WHITE PAPER

Building a Strong Foundation for Pediatric Palliative Care in Connecticut Series

Improving Data Collection:

An introduction to comprehensive case review

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I. INTRODUCTION

DEFINING PALLIATIVE CARE

Palliative care is a type of medical care focused on improving quality of life for patients with serious illnesses and their loved ones. This is accomplished through a variety of services, ranging from medication prescribed by clinicians to spiritual support provided by chaplains. For pediatric patients, palliative care also includes services for caregivers and siblings, such as psychotherapy, social worker support, and respite care.[1]

A growing body of high-quality research demonstrates that palliative care improves overall quality of life, increases patient and family satisfaction with care, and reduces avoidable costs. It can even help prolong life. For example, studies have found that palliative care[2]:

- reduced adult patients' symptom burden by 66%;
- reduced hospital admissions by 50% and emergency department visits by 35%;
- reduced hospital readmissions by 48% for adult patients with advanced cancers;
- lowered the cost of inpatient services by 28% for adult oncology patients; and
- lowered hospital/emergency department transfers for adult patients in skilled nursing facilities by 35%.

Most empirical research on palliative care involves adult patients, with more dedicated pediatric palliative care (PPC) research sorely needed. That said, the comparatively few studies that focus on pediatric palliative care demonstrate similar results.[3] Although pediatric and adult palliative care produce the same general benefits, and have the same general objectives, pediatric patients have distinct needs that often require different processes, tools, and approaches to care.[4]

A Holistic Approach to Improving Quality of Life

Palliative care is a relatively new yet fast-developing field. The first palliative care programs emerged in the 1980s as an outgrowth of the hospice movement, which sought to ease the suffering of patients nearing the end of their lives.[5] Now over 90% of large hospitals (over 300 beds) have palliative care teams, clinicians can seek board certification in palliative care, and many of the leading medical and nursing schools include palliative care as a mandatory requirement in their curricula.[6] As with palliative care research, the bulk of the growth in palliative care programs has focused on adult patients.

Despite these developments, the scope and benefits of palliative care for both adult and pediatric patients are still broadly misunderstood. Medical professionals, policymakers, and the public alike often believe that palliative care is just another name for hospice care. But palliative care is not only for terminally ill patients who have exhausted their curative treatment options—patients can and do receive palliative care alongside curative treatment.[7] The American Medical Association and the American Academy of Pediatrics both recommend that patients begin palliative care as soon as possible after they are diagnosed with a serious illness.[8]

Palliative care is also commonly misunderstood as a narrow type of care focusing only on the management of physical pain. But palliative care is holistic. Unlike many other areas of medicine, it is defined by an overarching objective—improving quality of life for patients and their families by reducing all kinds of pain, including emotional and spiritual suffering—instead of a particular range of services, type of provider, or setting.[9]

This holistic approach is the key to palliative care's benefits. But the lack of rigid categories or labels can make it difficult to identify what the term "palliative care" encompasses in a particular context. Defining palliative care is not just an academic exercise. It can determine not only what services patients receive, but where they receive them, and what those services cost.

Primary & Specialty Palliative Care

Palliative care is often divided into two tiers: "primary" and "specialty."

Primary palliative care is provided by frontline health care workers—those who do not specialize in palliative care—as part of their standard practice. Patients and their families may receive primary palliative care at home, at an outpatient clinic, or in the hospital. This kind of palliative care is not meant to be comprehensive; rather, it focuses on communication with patients and their family members, general symptom management, and identifying patients who could benefit from referral to one or more specialists.[10]

Specialty palliative care, as the name suggests, is provided by an interdisciplinary team of specialists—i.e., health care professionals who have received advanced training in symptom management, patient-provider communication, and other competencies necessary to support patients with complex health needs. Patients are more likely to receive specialty palliative care in a hospital or outpatient setting than at home. This kind of palliative care is meant to be comprehensive.[11]

Most patients with serious illnesses could benefit from specialty palliative care. Primary palliative care is also crucial, however, as there is a nationwide shortage of palliative care specialists, which is particularly for pediatric patients. Connecticut is no exception. While there are thousands of children in Connecticut with serious illnesses, there are only three board-certified pediatric palliative care physicians in the entire state.[12]

CONNECTICUT NEEDS

STATE-SPECIFIC PEDIATRIC PALLIATIVE CARE DATA

Connecticut medical professionals, researchers, policymakers, and families are working together to improve access to high-quality palliative care for the state's seriously ill children. As part of that effort, we wrote a white paper addressing two foundational barriers to access: (1) limited insurance coverage and (2) a shortage of frontline professionals with training in core palliative care competencies.

To address these barriers, we recommended (1) establishing a statewide insurance coverage pathway and (2) expanding primary palliative care training for pediatric clinicians.[13]

These recommendations can be implemented immediately. Building upon them, however, will require more data.

Very little of the existing data and research on pediatric palliative care (PPC) is from Connecticut. Currently, there is no reliable source of statewide data on:

- How many children in the state may benefit from PPC, and what illnesses these children have;
- How many CT children are currently receiving PPC;
- How PPC is being provided (e.g., what services are provided, by whom, and where);
- The extent to which private insurers operating in the state cover PPC services; or
- Cost savings for patients' families or health systems.

There are several potential reasons for the paucity of PPC data in Connecticut:

- **PPC is not clearly defined.** The holistic and two-tiered character of palliative care delivery may be an obstacle to data collection. Various project collaborators may have high-quality data available for aggregation or analysis that have not been identified as relevant to PPC.

- **PPC delivery is complex.** There are many different kinds of providers, including doctors, nurses, social workers, and chaplains, who all provide care in a variety of settings to a heterogeneous patient population. Some patients, meanwhile, may receive PPC services in multiple settings throughout their illness—or even simultaneously.

- **Medical billing is not structured for PPC services.** Due to a widespread lack of palliative care-specific billing codes, even for specialty palliative care, patient's medical records may not label the services they receive as "palliative."

- **PPC is either misunderstood by or unknown to patients, their families, and clinicians.** Although this is beginning to change, there has yet to be the sort of groundswell of public recognition that has led to improved data collection for other patient populations and types of care.

II. IMPROVING DATA COLLECTION

A. The First Step: Developing Working Definitions

Community members, policymakers, practitioners, and researchers in Connecticut should develop a reliable and widely accessible mechanism for collecting comprehensive statewide data that, when aggregated, can provide answers to basic questions about PPC in Connecticut:

- **Who** is eligible to receive PPC and who is actually receiving PPC services;
- **What** services are offered, including at what cost;
- **Where** patients are receiving these services; and
- **When** patients are referred to specialist PPC providers.

Before doing so, however, project collaborators **must decide how to define the scope and content** of PPC for purposes of initial data collection.

To best reflect the holistic character of PPC, and create a strong foundation for future data collection, we recommend adopting a set of consensus working definitions. The idea of improving the quality of life for patients and families, while the core of palliative care, is likely too open to interpretation to allow for standardized data collection. A set of definitions would prevent confusion and allow for a range of interpretations to be identified and tracked.

To develop these definitions, project collaborators could **survey the definitions of "palliative care" and "pediatric palliative care"** used by other states, palliative care organizations, hospitals, and others in the palliative care space.

This survey should include not only general definitions of "palliative care" but also functional definitions gleaned from statutes, regulations, standards, internal policy documents, and the work of care providers. In this way, the survey could produce a sketch of the practical boundaries of PPC delivery—how various providers translate the basic mandate to "improve quality of life for patients and their families" into concrete interventions.

In conducting this survey, or similar foundational work, project collaborators should try to cast a wide net. The consensus working definitions should be broad. It is unlikely that being overinclusive will result in a significant increase in the cost or complexity of data collection. A significant risk of being underinclusive, however, is that the data collected provides only a partial picture of pediatric palliative care in Connecticut, with some services or children who should be counted going unidentified.

As described in the previous section, there are multiple barriers to the collection of comprehensive, high-quality PPC data. Accordingly, any working definitions should extend well beyond those services, providers, circumstances, and the like that are generally classified as belonging to "palliative care."

Some Connecticut programs, such as Medicaid waivers serving children with complex health care needs, offer services that could be classified as "palliative care" but are referred to by other names. Children in these programs may have unmet palliative care needs, despite the fact that they are receiving some palliative care services. Similarly, frontline clinicians who mistakenly believe that palliative care is synonymous with hospice care may attend to the suffering of their seriously ill patients without identifying their work as palliative in nature.

II. IMPROVING DATA COLLECTION

B. The Next Step: Comprehensive Case Review

Once project collaborators agree on a set of working definitions, we recommend following a proven model for public health data collection: **maternal mortality review committees**.

These committees conduct comprehensive reviews of individual cases of maternal death, collecting both medical and nonmedical data in the process, seeking to determine which deaths could have been prevented, and if so, how.[14]

This mode of data collection is not just for mortality. It is useful for any adverse health outcome that is difficult to track through conventional sources of public health data. Some adverse health outcomes can be tracked through existing data sources because there is a clear definition or other broadly accepted means of identifying them. For example, there is general consensus on how melanomas should be staged, and what test results indicate heart disease. Others are too complex, or simply too under-studied, and require dedicated data collection efforts.

The comprehensive case review approach is a way to collect data on the "who, what, where, & when" of adverse health outcomes – in order to determine the "why."

Pediatric palliative care data is similarly hard to track through conventional means. PPC is both complex and under-studied. Accordingly, it is a prime candidate for the type of comprehensive case review approach modeled by maternal mortality review committees.

Maternal mortality data was quite poor before the development of **maternal mortality review committees** and related interventions.

Death certificates, the primary source of that data, did not reliably include information about a decedent's pregnancy status; as a result, many pregnancy-associated deaths went unreported, and common causes of maternal mortality went unidentified and unaddressed.[15] There was also a lack of consensus on what qualified as a "pregnancy-associated" (and thus "maternal") death.[16]

Maternal mortality review committees were not only able to implement a standardized approach for identifying pregnancy-associated deaths, but determine the factors contributing to those deaths, and recommend carefully targeted interventions.[17]

III. A PROVEN MODEL FOR DATA COLLECTION

An Overview of Policy Recommendations

Core Recommendation:

A "Pediatric Palliative Care Review Committee" modeled after maternal mortality review committees

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Potential Growth Opportunity After Core Recommendation Is Implemented:

Integration of Pediatric Palliative Care Review Committee into a multi-organization quality care collaborative, modeled after maternal and perinatal quality care collaboratives

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Less Resource-Intensive Alternative to Core Recommendation:

Analysis of state-specific data from already existing national data on pediatric palliative care, directed by the Connecticut Children's Health, Advocacy, Management and Palliative Care Working Group

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III. A PROVEN MODEL FOR DATA COLLECTION

A. The Comprehensive Case Review Approach in Action: Maternal Mortality Review Committees

In creating a robust data infrastructure around PPC, Connecticut does not have to start from scratch. Maternal Mortality Review Committees (MMRCs) are a proven, scalable model for collecting public health data and identifying opportunities for effective interventions.

MMRCs are multidisciplinary committees that collect data on deaths that occurred during or within one year of pregnancy and, using this data, develop recommendations for medical professionals and policymakers to prevent additional deaths. MMRCs are usually embedded within a state public health agency to facilitate data collection, but committee members include clinicians, patient advocates, community members, and other non-governmental collaborators in addition to agency employees.[18]

Although MMRCs focus on maternal mortality, the model is useful for gathering data on many different kinds of adverse health outcomes, including lack of access to pediatric palliative care.

This section provides an overview of MMRCs, describes how Connecticut's own MMRC operates, and then explores how the MMRC model can translate to pediatric palliative care.

III. A PROVEN MODEL FOR DATA COLLECTION

MMRCs collect and analyze data through a **comprehensive case review approach**. First, MMRCs work with vital records offices and epidemiologists to match death certificates with live birth and fetal death records to identify deaths potentially associated with pregnancy. An MMRC may also look to additional sources of information, such as hospital records, media reports, or obituaries, to locate potential pregnancy-associated deaths.[19]

Identifying the "Who, What, Where, & When" to Determine the "Why"

Once an MMRC has identified a potentially pregnancy-associated death, the case review begins. Professionals with the legal authority and technical expertise to collect sensitive health data—generally state or local health department employees—collect as much information as they can about the case from both medical and nonmedical sources. In addition to vital records, hospital records, media reports, and obituaries, they may use autopsy reports, other medical records, social services records, and interviews to develop a comprehensive view of the case.[20] Because MMRCs are focused on prevention, this data collection process is meant to be as broad and as thorough as possible; the best opportunity for an intervention in a particular case may have been long before the death, or found in an unexpected context.

Information gathered is then de-identified and compiled for committee members to review. To reduce opportunities for error and help ensure that data from different MMRCs can be compared and aggregated, the CDC developed a standardized "decisions form" for MMRCs to use during their review.[21] The form asks a series of detailed questions about the circumstances of the death under review and about the committee's consensus recommendations for preventing similar deaths in the future. Questions are accompanied by definitions for key terms and additional explanations (*see Figs. 1 and 2, pgs. 14-15*).

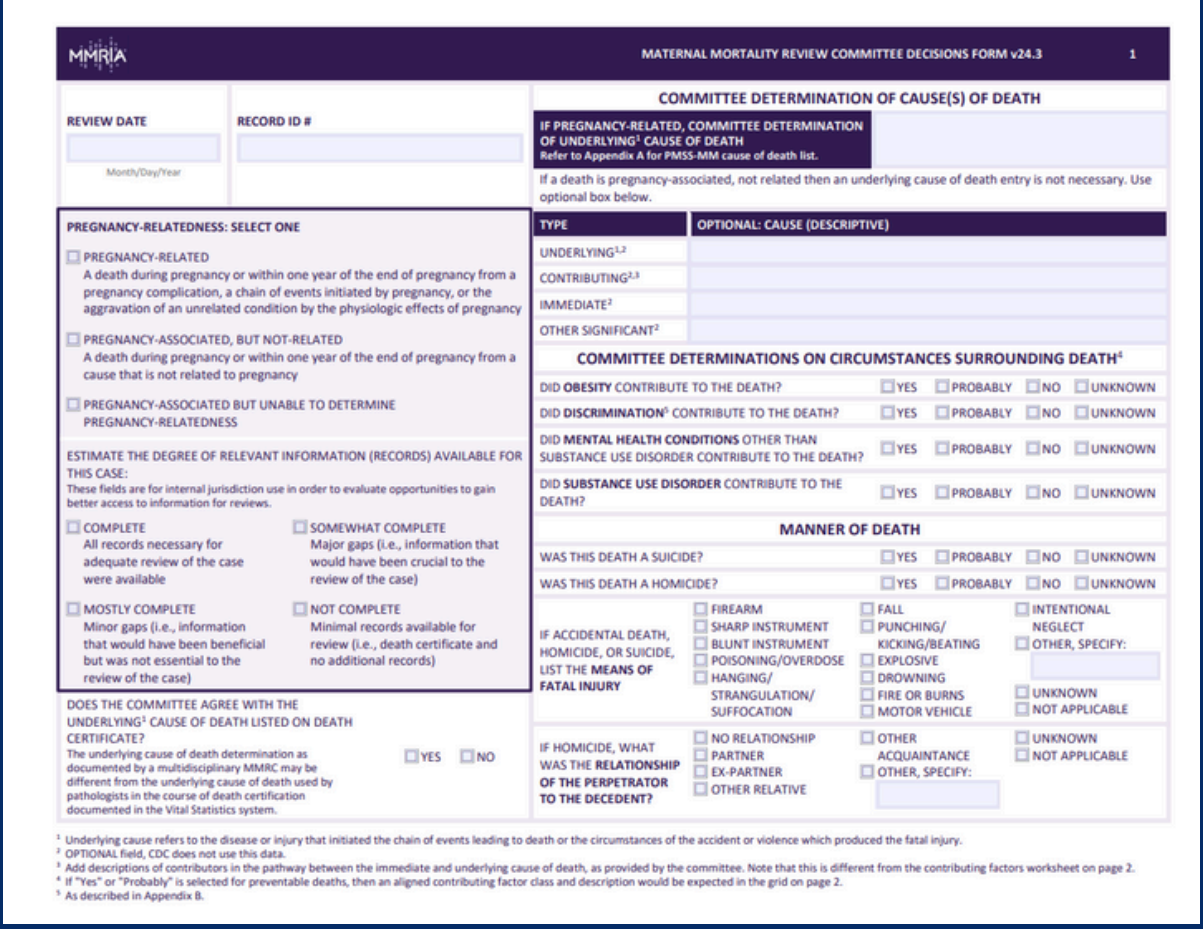
Individual MMRCs have historically received funding and guidance from the CDC and through Title V Maternal and Child Health Services Block Grants, which are administered by the Health Resources and Services Administration. The bulk of this funding supports the government employees who gather and de-identify data from the sources listed above. The funding also allows MMRCs to conduct more sophisticated data analyses and publicize their work through annual reports.[22]

During his first term, President Trump signed the Preventing Maternal Deaths Act, which funded the CDC's Enhancing Reviews and Surveillance to Eliminate Maternal Mortality (ERASE MM), a maternal mortality prevention program.[23] Housed within the program is a data tracking platform called the Maternal Mortality Review Information Application (MMRIA) that MMRCs may use if they so choose. The specially-built platform, which replaced an earlier data system, is designed to facilitate MMRCs' work by providing a standardized, easy-to-use framework for collecting, analyzing, compiling, and sharing data.[24] The CDC also collects data on national maternal mortality rates and trends through its Pregnancy Mortality Surveillance System, which sources data from death certificates linked to birth or fetal death records.[25]

CONNECTICUT'S MATERNAL MORTALITY REVIEW COMMITTEE

Connecticut's MMRC was established by the state legislature in 2018. In 2024, the MMRC had 2 co-chairs and 30 total members—17 with a clinical background, and 13 with a non-clinical background. It also included a nurse abstractor (who de-identifies the data) and informant interviewer.[26] Like other MMRCs, it is part of the state Department of Public Health. The MMRC's statutory authority and location within a state agency allows it to collect sensitive health information. To safeguard the confidentiality of the cases reviewed, committee members see only professionally de-identified data.[27]

Connecticut's MMRC uses the CDC's MMRIA data tracking platform and, upon completion of review, disseminates its findings to the public. In 2024, it released findings on deaths occurring in the years 2020 and 2021 and 56 recommendations.[28]



MMRIA — MATERNAL MORTALITY REVIEW COMMITTEE DECISIONS FORM v24.3 — 1

REVIEW DATE (Month/Day/Year) | RECORD ID #

PREGNANCY-RELATEDNESS: SELECT ONE

- ☐ PREGNANCY-RELATED — A death during pregnancy or within one year of the end 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 — A death during pregnancy or within one year of the end of pregnancy from a cause that is not related to pregnancy
- ☐ PREGNANCY-ASSOCIATED BUT UNABLE TO DETERMINE PREGNANCY-RELATEDNESS

ESTIMATE THE DEGREE OF RELEVANT INFORMATION (RECORDS) AVAILABLE FOR THIS CASE:
These fields are for internal jurisdiction use in order to evaluate opportunities to gain better access to information for reviews.

- ☐ COMPLETE — All records necessary for adequate review of the case were available
- ☐ SOMEWHAT COMPLETE — Major gaps (i.e., information that would have been crucial to the review of the case)
- ☐ MOSTLY COMPLETE — Minor gaps (i.e., information that would have been beneficial but was not essential to the review of the case)
- ☐ NOT COMPLETE — Minimal records available for review (i.e., death certificate and no additional records)

DOES THE COMMITTEE AGREE WITH THE UNDERLYING[1] CAUSE OF DEATH LISTED ON DEATH CERTIFICATE? ☐ YES ☐ NO
The underlying cause of death determination as documented by a multidisciplinary MMRC may be different from the underlying cause of death used by pathologists in the course of death certification documented in the Vital Statistics system.

COMMITTEE DETERMINATION OF CAUSE(S) OF DEATH

IF PREGNANCY-RELATED, COMMITTEE DETERMINATION OF UNDERLYING[1] CAUSE OF DEATH
Refer to Appendix A for PMSS-MM cause of death list.

If a death is pregnancy-associated, not related then an underlying cause of death entry is not necessary. Use optional box below.

TYPE	OPTIONAL: CAUSE (DESCRIPTIVE)
UNDERLYING[1,2]	
CONTRIBUTING[2,3]	
IMMEDIATE[2]	
OTHER SIGNIFICANT[2]	

COMMITTEE DETERMINATIONS ON CIRCUMSTANCES SURROUNDING DEATH[4]

DID **OBESITY** CONTRIBUTE TO THE DEATH?	☐ YES	☐ PROBABLY	☐ NO	☐ UNKNOWN
DID **DISCRIMINATION**[5] CONTRIBUTE TO THE DEATH?	☐ YES	☐ PROBABLY	☐ NO	☐ UNKNOWN
DID **MENTAL HEALTH CONDITIONS** OTHER THAN SUBSTANCE USE DISORDER CONTRIBUTE TO THE DEATH?	☐ YES	☐ PROBABLY	☐ NO	☐ UNKNOWN
DID **SUBSTANCE USE DISORDER** CONTRIBUTE TO THE DEATH?	☐ YES	☐ PROBABLY	☐ NO	☐ UNKNOWN

MANNER OF DEATH

WAS THIS DEATH A SUICIDE?	☐ YES	☐ PROBABLY	☐ NO	☐ UNKNOWN
WAS THIS DEATH A HOMICIDE?	☐ YES	☐ PROBABLY	☐ NO	☐ UNKNOWN

IF ACCIDENTAL DEATH, HOMICIDE, OR SUICIDE, LIST THE **MEANS OF FATAL INJURY**

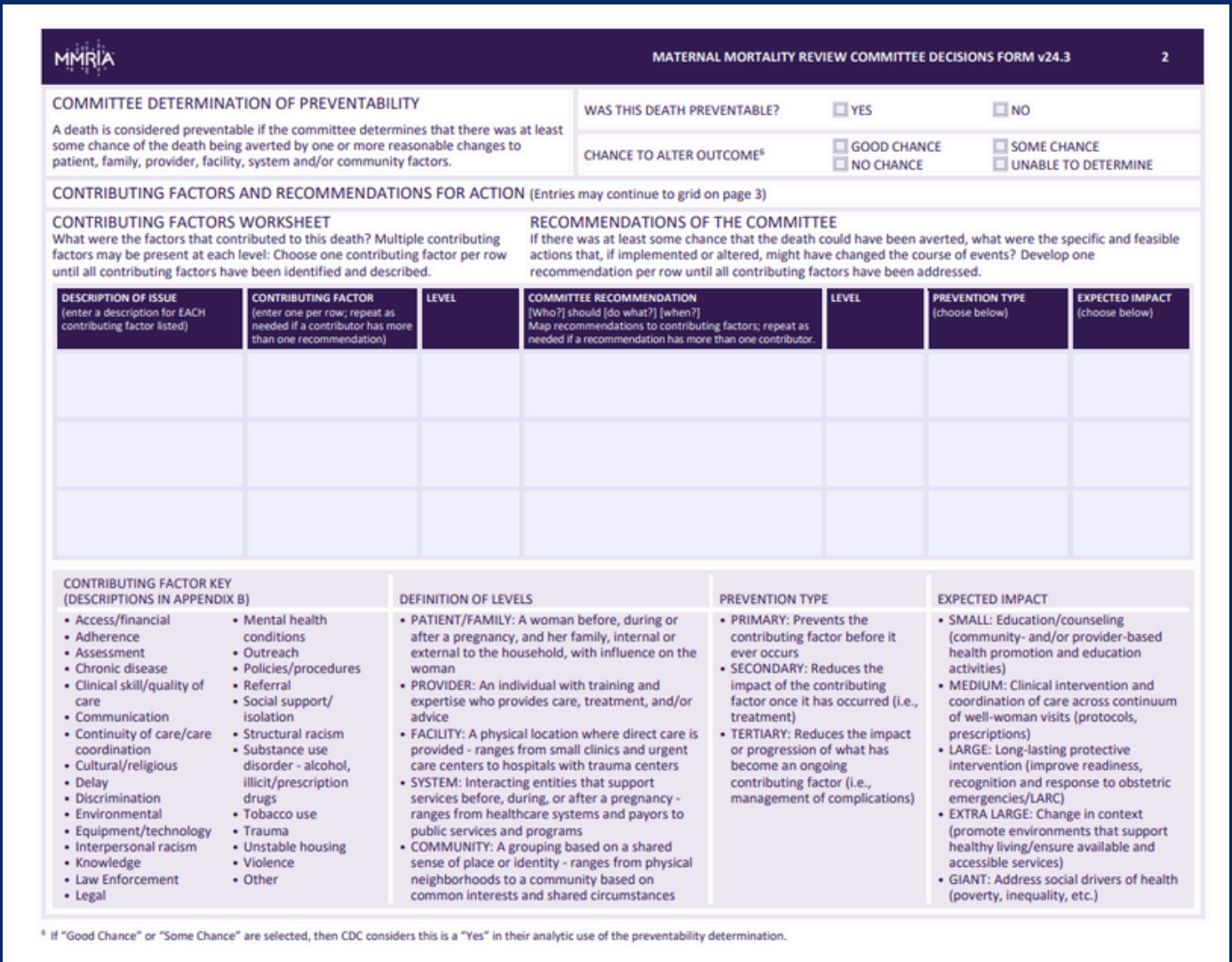
- ☐ FIREARM
- ☐ SHARP INSTRUMENT
- ☐ BLUNT INSTRUMENT
- ☐ POISONING/OVERDOSE
- ☐ HANGING/ STRANGULATION/ SUFFOCATION
- ☐ FALL
- ☐ PUNCHING/ KICKING/BEATING
- ☐ EXPLOSIVE
- ☐ DROWNING
- ☐ FIRE OR BURNS
- ☐ MOTOR VEHICLE
- ☐ INTENTIONAL NEGLECT
- ☐ OTHER, SPECIFY:
- ☐ UNKNOWN
- ☐ NOT APPLICABLE

IF HOMICIDE, WHAT WAS THE **RELATIONSHIP OF THE PERPETRATOR TO THE DECEDENT?**

- ☐ NO RELATIONSHIP
- ☐ PARTNER
- ☐ EX-PARTNER
- ☐ OTHER RELATIVE
- ☐ OTHER ACQUAINTANCE
- ☐ OTHER, SPECIFY:
- ☐ UNKNOWN
- ☐ NOT APPLICABLE

[1] Underlying cause refers to the disease or injury that initiated the chain of events leading to death or the circumstances of the accident or violence which produced the fatal injury.
[2] OPTIONAL field, CDC does not use this data.
[3] Add descriptions of contributors in the pathway between the immediate and underlying cause of death, as provided by the committee. Note that this is different from the contributing factors worksheet on page 2.
[4] If "Yes" or "Probably" is selected for preventable deaths, then an aligned contributing factor class and description would be expected in the grid on page 2.
[5] As described in Appendix B.

Fig. 1: First page of the CDC-developed "decisions form."



MMRIA — MATERNAL MORTALITY REVIEW COMMITTEE DECISIONS FORM v24.3 — 2

COMMITTEE DETERMINATION OF PREVENTABILITY

A death is considered preventable if the committee determines that there was at least some chance of the death being averted by one or more reasonable changes to patient, family, provider, facility, system and/or community factors.

WAS THIS DEATH PREVENTABLE?	☐ YES	☐ NO
CHANCE TO ALTER OUTCOME[6]	☐ GOOD CHANCE ☐ NO CHANCE	☐ SOME CHANCE ☐ UNABLE TO DETERMINE

CONTRIBUTING FACTORS AND RECOMMENDATIONS FOR ACTION (Entries may continue to grid on page 3)

CONTRIBUTING FACTORS WORKSHEET

What were the factors that contributed to this death? Multiple contributing factors may be present at each level: Choose one contributing factor per row until all contributing factors have been identified and described.

RECOMMENDATIONS OF THE COMMITTEE

If there was at least some chance that the death could have been averted, what were the specific and feasible actions that, if implemented or altered, might have changed the course of events? Develop one recommendation per row until all contributing factors have been addressed.

DESCRIPTION OF ISSUE (enter a description for EACH contributing factor listed)	CONTRIBUTING FACTOR (enter one per row; repeat as needed if a contributor has more than one recommendation)	LEVEL	COMMITTEE RECOMMENDATION [Who?] should [do what?] [when?] Map recommendations to contributing factors; repeat as needed if a recommendation has more than one contributor.	LEVEL	PREVENTION TYPE (choose below)	EXPECTED IMPACT (choose below)

CONTRIBUTING FACTOR KEY (DESCRIPTIONS IN APPENDIX B)

- Access/financial
- Adherence
- Assessment
- Chronic disease
- Clinical skill/quality of care
- Communication
- Continuity of care/care coordination
- Cultural/religious
- Delay
- Discrimination
- Environmental
- Equipment/technology
- Interpersonal racism
- Knowledge
- Law Enforcement
- Legal
- Mental health conditions
- Outreach
- Policies/procedures
- Referral
- Social support/ isolation
- Structural racism
- Substance use disorder - alcohol, illicit/prescription drugs
- Tobacco use
- Trauma
- Unstable housing
- Violence
- Other

DEFINITION OF LEVELS

- PATIENT/FAMILY: A woman before, during or after a pregnancy, and her family, internal or external to the household, with influence on the woman
- PROVIDER: An individual with training and expertise who provides care, treatment, and/or advice
- FACILITY: A physical location where direct care is provided - ranges from small clinics and urgent care centers to hospitals with trauma centers
- SYSTEM: Interacting entities that support services before, during, or after a pregnancy - ranges from healthcare systems and payors to public services and programs
- COMMUNITY: A grouping based on a shared sense of place or identity - ranges from physical neighborhoods to a community based on common interests and shared circumstances

PREVENTION TYPE

- PRIMARY: Prevents the contributing factor before it ever occurs
- SECONDARY: Reduces the impact of the contributing factor once it has occurred (i.e., treatment)
- TERTIARY: Reduces the impact or progression of what has become an ongoing contributing factor (i.e., management of complications)

EXPECTED IMPACT

- SMALL: Education/counseling (community- and/or provider-based health promotion and education activities)
- MEDIUM: Clinical intervention and coordination of care across continuum of well-woman visits (protocols, prescriptions)
- LARGE: Long-lasting protective intervention (improve readiness, recognition and response to obstetric emergencies/LARC)
- EXTRA LARGE: Change in context (promote environments that support healthy living/ensure available and accessible services)
- GIANT: Address social drivers of health (poverty, inequality, etc.)

[6] If "Good Chance" or "Some Chance" are selected, then CDC considers this is a "Yes" in their analytic use of the preventability determination.

Fig. 2: Second page of the CDC-developed "decisions form."

III. A PROVEN MODEL FOR DATA COLLECTION

B. Implementing the Review Committee Model: Connecticut's Infant Mortality Review Committee

The MMRC's comprehensive case review approach can be, and has been, applied successfully in other circumstances—with little need for adaptation. Although the approach is most commonly associated with MMRCs, it is useful for any adverse health outcome, particularly those that are difficult to track through conventional sources of public health data.

Connecticut established an Infant Mortality Review Committee (IMRC), which follows the general structure and format of its MMRC, in October 2023.[29] The IMRC is a multidisciplinary committee authorized by statute and is part of the Connecticut Department of Public Health.[30] Through comprehensive case review, it seeks to identify preventable infant deaths, describe trends, and develop recommendations to prevent additional deaths and eliminate disparities in health outcomes. Medical records and other sources of personal health information are kept confidential, but the IMRC does host monthly public meetings.[31]

Although the CDC does have multiple programs aimed at preventing infant deaths, it does not operate an "ERASE MM"-like program that offers guidance and standardized materials for state- and local-run IMRCs. Unlike Connecticut's MMRC, the IMRC does not use a standardized "decisions form" or other materials from the CDC (though it has historically received federal funding through the CDC). Instead, the IMRC collaborates with the National Center for Fatality Review and Prevention, a program of the nonprofit Michigan Public Health Institute that offers many of the same resources for IMRCs that ERASE MM does for MMRCs, including a data platform similar to the Maternal Mortality Review Information Application.[32]

III. A PROVEN MODEL FOR DATA COLLECTION

C. Integrating Review Committees into Multi-Organization Centers of Excellence: The California Quality Care Collaboratives & Connecticut's Own Perinatal Quality Care Collaborative

MMRCs can be established on their own or integrated into a larger entity. Because MMRCs and case review committees like them focus on preventing adverse health outcomes, they are a natural fit for "quality care collaboratives." These organizations are, in effect, multi-organization Centers of Excellence. They use a panoply of tools—from case review committees to empirical research studies to community outreach and more—to develop and implement policies that improve health outcomes.[33]

Most states have a perinatal quality care collaborative, and a few have a maternal quality care collaborative. These collaboratives focus on building robust data platforms that can support ongoing quality improvement initiatives for mothers, birthing people, and infants.[34] None focus on palliative care or on older Children and Youths with Special Health Care Needs (CYSHCN). However, as with MMRCs, the quality care collaborative models are not content-specific. They could be employed—without much need for adaptation—for pediatric palliative care, or the CYSCHN population more broadly.

This section provides an overview of California's maternal and perinatal quality care collaboratives, which are among the oldest and most robust in the nation, as well as Connecticut's perinatal quality care collaborative.

California Maternal Quality Care Collaborative & Perinatal Quality Care Collaborative

California's MMRC, called the California Pregnancy-Associated Mortality Review, conducts reviews of all pregnancy-associated deaths as well as reviews focused on a single topic, such as obstetric hemorrhage or COVID-19. It is part of a larger, multi-collaborator organization called the California Maternal Quality Care Collaborative (CMQCC).[35] The CMQCC was founded in 2006 as a joint effort of Stanford Medicine and the State of California. Since then, the organization has produced empirical research, developed and disseminated quality improvement toolkits, spearheaded community outreach initiatives, and maintained a Maternal Data Center that provides California hospitals with perinatal performance metrics and quality improvement insights.[36] California's current maternal mortality rate is about half of the U.S.'s overall rate, and it has been lower than the U.S. overall rate since 2007.[37]

The MMRC's integration into a collaborative, alongside other committees, research groups, member hospitals and other health providers, and a dedicated staff, both facilitates its own work and enhances the work of other entities within the collaborative. The structure makes information sharing, coordination, and cooperation between entities smoother and less resource-intensive—allowing the CMQCC to target not only maternal morbidity, but serious nonfatal conditions (morbidities) as well.[38]

To date, the CMQCC's quality improvement recommendations have been successfully implemented in toolkits targeting hemorrhage, hypertensive disorders, venous thromboembolism, sepsis, and cardiovascular disease. The CMQCC combines these toolkits with dedicated statewide outreach initiatives to ensure hospitals have the training and resources needed to use them.[39]

Take hemorrhage as an example: As reported in the American Journal of Obstetrics and Gynecology in 2017, hospitals collaborating with the CMQCC saw a 20.8% reduction in severe complications (morbidity) among women with hemorrhage between 2014 and 2016. Comparison hospitals saw a reduction of only 1.2% for the same period.[40] The CMQCC updated the toolkit in 2022, based on new data and research.[41]

California also has Perinatal Quality Care Collaborative (PQCC), which is a network of the state's neonatal intensive care units and High Risk Infant Follow-up clinics.[42] It is older than the CMQCC and has a narrower scope, but both collaboratives are housed at Stanford Medicine and focus on high-quality data collection and data-informed quality improvement.[43] The PQCC's central data repository, the NICU Database, includes information on the care provided in NICUs for neonates meeting certain eligibility criteria as well as acute transports into and out of the NICU. Collected data is used in quality improvement toolkits and research.[44] In 2024, the PQCC reported a 21% decline in mortality for very low birth weight neonates in participating NICUs.[45]

The High Risk Infant Follow-up Clinics, a program of California Children's Services, create a continuum of care for Children with Special Health Care Needs transitioning from the NICU to outpatient care. The program provides a supportive structure for data collection, analysis, and reporting to other collaborators through a Reporting System connected to the NICU Database.[46] This connection allows participating hospitals to track outcomes for children discharged from the NICU for the first three years of their lives.[47]

Connecticut Perinatal Quality Care Collaborative

The Perinatal Quality Care Collaborative is part of the Connecticut Hospital Association, which "represents hospitals and health-related organizations." Participating organizations include the state Department of Public Health; various Federally Qualified Health Centers; the state's large health systems, Hartford and Yale; and some independent associations of specialists.[48] The collaborative disseminates resources for clinicians and families developed by its participating organizations, but does not produce its own peer-reviewed research, and does not maintain its own data center, reporting system, or similar data platform.[49]

III. A PROVEN MODEL FOR DATA COLLECTION

D. A Less Resource-Intensive Alternative to Review Committees: The Texas Palliative Care Interdisciplinary Advisory Council's State-Specific Analysis of Existing Nationwide Data

The MMRC model requires the state to dedicate resources—namely employee hours and funds—to data collection. If it is not feasible for Connecticut to dedicate that level of financial and institutional support to a "pediatric palliative care review committee," there is an alternative: extracting state-specific data from existing sources of nationwide data.

Texas, which has an MMRC and a perinatal care collaborative, took this alternative approach for palliative care. The Texas legislature established the Texas Palliative Care Interdisciplinary Advisory Council in 2015.[50] As part of its work, the Council recommended that the state's public health agency—the Texas Health and Human Services Commission—conduct routine analyses of the Texas-specific data that the American Hospital Association collects through its Annual Survey of Hospitals.[51] (This is the same data source that the Center to Advance Palliative Care (CAPC) uses to develop its state scorecards.[52]) These analyses focused on the total number of palliative care programs—palliative care broadly, not pediatric—in hospitals as well as the relative availability of such programs in different regions across the state.[53]

IV. BUILDING A PEDIATRIC PALLIATIVE REVIEW COMMITTEE IN CONNECTICUT

A. An Overview

Connecticut can establish a "Pediatric Palliative Care Review Committee" through the state legislature, following the example of Connecticut Statute § 19a-59i(a), which established the state's MMRC.[54] It would be the first MMRC-like model to focus on pediatric palliative care.

The committee's objective would be to identify children with serious illness who could have benefitted from high-quality palliative care but did not have sufficient access to it. This objective is more complex than that of MMRCs. But the underlying idea is the same: Collect state and local data in order to identify the causes of an adverse health outcome and assess if and how those causes could be addressed, and by whom, so that the adverse health outcome is prevented in future.

Building on the MMRC framework, a "Pediatric Palliative Care Review Committee" could have a nearly identical structure to a MMRC. The comprehensive case review approach of MMRCs is appropriate for any adverse health outcome. It is especially well suited to the challenges of gathering pediatric palliative care data discussed above. Like maternal mortality before the advent of MMRCs, lack of access to high-quality pediatric palliative care is under-studied, and as a result, the overall quality of available data is poor. Just as many maternal deaths were not identified as pregnancy-associated, many pediatric patients with serious illness are not identified as eligible for palliative care. The lack of access to high-quality palliative care is likely preventable in most, if not all, cases—but the underlying causes of this lack of access are not well understood.

MMRCs are investigatory bodies. They seek to identify underexplored factors—environmental, social, and cultural as well as medical—that contribute to maternal deaths and produce health disparities. This foundational work creates a map for future data analyses, research studies, and policymaking.

In the same vein, a pediatric palliative care review committee would identify underexplored factors that block Connecticut children and their families from accessing high-quality palliative care.

B. Funding

Connecticut could explore federal funding through a Title V block grant through the Maternal and Child Health Bureau of the Health Resources and Services Administration, if those grants remain available. Many states, including Connecticut, have already used Title V block grants to fund both MMRCs and programs for children with special health care needs.[55]

C. Committee Structure & Relationship with the Pediatric Palliative Care Task Force

Like Connecticut's MMRC and IMRC, the proposed committee should be multidisciplinary. In addition to clinicians and medical professionals, committee members should include patient advocates and community representatives.

To the extent possible, the committee should use standardized data collection and review procedures along the lines of the CDC's materials for MMRCs. Ideally, the committee would have a "decision form" of its own and

some manner of data tracking platform for building and maintaining a database. This would not only help ensure that the committee's own practices remain consistent over time, but also allow Connecticut to package the model for use by other states—which would, in turn, make it possible to develop an accurate nationwide dataset and make comparisons across states. It may be necessary for the committee to work with outside collaborators and experts to develop such procedures. For the committee's data to be useful and used, its procedures must align with all relevant best practices for data collection, analysis, storage, and dissemination. There must also be reasonable consensus among collaborators as to the nature and scope of the procedures.

The committee could be structured as an outgrowth of the already-established Connecticut Children's Health, Advocacy, Management and Palliative Care Working Group, with some members of the Working Group also serving as members of the committee. If the committee were structured this way, as opposed to creating an entirely separate group, the establishing legislation and written committee procedures should clearly define the boundaries between the Working Group and the committee. Strong privacy protections, including clear rules for data sharing, are necessary to ensure the confidentiality of the sensitive information that the committee must handle as part of the case review process.

APPENDIX

Maternal Mortality Review Committees: Background

MMRCs were developed in response to the U.S.' staggeringly high maternal mortality rate and enormous outcome disparities between racial and ethnic groups. Over 60% of maternal deaths that occur during or within one year of pregnancy are likely preventable.[56]

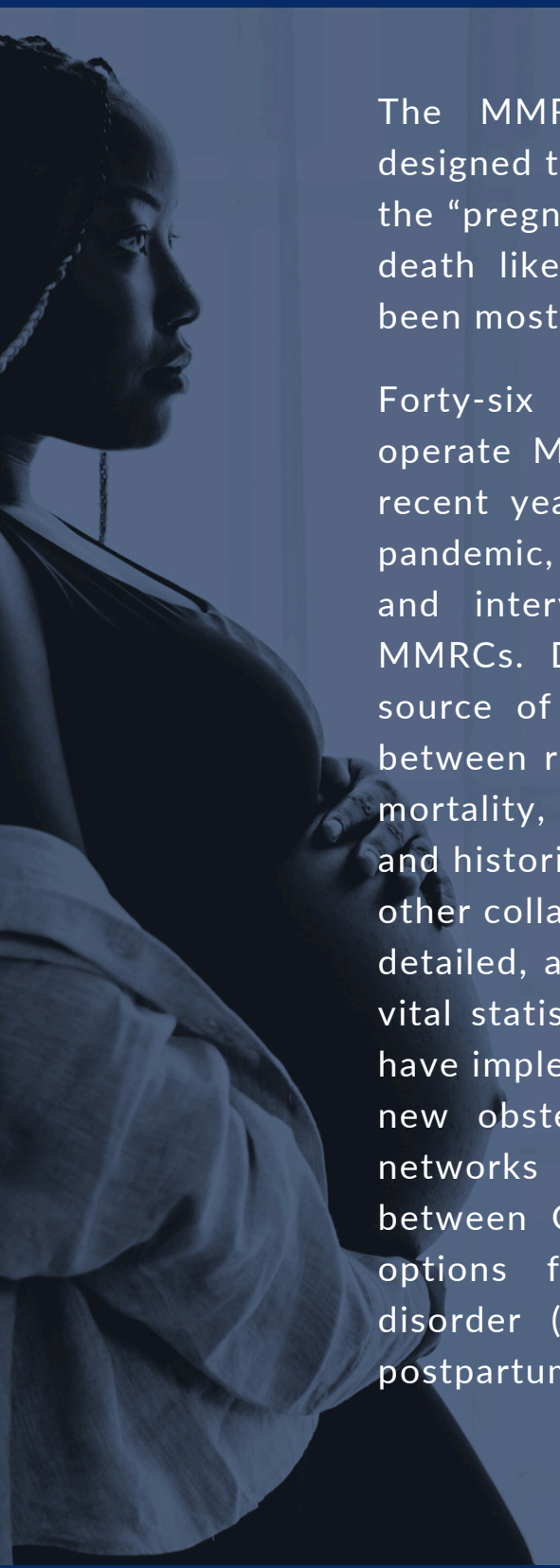
While the U.S.' overall maternal mortality rate is the worst among high-income countries, the rate for non-Hispanic Black women and pregnant people in the U.S. is higher still.[57] While there has been progress on bringing down maternal mortality rates for all groups, they are still high: by the most commonly used measure, and the most recent data, the overall U.S. rate is over 18 maternal deaths per 100,000 live births, and the rate for non-Hispanic Black women and pregnant people is almost triple that—50 maternal deaths per 100,000 live births.[58] The maternal mortality rate for non-Hispanic American Indian and Alaska Native (AIAN) women and pregnant people is likely higher than the overall U.S. rate as well, given historical comparisons, but there is no AIAN-specific rate for the most recent data.[59]

A few decades ago, health experts realized that there was very little data on the causes of maternal mortality, particularly deaths occurring more than a few weeks after pregnancy, because many maternal deaths were not identified as pregnancy-associated. Given that death certificates are a primary source of the data that goes into maternal mortality rates, if a death certificate has no indication that the death was associated with a pregnancy, that death is unlikely to be counted as a maternal death. (Some maternal deaths may be identified by matching a death certificate with a record of a

live birth or fetal death, but many calculations of the maternal mortality rate use only information from death certificates.)[60]

The immediate cause of a particular death can sometimes indicate that the death was directly related to a pregnancy, such as obstetric hemorrhage. In other cases, however, the relationship between the decedent's pregnancy and death may not be reflected in the immediate cause of death. The U.S. Standard Certificate of Death was revised in 2003 to add a checkbox with information about the decedent's pregnancy status in the year prior to death. The revised certificate was not fully implemented in all states until 2018.[61] Studies conducted before the 2003 revision suggested that up to half of all maternal deaths could not be identified through the information included on death certificates.[62]

The checkbox has improved the quality of maternal mortality data, but there are still errors—the certificate may be filled out incorrectly, or the decedent's actual cause of death may have been misidentified at some point before the death certificate was filled out. And the checkbox alone does not provide information about potential contributing factors, particularly those that are nonmedical. In 2017, Dr. Shalon Irving, a CDC epidemiologist and lieutenant commander in the U.S. Public Health Service Commissioned Corps, died of a sudden cardiac arrest three weeks after giving birth.[63] She had repeatedly sought help from her medical providers for swollen legs, severe headaches, fluid retention, and other signs of dangerously high blood pressure—including just six hours before her death.[64] Her research, life, and passing brought public attention to structural discrimination and biases that are often hidden in conventional means of collecting data but nevertheless lead to preventable deaths, particularly for Black women and pregnant people.[65]



The MMRC's comprehensive case review approach is designed to look beyond death certificates—which, even with the "pregnancy checkbox," cannot provide a full account of a death like Dr. Irving's, or what interventions would have been most effective at preventing it.

Forty-six U.S. jurisdictions, including Connecticut, now operate MMRCs. The maternal mortality rate has fallen in recent years, after a steep increase during the COVID-19 pandemic, in part thanks to improved outcome monitoring and intervention development through state and local MMRCs. Data collected by MMRCs has become a go-to source of information about lingering outcome disparities between racial and ethnic groups, current leading causes of mortality, the relative efficacy of particular interventions, and historical mortality rates. Researchers, policymakers, and other collaborators rely on MMRC data because it is far more detailed, and often more accurate, than data collected from vital statistics (death and birth records) alone. Many states have implemented MMRC-recommended initiatives, including new obstetric hemorrhage protocols (California), support networks for Black mothers (New York), collaborations between OB-GYNs and psychiatrists to expand treatment options for postpartum depression and substance-use disorder (New Hampshire), and home nursing visits for postpartum mothers (Indiana).[66]

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