INFORMANT INTERVIEW GUIDE FOR MATERNAL MORTALITY REVIEW COMMITTEES

V2







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Seasons

(Shared with permission from an informant)

For you are all the seasons, The anticipated change of leaves, letting go There is a promise that you will be green again The unexpected frozen air that seeps within Paralyzing with inhale, warmed with exhale The cold luminescence that floats above the snow peak An old familiar evergreen that knows what is to come An evergreen who knows when to shake its limb to let the warm touch within For underneath this evergreen dandelions seek to stretch For warm has reached the ground The warm air that dances among the blades of grass hoping they will join her The wishes that float, travel, and land for they know warmer weather is coming Change brings flowers into full bloom, and with this heat comes the clashing of skies-Thunderstorms, until there is the scent of clearing Only to bring us back again to changing leaves Who will once again let go. Just like the stars move with the sun, They believe change will come.

Introduction

The purpose of this document is to serve as a guide for jurisdictions as they plan and implement a maternal mortality review committee (MMRC) informant interview process. MMRC administrators and leaders will need to understand the overarching requirements for implementing informant interviews and ensure adequate capacity (finance and personnel) to carry out the process effectively. Jurisdictions should also ensure provisions foster a safe and supportive environment for interviewees. Respect and compassion are foundational tenets of this work.

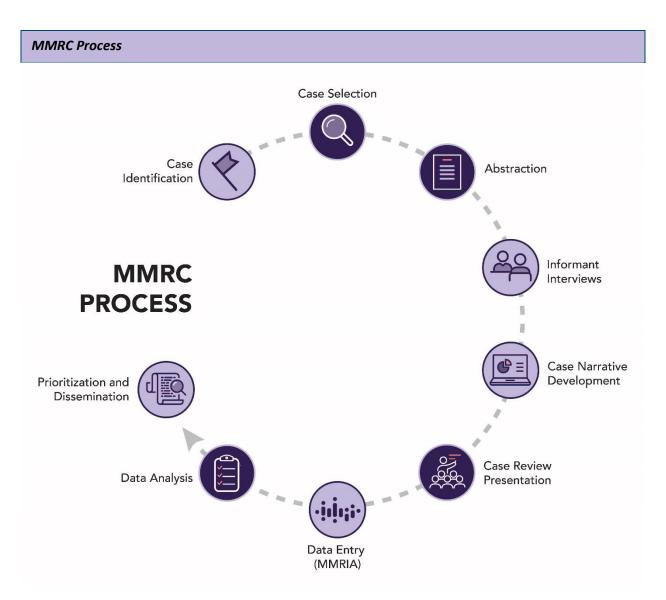
MMRCs can use this guide to establish a collaborative process for interacting with informants, including gathering and documenting critical information to develop a case narrative that presents a cohesive story for committee review.



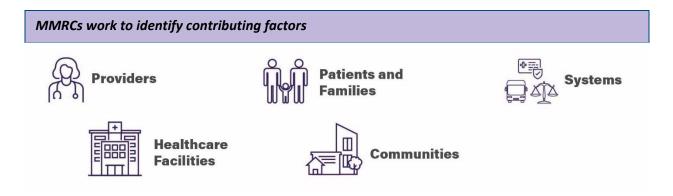
Background

Maternal mortality is a shattering event that affects family, friends, the healthcare team, and the wider community in which the individual lives and works. When maternal mortality occurs, family, friends, and healthcare professionals are left to wonder why such a tragedy happened, how it could have been prevented, and what can be done to ensure it doesn't happen to someone else. Public health surveillance of maternal mortality through MMRCs offers opportunities to explore and address these tragic events.¹

The goals of MMRCs are to identify the contributing factors to pregnancy-related deaths and implement recommendations to help prevent future deaths.² Historically, MMRCs have relied on data sources derived from administrative, medical and coroner, or law enforcement records. Typically, nurse abstractors review the records and synthesize their findings into a narrative, which committee members then review and use to determine pregnancy-relatedness, underlying cause of death, and preventability. They also use this information to identify contributing factors and formulate recommendations to prevent future deaths.³



MMRCs work to identify contributing factors at multiple levels: patient, family, provider, facility, systems, and community. Some contributing factors are easily identified, such as *continuity of care/care coordination* (e.g., poor coordination between obstetric and mental health and addiction medicine providers), while others emerge after careful synthesis of the information and committee discussion, such as *substance use disorder/violence* where substance use is used as a tool for control in relationships. In any one death, contributing factors typically occur in combination and across levels (e.g., patient/family, provider, facility, system, or community).⁴



Most MMRCs do not have access to the perceptions, experiences, and accounts of families or healthcare professionals and others who can add understanding regarding the circumstances of maternal mortality. However, when obtained through qualitative, participant-centered methods (i.e., via informant interviews), these data can provide multi-faceted perspectives on the individual's care experiences before and surrounding her death. These data can include what the individual knew and understood about her health, what those caring for her thought about her condition, and how these ideas informed their care plan. Informant interviews can provide rich contextual information to complement medical, first responder, and social service records, allowing MMRC members to comprehensively assess contributors of the death and make more effective recommendations for prevention.

MMRC abstractors review records to form the narratives that inform the MMRC determinations of underlying causes of death, pregnancy relatedness, preventability, contributing factors, and recommendations for action. For example, medical records containing providers' narrative notes describing changing clinical status and their reasoning for subsequent actions have been valuable qualitative data sources for MMRCs. These data provide insight into how the provider viewed the signs and symptoms and how this informed the care plan. However, the widespread adoption of Electronic Medical Record (EMR) systems, with standardized drop-down

MMRC abstractors review records to form the narratives that inform the MMRC determinations of the following:

- underlying cause of death
- pregnancy relatedness
- preventability
- contributing factors
- recommendations for action

boxes and abbreviated free text space, has greatly diminished the amount and quality of narrative notation, particularly nursing notes, in the medical record. As a result, EMRs are limited in their ability to provide information MMRCs need to review the events, such as conversations, clinical or non-clinical decisions, and actions that preceded the individual's death. Hospital records, in particular, do not typically incorporate insights from family members and healthcare personnel not directly involved at the time of death, such as prenatal care or mental health providers.⁵ Additionally, there may be barriers or challenges in obtaining mental health and substance use treatment records.

In some death investigations, interviews are conducted by a medical examiner, coroner, or law enforcement investigator, yet those interviews are designed to serve institutionally specific purposes,

such as obtaining sufficient data to determine the cause and manner of death or whether a crime was committed. In some cases, there may be little to no data systematically gathered to reliably document the perceptions and accounts of the decedent's family and friends. With this informational gap in

records and institutionally specific interviews, informant interviews are supplementary and effective methods for collecting information that provides greater context around the events leading to maternal mortality. Informants who personally knew the decedent can provide context and insight into her life and the factors that contributed to her death.

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Using informant interviews in conducting mortality reviews is not a new concept. Many countries have implemented various types of "social" or "verbal" autopsies to identify maternal deaths and their contributing factors.⁶ In 2004, the World Health Organization published *Beyond the Numbers,* which discusses the benefits of using information from community and family interviews when conducting internal facility reviews using medical records.⁷ For decades, the National Fetal and Infant Mortality Review Program in the U.S. has supported the use of family interviews to capture parents' perspectives following a fetal or infant death.⁸

Building the Framework for Informant Interviews



The first step in the informant interview process is developing a formal plan to identify and interview informants. The plan should be documented in the committee's policies and procedures guide and communicated to all those involved in the MMRC process, including committee leadership, staff, and members. The MMRC also needs to understand the statutes governing their process to ensure confidentiality, as well as when confidentiality may be legally required to be broken, such as when child abuse or harm to self or others is reported. The MMRC should use a standard informed consent form

(see Appendix B for an example) that outlines the purpose and protections of the interview and includes the texts of statutes that authorize the process and provide protection from discovery. Strong confidentiality protections can facilitate participation and disclosure in interviews. Finally, hiring an adequate number of appropriately skilled and trained interviewer(s) helps to foster a successful process (see "Section 3. Personnel").



1. Purpose and Scope

In the context of MMRCs, an informant interview aims to gain insight into the death and the context of the decedent's life. A well-written purpose statement clearly delineates how the information will be used, e.g., to inform the review of a death and identify opportunities for improving healthcare quality and systems of care. It is important for MMRCs to establish a standard procedure for explaining the interview's goals and how they fit into the MMRC process, with the informant receiving this information in both verbal and written formats. Establishing a standardized procedure for conveying the objectives and value of integrating an interview into the MMRC case review process ensures clarity and transparency.

Before initiating informant interviews, jurisdictions should carefully consider their priorities and capacity (i.e., scope). Although MMRCs may see value in pursuing informant interviews for all cases, practical limitations often make this unfeasible. The demand for interviews might surpass the available resources, including funding and personnel, particularly in jurisdictions with a high number of deaths.

To address these challenges, jurisdictions should adopt a strategic approach in prioritizing cases for informant interviews, prioritizing those that are likely to be pregnancy-related (see the list of PMSS-MM underlying causes of pregnancy-related death codes in Appendix A of the MMRIA Committee Decisions Form).⁹ The pregnancy-related nature of a case may not be immediately evident. Therefore, it may be necessary to obtain some preliminary information before deciding to pursue an interview.

Each jurisdiction should customize the priority of cases to reflect the nuances of their unique setting. For example, a region grappling with pronounced racial disparities may prioritize cases with causes of pregnancy-related deaths that disproportionately affect underserved communities.

While MMRCs are generally advised to refrain from pursuing interviews on cases that are unlikely to be pregnancy-related, some instances may justify an interview. For example, an interview can help to clarify the potential pregnancy-relatedness of deaths involving substance use and a history of Child Protective Services (CPS) involvement. (See also, *Consensus Pregnancy-Related Criteria for Suicide and Unintentional Overdoses*.¹⁰)

Special Considerations

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2. Authority and Protections

Every MMRC will need to understand the authority, protections, and rules under which they operate and develop an appropriate process for their jurisdiction. More MMRCs are realizing the value of informant interviews, and some have established explicit legislative authority to conduct them.^{11,12,13,14,15,16,17} Other MMRCs may not have specific legislative language for performing interviews but do so under the broader legislative authority of obtaining information for the MMRC process. Individual states may have rules or other processes in place that govern materials and outreach. The MMRC should use a standard informed consent form (see Appendix B for an example) that outlines the purpose and protections of the interview and includes the texts of statutes, which authorize the process and provide protection from discovery. Strong confidentiality protections can facilitate participation and disclosure in interviews.



3. Personnel

• Qualifications: Performing informant interviews is challenging, and having the appropriate personnel on board is key to your success. Effective interviewers should have expertise in bereavement counseling as well as specialized training and expertise in qualitative interviewing techniques and basic competencies in empathetic communication.^{2,8} Typically, MMRC jurisdictions hire licensed social workers (preferably licensed clinical social workers), while others have employed nurses to perform interviews. Both professions have demonstrated their suitability for the role; however, a background in social work brings a wealth of knowledge and expertise that significantly enhances engagement with families and communities. Additionally, individuals with social work backgrounds are skilled in providing essential grief and trauma-related support and offering

appropriate referrals to other community-based services. The jurisdiction may consider enlisting qualified staff or those willing to supplement existing skills, such as Regional Perinatal Coordinators trained in outreach, communication, and education. Some fetal and infant mortality reviewers have hired social workers, nurses, or other non-medical staff trained in family/peer counseling and outreach. Other candidates might include qualitative method experts.

It is imperative for jurisdictions to conduct a thorough assessment of the resources and needs within their region when determining the most effective professional background for the informantinterviewer role. This strategic evaluation ensures the individuals selected possess the optimal skill set and understanding required to navigate the complexities of this critical position. Additionally,

effective interviewers thoroughly understand how the interview fits into the overall maternal mortality review process and what information may and may not be shared with the informant. To maintain neutrality and avoid real or perceived conflicts of interest, interviewers should not have been directly involved in the care of the mother or baby.

 Cultural Sensitivity and Concordance: It is important for MMRC leadership or hiring personnel to take into consideration any maternal mortality disparities that exist in their area and, whenever possible, strive for cultural concordance between the interviewer and the population that is disproportionately affected. Cultural concordance occurs when individuals share one or more demographic characteristics such as gender, age, ethnicity, race, nation of origin, and/or social class. Interviewers need to be familiar with and knowledgeable about the cultural and ethnic background of potential informants and demonstrate

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sensitivity to how culture may influence how an individual understands and responds to maternal mortality or the questions being asked. The influence of culture on expressions and reactions to grief varies. Key factors affecting grief reaction include nativity, age, family traditions, gender, education and income, prior experiences with death and loss, and the historical background of the cultural group. Lived experiences play an important role, particularly for people who have experienced stigma, bias, racism, and other forms of discrimination from providers in the healthcare system and larger society.⁸

• **Training:** The MMRC should provide initial and ongoing training for the interviewers on the process and expectations, as well as the importance of maintaining confidentiality, effective communication techniques, and safety procedures (if the interviews take place in person). Interviewers should prioritize ongoing professional development through regular training and continuing education opportunities focused on grief, bereavement, and trauma responses. It is also important for the

MMRCs to establish mechanisms for the interviewers to debrief about the interview process, including access to emotional support resources when needed. Each MMRC will need to examine their available resources when deciding how to select, train, compensate, and support interviewers.



4. Outreach Preparation

• **Developing a Tailored Approach:** The Informant Interview Guide for Maternal Mortality Review Committees is a resource for jurisdictions to use in crafting their process. While referencing the guide, jurisdictions should consider their legislative authority, requirements, and regional and cultural considerations.

MMRCs should provide interviewers with any available information about the decedent's death before contact with informants. The MMRC staff may provide interviewers with access to the death certificate, infant birth or fetal death certificate if available, medical, first responder, and/or social service records, and other available information before initiating contact with informants. The MMRC staff can decide if initial contact with potential participants will be in person, via telephone, or otherwise (e.g., email).

• **Timing:** Determining the most appropriate timing for reaching out to families can be challenging. The interview timing depends on when the MMRC identifies the death, obtains access to documents that identify next of kin or close contacts, establishes contact with a potential informant, and that person's availability and readiness to participate. MMRCs are also sensitive and flexible regarding the preferences and timing of potential participants regarding interview participation. For example, informant interviewers should exercise care in the timing of their outreach to identify and avoid times that bear deep emotional significance for the families and close contacts (e.g., holiday seasons, anniversary dates of deaths, birthdays). Initiating outreach during these periods may unintentionally cause distress for those who have already endured significant loss and should be avoided.

To effectively address these concerns, jurisdictions should establish standardized contact timelines. These timelines should be thoughtfully crafted, considering regional nuances, cultural factors, and other information specific to the community. This comprehensive approach ensures a more empathetic and culturally sensitive engagement.

- Forms and Templates: The MMRC will need to create a standard outreach packet before the interviewer begins an assignment. The packet should include the following:
 - Introduction Letter: An introduction letter describes the purpose of the interview and how the
 participant was identified. An official MMRC representative can sign this letter and should
 include the reason for contacting the individual, a brief description of the maternal mortality
 review process, and the value of having the participant's input. The consent form (see below)

should also accompany the introduction letter. Refer to Appendix A for a Sample Introduction Letter.

- Consent Form: The consent form offers additional details about the purpose of the interview outlined in the introduction letter and includes information about the rights and protections of the participant and how the MMRC will incorporate interview data into the review process. The consent form clearly states what information interviewers cannot disclose to participants about the cause of death or other records being reviewed. The consent form also describes the MMRC's legislative authority and internal process for ensuring confidentiality and protection of the MMRC's discussions and findings from discovery or subpoena. The MMRC may have the consent form developed and/or approved by their authorizing entity, i.e., the state health department legal team. Provide a copy of the consent form to the participant for their records. Refer to Appendix B for a Sample Consent Form.
- Follow-Up Contact: If there is no response to the introduction letter or the interviewer cannot reach a potential informant by phone, sending a follow-up email or text may be helpful. Refer to Appendix C for sample templates.
- Scripted Guide for Initial Contact: MMRCs should develop a sample script to guide the interviewer and provide a uniform approach to introducing the interview process. An interview script can help guide the conversation to effectively obtain information without burdening the participants. Conversation scripts vary among MMRCs; some use them, while others do not. Rigidly structured scripted templates offer consistency but may limit the quality and quantity of the participant's account. A semi-structured interview script offers direction and consistency while still promoting open response. An unstructured interview script allows for open and free responses but limits the consistency or standardization of responses. Ideally, there is a balance in using open- and closed-ended questions. Refer to Appendix D for a Sample Initial Contact Script.
- Scripted Guide for Interview Conversation: A scripted guide is valuable for those seeking the right words or assistance in steering their conversations. This tool can be particularly supportive for informant interviewers who are new to their role and require additional guidance. Interview questions can address both medical and non-medical factors related to the death that may have occurred before, during, or up to 1 year after pregnancy ended. Having a subset of interview questions related to a particular cause of death can also be helpful. Interviewers can discuss factors such as the decedent's physical and mental health, medical care, prescription drug use, and provider relationships, as well as social factors, including housing, personal finances, substance use, child welfare, sexual and intimate partner violence, or other traumatic experiences. The interview conversation guide may begin with opening questions that ease the participant into the conversation. Good opening questions are neutral and broad but related to the decedent and the purpose of the interview. Ending the conversation with questions that allow the participant to reflect and/or offer additional information and resources can help the interviewer or participant move through any emotional difficulties during the interview and

support the participant after the interview concludes. **Refer to Appendix E for a Sample Conversation Guide.**

• **Critical Accommodations:** Interviewers should assess if accommodations are needed to foster communication with informants. Jurisdictions are strongly encouraged to proactively invest in translation and interpreter services. The jurisdiction may want to consider hiring a bilingual/multilingual interviewer, especially in regions where a substantial portion of the population is non-English speaking. When language interpretation services are necessary, interpreters should have a good understanding of both language and culture in the particular community context.

Informants may also need special services for the hearing or sight impaired. Jurisdictions can assess the need for special accommodations through various means. One approach is to address this matter during the initial or follow-up contact, either through written communication or a phone call. Committees can proactively inquire about the need for accommodations in the outreach letter or consent form. This proactive approach helps to identify and address potential accommodation needs from the outset, ensuring a more inclusive and supportive environment for informants. **Refer to Appendix F for resources.**

Jurisdictions should establish clear provisions that enable informant interviewers to use such resources without encountering delays in conducting interviews. Jurisdictions should also explore the option of developing outreach materials and informational brochures in languages other than English, catering to the diverse linguistic needs of their community.

Regarding other accommodations, while most informant interviews are traditionally conducted via telephone, it is crucial to consider alternative approaches when feasible. Some participants may prefer virtual or in-person interviews instead of telephone interviews. Jurisdictions should be flexible and responsive to individual preferences to make the process more inclusive and accessible.

Implementing Informant Interviews



5. Identifying and Contacting Potential Participants

Effective outreach methods are critical for effectively engaging with family participants in the informant interview process. Informant interviewers should employ cultural humility and compassion techniques to foster trust and facilitate open communication. Effective strategies begin with initiating contact with the identified next of kin listed on the death certificate or other contact person identified through the case abstraction process. Abstractors and informant interviewers should communicate routinely to ensure the

Important!

Abstractors and informant interviewers should communicate routinely to ensure the informant interviewer has access to records that will support contact with families.

informant interviewer has access to records that will support contact with families. These persons can be contacted by way of an outreach packet. This packet typically includes an introduction letter and consent form. If no response is obtained within 1-2 weeks, the interviewers should follow up with a phone call. If the contacts listed in the records are not responsive or available, the interviewer may need to explore other sources to locate alternative individuals to contact. Jurisdictions should carefully consider the time frame and maximum number of outreach attempts before concluding outreach efforts. As a reminder, interviewers should take care not to contact potential participants during times of heightened emotional distress or culturally inappropriate times. **Refer to Appendices A and B for Sample Templates.**

With the growing prevalence of text and email as a preferred communication method, some jurisdictions may find it beneficial to reach out to family members through text messages if phone calls go unanswered. It's worth noting that email addresses of next of kin are generally less readily available than phone numbers. So if jurisdictions choose to communicate via text or email, the jurisdiction and the informant interviewer should ensure the decedent's personal health information (PHI) is not disclosed during these interactions (e.g., emails should be encrypted as an additional safeguard). **Refer to Appendix C for a Sample Template of text and email communication**.



6. Steps for a Successful Conversation

- Language, Cultural Competence, Grief, and Bereavement
 - Language: Be mindful that using terms like "informant interview" may intimidate participants. Employing more empathetic and relatable language, such as, "I'd like to have a conversation with you about your loved one's passing," may create a more engaging connection. Alternative wording such as "conversation" or "discussion" may be better received than "interview." During the interview, employing an inclusive person-first language is essential. For example, rather than labeling an individual as suicidal, it is better to state that the individual died by suicide. Refrain from using stigmatizing language. For example, in cases involving elements of substance use disorder or mental health conditions, do not refer to an individual as a "substance abuser"; refer to them as a person with a substance use disorder. Using sensitive language plays a significant role in mitigating the negative stereotypes and biases associated with these conditions.
 - Practice Cultural Competence and Humility: Interviewers should proactively seek cultural awareness and understanding. Special emphasis should be placed on gaining insights into racial disparities present within the jurisdiction. Interviewers should also be aware of the biases and discrimination that may affect the community in which the decedent lived.
 - Grief and Bereavement Resources: Engaging in the informant interview process can be an emotionally charged experience for participants. Interviewers need to be prepared to offer compassionate support or follow-up resources depending on the participants' needs. Interviewers should have access to updated lists of specific community resources to refer participants, where applicable. Furthermore, the interviewer should be prepared to refer to community-based agencies, ensuring that bereaved families receive the support they need.

For example, interviewers may share information with families about available disease registries, such as the Amniotic Fluid Embolism Registry or the Preeclampsia Registry.^{18,19} These referrals provide participants with specialized information; potential social support within a knowledgeable, experienced community; and an opportunity to contribute to ongoing research and clinical care.



7. Post-Interview Closure

- Thank You Letter: Be certain to thank the participant for sharing their insights on the decedent's life and/or death. If relevant, acknowledge the strong emotions present during the interview, e.g., "I know at times talking about [first name of decedent] was difficult." The MMRC program may consider including information about who to contact with any questions about the process. The letter could include a list of local resources if the participant requested or might benefit from bereavement resources beyond what was provided during the interview. Family participants should be provided post-interview resources within 1-2 weeks of the interview. See Appendix G for a sample Thank You Letter.
- Interviewer Self-Care: It is crucial to recognize the sensitive nature of conducting informant interviews with family members and the potential effect of exposure to traumarelated information on one's well-being. Self-care is an essential measure to prevent vicarious trauma or burnout.

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Informant interviewers are strongly encouraged to integrate self-care practices into their daily work routines to counter the emotional toll of conducting interviews and safeguard their emotional and professional well-being. For instance, interviewers may structure schedules that allow breaks and provide time away from conducting interviews to attend to other job-related duties or fulfill committee/organizational needs. Interviewers are encouraged to join the Maternal Mortality Review Information Application (MMRIA) office hour sessions and open forums for peer support. Additional resources regarding self-care are available on the MMRIA SharePoint site at https://cdcpartners.sharepoint.com/sites/NCCDPHP/MMRIA.



8. Interview Summary

• **Developing the Interview Summary:** Interviewers are responsible for creating an informant interview summary, which provides an opportunity to humanize the decedent and her story by shedding light on facets of her life that may not be documented in other records. Include aspects of the decedent's life or medical care that will help the committee identify the cause of death, pregnancy-relatedness, preventability, contributors, and recommendations to prevent similar deaths in the future.

The summary should aim to provide a well-rounded perspective on the deceased and her medical history. When crafting the summary, incorporate quotes, when available, to express the views of the interview participant. Employ language that is respectful and unbiased. Remain objective and compassionate in telling the decedent's story.

- Integration Into the Final Case Narrative: Ultimately, interviewers should work with abstractors to integrate key interview components into the final case narrative in the MMRIA to provide context to the story. A strong emphasis should be placed on highlighting information relevant to committee members, especially details that could aid them in deliberations concerning the cause of death, pregnancy-relatedness, preventability, contributors, and recommendations to prevent future deaths.
- Documenting in the MMRIA: The MMRIA provides a designated Informant Interview Form for documenting an interview summary. The interviewer should consult with the abstractor about pertinent information that would be valuable to document on other MMRIA forms, such as the mental health profile or the Social and Environmental form.

Evaluation of the Informant Interview Process

Incorporating informant interviews into the process of MMRC case reviews is a recent development across jurisdictions. As sites establish guidelines for using informant interviews in case deliberations, it is crucial for jurisdictions to periodically and consistently evaluate the successes and challenges of their informant interview protocols and procedures. This evaluation can be facilitated through brief post-informant interview surveys distributed to family participants. MMRC team members' feedback, obtained through periodic surveys, can also be instrumental in gauging the impact of informant interviews on case deliberations and recommendation development.

As more regions adopt informant interviews, best practices and valuable insights will emerge. In conjunction with core leadership, the informant interviewer should proactively stay informed about evolving guidance to establish effective informant interview programs. Regular updates and a commitment to stay current will enhance informant interview practices.

Frequently Asked Questions

A jurisdiction may face various challenges and barriers while conducting informant interviews. To provide valuable guidance and insights that can assist both jurisdictions and informant interviewers in navigating these complexities, we have prepared a "Frequently Asked Questions" document related to informant interviews. This resource aims to address common questions and concerns, offering solutions and support to enhance the effectiveness of the interview process.

Appendix A: MMRC Sample Introduction Letter to Potential Informants

Dear [Potential Informant]:

We understand you and your family recently experienced the loss of [*name of individual or describe relationship, i.e., wife, daughter, etc.*]. We wish to express our sincere condolences on your loss.

[Jurisdiction] is conducting a maternal mortality review process to help understand why maternal deaths happen and how to prevent them. You were identified through information we obtained from [decedent name]'s next of kin or emergency contacts after her death. As part of our review of [first name of decedent]'s death, we wish to have a conversation with family members and friends who can provide us with information we cannot otherwise get using [first name of decedent]'s official records, such as how she was feeling and her experiences with healthcare. Maternal mortality review processes are detailed here: [insert link to jurisdictional website].

Please note, if you are involved in any legal action resulting from this death, we will not ask you to participate in an interview.

If there is no current legal action, and you voluntarily agree to participate, a trained interviewer will ask questions about [decedent name], including her health, family, and use of healthcare and social services. Many grieving family members find it helpful to talk about what happened with a trained, compassionate interviewer. The interview will take place [by phone, in your home, or in a quiet and comfortable place you choose], and can be scheduled at a convenient time. The interview may take about an hour to an hour and a half. With your permission, the interview will be audio-recorded so we can capture your full story.

We have attached a consent form with more information about our process. We look forward to hearing from you about your willingness to participate in an interview about [decedent name or describe relationship as stated above]'s death. Please contact [MMRC representative or interviewer name] to ask questions or schedule an interview using the information below.

Again, we express our condolences on your loss. Sincerely, [Jurisdiction] MMRC Name of MMRC representative or interviewer Contact information for MMRC representative

Appendix B: MMRC Sample Consent Form

Purpose of Interview

[Jurisdiction] is reviewing pregnancy-associated deaths to help understand why maternal deaths happen and how to prevent them.

We wish to interview family members and friends who experienced the loss of a loved one from a maternal death. You were identified through information we got from [*decedent name*]'s next of kin or emergency contacts after her death.

Please note, if you are taking legal action due to [*decedent's name*]'s death, we will not ask you to participate in an interview.

If there is no current legal action and you voluntarily agree to participate, a trained interviewer will ask questions about [*decedent name*], including her health, family, and use of healthcare and social services. The interview will take place by phone, in your home, or in a quiet place of your choice where you are comfortable, and can be scheduled at a time convenient for you. This interview may take about an hour to an hour and a half. With your permission, the interview will be audio-recorded so we can capture your full story.

Description of Potential Risk

Talking about the death of your loved one is difficult and may bring up strong emotions for you. The interviewer is not a professional counselor, but if you wish, they can provide you with names of professional counselors who can help you cope with your feelings about your loss.

You may stop the interview at any time if you do not want to continue. Your participation is voluntary. There is no cost for being interviewed other than your time and effort.

Description of Potential Benefits

You may find that talking about the death of your loved one can help with your grief. The interviewer can also provide you or your family information on available services to help you. The information you provide during this interview may help prevent other maternal deaths.

Confidentiality of Records

We will not let anyone know your name or what you told us. All information identifying you, the family, or the health providers will be kept confidential outside the review process staff and consultants. All of [Jurisdiction] maternal mortality review process staff and consultants have signed oaths of confidentiality. All records, including audio-recordings, will be kept in a secure, locked location. Confidentiality and anonymity will be protected to the full extent permitted by law. The interviewer cannot disclose protected records information to you, such as medical history and medical test results.

Mandated Reporters

Please note that any discovered danger to children or adults must be disclosed to authorities to prevent future harm.

Compensation

There is no monetary compensation for participating in the interview.

Voluntary Participation

Your participation in this process is completely voluntary. You do not have to be interviewed. You do not have to answer any question you do not wish to answer. You are also free to end the interview at any time.

Special Accommodations

Date: _____

Please let us know if you need language translation or hearing- or sight-impaired accommodation(s) so we can obtain appropriate support services.

Questions

If you have questions about the interview or [Jurisdiction's] process for reviewing pregnancy-associated deaths, you may call [*social worker, nurse abstractor, or staff member name*] at (---) --- - ----.

Consent

The purpose of the interview was fully explained to me.

I voluntarily agree to participate in the interview as part of [*Jurisdiction*]'s maternal mortality review process. I agree to the interview being audio-recorded. I understand that all information obtained from the interview will be strictly confidential to the fullest extent allowable by law, and identifying information will not appear in any publications or reports or be given to anyone outside the review process.

 [If by phone, obtain audio-recorded verbal consent from participant]

 [If in person, obtain a physical signature from participant]

 Participant Name:

 Signature:

 Date:

 Interviewer's Name:

 Interviewer's Signature:

Appendix C: MMRC Sample Text and Email Communication

Text Message Template:

Hello, I hope this message finds you well. My name is [Interviewer's Name], and I am reaching out to request a callback. Unfortunately, after several attempts, I have not been able to reach you by phone. Due to the sensitive nature of the information, I would appreciate if you could return my call at your earliest convenience. Please contact me at [Office Phone Number] during [Insert Office Hours]. Thank you.

Email Template:

Subject: Request for Callback

Dear [Recipient's Name],

I hope this message finds you well. My name is [Interviewer's Name], and I am reaching out to request a callback. Unfortunately, after several attempts, I have not been able to reach you by phone. Due to the sensitive nature of the information, I would appreciate if you could return my call at your earliest convenience. Please contact me at [Office Phone Number] during [Office Hours]. Thank you for your attention to this matter, and I look forward to speaking with you soon.

Sincerely,

[Jurisdiction] MMRC Name of MMRC representative or interviewer Contact information for MMRC representative

Appendix D: MMRC Sample Initial Contact Script for Informant

Interviews

Hello, my name is ______, and I am a [title such as nurse or social worker] from the [organization/program] that is reviewing [first name of decedent]'s death. I am very sorry for your loss.

[Pause and provide empathetic acknowledgment, then move into the reason for the call.]

We are following up to see if you received the letter we sent.

IF THEY DID NOT RECEIVE THE LETTER, PROVIDE KEY POINTS:

I apologize that you did not receive the letter we sent, but I can tell you why we want to talk to you about [first name of decedent]'s death.

- As part of our review of [first name of decedent]'s death, it would help us understand what happened to her by talking with a family member or close friend.
- The purpose of this interview and our overall review process is to better understand the events leading to [first name of decedent]'s death. We hope that by listening to you, we can learn how to prevent this from happening to other women and their families.
- Everything we discuss in this interview will be confidential, and your participation is voluntary. This interview will probably take no longer than [provide a time estimate—1 to 1 1/2 hours is reasonable], but we will talk as long as you are comfortable.

Are you willing to talk with us about [first name of decedent]'s death?

IF THEY DID RECEIVE THE LETTER, PROVIDE KEY POINTS:

As part of our review of [*first name of decedent*]'s death, it would help us understand what happened to her by talking with a family member or close friend. Are you willing to talk with us about [first name of decedent]'s death?

IF INFORMANT IS NOT WILLING OR EXPRESSES UNCERTAINTY

[Ask about their concerns and what additional information they need, and if they are not willing, ask:]

Might someone else who knew [first name of decedent] be willing to participate in our interview?

[Listen, document the response, including name/contact information for another possible informant; thank them and express condolences for their loss.]

IF INFORMANT IS INTERESTED IN SCHEDULING A SPECIFIC DATE AND TIME:

[Schedule the interview. Ask how they want to be reminded (by phone/text/email). Consider sending a copy of the questions via hardcopy or email if they do not wish to converse verbally; consider interviewee literacy before approaching in this manner.]

IF INFORMANT ANSWERS THEY CAN TALK NOW

We greatly appreciate your willingness to share about [first name of decedent].

[IF IN PERSON–provide them a copy of the consent form for their review and get a signature.]

[IF ON PHONE–read the informed consent form and obtain verbal informed consent. Ask for permission to record the verbal consent. If accepted, move to the conversation guide questions in Appendix E.]

Appendix E: MMRC Sample Scripted Guide for Interview

Conversations

INTRODUCTION

Hello. My name is ______ and I am a [title such as a nurse or social worker] from the [organization/program] that is reviewing [first name of decedent]'s death. I am very sorry for your loss.

[Pause and provide empathetic acknowledgment, then move into the reason for the call.]

Is this still a good time for you to talk about [first name of decedent]'s death?

We greatly appreciate your willingness to share about [first name of decedent].

INFORMED CONSENT

You may or may not have received the consent document we sent. I will read the consent form to provide detailed information about the purpose of our talk and what you can expect.

[Read consent form; Appendix B]

Do you have any questions about the consent document I read?

[Address any questions/concerns]

As I mentioned while reading the consent document, our conversation will be audio-recorded. The [Jurisdiction] maternal mortality review team believes that everything you have to say is important and can help with the review of [first name of decedent]'s death. Therefore, I would like to record our discussion so we don't miss anything. Do you feel comfortable with recording our discussion?

Okay, I will turn on the audio-recorder and ask for your consent to participate.

[Start audio-recorder]

After I read the following statement, please tell me if you consent to participate in our discussion about [first name of decedent]:

"The purpose of the interview was fully explained to me. I voluntarily agree to participate in the interview as part of [Jurisdiction]'s maternal mortality review process. I agree with our talk being audio-recorded. I understand that all information obtained from our conversation will be strictly confidential, and identifying information will not appear in any publications or reports or be given to anyone outside the review process."

[Obtain verbal consent, document the date/time, and provide the interviewer's name who obtained verbal consent from the participant.]

OPENING STATEMENTS

Before we begin, I want to remind you that we want to know your point of view, so there are no right or wrong answers to these questions. If you are uncomfortable answering a question, let me know and we can skip it.

There might be pauses between questions. I want to give you time to answer the questions, which will help me take notes on what you are saying.

Do you have any questions before we start?

[Address any questions/concerns]

Ok, let's get started.

Conversation Guide Tip: Opening statements with family participants should foster a comfortable and supportive atmosphere. The interviewer should briefly offer the opportunity to revisit the mission and goals of the MMRC and the purpose of the interview and answer any questions regarding the consent form.

BRIEF SOCIAL HISTORY

Let's begin our conversation by getting to know [first name of the decedent]. I'll start by asking about her personality and home life.

Getting to Know Your Loved One

- **1.** What would you like me to know about [first name of decedent]? Probe for information or insights into the decedent's hobbies, interests, personality, nicknames/preferred names, fond memories, etc.
- 2. What was [first name of decedent]'s day-to-day routine? Probe for information on whether the decedent was employed, enrolled in school, etc.
- 3. [If applicable, based on information about the death] ask **Do you know if** [first name of decedent] knew she was pregnant before her death? How did she feel about the most recent pregnancy?
- 4. Did [first name of decedent] have access to the support of family and/or friends during her pregnancy and/or during the time before she died?

Social Determinants and Chronic Stressors

In the next part of the interview, we'll ask about [first name of the decedent]'s everyday difficulties or challenges. This helps us understand the stress she might have faced around the time she passed away.

- 5. Was English the primary language or first language of [first name of the decedent]? If not, did she express any challenges or barriers with English as a second language? (Assess for challenges related to employment opportunities, healthcare access, cultural integration, etc.)
- 6. Did [first name of decedent] ever worry about having money or health insurance to cover her bills and medical care during or after her most recent pregnancy [if applicable]?
 - If yes, say: Tell me what issues [first name of decedent] was having with covering her bills or medical care.

Probe: [Try to ascertain the timeline of events]

7. How did [first name of decedent] feel about where she lived during or after her most recent pregnancy [if applicable]?

Probe: Assess for homelessness and housing status, who she lived with, neighborhood safety, access to services, distance to work, or other things that may have affected her health.

8. What kind of support did [first name of decedent] have to help with her needs during or after pregnancy [if applicable]?

Probe: Assess for food insecurity, lack of medical care, financial assistance needs, advice, information, and emotional support.

- Did they help her after she had her baby?
- 9. To your knowledge, did lack of transportation keep [first name of the decedent] from medical appointments, meetings, work, or from getting things needed for daily living?
- 10. To your knowledge, did lack of childcare keep [first name of the decedent] from medical appointments, meetings, work, or from getting things needed for daily living?
- 11. To your knowledge, was there any history of Child Protective Services (CPS) involvement?
- 12. To your knowledge, while pregnant or after giving birth, did [name of the decedent] spend any time in a jail, prison, detention center, or juvenile correctional facility? Was there any history of Child Protective Services (CPS) visiting the home?
- **13.** [If not the spouse or partner] **How would you describe** [first name of decedent]'s relationship with the father of her baby?

Probe: Clarify the relation of the baby's father to the decedent (i.e., spouse/partner). Opportunity to inquire about domestic violence or intimate partner violence.

HEALTH HISTORY AND HEALTHCARE EXPERIENCES

Now, I would like to ask you some questions about [first name of the decedent]'s healthcare history and experiences.

General Health

- 14. Did [first name of decedent] have any pre-existing conditions (diabetes, high blood pressure, sickle cell anemia, asthma, obesity, etc.)?
- **15.** Was [first name of the decedent] **someone who liked to stay active and do physical activities regularly**?
- 16. Was [first name of decedent] taking medications before, during, or after her most recent pregnancy [if she lived postpartum]? This could include prescriptions, over-the-counter medicines, vitamins, or supplements.
 - ▼ If yes, say: Please tell me what medications, vitamins, or supplements she was taking _____.
 - Before pregnancy
 - During pregnancy
 - After pregnancy [If applicable]

Keep probing until complete. Be sure to capture the relevant period for every medication (before/during/after pregnancy).

- 17. Do you know how many times [first name of decedent] had been pregnant in her life? (Include miscarriages, abortions, live births, and number of living children.)
- **18.** [If she had previous pregnancies] **Do you know if** [first name of the decedent] **had any physical complications with a previous pregnancy?**

Probe: High blood pressure, seizures, diabetes, blood clots, bleeding, depression/anxiety, C-section recovery issues, infection, severe tears, baby in NICU, stillbirth, etc.

About the Pregnancy

The next questions will focus on [name of the decedent]'s most recent pregnancy.

19. What can you tell me about the healthcare [first name of decedent] **received while she was pregnant?**

Probe:

- How did she find or select her care provider?
- What type of provider did she see (general obstetrician [OB], maternal-fetal medicine specialist/perinatologist, family medicine, certified nurse midwife, other midwife)?
- How often did she get healthcare while she was pregnant?
- Did she see the same person each time?
- Did she have challenges getting to her prenatal appointments?

20. How did [first name of decedent] feel about the care she received from her doctor, midwife, or nurse while she was pregnant?

Probe:

- Did she feel the (doctor/midwife/nurse) was respectful and listened to her concerns?
- Did she seem comfortable with or confident about her doctor/midwife/nurse?
- Did she feel they were giving her quality care? [Elicit examples]
- 21. Did [first name of the decedent] have any physical complications during her most recent pregnancy?

Probe: High blood pressure, seizures, diabetes, blood clots, bleeding, depression/anxiety, C-section recovery issues, infection, severe tears, baby in NICU, stillbirth, etc.

- 22. Was [first name of decedent] told to go to any other doctors, clinics, or hospitals at any time while she was pregnant?
 - ▼ If yes, ask: Was [first name of decedent] able to see the [provider or clinic or hospital] she was referred to?
 - ▼ If yes, ask: Can you tell me more about what happened when she saw the other doctor?
 - If no, ask: Why was [first name of decedent] unable to see the doctor/clinic/hospital she was referred to?

Labor and Delivery/Postpartum

If applicable: The next set of questions will focus on the period shortly after [name of the decedent] gave birth.

23. [If she lived postpartum] What can you tell me about the healthcare [first name of decedent] got after she had her baby?

Probe:

- Did she see her doctor or midwife a few weeks after she had her baby?
- Did she have challenges getting to her postpartum appointments?
- Was she having complications or other health concerns after she had her baby that caused her to see a doctor? Please explain.
- 24. [If she lived postpartum] How did [first name of decedent] feel about the care she got from her doctor, midwife, or nurse after she had her baby?

Probe:

- Did she feel that the (doctor/midwife/nurse) was respectful and listened to her concerns?
- Did she seem comfortable with or confident about her doctor/midwife/nurse?
- Did she feel they were giving her quality care?

[Elicit examples]

25. [If she lived postpartum] Did you feel she was ready to go home after giving birth to the baby?

Emotional and Mental Health History

During pregnancy and after giving birth, people can experience many different emotions. The next questions I'll ask are about [name of the decedent]'s emotional well-being during pregnancy and after giving birth.

- 26. Did [first name of decedent] experience anxiety, depression, or other mental health challenges during or after her most recent pregnancy?
 - ▼ If yes, ask: How was she feeling mentally or emotionally?
- 27. From your perspective, what was her mood like during pregnancy (and postpartum)? Did she share any struggles with you?
- 28. Was [first name of decedent] seeing a provider or a counselor for her emotional or mental health?

Probe: If she was (seeing a mental health professional), explore if the deceased was compliant with attending sessions. Were there any barriers to accessing her counselor? Did she feel that seeing a counselor was helpful?

- 29. What was her experience with the provider or counselor she saw [if applicable]?
- **30.** How were [first name of decedent]'s relationships with others affected by her emotional or mental health?
- 31. Sometimes, traumatic experiences affect how women experience pregnancy and childbirth. Do you know if [first name of decedent] was abused or neglected as a child?
 - ▼ If yes, ask: What can you tell me about those experiences?
 - If yes, ask: Did she get any counseling or other professional help to cope with those traumatic experiences?
 Probe for type, frequency, length, age, and relationship with perpetrators during experiences of abuse or neglect.
- **32.** Did we leave anything out about [first name of decedent]'s life and health experiences that you'd like to share now?

Substance Use History

I will now ask questions about whether [name of the decedent] had a history of alcohol or drug use.

33. Did [first name of decedent] happen to [drink, smoke, or use drugs] during or after her most recent pregnancy?

Probes:

- Take prescription narcotics
- Drink alcohol
- Smoke cannabis
- Vape
- Smoke cigarettes or use any other tobacco products

[Identify the time frame of use: during pregnancy or the postpartum period]

- ▼ If yes, ask: How do you think the substance use affected [first name of decedent]'s ability to do her regular activities or care for her baby [if applicable]?
- If yes, ask: Did [first name of decedent] get counseling or treatment because she was using _____?

Conversation Guide Tip: Jurisdictions may find it beneficial to develop additional subset questions when dealing with cases that have confirmed histories of substance use or other mental health conditions. Including supplementary questions about substance use history, access to treatment, and other relevant details can provide more comprehensive insights and contribute to a fuller understanding of the situation.

Discrimination and Bias

The upcoming questions aim to understand if you believe [name of the decedent] was treated unfairly by any of her healthcare providers.

- 34. Did [first name of decedent] share with you any experiences with providers where she felt mistreated or dismissed?
- **35.** Did [first name of decedent] share with you any experiences with providers where she felt frustrated, discouraged, discriminated against, or ignored by her providers?

THE TERMINAL EVENT

Factors and Circumstances Surrounding the Death

In the next set of questions, we will discuss the events and circumstances leading up to [name of the decedent's] death.

36. Did [first name of decedent] tell you she was concerned about her pregnancy or health before her death?

37. What do you know about the events leading to [first name of decedent]'s death?

Probes:

- What information did she or the family have regarding her condition and treatment?
- What was the family told about the cause of death?

[Keep probing gently; this is likely to be an emotional time in the interview]

38. What do you think was the cause of [first name of decedent]'s death?

Probes: Who notified the family about her death? (paramedics, coroner, ER staff, etc.)

39. Who spoke to you about what happened to [first name of decedent]?

[Try to ascertain whether there is any confusion or disagreement among the family about the cause of death or how it was determined]

Preventability

- **40.** Do you feel [first name of decedent]'s death could have been prevented? (If yes, probe for their reason.)
- **41. What could be done to better help women like** [first name of decedent] **from pregnancy-related loss of life?**

Probe:

• What advice would you give to doctors, midwives, nurses, or other healthcare providers caring for women like [first name of decedent]?

CLOSING STATEMENTS

We are nearing the end of our interview. I want to pause and thank you for sharing with me today.

- **42.** What advice would you give to families like yours? How are you coping with [first name of decedent]'s death?
- 43. We prepared a list of resources that may be helpful. Would you like to have the list?
 - ▼ If yes, ask: How would you like me to send the list (mail/email)?

[List could include resources/support groups on grief, disease/condition, specific resource organizations, local social workers, etc.]

▼ If no, tell the participant how they may get resources later.

Thank you so much for talking with me. I'd like to check in and ask how this interview experience has been for you, and ask whether you have suggestions for me or the maternal mortality review process to better improve how we gather information about maternal deaths like [first name of decedent]'s.

Conversation Guide Tip: The closing statements of the interview should offer sincere gratitude to the participant for their participation. A brief, needs assessment should be performed to gauge the need for referrals or additional support.

Appendix F: Resources for Critical Accommodations

Services for Non-English Speaking or Limited English Proficiency: <u>Title VI</u> of the Civil Rights Act of 1964 requires recipients of Federal financial assistance to take reasonable steps to make their programs, services, and activities accessible to eligible persons with limited English proficiency.

- Interpreters and Interpretation (registry for certified interpreters): https://www.lep.gov/interpretation
- Considerations for Working with Interpreters: Organizations Considerations for Working with Interpreters Worksheet (hhs.gov)

Services for the Deaf or Hard of Hearing:

- Registry of Interpreters for the Deaf, Inc. (RID): Registry of Certified Sign Language Interpreters. Website: <u>https://rid.org</u> or call (703) 838-0030 (voice) or (703-838-0459 (TTY)
- National Association of the Deaf: <u>NAD Directories</u> provides information at the state level, including a directory of deaf interpreters.

Services for the Blind or Visually Impaired:

- American Foundation for the Blind: <u>afb.org</u>
- American Council of the Blind: <u>acb.org</u>
 - Federal Disability Rights Office: www.fcc.gov/accessibility

Appendix G: MMRC Sample Thank You Letter

Dear [Participant Name],

Thank you for sharing your loved one's story with us. We appreciate your help and honesty in answering tough questions about the loss of someone you care about. Your involvement is valuable in making things better for moms everywhere.

We hope more families like yours will share their loved one's story. The details you shared are important, and we aim to learn from them to improve future birthing experiences and outcomes for mothers and babies.

Once again, thank you for sharing your experience with us.

Sincerely,

[Jurisdiction] MMRC Name of MMRC representative or interviewer Contact information for MMRC representative

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- ¹² Oklahoma (State). Legislature. House. *Maternal Mortality Review Act*. HB 2334. 2019 Session.
- ¹³ Georgia (State). Legislature. Senate. An Act relating to the Department of Public Health, so as to require the Department of Public Health to establish the Maternal Mortality Review Committee to review maternal deaths. SB 273. 2013-14 Session.
- ¹⁴ Indiana (State). Legislature. Senate. An Act to amend the Indiana Code concerning health. SB 142. 2017-18 Session.
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¹⁸ <u>http://preeclampsiaregistry.org/</u>

¹⁹ https://www.afesupport.org/research/