Parental Interview Guidance

National Center Guidance Report

June 2020
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"Maternal interviews are hard to get, but they are most beneficial to understanding the death of the infant. Stories are data with a soul. The maternal interview provides the mom’s story with details that come from the heart."

Teri Conard, Fetal & Infant Mortality Coordinator, Indianapolis, Indiana
The Fetal and Infant Mortality Review (FIMR) process is a continuous quality improvement process addressing systems of care and service delivery that impact families and infant populations.

Introduction

FIMR began in the mid-1980s, when nationwide concern over high infant mortality rates intensified. The Department of Health and Human Services (HHS), Maternal and Child Health Bureau (MCHB), has supported the FIMR process since its inception. About 180 communities are currently using the FIMR model to address infant mortality and infant mortality disparities. Local FIMR teams are community improvement experts who use data and personal stories of loss to make improvements in their communities and prevent future fetal and infant deaths.

This guidance focuses on the collection of those personal stories as a key and foundational element of the FIMR process.
The collection of these stories has, until the publication of this guidance, been referred to as the maternal interview. The National Center acknowledges that not everyone who carries and loses a baby self-identifies as a woman or a mother. It is important to respectfully include these parents’ experiences as fatality review teams seek equity and justice on behalf of vulnerable populations. Teams can accomplish this by referring to the experience of a "childbearing parent," or calling this process a “family or parental interview,” as is done throughout this guidance.

The FIMR Parental Interview

FIMR is a community-based, action-oriented process to examine fetal and infant fatalities in order to assess gaps in service systems and make necessary changes to improve fetal and infant outcomes. In order to have the most thorough examination, FIMR teams collect information in two ways:

- **Comprehensive, de-identified data abstraction from relevant sources, including medical, human services, and social services records**
  
  These records allow teams to evaluate the concrete data included in records, including screenings, scope and regularity of care received, types of referrals made, and services provided.

- **Confidential parental interviews**

  Interviews provide a narrative and key details that are unavailable elsewhere, including the context of the pregnancy and the baby’s life.

The use of population statistics and quantitative data collected through FIMR case abstraction are invaluable to practitioners and public health professionals as they plan and improve programs to intervene for prenatal, perinatal, and infant health. Still, the personal narratives bereaved parents share provide uniquely insightful information about their experiences before, during, and after the death of their babies. These insights are not available from any other source, and they have implications for these same programs and interventions that benefit from quantitative data elements. Strategies to address problems at the local level are most effective when vital statistics are considered alongside families' personal stories.

Collectively, statistics and personal narratives provide quantitative and qualitative information about the conditions affecting fetal and infant outcomes within a given community and lead to improved health and services for the nation’s parents, infants, children, and families.
The following process flow chart demonstrates how these two unique sources of information contribute to the review:

**Case Identification: Notification of fetal and infant deaths**
- Hospitals
- Clinics
- Perinatal Programs
- Public Health Department
- Providers
- Vital Records

Parent agrees to interview

Contact with parents established
- Emotional support
- Education
- Information and referrals

Interview declined

Abstract medical and health/social service records

De-identified case summary prepared

Conduct multidisciplinary team review of the case

Identify systems issues, gaps in services, resources & needs

Generate findings & recommendations to improve systems of care & community resources

**Community Action Team (CAT)**
- Implement programs and activities that address recommendation
- Prioritize interventions

**Improved systems of care and resources for women, infants, and families**
Community Benefit

While data availability and analytics become more sophisticated, FIMR teams have started to examine qualitative data elements to determine if parents experienced domestic violence, lived in unsafe neighborhoods when their babies died, or if they lived in areas of concentrated poverty. While a home visiting record may indicate a parent had rides to prenatal appointments provided through a Medicaid plan, only a parent can tell you if a driver asked them not to bring their toddler with them next time, requiring them to get childcare they could not afford, making it impossible for them to get to their prenatal visits. These personal experiences have profound impacts on poor fetal and infant outcomes, and public health professionals will only learn about them through listening to parents' stories.

The ongoing collection of qualitative data through the FIMR parental interview is a unique feature of the program that has implications not only for fetal and infant mortality, but also for maternal and infant morbidity and wellness.

FIMR is designed as a sentinel case model, acknowledging that a fetal or infant death is an unexpected, worst-case outcome, and that the future risk of not making intervention to improve systems of care and service delivery for pregnant parents and babies would be significant. These same systems of care and service delivery, left un-improved, would pose risks that may not end in a worst-case outcome; but addressing the gaps in systems of care and service delivery will improve the experiences of all parents and babies who receive these services.

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1 [https://www.healthybabiesbaltimore.com/](https://www.healthybabiesbaltimore.com/)

Field Note

The Baltimore City FIMR has undertaken a project to make comprehensive recommendations around pregnancy and behavioral health. They focused on addressing racial disparities in fetal-infant mortality and are shifting to a deeper emphasis on structural racism and other upstream factors underlying the disparities to move the needle around extremely preterm births. The *B'more for Healthy Babies* team (the FIMR Community Action Team (CAT)) have all participated in the *Undoing Racism Workshop* with The People's Institute for Survival and Beyond. Through parental interviews, the Baltimore FIMR project is also seeking to better document and understand childbearing parents’ experiences of racism during pregnancy and throughout the life course, to demonstrate to providers and the community the critical importance of being explicitly anti-racist in their work.
Parents who have experience with these systems—their strengths and their weaknesses—and go on to experience a fetal or infant death, are uniquely qualified to speak to the ways these community systems function and to provide insights that can inform ongoing quality improvement efforts related to community assets and deficits. The FIMR Interview provides insight into the social determinants of health (SDoH)\(^2\) that may have impacted the parent’s and/or infant’s health. Differences in health are striking in communities with unstable housing, poverty, unsafe neighborhoods, or substandard education. Parents’ stories can also shed light on experiences of racial or other types of discrimination in seeking and receiving quality medical care. Many FIMR programs describe interviews as a key strategy to understand how the lived experience of women of color can influence maternal and child health outcomes.

\(^2\) https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health
Benefit to Bereaved Parents & Families

While communities benefit from hearing about the experiences childbearing parents and families have with service delivery systems through the interview, parents themselves often find value in sharing their personal stories of loss. Many are grateful for the opportunity to talk about the baby that died and to honor their memories by sharing stories or mementos. This can help facilitate the bereavement process. Parents and families may find the idea they are helping other families and possibly preventing other losses very healing.

“When I received your letter with the butterfly, it made me feel good. I carried that letter with me everywhere I went. When you came by my house, I was not there because I did not want to talk to you or anyone else about the death of my baby. One day, I was looking at that butterfly and decided to call. Best decision I made.”

Comments from a bereaved mother to her FIMR interviewer

If a parent had negative experiences with community-level systems, addressing it in a FIMR interview shows them that there are those in the community who care about the experience; it affirms that they are not merely complaining, but that the challenges they experienced are real and worthy of attention. The FIMR Case Review Team (CRT) has decision-makers from multiple systems who will read and hear their words and prioritize putting recommendations into action on their behalf.

While FIMR teams ideally attempt an interview with all bereaved childbearing parents, the burden of infant mortality is disproportionately borne by communities of color and low-income communities. Both groups have experienced historic disenfranchisement. The FIMR parent interview allows bereaved parents in these communities to give voice to their experiences in a way that dignifies and validates their experiences and their loss.

In addition to collecting valuable information about the experiences bereaved parents had with service-delivery systems in the community and giving them the opportunity to honor and remember their babies, the FIMR interview provides an important opportunity to connect bereaved families to needed services. Interviewers encounter parents at a very vulnerable time: a time when they may find it challenging to manage their usual routines and responsibilities. Common referrals interviewers make are to community-based bereavement services, peer support or counseling groups, or additional services such as family planning, child development services, or Women, Infants, and Children (WIC) for nutritional support.
Challenges

It is common for FIMR teams to find it challenging to get in touch with childbearing parents, or to encounter parents who are reluctant to participate in the interview. Some teams find this disheartening, and they are tempted to focus most of their energy and resources on case abstraction.

If FIMR teams take one thing away from this guidance, let it be this:

It is impossible to overstate the value of even one interview.

This is especially true for teams who have a difficult time completing them. If a team has seen the perceptions or conclusions in a case review meeting change instantly when the details of the interview were shared, they will need no convincing. The stories are powerful, and they can completely alter the understanding of the context and details of the case review.

While a case review meeting without a parent/family interview is always valuable and worthwhile, there is a great deal the team cannot know or assess without hearing from the childbearing parent, and recommendations they make will be limited without their insights. Knowing this, teams make great efforts to conduct interviews. Unfortunately, many parents are still difficult to contact or are reluctant to participate. While this guidance addresses ways teams have found to be most helpful when contacting parents and soliciting interviews, understanding the reasons why they may be declining interviews is important. Does the community have historic distrust of government entities like the health department? Are they hesitant to invite an interviewer to their home for fear of being judged? Are they too overwhelmed with life, responsibilities, and grief to consider participating? Are there cultural practices or beliefs that may inhibit parents from participating in the interview? As teams make efforts to conduct interviews, it is important to proceed with compassion and understanding, with both the parents who do and do not participate, and with their own efforts to get parents to participate.
The Parental Interviewer

The role of the interviewer is a distinct one. They are the only FIMR staff that bereaved parents will encounter, and the interview is a very vulnerable experience. It is important the interviewer be a supportive listener who champions the FIMR methodology, understanding its potential to change and improve communities.

Interviewers should understand the community in which interviews will be conducted, and have a calm and trustworthy demeanor and a compassionate approach. Ideally, an interviewer will be a community member who understands the social contexts the parents encounter. They need to be comfortable with the topic of death and in some of the awkward silences or emotional responses prompted by parents’ grief.

The interviewer should have experience in pregnancy and/or parental and child health and feel confident communicating in a clear, culturally-sensitive manner to both engage parents and explain and review the details of the interview, including the consent form. They should have a clear understanding of the confidentiality obligations related to FIMR and be prepared to comply with public health and safety codes, including obligations as a mandated reporter.

If the interviewer has never conducted home or community visiting before interviewing for FIMR, it may be helpful to shadow a public health home visitor who serves the community in which most interviews will be conducted. It may also be helpful to participate in professional development opportunities that address home visiting, motivational interviewing techniques, disparities, health equity, and bereavement support. Some relevant resources are shared in the resource list and appendices at the end of this guidance.

Finally, it is important that the interviewer have a comprehensive understanding of the local service systems and the ways in which they interact with each other. While interviewers cannot be experts on every agency or organization in their communities, a working knowledge is important, as it informs the follow up questions, quality of the interview, and the referrals made in the interview context.
Locating & Contacting Families

Interviewers typically contact parents through mailing a contact letter, calling them on the phone, or visiting the address of record. In most cases, contact information is included in the vital records, either a physical address or email address. If there is an email address listed anywhere in the records, that is sometimes the easiest way to make initial contact.

This initial contact should:

□ **Acknowledge the baby’s death**

   Whether reaching out through phone or mail, it is important that staff lead with sympathy for the parent’s loss.

□ **Provide information about the FIMR program**

   Many teams provide a program brochure or refer parents to a program website. Attention to literacy levels is critical for any materials provided to families. If the initial contact is a call, it is helpful to have a script or conversation outline to ensure that all the necessary information is provided to parents.

□ **Introduce the purpose of the interview**

   It should be clear to parents that the goals of the program and the interview are to help the community understand their story and their child’s story and prevent future infant deaths.

□ **Request participation in the interview**

   Teams sometimes find it difficult to locate and establish contact with parents who have recently lost a baby. It is common for parents to relocate after the death of their babies for many reasons, including stress and grief associated with the loss. Families sometimes relocate due to the external pressures of the social determinants of health, including unaffordable housing and safety issues within their homes or neighborhood. While these parents can be difficult to locate, their insights into the factors in their infants’ deaths are an invaluable addition to the FIMR case review. Furthermore, they deserve the opportunity to tell their story as much as parents who may be easier to find. One of the benefits of the FIMR process is its ability to elevate voices that may not otherwise be heard. Regardless of the case, program staff should pursue every interview as the invaluable resource that it is, understanding that an equitable approach requires teams to be persistent when locating a parent, even when it proves difficult. The team should determine guidelines for thoroughly attempting interviews.
It can be helpful for interviews to begin after case abstraction has begun for FIMR, as parents' contact information is often located in the medical records. Contact options may include phone numbers, physical addresses, and email addresses. While Institutional Review Board's (IRB) approval is not always obtained for FIMR, their input can be a way to ensure that HIPPA standards are being followed and to give partners confidence in the data collection methods.

If contact information is not readily available from vital records or medical records, consider the following avenues:

- Family members
- Friends or neighbors
- Utility companies
- Online searches
- Social media searches
- Post offices for forwarding addresses
- Direct or social service providers (WIC, home visiting, etc.)

**CONFIDENTIALITY CONCERNS**

Please check with your local or state lead agency to determine if there are any confidentiality concerns about using any of these communication methods to reach out to parents.
No third party should be able to deduce from your communication that you are reaching out to discuss a baby’s death.

Remember to always prioritize parents’ privacy.

Communication with other family members, residents, or neighbors should include only general information. Never indicate why the FIMR program is attempting to locate a parent—this includes naming Fetal and Infant Mortality Review. It is appropriate to refer to your larger agency when introducing yourself. This includes any type of envelopes the program may use in outreach mailings to parents.

Instead of referring to FIMR, let inquiries and mailings refer to the health department or hospital. To respect family privacy, some teams put an additional, program-specific envelope inside an addressed envelope that does not identify the program. It is important to give parents and families privacy and control over their own stories in this moment since so many felt no control through the death and related processes.
In some instances, teams have been able to establish relationships with local hospitals who have arranged to directly refer bereaved parents to the FIMR program for an interview by introducing the program to them after the baby’s death. This connection removes the task of locating parents; it also allows parents to be introduced to the process prior to any outreach from the program.

While different FIMR teams take different approaches to timing, teams who make contact earlier after the death tend to be more successful in eventually completing interviews. Many FIMR teams use death certificates from vital records to be alerted that a baby has died; some teams have access to those records much quicker than others do. Generally, an earlier initial contact yields better results where interviews are concerned, so the sooner the FIMR team can know about a death, the better.

Though it is typically an interview with the childbearing parent, there are times when it is appropriate for a mother, father, or other primary caregiver to be interviewed. For example, an infant’s grandmother may have been the primary caregiver in a case involving a teen mother. When this is appropriate, all the same information applies regarding avenues for contact, maintaining privacy and confidentiality, and moving forward with requesting the interview. Sample contact letters and scripts for telephone calls are included in the appendix.

There are times when interviewing is not recommended. Interviewers may want to be sensitive and not contact parents around the holidays, or the anniversary of the infant’s birth or death. Caution is recommended for parents who may be in litigation with providers or institutions over the circumstances of the infant’s death. FIMR programs may want to consult with local law enforcement prior to interviewing parents or family members who are potentially under investigation for complicity in the death of their infant. FIMR programs have interviewed parents who are incarcerated for other crimes; these parents may have important stories to tell.
Confidentiality, Consent, and Ethical Considerations

The FIMR model adheres to strict principles of confidentiality. One of the ways confidentiality is ensured is through strict de-identification of cases. This includes the assurance of confidentiality and case de-identification to parents in the interview process. When explaining the FIMR process to parents and families, they should be told that they can name providers and programs, but that FIMR will be removing those names and identifiers before the case comes to the review team. In smaller communities, FIMR team members may recognize a case or have even supplied records for the case review.

During the review process itself, members are reminded not to add any information during the discussion that would compromise the anonymity of the case. Additional information can be shared outside of the meeting if there are important details to add.

In general, the components of the consent form should include the purpose of the interview, steps taken to protect confidentiality, potential benefits and risks for the participant, and agreement to participate. The consent form should also include a statement indicating that interviewers are mandated reporters. If, during the interview, information is shared that indicates child abuse or neglect of the deceased infant or surviving children, it will be reported. A sample of the interview consent form is included in the appendix.

Teams may opt to include the consent form in the initial contact letter sent to families.

Parents should have ample time to review the consent form. This allows them time to review the document. The interviewer should bring an extra copy for the parents to sign prior to the interview. In obtaining consent, it is important for the interviewer to emphasize to the family the process is entirely voluntary and that they may stop the interview or any portion of it at any time.

Some FIMR programs have used a small gift to thank parents for their time and participation in the interview process. Any incentive provided to parents should not seem so generous as to be coercive. This is a fine line programs walk when they decide to provide a token of appreciation or a remembrance for participation in the interview. Examples of appropriate gifts teams have provided include journals, candles, small plaques or figurines, grocery coupons, or gift cards. One FIMR interviewer created personalized memory boxes for the parents she interviews. The memory boxes are decorated and have the baby’s names on them. Inside the box is a candle, a rose, and a poem in a picture frame in memory of the baby. When providing remembrance items, it is extremely important to take culture, context, and parental beliefs into account. Cultural expressions of grief can be particularly sensitive.
After the interview, it is vital to protect parents’ privacy and preserve all information with confidentiality. Interviewers accomplish this by storing consent forms and any interview materials in a secure location, by locking their computers and password-protecting files that contain interview materials and lists of participants. FIMR staff should consult their agency document retention protocols, and shred documents in accordance with those guidelines at minimum. It is preferred that once an interview is complete, and any pending incentives have been delivered to the parent, that any record of the interview—other than the de-identified summary—be shredded, deleted, or otherwise destroyed.

**Conducting the Interview**

The first concern before the interview begins is that the parent understands and signs the consent form. The parent should not be asked any questions about the baby or their experience until they have given written consent.

Once the interview consent form is signed, the interview may begin. Time may be spent in the beginning of the interview reiterating sympathy for their loss, putting the family at ease, and reassuring them that there are no wrong answers. A simple and effective way to begin the interview is to ask the parent about the pregnancy and when they first found out about being pregnant. Once a caring and comfortable atmosphere has been created, the interviewer may ask the parent to describe the events leading up to the death of the infant in their own words.

**SAMPLE:**

Thank you so much for meeting with me today, Alyssa. I would love to hear about Caleb. What do you remember about him?

Interviewers should always talk about the baby by name if the child was named in the birth and/or death records. One should check with the parents to confirm if it is culturally appropriate to use the infant's name. In some cultures, using the deceased child's name is considered taboo. If the infant’s name is not known, it is appropriate to refer to the infant as “your baby.”

The interview should focus on the parent’s experience leading up to the time of the baby’s death, including the time of conception and the pregnancy. The goal is to hear the parent’s comprehensive experience including their social context, employment, relationships, physical and medical experience, as well as that of their baby. It is important to keep in mind that the FIMR process will be examining the parent’s story in the broader community, systems-level context, so any insights they are able to provide into those systems—when they worked well and when they didn’t—will be particularly informative in the case review context.
The FIMR Interview portion of the *FIMR Case Report Form, National Fatality Review-Case Reporting System (NFR-CRS)* (URL: https://bit.ly/2BmHj5Y) contains the minimum data points that are collected in the interview context. Interviewers can use these questions as a guide for their interactions with the parent. Ideally, the local or state program will craft an interview script or outline that thoughtfully inquiries about all the questions in the Case Report Form, and interviewers can consistently use it as a guide to allow for standardized practice. The beauty of the in-person interview is that it also allows for the interviewer to ask follow-up questions and inquire about the parent's and family's needs in the context of the interview.

**The NFR-CRS Case Report Form and other interview guidance tools should be used to guide, but not dictate, the interview discussion.** An interview should never feel like a checklist of data points. Being familiar with the interview questions will allow the interviewer to probe for certain areas while the parent's story is unfolding. Open-ended questions are the best way to start the discussion. A semi-structured interview format may work well, starting with pregnancy and the circumstances around it and then, as prompting is needed, move chronologically through the delivery, neonatal and postpartum experiences, through the infant's death and its aftermath.

The most important aspect of the interviewer's job is to use active listening skills and to respond to the parent's story with compassion.

Most successful interviewers do not take notes during the interview, but may, with permission, jot down a few key reminder words to ensure they captured the critical elements shared. Some FIMR programs have begun to record the interviews so that stories are captured in exactly the parents' own words with actual transcripts provided to the review team.

The length of the interview may vary. It is generally about 1–3 hours, or for as long as necessary for the parent to tell their story. Some have a lot to say and many questions to ask the home interviewer. The home interviewer may be the first and only person the parent has had an opportunity to talk with about the baby's death. The interview may be done in one or two visits.

At the conclusion of the interview, thank the participant, and provide any tokens of appreciation that the program supplies. Before leaving, provide an evaluation of the interview process to the parent. This provides an opportunity for program staff to hear feedback from participants on their experience in the interview and improve their processes in the future. Schedule any follow-up visits if needed, either to complete the interview process or to provide the family with needed resources.
Alternative Methods

There are times when it is very challenging to find a convenient time or place to connect with a parent or family for the interview. Some parents are hesitant to have an in-person interview. In instances such as these, some FIMR teams have begun exploring alternative methods to allow the parent’s voice to be heard as a meaningful part of the FIMR process. Both phone interviews and surveys have been utilized in local communities to serve this purpose.

An in-person interview is always the ideal way to include the parental experience in a FIMR case review.

The in-person interview is the richest way to collect this qualitative information, and it allows the interviewer to connect the parents to needed community services. Conducting the interview in the parent’s home also provides the opportunity to gain insights into their physical environment and better understand the home life of the family. In-person interviews may also be conducted in locations other than the parents’ homes as long as privacy and confidentiality can be maintained. Interviews have been conducted at providers’ offices, coffee shops, parks, playgrounds, or the health department.

Interviewing parents over the phone may be an effective way to gain information if the in-person interview is not possible. A parent may ask if they can participate over the phone or decline when asked for an in-home interview. In these cases, it is appropriate to consider the phone interview option as it may allow the interviewer to ask follow-up questions and respond to the parent in a conversational way. It is still recommended that consent for the interview is obtained, with a script following the same guidance as the written consent form. Two parties will be required to verify the parent’s consent to participate.

Providing a survey to parents is another way to try to understand their experiences. Some parents may be more likely to take a survey than accept the request for an interview. This limits the narrative insights that can be gained from an interview, providing only quantitative data from the parent’s perspective. It is more impersonal, and the FIMR survey may compete with other public health and hospital-based surveys about the parent’s experience.

Despite these drawbacks, it still provides the opportunity for teams to learn about parents’ experiences and should be considered as an option when the in-person or phone interview are not viable options.

If exploring the option of a survey, check with state or local project guidelines to determine if the survey method is allowed. Whatever interview method is used, the parent’s requests should be accommodated whenever possible.
Bereavement Support & Resources

When talking to the parent or other family members in the home, the interviewer should be prepared for a variety of emotional responses. Interviewers do not assume the role of a professional grief counselor; however, they are uniquely situated to offer emotional support to parents and families in addition to providing needed referrals to health or social services. Interviewers should compile a comprehensive list of culturally-appropriate community resources, support groups, and educational materials. Many hospitals’ social work teams or chaplains have lists of local community resources. Interviewers should have enough background in bereavement that they are able to recognize complicated grief responses and identify the need to refer parents to a professional counselor or other mental health professional. Typical expressions of grief may be categorized into these four areas: Feelings, Physical Symptoms, Cognition, and Behaviors.3

3 Bereavement Experiences after the Death of a Child: Grace H. Christ, D.S.W., George Bonanno, Ph.D., Ruth Malkinson, Ph.D., and Simon Rubin, Ph.D.
FEELINGS

- Sadness
- Anger
- Guilt and self-reproach
- Anxiety
- Fatigue
- Helplessness
- Shock and numbness
- Yearning

PHYSICAL SYMPTOMS

- Headache
- Loss of appetite
- Difficulty sleeping
- Weakness
- Aches, heaviness, hollow feeling
- Tightness in throat or chest

COGNITION

- Disbelief
- Confusion
- Inability to concentrate
- Pre-occupation
- Difficulty making decisions
- Sense of "presence" of the baby
- Hallucinations

BEHAVIORS

- Crying
- Sighing
- Restless hyperactivity
- Absent mindedness
- Social withdrawal
- Visiting places or carrying reminders of the deceased

GRIEF RESPONSE

It is important to assure parents that the above responses are often experienced by grieving family members and that everyone's grief response is extremely individual and may be influenced by multiple factors.

Portray grief as a lifelong process that is unique to everyone, not simply an episode or a phase. See the appendix for additional resources on the grief response and how to recognize complicated grief responses.
Self-Care

Everyone who is engaged in the FIMR process, especially the interviewer, can be affected by the repeated exposure to traumatic information, a condition referred to as vicarious trauma.

Vicarious trauma is experienced or felt when hearing about someone else's trauma or stories like the parental interview stories, as opposed to trauma that is experienced firsthand.

All interviewers are encouraged to regularly take stock of their reactions and need to engage in self-care. Interviewers who learn to cope with their responses are better able to maintain balance, making them a better resource to the families they interview and serve.
There are several helpful resources on self-care listed below:

1. **NCFRP Webinar – Recognizing and Responding to Vicarious Trauma in Fatality Review** (URL: [https://bit.ly/3530gFz](https://bit.ly/3530gFz))

   
   This is a list of assessment tools intended to measure burnout, social connections, psychological distress and vicarious trauma.

3. **To replenish yourself:**
   - Take responsibility for your personal well-being
   - Make professional boundaries and stick to them
   - Actively grieve your own losses
   - Offer and seek support from other FIMR parent interviewers
   - Identify ten things you do that make yourself healthy and happy

4. **To be a healthy caregiver:**
   - Know both your strengths and your limitations
   - Be aware of your reactions and emotions and recognize when they change from positive to negative
   - Know when you need to say “no”
   - Take responsibility for your own needs before seeing to others'
   - Follow your own personal joy; do the things that make you happy
Conclusion

The family interview is a unique and defining feature of the FIMR process. The interview informs communities of the need and challenges parental and infant populations encounter, elevating the experiences of bereaved parents. Trusting and valuing the stories parents tell allows fatality review teams to better understand the context of the deaths and the resulting fatality review data, providing a lens through which to more accurately examine the case. The interview also provides an opportunity to link parents to needed resources, provide bereavement support, and give them a compassionate professional to listen to the story of their child’s death. If completing interviews becomes challenging, it is important for coordinators and interviewers to revisit the reason they are seeking them in the first place: there are pieces of the puzzle of the baby’s death that only the family can share, and any examination of the case is incomplete without their insights. With compassion and persistence, FIMR teams will hear parent’s stories of loss and maximize the impact of those stories by using them to craft effective, relevant interventions to increase the health and safety of their communities.

Additional Resources

- **Maternal Interviews** – Video training module from the National Center for Fatality Review and Prevention (URL: https://bit.ly/2W5wMUz)
- **Maternal/Family Interview Module** (ACOG) (URL: https://bit.ly/2A0gp37)
- **Using Health Equity in Fatality Review Module** (URL: https://bit.ly/2KZN9vP)
- **Improving Racial Equity in Fatality Review (Tool Kit)** (URL: https://bit.ly/2WwdGpS)
- **Home Visitor Safety** (URL: https://bit.ly/2WyyIC7)
- **Motivational Interviewing** (URL: https://bit.ly/35BNAFO) and UW Medicine Department of Psychiatry and Behavioral Sciences (URL: https://bit.ly/3b6aNBs)
- **Bereavement Support for Families and Professionals, NCFRP Webinar** (URL: https://bit.ly/3530gFz)
# Appendices

The example documents provided here are based on documents developed by FIMR teams across the country. They are provided as examples to equip teams to create similar resources in partnership with their respective agencies.

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APPENDIX A:

Sample Position Description (Qualifications) for Parental Interviewer

PROGRAM DESCRIPTION

The overall goal of Fetal and Infant Mortality Review (FIMR) is to enhance the health and well-being of women, infants and families by improving the community resources and service delivery systems available to these families. FIMR brings together key members of the community to examine information from individual cases of fetal and infant death to identify the factors that contributed to those deaths, determine if those factors represent system problems that require change, fashion recommendations for change, and assist in the implementation of change.

JOB RESPONSIBILITIES

This position involves carrying out FIMR program tasks which include finding, contacting and interviewing the mother, parent, or another family member who has experienced the loss of a fetus or infant; gathering additional case information as needed; maintaining links with contract agencies and local providers; assisting in the development of case summaries; participating in case review group meetings; assisting in dissemination of program results to the community. Position will report to the FIMR program coordinator.

QUALIFICATIONS

Experience in home visiting, community outreach, case finding or conducting interviews. Excellent communication skills, sensitivity to needs and experiences of grieving families. Ability to work independently, with a flexible schedule, including some evenings and weekends. Knowledge of pregnancy and perinatal issues. Bachelor’s degree preferred, with at least five years’ experience in a community agency, health provider or similar setting. Must have car with valid insurance.

SALARY

Commensurate with skills and experience.
APPENDIX B:
Sample Protocol for Contacting/Engaging Parents and Families in the FIMR Interview

INITIAL CONTACT

Several methods for the initial contact may be considered. Some programs partner with hospital staff and contact the parents while still in the inpatient setting. This purpose of this contact is first to assess the parents’ need for referrals and resources related to bereavement, and to gently introduce the idea of the parent interview at a later date. Some programs arrange for a FIMR program brochure to be included in the discharge information packet, a brochure that explains the program and provides some local grief and bereavement resources.

Many FIMR programs use a letter or sympathy card for initial contact. Confidentiality is ensured by omitting the name of the FIMR program from the return address. In some cases, programs send a letter with a self-addressed reply note that allows the parents to indicate whether they wish to be contacted. Another strategy is to give a date and time for an initial contact, such as “Our public health nurse, Susan, will be able to visit you on Thursday, August 16, at 2 p.m. If that is not convenient for you, please contact our office to re-schedule.” Whatever method is used, the language in the letter should be simple, consistent, and written at about a fourth-grade reading level. Bereaved parents often are not able to concentrate or struggle through long letters.

Phone contact may be used if the FIMR program has that information. Telephoning can impose some limitations on communication because the interviewer may miss nonverbal cues. However, it can be useful for making an initial contact in a timely manner. The person who makes the initial contact should be sure to review any background information on the family and infant before making the call. The caller should identify herself or himself and state the name and purpose of the program before proceeding with the conversation. The caller should try to establish an atmosphere of trust by using a gentle, reassuring approach. People who are hurting are especially sensitive to voice tone and the way information is presented. Personal names should be used to increase the level of trust. Phone contact may be used for initial contact, or as a follow up to the mailed letter or sympathy card.

Here is an example of a potential telephone script:

“Hello, _______. My name is ___. I am from ____ (agency) and am calling to follow up on a letter that I sent you last week,” or ”I am calling to follow up on the brochure you may have received at the hospital.”

“______, I was so very sorry to hear about the loss of ________ (baby’s name, if known, and if culturally appropriate to use infant’s name, or your daughter/son/baby).”

The parents’ response will determine the interviewer’s next response. There may be a period of silence.
“My letter (or the hospital brochure) was about an important community program that I am involved with. The purpose is to learn about each baby’s death in our area and to find ways to help families such as yours in the future.”

If no questions are voiced, the caller can then clarify the interview process and set a date and time to meet with the family.

“I would like to make an appointment to visit you and hear your story. What would be convenient for you?”

Before hanging up, the interviewer may let the parents know about educational materials that are available.

“I have informational materials that I can bring for you. I also have information for children, grandparents, and other family members. Is there any specific information that may be helpful to you?”

The interviewer should leave a telephone number where she can be reached so the family can change the appointment if needed or desired.

In some communities, a home visit is the most appropriate first contact. The advantage of an in-person visit is that the parents may identify with a warm and friendly face and may come to see the interviewer as supportive and non-threatening. This contact may simply be to establish a convenient future time for the interview, but sometimes results in an immediate acceptance and interview.

The approaches vary significantly across FIMR programs, and communities need to establish what works best for their population. Programs may find it helpful to engage a parent or several families who have previously experienced a loss and ask for their input.

One community’s sample protocol:

- FIMR brochure is included in hospital discharge packet. Labor and Delivery nurse or post-partum discharge nurse may mention that someone from the local FIMR program may be in touch with the parents in the next few weeks to see how they are doing.
- Follow up letter is sent to family within one to two weeks of discharge from the hospital.
- Follow up phone call to family one week after letter is sent.
- May repeat phone call up to two more times.
- In person or “drop by” visit if no response to letter or phone call.
- Maximum number of “touches” with the family is five times, and can be a combination of letters, phone calls and in-person visits. Respect for a decline is always observed.
APPENDIX C:

Sample Outreach Letter

The Detroit Health Department (DHD) learned about the loss of your baby, Name of baby. On behalf of the Detroit Health Department, please accept my deepest sympathy for your loss. Grief is a difficult journey, especially when it involves the loss of one so precious.

I am the Maternal Interviewer for the Detroit Health Department and I would like to talk to you and offer you services that you may not be aware of. I will be in your neighborhood on Friday, January 24, 2020 between 12:00 noon and 5:00 p.m. and I will stop by. If this is not a good time for you please call me at phone number, & email address to set a time that is more convenient for you.

I am looking forward to speaking with you.
Sincerely,

Mildred Johnson
Maternal Interviewer
Community Outreach Coordinator
Detroit Health Department
Cell phone: (313) 522-5054 or office phone: (313) 876-0340
Email: johnsonmil@detroitmi.gov
• Often, people wonder how I obtain their contact information and I understand that question and concern. I work with the Hospitals and the Health Department in St. Joseph County to study infant loss and therefore am informed when a baby less than one year old dies.

• You may remember receiving the enclosed flyer among the other materials you received at the hospital. Though I have access to this information, I do not share it with anyone else and any conversations that I have with you will be completely anonymous and confidential. All of the information that would identify you is removed from the study.

• The purpose of our study is to find ways to make our community a healthier place for babies and a more supportive place for mothers and families. The best way we have found to accomplish this is to speak to you, a mother who has gone through the sudden loss of your baby. It is just a one-time interview and usually takes about one to two hours, depending on how much you want to share. Your significant other and other family members are welcome to participate too.

• A lot of moms think they don’t have anything to share with me, but what I find is that everyone does. Maybe you had trouble with your insurance or care or wished that someone would have given you more information. Maybe you were completely happy with your care. Either way, speaking to you is how our community can learn and it is a way for you to tell your baby’s story and help other moms and babies in our county.

• I speak to mothers over the phone or in person at their home or a public place like a restaurant. The time and place is entirely up to you.

• Meijer grocery store has donated $20 gift cards to share with the families as a thank you for sharing their story.
What to Do After the Loss of a Baby

Losing a baby is hard physically and emotionally. Here are some suggestions on how to take good care of yourself.

Rest & Sleep
It is common to have problems sleeping. Try resting during the day if you can’t sleep at night.

Exercise
Do some activity everyday.

Don’t Expect to ‘Get Over It’
You will experience happy times again in your life, but you may never ‘get over it’.

Talk with Others
Consider seeking out others through support groups, church groups, friends and family.

Honor Your Feelings
Embrace your emotions. They may range from anger to sorrow to hope – everyone reacts differently.

Remember...
All people grieve differently. What is right for someone else might not be right for you.

Summit County Public Health
1867 West Market Street
Akron, Ohio 44313
WWW.SCPHOH.ORG

Fetal Infant Mortality Review
Program Coordinator
Sandy Waino, RN/PHN
330-926-5754
swaino@schd.org

Summit County Public Health complies with applicable Federal Civil Rights laws and does not discriminate on the basis of race, color, national origin, age, disability, or sex.

ATENCION: si habla español, tiene a su disposición servicios gratuitos de asistencia lingüística. Llame al 1-800-311-1232.

Sharing your story can honor your baby’s life and may help save the lives of others.

Funded by Ohio Department of Health/Federal Government, Bureau of Maternal and Child Health, Maternal and Child Health program

revised 9/22/2017
Your Story

If you recently suffered the loss of a baby during pregnancy, after birth or up to the first year of life, the FIMR Program would like to extend our deepest sympathy.

The Summit County Fetal Infant Mortality Review program would like to hear your story. By sharing your experience you can help improve future pregnancy outcomes and infant lives in our community.

Your story is a unique personal journey. You can provide vital information about your experiences with medical and social service providers that would otherwise never be known. With your help we can learn more about how to reduce fetal and infant deaths.

Why should I tell my story?

Your story could help create changes in community services such as:

- Increasing awareness about infant loss through education
- Improving healthcare systems
- Changing policies
- Creating helpful resources for patients and families

Our program offers referrals to community resources and grief support. Consider spending time talking with a nurse in your home or another meeting place about your pregnancy. All information shared that identifies you, your child, family and healthcare providers will be kept private and confidential.

“Death leaves a heartache no one can heal, love leaves a memory no one can steal.”

- Richard Puz

The program is voluntary and free of charge. If you would like to schedule a home visit to share your story or if you have questions, please call us at 330 - 926 - 5754
APPENDIX F:

Sample Consent for Parental Interview

PURPOSE OF THE INTERVIEW

(NAME of sponsoring agency) is conducting a Fetal and Infant Mortality Review (FIMR) Program. The purpose of this program is to identify ways we can strengthen the systems of care and resources available to families, to prevent future deaths. We talk to parents and families who have recently experienced a loss, with the hope of learning from you how we can prevent other families from experiencing such a loss. Your participation is voluntary. If you agree to participate, a trained interviewer from the (NAME of sponsoring agency) will listen to your story and ask you some questions about the death of your baby and about your pregnancy, health, family and use of health care and social services. The interview will take place in your home, or in a convenient location of your choosing, at a time that is best for you. The interview will take about one hour. Although participation in this program may not benefit you or your family directly, it may help to prevent other families in the future from losing their baby.

DESCRIPTION OF POTENTIAL RISK

Talking about the death of your baby may be sad or difficult for you. The interviewer is not a professional counselor but if you wish, will give you the names of professional people who can help you deal with the loss of your baby. If, during the interview, you feel you do not want to continue, you may ask the interviewer to stop the interview at any time. You may also choose not to answer any specific question. There is no expected risk of injury for participants in this study.

DESCRIPTION OF POTENTIAL BENEFITS

Participation in the interview may be a positive experience for you. You may find that talking about the death of your baby can help ease the pain of your loss. In addition, the information you provide to this program may help prevent the loss of a baby for future families.

CONFIDENTIALITY OF RECORDS

All information that identifies you, your family or your health providers will be removed before the interview information is reviewed. All Fetal and Infant Mortality Review staff and consultants have signed an oath of confidentiality. Therefore, confidentiality will be protected to the full extent permitted by law. Your information will only be shared with the multidisciplinary community team.

MANDATED REPORTERS

The maternal interviewer is a mandated reporter, by law. Every effort is made to keep all information you share with the program confidential and anonymous. If, however, during the interview, abuse or neglect of your baby, or suspected abuse or neglect of surviving children in the home is revealed, the interviewer must follow state law about reporting it to the appropriate child welfare agency.
VOLUNTARY PARTICIPATION

Your participation in this program is completely voluntary and you may decline to answer any questions that you do not wish to answer. You are also free to end the interview at any time without any consequences to you or your family.

QUESTIONS

If you have questions concerning the interview or the Fetal and Infant Mortality Review Program, you may call (Name of contact person), collect, at the (NAME of sponsoring agency) at (contact phone number).

CONSENT

I have read this form and understand the purpose and conditions for participation in the Fetal and Infant Mortality Review Program. I agree to participate in an interview. I understand that all information obtained from the interview will be strictly confidential, and that neither my name, my baby’s name nor the name of anyone else in my family will appear in any publications or reports or be given to anyone else.

<table>
<thead>
<tr>
<th>Consent to release name and contact information, (Optional)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I give consent for my name and contact information to be released for the purpose of referrals for additional services:</td>
</tr>
<tr>
<td>Date_________________ Signature____________________________________________________</td>
</tr>
<tr>
<td>I consent to receiving future follow-up visits from the FIMR personnel. I understand that these are voluntary, and I may discontinue these services at any time.</td>
</tr>
<tr>
<td>Date_________________ Signature____________________________________________________</td>
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</tbody>
</table>

Print Name: _____________________________________________________________________________

Signature: _______________________________________________________________________________

Date: ___________________________________________________________________________________

Interviewer’s Name: _______________________________________________________________________

Interviewer’s Signature: ___________________________________________________________________

Date: ___________________________________________________________________________________
APPENDIX G:

Bereavement Resources

PROFESSIONAL ARTICLES

- Guidelines for health care professionals supporting families experiencing a perinatal loss
  (URL: https://bit.ly/2YDEPd6)
- Complicated grief after perinatal loss
  (URL: https://bit.ly/2L7GfEU)
- Caring for Families Coping With Perinatal Loss

WEBSITES

- CJ First Candle (URL: https://bit.ly/3fsVNM): Non-profit committed to the elimination of Sudden Infant Death Syndrome, Sudden Unexpected Infant Death and preventable stillbirths through education and research while providing support for grieving families who have suffered loss.
- Miss Foundation (URL: https://bit.ly/3fxnIjI): Counseling, advocacy, research, and education services to families experiencing the death of a child.
• Perinatal Hospice and Palliative Care (URL: https://bit.ly/2W8eBxy)


• Association of SIDS and Infant Mortality Programs (ASIP) (URL: https://bit.ly/2W7ShnW): Promotes policy and practice for professionals who respond to infant and child death, and is committed to bereavement support, risk reduction and prevention services.

• NFIMR Voices from the Community - Cross Cultural Expressions of Grief (URL: https://bit.ly/2L6dx75)
“A story is a way to say something that can’t be said any other way, and it takes every word in the story to say what the meaning is. You tell a story because a statement would be inadequate. When anybody asks what a story is about, the only proper thing is to tell them to read the story.”

(Flannery O’Connor, “Mystery and Manners: Occasional Prose,” p. 96, Macmillan)