations, for the purpose of reducing the morbidity or mortality from any cause or condition, shall be confidential and shall be used solely for the purposes of medical or scientific research...</p> <p>C.G.S.A. § 19a-25</p>		<p>Disclosure of identifiable health data (a) The department shall not disclose identifiable health data unless: ... (2) The disclosure is to health care providers, the local director of health, the department, another state or public health agency, including those in other states and the federal government, or other persons when deemed necessary by the department in its sole discretion for disease prevention and control pursuant to section 19a-215 of the Connecticut General Statutes or for the purpose of reducing morbidity and mortality from any cause or condition, except that every effort shall be made to limit the disclosure of identifiable health data to the minimal amount necessary to accomplish the public health purpose.</p>

State	Cases Reviewed	Purpose	Notification	Records Reviewed	Process for Obtaining Records	Confidentiality	Requesting Records from other Jurisdictions	Sharing Records with Other Jurisdictions
Rhode Island	<p>For a multidisciplinary maternal mortality review committee for review of maternal deaths of women that occur during pregnancy, delivery, or within one year of the end of pregnancy.</p> <p>RIGL §23-4-3 http://webserver.rilin.state.ri.us/Statutes/TITLE23/23-4/23-4-3.HT</p>	<p>Reducing the prevalence of maternal deaths by examining emerging trends in such deaths, identifying potential demographic, geographic, and structural points for prevention, and other factors.</p> <p>This committee shall develop recommendations for the prevention of maternal deaths and disseminate findings and recommendations to policy makers, healthcare providers, healthcare facilities, and the general public.</p> <p>RIGL §23-4-3</p>	<p>This committee has the authority to request and receive data from vital records, healthcare providers, healthcare facilities, pharmacy records, and any other agencies or officials having information that is necessary for the committee to carry out its duties under this section.</p> <p>RIGL - §23-4-3</p>	<p>Vital records, healthcare providers [records], healthcare facilities [records], pharmacy records, and any other agencies [records] or officials [records] having information that is necessary for the committee to carry out its duties under this section.</p> <p>RIGL - §23-4-3</p>	<p>This committee has the authority to request and receive data from vital records, healthcare providers, healthcare facilities, pharmacy records, and any other agencies or officials having information that is necessary for the committee to carry out its duties under this section.</p> <p>RIGL - §23-4-3</p>	<p>The work product of the maternal mortality review committee shall be confidential and protected under all applicable laws, including the federal Health Insurance Portability and Accountability Act of 1996 and the Rhode Island confidentiality of health care information act (chapter 37.3 of title 5) and shall be exempt from the provisions of chapter 2 of title 38 and shall be deemed privileged pursuant to § 23-17.21-8;</p> <p>RIGL - §23-4-3</p>	N/A	N/A

	Month and Day of: Last Normal Menses, Estimated Date of Confinement (Estimated Date of Delivery), First Prenatal Visit, First Ultrasound, Last Prenatal Visit
	Name, City and State of Intended Birthing Facility
ER Visits and Hospitalizations	First Name, Middle Name, Last Name, Maiden Name
	Medical Record Number
	Month and Day of Arrival at Hospital/ER, Admission to Hospital, Discharge from ER/Hospital
	Facility Name, City, Zip Code, County
Other Medical Office Visits	Medical Record No
	Location of Medical Care Facility - City, Zip Code, County
Medical Transport	Month and Day of Medical Transport
	Date/Times of: Transport Vital Signs, Departure, Arrival, Patient Contact
	Place of Destination
Informant Interviews	Informant Name
	Month and Day of Interview

MMRIA User Guide

De-identified Fields

Within each case, you will see all of the forms that your committee's abstractors can access. However, you will see that the following fields are de-identified:

Table 2 - De-identified Fields

Form	Fields
Home Record	First Name, Middle Name, Last Name
Death Certificate	Local File No.
	Place of Last Residence - City, Zip Code, County
	City of Birth
	Place of Injury (Place Name)

	Location Where Injury Occurred - City, Zip Code, County
	Place of Death - Facility Name, City, Zip Code, County
Birth/Fetal Death Certificate- Parent Section	Delivery Facility Name
	Name of Facility Mother Transferred From
	Facility of Delivery Location - City, Zip Code, County
	Father's First Name, Middle Name, Last Name
	Father's Day of Birth
	Father's City of Birth
	Mother's First Name, Middle Name, Last Name, Maiden Name, Medical Record Number
	Mother's City of Birth
	Location of Residence - City, Zip Code, County
	Last Normal Menses
Birth/Fetal Death Certificate- Infant/Fetal Section	Newborn/Fetus First Name, Middle Name, Last Name
	State File No., Local File No., Medical Record No.
	Facility- Name, City and State
Autopsy Report	Month and Day of Autopsy
	Jurisdiction
Prenatal Care Record	Prenatal Care Record No.
	Location of Primary Prenatal Care Facility - City, Zip Code, County
	Month and Day that Birth Control was Discontinued

¹ The work is funded through a grant award to New Hampshire from the Centers For Disease Control, "Preventing Maternal Deaths: Supporting Maternal Mortality Review Committees", CDC-RFA-DP19-1908.

² CDC, Trends in Pregnancy-related deaths in the United States: 1987-2017.

<https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#trends>

³ <https://reviewtoaction.org/>

⁴ The CDC guidance on which cases an MMRC should review is that the state of review is the deceased individual's state of residence as listed on their death certificate. See

<https://www.reviewtoaction.org/sites/default/files/2021-03/Reference%20Guide%20for%20Pregnancy-Associated%20Death%20Identification.pdf>.

⁵ See CDC, Trends in Pregnancy-related deaths in the United States: 1987-2017.

<https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#trends>

⁶ See Review to Action, a partnership between the Association of Maternal and Child Health Programs (AMCHP) and the Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM) administered by the CDC at <https://reviewtoaction.org/learn/definitions>; see also National Center for Injury Prevention and Control, Centers for Disease Control and Prevention, Maternal mortality (2019)

<https://www.cdc.gov/reproductivehealth/maternal-mortality/index.html>.

⁷ Review to Action/LEARN/DEFINITIONS at <https://www.reviewtoaction.org/learn/definitions>; see also, NH RSA 132:29.

⁸ The American College of Obstetricians and Gynecologists, [List of State Maternal Mortality Review Committees, POCs, and AIM](#) (Sept. 2019); Guttmacher Institute [Maternal Mortality Review Committees](#), (last visited Feb. 1, 2021).

⁹ Guidance from the Centers for Disease Control asserts that the state that conducts the MMRC review should be the state of which the decedent is a resident, as noted on their death certificate.

¹⁰ Centers for Disease Control and Prevention, Pregnancy Mortality Surveillance System,

<https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm>, (last visited Feb. 2, 2021)

¹¹ CDC/Health/Pregnancy Mortality Surveillance System at <https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm#trends>

¹² Maternal Mortality in the United States: A Primer, The Commonwealth Fund, December 16, 2020 at

<https://www.commonwealthfund.org/publications/issue-brief-report/2020/dec/maternal-mortality-united-states-primer>.

¹³ <https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm>

¹⁴ U.S. Dept. of Health & Human Services, Healthy Women, Healthy Pregnancies, Healthy Futures: Action Plan to Improve Maternal Health in America at 48 (Dec. 2020), https://aspe.hhs.gov/system/files/aspe-files/264076/healthy-women-healthy-pregnancies-healthy-future-action-plan_0.pdf

¹⁵ U.S. Dept. of Health & Human Services, Healthy Women, Healthy Pregnancies, Healthy Futures: Action Plan to Improve Maternal Health in America at 53 (Dec. 2020), https://aspe.hhs.gov/system/files/aspe-files/264076/healthy-women-healthy-pregnancies-healthy-future-action-plan_0.pdf

¹⁶ U.S. Dept. of Health & Human Services, Healthy Women, Healthy Pregnancies, Healthy Futures: Action Plan to Improve Maternal Health in America at 8 (Dec. 2020), https://aspe.hhs.gov/system/files/aspe-files/264076/healthy-women-healthy-pregnancies-healthy-future-action-plan_0.pdf; Centers for Disease Control and Prevention, [Pregnancy-related Deaths](#) (last visited Feb. 3, 2021).

¹⁷ Aggregating many years to achieve a stable rate is not recommended because of changes in the numbers over time as well as changes in how the deaths are classified by the MMRC. For example, the NH MMRC adoption of published standardized criteria to determine the pregnancy-relatedness of drug-related deaths has likely influenced classification. When deaths are classified differently over time it can be misleading to aggregate them

within a single statistic. For NH's reporting, see New Hampshire's 2020 Annual Report on Maternal Mortality at <http://www.nnepqn.org/wp-content/uploads/2021/01/2020-Annual-New-Hampshire-Report-on-Maternal-Mortality-FINAL-10-21-2020-002.pdf>

¹⁸See U.S. Government Accountability Office, Maternal Mortality: Trends in Pregnancy-Related Deaths and Federal Efforts to Reduce Them at 23 (March 2020), <https://www.gao.gov/assets/710/705331.pdf>

¹⁹ Preventing Maternal Deaths Act of 2018, Pub. L. No. 115-344, 132 Stat. 5047 (2018); codified at 42 U.S.C. § 247b-12, <https://www.law.cornell.edu/uscode/text/42/247b-12>

²⁰ Khiara Bridges, "Racial Disparities in Maternal Mortality," 95 NYU L. Rev. 1229, 1292 (Nov. 2020).

²¹ 42 U.S.C. § 247b-12(3)(A), <https://www.law.cornell.edu/uscode/text/42/247b-12>

²² Centers for Disease Control and Prevention, ERASE MM Program, https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Ferasemm%2Findex.html, (last visited Feb. 4, 2021)

²³ The states funded through ERASE MM are Alaska, Arizona, California, Colorado, Connecticut, Delaware, Illinois, Indiana, Kansas, Louisiana, Mississippi, Missouri, New Hampshire, New Jersey, New Mexico, New York, North Carolina, Ohio, Pennsylvania, Tennessee, Texas, Utah, Washington, Wisconsin, Wyoming and most recently Florida, Georgia, Iowa, Maryland, Montana, and Nevada. The Utah MMRC reviews cases on behalf of Wyoming. Centers for Disease Control and Prevention, ERASE MM Program, <https://www.cdc.gov/erasemm>

²⁴ Centers for Disease Control and Prevention, ERASE MM Program, https://www.cdc.gov/reproductivehealth/maternal-mortality/erase-mm/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Ferasemm%2Findex.html, (last visited Feb. 4, 2021)

²⁵ Report from Nine Maternal Mortality Review Committees, <https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf>

²⁶ MMRIA User Guide FAQ, p. 89 reads: Question: "Can CDC or other states see my state's data? No, CDC and other states cannot view your data unless you choose to share it MMRIA User Guide." (Dec. 2019), https://www.cdc.gov/reproductivehealth/maternal-mortality/docs/pdf/MMRIA-User-Guide-Version-tagged_508c.pdf

²⁷ MMRIA User Guide (Dec. 2019), https://www.cdc.gov/reproductivehealth/maternal-mortality/docs/pdf/MMRIA-User-Guide-Version-tagged_508c.pdf

²⁸ Report from Nine Maternal Mortality Review Committees, <https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf>

²⁹ Khiara Bridges, "Racial Disparities in Maternal Mortality," 95 NYU L. Rev. 1229, 1289 (Nov. 2020).

³⁰ Centers for Disease Control and Prevention, Pregnancy Mortality Surveillance System, <https://www.cdc.gov/reproductivehealth/maternal-mortality/pregnancy-mortality-surveillance-system.htm>, (last visited Feb. 3, 2021)

³¹ Centers for Disease Control and Prevention, National Center for Health Statistics, Maternal Mortality, <https://www.cdc.gov/nchs/maternal-mortality/index.htm>, (last visited Feb. 3, 2021)

³² Kaiser Family Foundation, Analysis of Federal Bills to Strengthen Maternal Health Care (Dec. 21, 2020), <https://www.kff.org/womens-health-policy/fact-sheet/analysis-of-federal-bills-to-strengthen-maternal-health-care/>

³³ Centers for Disease Control and Prevention [Erase MM Program](#) (last visited Feb. 3, 2021).

³⁴ Katy Backes Kozhimannil et al., Beyond the Preventing Maternal Deaths Act: Implementation and Further Policy Change, Health Affairs (Feb. 4, 2019), <https://www.healthaffairs.org/doi/10.1377/hblog20190130.914004/full/>

³⁵ P.L. 104-191 (1996).

³⁶ 45 C.F.R. § 160.203, <https://www.law.cornell.edu/cfr/text/45/160.203>

³⁷ Office for Civil Rights (OCR) Privacy Brief, *Summary of the HIPAA Privacy Rule*, (May 2003), <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>

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- ³⁸ Department of Health and Human Services, Summary of the HIPAA Privacy Rule, <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html>, (last visited Feb. 7, 2021)
- ³⁹ 45 C.F.R. § 164.502(a)).
- ⁴⁰ 42 U.S.C. § 1320d–7(b)
- ⁴¹ 45 C.F.R. §§ 164.104, 164.306, 164.502
- ⁴² 45 C.F.R. §§ 164.506–508; see also <https://fas.org/spp/crs/misc/R45631.pdf>
- ⁴³ 45 C.F.R. §§ 164.502(d)(2), 164.514(a) and (b).
- ⁴⁴ The Network for Public Health Law, HIPAA Hybrid Entity Coverage Assessments, (Feb. 27, 2019), <https://www.networkforphl.org/resources/resource-collection-hipaa-hybrid-entity-toolkit/hipaa-hybrid-entity-coverage-assessments/>
- ⁴⁵ 45 C.F.R. § 164.103
- ⁴⁶ The Network for Public Health Law, HIPAA Hybrid Entity Coverage Assessments, (Feb. 27, 2019), <https://www.networkforphl.org/resources/resource-collection-hipaa-hybrid-entity-toolkit/hipaa-hybrid-entity-coverage-assessments/>
- ⁴⁷ Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82462, 82463 (Dec. 28, 2000) (codified at 45 C.F.R. pt. 164) (preamble)
- ⁴⁸ 45 CFR § 160.203; 45 C.F.R. Part 160, Subpart B; <https://www.hhs.gov/hipaa/for-professionals/faq/399/does-hipaa-preempt-state-laws/index.html>
- ⁴⁹ 45 C.F.R. § 164.502(a)(1)
- ⁵⁰ U.S. Department of Health and Human Services, Summary of the HIPAA Privacy Rule <https://www.hhs.gov/hipaa/for-professionals/privacy/laws-regulations/index.html> (last visited Feb. 8, 2021)
- ⁵¹ Jessica Quinn et. al, “A Delicate balance: New Privacy Challenges for Public Health Disclosures During the COVID-19 Pandemic” American Health Law Association (Jul. 24, 2020).
- ⁵² 45 C.F.R. § 164.512(a), https://www.ecfr.gov/cgi-bin/text-idx?SID=54e825773cbadbcbdd6ac9a7b57bdd9&mc=true&node=pt45.1.164&rgn=div5&se45.1.164_1512
- ⁵³ U.S. Department of Health and Human Services, HIPAA FAQ “May a covered entity disclose protected health information to a Protection and Advocacy system where the disclosure is required by law?,” <https://www.hhs.gov/hipaa/for-professionals/faq/909/may-a-covered-entity-disclose-information-to-a-protection-system/index.html> (last visited Feb. 8, 2021)
- ⁵⁴ 45 C.F.R. § 164.512(b)(1)(i)
- ⁵⁵ 45 C.F.R. § 501
- ⁵⁶ Standards for Privacy of Individually Identifiable Health Information, 64 Fed. Reg. at 59929.
- ⁵⁷ 45 C.F.R. § 164.512(b)(2)
- ⁵⁸ See Lucy Hodder and Lauren LaRoche presentation “SUD Confidentiality and Updates to 42 CFR Part 2: A Two-Part Series.” https://chhs.unh.edu/institute-health-policy-practice/focal-areas/health-law-policy#collapse_2907
- ⁵⁹ The Preventing Maternal Death Act, H.R. 1318 – 115th Congress (2017-2018) <https://www.congress.gov/bill/115th-congress/house-bill/1318/text>
- ⁶⁰ RSA 132:30(I), <http://www.gencourt.state.nh.us/rsa/html/X/132/132-30.htm>
- ⁶¹ RSA 132:30(IV), <http://www.gencourt.state.nh.us/rsa/html/X/132/132-30.htm>
- ⁶² RSA 132:31(II), <http://www.gencourt.state.nh.us/rsa/html/X/132/132-31.htm>
- ⁶³ MA Research and Data Access Review Committee, Approval, September 14, 2012
- ⁶⁴ 111 MGL § 24A; 105 CMR §§ 305.040, 305.080.
- ⁶⁵ Ch. 348 of the Acts of 2020, An Act to Reduce Racial Inequities in Maternal Health, <https://malegislature.gov/Laws/SessionLaws/Acts/2020/Chapter348>
- ⁶⁶ 105 CMR 130.628
- ⁶⁷ 18 VSA § 1552(e)
- ⁶⁸ 18 VSA § 155(a)(2)
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⁶⁹ 22 M.R.S. § 261(1)(B)

⁷⁰ CGS § 19a-59i

⁷¹ CGS § 19a-59h

⁷² CGS § 19a-25

⁷³ RI ST § 23-4-3 (12)(i)

⁷⁴ *Supra*, notes 42-46. The Privacy Rule permits covered entities to disclose PHI without authorization to a public health authority that is authorized by law to receive such reports for the purpose of preventing or controlling disease, injury, or disability. This includes the reporting of a disease or injury, reporting vital events such as births or deaths, and conducting public health surveillance, investigations, or interventions. A public health authority is defined as an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe. The definition also extends to a person or entity acting under a grant of authority from or contract with such public agency. In addition to being a public health authority, the entity seeking the information must also be “authorized by law” to receive it. This requirement is satisfied when there is a legal basis for the activity; it does not require a specific law authorizing the collection of the information requested.

⁷⁵ John Mountjoy, *Interstate Compacts State Solutions – By the States and for the States*, The Council of State Governments, <https://www.csg.org/knowledgecenter/docs/ncic/StateSolutions.pdf> (last visited Feb. 12, 2021).

⁷⁶ Andrew Winston, *Interstate Compacts in the United States* The Law Library of Congress, Global Research Center (June 2018), <https://www.loc.gov/law/help/interstate-compact/us-interstate-compact.pdf> (last visited Feb. 12, 2021).

⁷⁷ The Council of State Governments, National Center for Interstate Compacts Database, <http://apps.csg.org/ncic/Default.aspx> (last visited Feb. 12, 2021).

⁷⁸ Valerie Smith, *Nurse Licensure Compact: Conducting Investigations & Discipline Across State Lines*, (undated presentation), https://www.ncsbn.org/2014DCM_VSmith.pdf (last visited Feb. 12, 2021).

⁷⁹ Maternal Mortality Review Committee Abstractor Manual, Version 2, MMRIA, Review to Action. <https://reviewtoaction.org/national-resource/maternal-mortality-review-committee-abstractor-manual>