



# **Kalamazoo County Fetal Infant Mortality Review (FIMR): Project Description**

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## 1) Executive Summary of Kalamazoo County FIMR

The global health and well-being of children and family can be measured by infant mortality rate. The infant mortality rate not only is a measurement of the death risk of infants, but also represents the significance of the society taking care of the most vulnerable groups of citizens. Defining and improving various factors of infant mortality will lead to benefit of the overall health status of the community. Since 1912, the US began monitoring the infant mortality data.

Fetal Infant Mortality Review (FIMR) is a public health surveillance effort, per designation at the state, county, and local level as an improvement strategy targeting maternal and infant health to promote health equity at a community-level.

Therefore, FIMR is an evidence-based community level prevention strategy that can address the challenges of infant mortality. One unique function of FIMR is the data collected is frequently excluded from general vital statistics and allows for the monitoring of medical healthcare system. This program brings together a multi-disciplinary team that reviews infant and fetal deaths in order to assess current processes, identify gaps, disseminate recommendations, and take action to improve community systems and resources for women, infants, and families. The information obtained from FIMR case reviews is being used to guide community-based programs, introduce policy development, and maintain quality services and resources as part of a continuous quality improvement (CQI) process.

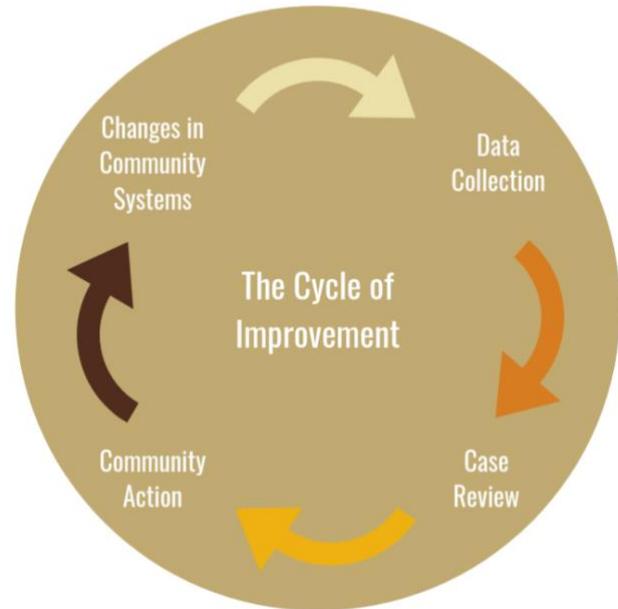
The Kalamazoo County FIMR began meeting in 1997. This FIMR has a rich history, first initiated by 1998 under Arthur James MD, and recently restructured in an academic-community partnership between the new medical school, Western Michigan University Homer Stryker MD School of Medicine (WMed), and the county public health department, Kalamazoo County Health and Community Services (KCHCS), in 2014.

## 2) The Benefits

The FIMR process provides many **benefits to the systems of care**. These benefits include:

- a. Expanding available services through cooperative programming and joint funding;
- b. Planning for better coordinated services through inter-agency networking and communication;

## The FIMR Process



- c. Developing a greater understanding of community needs for the broader field of maternal and child health;
- d. Learning from diverse perspectives of Case Review Team members from varied backgrounds;
- e. Reducing inter-agency conflicts by putting aside issues of competition and turf, to focus on common local problems affecting health care delivery systems and reduced resources;
- f. Mobilizing community action to effect needed changes through the strength of collective advocacy as well as through actions of individual organization leaders;
- g. Fostering personal and professional development among their participating members;
- h. Achieving enhanced visibility and credibility for family issues with policy makers, funders, the media and the broader community;
- i. Decreasing costs by avoiding duplication of services;
- j. Conserving resources by identifying resource-saving opportunities.

The FIMR process also provides **benefits to the families involved in the interview process**. These benefits include:

- a. Giving an opportunity to tell their story;
- b. Connecting to community resources;
- c. Working with an interviewer to address barriers;
- d. Addressing the struggles of the grief and bereavement process;
- e. Completing bereavement exercises;
- f. Enhancing the service systems and community resources that support the health and well-being of women, infants, and families.

### **3) The Process**

Individual cases of infant death are investigated and summarized in perspective of social culture, economy and sanitation by multi-sector teams. For each case of fetal or infant death to be reviewed, information is collected from a variety of sources, which may include: physician and hospital records, home visits, and relevant community program records. Once this information is gathered it is given to a Family Interviewer. The Family Interviewer then meets with the family, usually the mother, to obtain additional information regarding the families' experience of the death. The case is then presented to the Case Review Team (CRT). Recommendations from the CRT are presented to a team of individuals referred to as the community action team (CAT). The CAT translates the CRT recommendations into strategies for action and implement interventions designed to address the identified problem. Continuous examination of FIMR cases allows for on-going evaluation of the system of care to ensure problems are resolved and to reveal if new actions are required.

#### **a. Records Abstraction**

Cases that qualify for review include fetal deaths (i.e. fetuses that are born 20+ weeks gestation but are stillbirths), and infant deaths (i.e. infants that die before their first birthday) who were: Kalamazoo County residents at death, where the

death occurred in Kalamazoo County, or their mother was a Kalamazoo County resident at the time of delivery.

These deaths may be identified in one or more of the following methods:

- i. Death certificate on file at Kalamazoo County Clerks' Office;
- ii. Death certificate sent by Michigan Department of Community Health for the Kalamazoo County FIMR review;
- iii. Identification of death by Kalamazoo County hospital.

Information collected for FIMR reviews include the infant under review, the mother of the infant as named on the birth and/or death certificate, and the father of the infant as named on the birth and/or death certificate. The period of time included in the review of these individuals will span:

- i. The year prior to birth including the prenatal and immediate pre-conceptual period;
- ii. During the infant's life;
- iii. The two months after infant death including the analysis of community response to deaths.

FIMR reviews consider all potential psycho-social and medical factors: those directly related to the death itself, labeled "contributors," and those indirectly related, labeled "present." At a minimum, National FIMR recommends collecting information on the following factors (see Case Summary Template):

- i. Medical conditions and care of mother during pre-conceptual, prenatal, delivery, inter-conceptual periods;
- ii. Medical condition and care of infant including delivery, newborn or neonatal intensive care (NICU), and pediatric periods;
- iii. Substance use of the mother and father;
- iv. Violence present interpersonal or neighborhood-level;
- v. Environmental conditions of the physical, social, emotional status of parents, family, neighborhood, community;
- vi. Systems and services including housing, transportation, public health, employment, education, food, etc. that are available, the family qualified for, and that the family receives.

Per national and state FIMR guidance, medical data, from primary care, hospitals and medical examiner's office, will be abstracted by a designated Data Collection team. This team develops data collection procedures and agreements with each agency that allows the Data Collection team access to the information needed for FIMR review. Mental health data and non-medical agency data (i.e. public health, criminal justice, child protective services, community service agencies, mental health) is abstracted and submitted by the agency itself to the FIMR team. The possible submission options include:

- i. Copies of actual agency files, either electronic or paper, that are redacted per agency guidelines;
- ii. Written summary of relevant events and conditions;
- iii. Verbal summary or clarification of relevant events and conditions;

- iv. Data Collection team members, with appropriate agency training and permissions, are given access to agency records and conduct the review and abstraction of relevant events and conditions themselves.

The Kalamazoo County FIMR is committed to confidentiality of the infant; the infants' family; of the agencies; and of agency staff. To preserve this confidentiality, data is collected in advance of FIMR CRT meetings, assembled by the Data Collection team into a narrative case document, the Case Summary Template, which is the document used at FIMR CRT meetings. In order to synthesize the relevant information into a case narrative, data collection occurs prior to a CRT meeting. Per Michigan Department of Community Health, the Case Summary will be shared by the Data Collection team for review the week before the meeting; no new data can be introduced at FIMR meetings. If additional information is known to a CRT participant, it may not be shared at the meeting, but can be shared with the Data Collection Team afterwards using the established data collection procedures herein. The Case Summary will then be updated and the Issues and Recommendations form will be subsequently finalized. All CRT meeting attendees sign a confidentiality agreement. In addition, the FIMR CRT facilitator, from the Data Collection team, reminds attendees of their responsibility for maintaining this confidentiality.

**b. Family Interviews**

The family interview provides critical information about the circumstances and the care the mother, father, and infant experienced leading up to the death of the infant. The families are given the opportunity to give their perspective on:

- i. What happened;
- ii. How it felt;
- iii. What they understood about why it happened;
- iv. Which resources they found useful;
- v. What recommendations they have regarding the process of care or the resources available to families experiencing these circumstances.

The family interviews are conducted by professional Family Interviewers who have received training in the cycles of grief, in conducting interviews, and in providing resource referrals for families. Family contact information is obtained via public records and from abstracted records. After the Family Interviewers receive the family's information, they use the following process:

- i. Mail introductory letter to family expressing condolence for their loss and explaining the FIMR program;
- ii. Phone contact is then made to answer questions about FIMR and to invite to participate in a voluntary and confidential interview;
- iii. If agreed, then a face to face meeting is scheduled, at a location and time of the parents' choosing;
- iv. If not interested, then a bereavement resource packet is mailed to them;
- v. Family Interviewers then conduct a structured family interview.

After the interview is complete, the Family Interviewer follow-ups up with the family with available resources and five optional subsequent visits. Families may not want to participate in follow-up visits or all five visits and they are able to opt-out at any time. The visits are intended to address the reoccurring issues provided by the FIMR Case Review Team. The goal is for families to receive the tools and resources, provided by the family interviewer, that promote supportive grieving and healthy coping. These follow-up visits can take place either in-person or over the phone. The context of the visits are based on the Family Needs Intake Checklist and Family Progress Form. The role of the Family Interviewer is to provide referrals and contact to service providers that may benefit the family, especially in terms of bereavement. All families fill out an Exit Survey at the end of their participation with FIMR.

**c. Case Review Team (CRT)**

The CRT includes a broad range of providers, institutions, advocates, professional organizations such as: Hospital & Primary Care, Behavioral Health, Public Health, Criminal Justice, Child Welfare, and Community Members. The goal of the CRT is to: (1) review individual cases; (2) identify system gaps; and (3) draft recommendations.

During the CRT meetings, participants ask questions regarding barriers the families faced during the time of death and possible solutions regarding those barriers. The questions from the CRT may include:

- i. Did the family receive the services or community resources they needed?
- ii. Were the services and resources culturally and linguistically appropriate?
- iii. Are there gaps in the system that need to be addressed?
- iv. What does this case tell us about how families are able to access existing local services and resources?

As a result of these questions, the CRT identifies barriers of healthcare and how services are delivered. The CRT then offers recommendations for system-level action to improve policies and services that affect women, infants, and families in Kalamazoo County. Recommendations made by the CRT are shared at the local, state and national level, to community members, professionals, or public officials. Regardless of the audience or the venue, no single FIMR case is described in any way that would enable re-identification, with all case-descriptive information reported in the aggregate.

**d. Community Action Team (CAT)**

The CAT is a critical process that operates as a feedback mechanism for FIMR to ensure that CRT recommendations are implemented and systems gaps are resolved. The role of the CAT is to: (1) synthesize data; (2) prioritize issues; and (3) take action. Members of the CAT included: Institutional Administrators, Community Leaders, Government, and Funders.

#### **4) Data Sharing**

Because data collection involves the use of protected identifiers and sensitive information, data transfer and storage is conducted following HIPAA guidelines. Additional procedures that are necessary to comply with agency-specific restrictions are agreed upon between the agency and the FIMR Data Collection team.

## Appendix A: Case Summary Template

Case Number: \_\_\_\_\_ County: \_\_\_\_\_  
 Cause of Death: \_\_\_\_\_  
 Date of Baby's Birth: \_\_\_\_\_ Sex: \_\_\_\_\_  
 Age at Death: \_\_\_ months \_\_\_ days \_\_\_ hr \_\_\_ min  
 Birth Weight: \_\_\_\_\_ grams  
 Gestational Age at Birth: \_\_\_\_\_ weeks

Date Reviewed: \_\_\_\_\_  
 Place of Death: \_\_\_\_\_  
 Manner of Death: \_\_\_\_\_  
 Entrance to Care: \_\_\_\_\_  
 # Prenatal Visits: \_\_\_\_\_ # Missed Visits: \_\_\_\_\_  
 Apgar 1 min: \_\_\_\_\_ 5 min: \_\_\_\_\_

Age of Mother: \_\_\_\_\_  
 Race of Mother: \_\_\_\_\_  
 Country of Birth: \_\_\_\_\_  
 Language: \_\_\_\_\_  
 Education of Mother: \_\_\_\_\_  
 Special Education Issues: \_\_\_\_\_  
 Mother Employed: \_\_\_\_\_  
 Marital Status: \_\_\_\_\_  
 Living Arrangements: \_\_\_\_\_  
 Insurance During Pregnancy: \_\_\_\_\_

Age of Father: \_\_\_\_\_  
 Race of Father: \_\_\_\_\_  
 Country of Birth: \_\_\_\_\_  
 Language: \_\_\_\_\_  
 Education of Father: \_\_\_\_\_  
 Father Employed: \_\_\_\_\_  
 Tobacco Use: \_\_\_\_\_  
 Alcohol Use: \_\_\_\_\_  
 Drug Use: \_\_\_\_\_  
 Mental Health Issues: \_\_\_\_\_

Height of Mother: \_\_\_\_\_  
 Pre-Pregnancy Weight: \_\_\_\_\_  
 Weight at Delivery: \_\_\_\_\_  
 Weight Gain: \_\_\_\_\_  
 BMI:  Underweight  Normal  Overweight  Obese

WIC Enrolled:  
 Yes  No  Referred  
 Breastfeeding  
 Initiated  Planned  Not Planned

Tobacco Use: Ever \_\_\_\_\_ Before Knew \_\_\_\_\_ After Knew \_\_\_\_\_ Describe: \_\_\_\_\_  
 Alcohol Use: Ever \_\_\_\_\_ Before Knew \_\_\_\_\_ After Knew \_\_\_\_\_ Describe: \_\_\_\_\_  
 Drug Use: Ever \_\_\_\_\_ Before Knew \_\_\_\_\_ After Knew \_\_\_\_\_ Describe: \_\_\_\_\_  
 DV Screening:  Yes  No  Unknown DV Present:  Yes  No Describe: \_\_\_\_\_  
 Mental Health Issues:  Yes  No  Unknown Describe: \_\_\_\_\_  
 Police Reports:  Yes  No  Unknown Describe: \_\_\_\_\_

### Maternal History (Not Including This Infant):

# Total Pregnancies: \_\_\_\_\_  
 # Term Deliveries: \_\_\_\_\_  
 # Preterm Deliveries: \_\_\_\_\_  
 # SABS: \_\_\_\_\_  
 # VIPs: \_\_\_\_\_  
 # Living Children: \_\_\_\_\_  
 # Infant Deaths: \_\_\_\_\_  
 # Stillborns: \_\_\_\_\_

#	Birth Yr	MA	GA	BW	Outcome	Cause of Death/ Comments
1						
2						
3						
4						
5						

**This summary is based upon the following records review:**

<b>Records</b>	<b>Agency</b>
	Child Protective Service
	Court: Child Abuse/Neglect, Family Court, Juvenile Delinquency, Paternity/Child Support
	Domestic Violence Shelter
	Early Intervention Program
	EMS (in hospital records)
	Federally Qualified Health Clinic: OB, Pediatrics, Primary Care, WIC
	Health Department: Maternal Infant Health Programs, Special Child Health Services, WIC
	Hospital Clinics: OB
	Maternal Infant Health Programs
	Medical Examiner
	Mental Health and Substance Abuse Services
	Pediatrics
	Planned Parenthood
	Prosecutor: Criminal Court Records, Police

**Referrals**

- CPS Referral: \_\_\_\_\_  Attended  Not Attended
- Dental Services: \_\_\_\_\_  Attended  Not Attended
- Domestic Violence Service Agency: \_\_\_\_\_  Attended  Not Attended
- Maternal Infant Health Program: \_\_\_\_\_  Attended  Not Attended
- Mental Health Services: \_\_\_\_\_  Attended  Not Attended
- Prenatal Education Class: \_\_\_\_\_  Attended  Not Attended
- Substance Abuse Treatment: \_\_\_\_\_  Attended  Not Attended
- Other Services: \_\_\_\_\_  Attended  Not Attended

**SUMMARY BRIEF**

	<u>Medical Record Abstraction</u>	<u>Family Interview</u>
Pre-conceptional		
Prenatal		
Labor & Delivery		
Neonatal		
Postpartum		

**SEQUENCE OF EVENTS**

<b>Prenatal (During Pregnancy)</b>				
<b>Timeframe</b>	<b>Event</b>	<b>Reason</b>	<b>Outcome</b>	<b>Notes</b>

Prenatal NOTES:

<b>Labor &amp; Delivery</b>				
<b>Timeframe</b>	<b>Event</b>	<b>Reason</b>	<b>Outcome</b>	<b>Notes</b>

Labor & Delivery NOTES:

<b>Neonatal</b>				
<b>Timeframe</b>	<b>Event</b>	<b>Reason</b>	<b>Outcome</b>	<b>Notes</b>

Neonatal NOTES:

<b>Postpartum (After Discharge)</b>				
<b>Timeframe</b>	<b>Event</b>	<b>Reason</b>	<b>Outcome</b>	<b>Notes</b>

Postpartum Post-Discharge NOTES:

**AUTOPSY Notes:**

**FAMILY INTERVIEW DETAILS/TRANSCRIPT:**

## **Appendix B: Family Interview**

### **Structure of Family Interview**

#### **Tips for Family Interviewers:**

- Show EMPATHY, EMPATHY, EMPATHY
- Be prepared for an emotional discussion
- Pay attention to mother and/or father's body language to gauge their comfort with question
- Your job is to ask questions and listen: NOT to judge, NOT to be a therapist

#### **Steps for Beginning of Interview**

- Introduce yourself, wear nametag, give family your business card
- Review format of interview: length, can be multiple sessions, etc.
- If others in room, ask for privacy and if possible, ask ahead of time, if want to be alone or have someone there
- Refer to baby by his or her name throughout the interview

#### **Overview of Interview**

My name is (NAME). First of all, know that I am so, so sorry for the death of your baby, (NAME). I extend my sympathy to you and your family. Just to remind you, I am a home interviewer for Kalamazoo County Fetal Infant Mortality Review (FIMR). This is a program that looks at the death of any infant in our community, to learn everything possible from these tragedies so that, if at all possible, they might be prevented from happening again.

#### **A. PURPOSE OF INTERVIEW**

1. Capture information that doesn't appear in any official records...the family's experience
2. Support for family (listen, validate feelings of loss, link to grief / other resources)

#### **B. EXPLAIN RECORDING**

What I want you to know is that I will be recording, so that I can focus on you and what you say. We can stop recording if there's something that you want to say off the record. Ask if okay to record. Let's get the paperwork out of the way so we can talk.

-----START RECORDING-----

#### **C. CONSENT**

1. Explain purpose
2. Read, if necessary
3. Signatures
4. "I'm a mandated reporter. That means that if there is something you say to me that suggests you have abused or neglected one of your children, I have to file a CPS report, by law."

-----START INTERVIEW-----

I'm going to ask you to share your story in your own words. I may have questions or ask for more detail. You may or may not want to talk about that....and that's okay, just say you want to skip that.

#### D. PREGNANCY

Tell me what you want me to know about your pregnancy experience. What it was like for you, and how you felt.

If needed....

1. In the year before you got pregnant, tell me about your life. PROBES...
  - a. Where were you living?
  - b. How did you afford this living arrangement?
  - c. Were you working?
2. Can you tell me about your experiences during this and previous pregnancies?  
PROBES ...
  - a. Have you ever been pregnant before?
  - b. Can you tell me about your experiences?
  - c. Did you have someone in your life to provide you with emotional support during the pregnancies?
  - d. What type of things did they do to make you feel supported?
3. Can you tell me how you felt when you realized that you were pregnant?  
PROBES ...
  - a. How many weeks were you when you realized you were pregnant?
  - b. What did the father of the baby, family and friends say when they learned you were pregnant?
  - c. Did you feel you had someone to go to for information and questions?
4. What was your experience with medical insurance during your pregnancy?  
PROBES...
  - a. What kind of insurance did you have during your pregnancy?
  - b. Did you encounter problems with the insurance, if so what type of problems and were they resolved?
5. What were your experiences with health care services like during your pregnancy? PROBES...
  - a. Did you receive prenatal care (pnc), is yes then where?
  - b. When did you start...did you get pnc as early as you wanted, if so, what influenced the start of your pnc visits?
  - c. Did you miss any visits, if so why?
6. When you think back to your pregnancy, is there anything you wished you or your provider could have done differently?

## E. HOME VISITATION

Did anyone ever talk to you about mother-baby home visitation programs? What did they say?

1. Did you want to be part of the program?
2. Did you participate? Did anyone ever visit you?
  - a. **If yes**, how was that for you? How did the visits go?
  - b. Did they visit you often enough? Did you want more, or want less?
  - c. Did you like your home visitor? Did you trust them? Feel comfortable with them? Did they listen to what you had to say?
  - d. Did they have good follow-through; could you depend on them?
  - e. Is there anything you wished your home visitor could have done differently?
  - f. **If no**, why not?

## F. DELIVERY

1. Tell me about your experience with your delivery. What it was like for you, and how you felt. PROBES...
  - a. How did you feel about the medical staff's communication with you about what was happening during the delivery?
  - b. Did the medical staff or anyone else (who?) provide you with emotional support during the delivery, if so how?
  - c. What else could have been done to make the experience easier?
  - d. Were you able to hold your baby after delivery, if so, what was that experience like for you?
2. When you think back to your delivery, is there anything you wished you or your provider could have done differently?

## G. FATHER OF BABY

1. Tell me about your relationship with your baby's father. PROBES...
  - a. What were the best things about your relationship?
  - b. What were some of the problems you two experienced?
  - c. Did his behavior change as your pregnancy progressed?
  - d. How was he supportive, how was he helpful?
  - e. If not, how was he not? If not, what do you wish he had done differently?

## H. BABY AT HOME

So now I'm going to ask you some questions about your baby...

1. Once you came home, what was that like for you and your baby? Were you excited to come home or not ready to come home?
  - a. Did you have the support you needed?
  - b. Who was your support? Who else? (probe types of support: money (\$20) for diapers, food, watching baby so could nap, etc.)
  - c. How did they help you?
  - d. (if no to above) What would have helped you? What support would you have needed?

2. Did [NAME] have a safe place to sleep?
  - a. Can you describe where the baby slept? What about for naps? Did your baby ever sleep on the couch, with you or others? What did you do if your baby fell asleep on you?
  - b. What else was in the crib/sleeping area with your baby? Did your baby sleep with blankets or pillows?
3. Did your baby make it to his/her first well-baby check-up? How was that?
 

PROBE...

  - a. How many checkups did your baby get?
  - b. How were you treated? Did you like the doctors there?
  - c. How did you get to the appointments?
  - d. Did you ever miss any appointments? Why?
  - e. Did you ever worry about your baby being sick?
  - f. Where did you go when your baby was sick?
  - g. Did the doctors take good care of your baby?
  - h. When you think back to your baby's doctor visits, is there anything you wished you or the provider could have done differently

So now I'm going to ask you some questions that may be very difficult for you to answer. For that I apologize...

#### I. DEATH AT HOME

I want you to think back to when your baby passed...

1. The day before, was your baby acting normal? PROBES...
  - a. Eat ok?
  - b. Sleep ok?
  - c. Any sniffles or anything else?
  - d. Crying more than normal?
2. The day your baby passed, how did that day start out for you and your baby?
 

PROBES...

  - a. Where was the baby?
  - b. What time did you get up?
  - c. What did you do after you got up?
  - d. What was your daily routine?
3. And then what happened? And then what? PROBES...
  - a. Anybody else in your home with you?
  - b. Who made the 911 call? Who came (police, CPS, EMS, ME, family, friends, father of baby)?
  - c. And then what happened?
  - d. How did you feel / what was this like for you?
4. How were you treated? PROBES...
  - a. How would you have wanted to be treated?
  - b. What could have been done better?
  - c. What was the most helpful for you?
  - d. What was the worst?
5. When you think back to that day, is there anything you wished you or any of the people involved could have done differently?

## J. DEATH AT HOSPITAL

I want you to think back to the day your baby passed...

1. Can you tell me what happened? And then what? PROBES...
  - a. How did you feel / what was this like for you?
  - b. Did you understand what was happening?
  - c. Where your questions answered?
2. How were you treated? PROBES...
  - a. How would you have wanted to be treated / What could have been done better?
  - b. What was the most helpful for you?
  - c. What was the worst?
3. When you think back to that day, is there anything you wished you or any of the people involved could have done differently?

## K. RIGHT AFTER DEATH

These next questions are about what happened after your baby passed...

1. How was your baby's death explained to you? PROBES...
  - a. Was it described clearly?
  - b. Who explained it to you?
  - c. Could it have been done better? How?
2. Did someone give you information/talk to you about funeral arrangements?
  - a. Were you given the choice of cremation or burial?
  - b. Did you decide to have a funeral or memorial service for the baby?
  - c. Were you given the choice of autopsy or not? If you chose "no autopsy," what was your reason?
3. Did you get a chance to hold your baby, to say goodbye?
  - a. What was that like for you?
  - b. What could have been done better?
4. Throughout, was there anything that you, as a parent, questioned but didn't get a chance to ask, or asked and didn't get an answer?

## L. POST LOSS

1. Can you explain to me what was going on for you during the week after your baby passed?
  - a. Where did you stay?
  - b. Who was with you? How long did they stay?
  - c. What was helpful for you?
  - d. What was hardest for you?
  - e. Looking back, is there anything you wish had gone differently?
2. How about in the months after?
  - a. Where did you stay?
  - b. Who was with you? How long did they stay?
  - c. What was helpful for you?
  - d. What was hardest for you?
  - e. Looking back, is there anything you wish had gone differently?
3. How about now? How are you doing?
  - a. Do you feel like you are getting back to normal?

- b. Are you sleeping ok? Eating ok?
- c. Are you getting out of the house? Do you work? Go to school? See friends/family?
- d. Sometimes it is difficult to recognize depression, so we ask everyone these 10 questions [EDINBURGH]
- e. Are you self-medicating? In the past week, how often have you used...
  - i. Alcohol (if more than 4+ drinks/day...
  - ii. Illegal drugs
  - iii. Prescription drugs for a non-medical reason

-----PROVIDE RESOURCE LIST-----

#### M. GRIEF

1. Everyone grieves differently, and the death of a child can be really hard on relationships. How has the father of your baby been coping? Are you still together? Do you see each other? PROBES...
  - a. Is he depressed?
  - b. Is he self-medicating?
  - c. Has his behavior changed...How?
  - d. What happens when you guys argue? Do things get physical (throwing things, hitting, pushing, spitting, forced sex)?

-----REFER TO DOMESTIC VIOLENCE RESOURCES AND CPS IF CHILD INVOLVED IN ONGOING PHYSICAL VIOLENCE AGAINST MOM-----

- e. How was he supportive, how was he helpful?
  - f. How was he not...? If not, what do you wish he had done differently?
2. Different things help different people – some find relief talking to their family, others prefer a counselor, still others like support groups. What has helped you? What have you tried? Would to like to try... [OFFER GRIEF LIST]
    - a. How did you learn of...
    - b. [for grief/bereavement support used] How was that for you? What parts helped? What could be improved?
    - c. What would have helped? What would you recommend to us/FIMR for helping other families who have lost a child?
  3. What method of birth control are you using now/did you choose?
    - a. (if birth control) How's that working for you? Where did you get it?
      - i. Probe if they are taking it correctly.
    - b. (if no) why not... are you trying to get pregnant?
      - i. (if not)...give RESOURCE

#### N. END OF INTERVIEW

We thank you for your time and for sharing your story. You are helping us figure out how to help other families who may be facing many of the same problems.

1. Do you have any suggestions regarding the contact attempts made prior to interview?

If you think of anything after I leave please feel free to call or email me. I would be happy to come back again to talk more. Is it okay if I call you in a couple weeks to see how you are doing?

**NOTE: IF YOU HAVEN'T SCHEDULED FATHER OF BABY'S VISIT OR HAVEN'T BEEN ABLE TO REACH HIM, USE THIS OPPORTUNITY TO TALK TO/CONTACT HIM.**

## **Appendix C: Needs Checklist**

### **Family Needs Intake Checklist**

**1. What type of health insurance do you receive?**

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**2. Last grade completed?**

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**3. Employment Status?**

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**4. Housing Status? (Rent, Own, Homeless) Current living arrangements?**

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**5. Monthly income?**

---

**6. Marital status?**

---

**7. Do you receive any form of government assistance? (TANF, SNAP, WIC)**

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**8. Do you have reliable transportation? (form of transportation used)**

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**9. Do you and your family have a primary care physician?**

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**10. Have you ever been diagnosed with a mental or medical condition?**

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**11. Do you use any illegal substance?**

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**12. Do you drink alcohol?**

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**13. What does your support look like? Do you have any support from family, friends or other?**

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**14. In the past month have you struggled to provide food for your family?**

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**15. Do you have childcare needs?**

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**16. Do you have access to resources?**

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**17. How is the FOB treated by providers? Is he included in conversations pertaining to your children?**

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**18. How well are you and the FOB co-parenting?**

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**19. Have you had any issues paying medical bills?**

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**20. Have you missed doctor appointments due to financial issues?**

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**21. Are you afraid someone may hurt you?**

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**22. How is communication between you and your provider?**

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**23. Do you feel heard by your doctor?**

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**24. Are messages you receive from different health care professionals consistent?**

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**25. Do you participate in any home visitation programs?**

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**26. Do you have CPS involvement now or in the past?**

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**27. How often do your providers follow-up with you (mental, HV, medical providers)**

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## Appendix D: Family Progress Form

### Family Progress Form

<b>Case #:</b>	<b>Date:</b>	<b>Visit #:</b>	<b>Interviewer:</b>
<b>Identified Needs:</b>	<b>Intervention:</b>	<b>Goals for next visit:</b>	<b>Comments:</b>

## **Appendix E: Exit Survey**

### **Family Exit Survey**

**1. The follow-up visits helped me to cope with the loss of my baby.**

- Strongly agree
- Agree
- Somewhat agree
- Disagree
- Strongly disagree
- No opinion

**2. The resources provided by the interviewer helped me with some of the other problems in my life.**

- Strongly agree
- Agree
- Somewhat agree
- Disagree
- Strongly disagree
- No opinion

**3. Is there anything else the interviewer could have done to help you?**

**4. Additional comments:**

## Appendix F: Strengths & Gaps Template for Case Review

### Fetal Infant Mortality Review Case Review

Date: \_\_\_\_\_

Case #: \_\_\_\_\_

<b>Strengths</b>	
<ul style="list-style-type: none"> <li>• <b>What went right?</b></li> <li>• <b>Where was there good intention, and people trying to do the right thing?</b> <ul style="list-style-type: none"> <li>○ Mother of baby (MOB), father of baby (FOB), family, friends, neighbors, community</li> <li>○ Provider treatment and quality (medical, social service, public health, etc.)</li> <li>○ Resources (food, housing, cribs, etc.)</li> <li>○ Programs, services, and treatment options</li> <li>○ Coordination and safety net service delivery, access, and referrals</li> </ul> </li> </ul>	<b>1.</b>
	<b>2.</b>
	<b>3.</b>
	<b>4.</b>
	<b>5.</b>
	<b>6.</b>
	<b>7.</b>
	<b>8.</b>

<b>Gaps</b>	
<ul style="list-style-type: none"> <li>• <b>Problems faced by MOB and family?</b></li> <li>• <b>Challenges faced by providers and programs?</b></li> <li>• <b>What could have gone better?</b></li> <li>• <b>What would have made a difference?</b></li> </ul>	<b>1.</b>
	<b>2.</b>
	<b>3.</b>
	<b>4.</b>
	<b>5.</b>
	<b>6.</b>
	<b>7.</b>
	<b>8.</b>

## Appendix G: Causes of Death Table

Table 1. Cause of Death by Race and Socioeconomic Status							State, Year
		People of Color		White-Only		Total	Total (#)
		Medicaid	Non Medicaid	Medicaid	Non Medicaid		
Non-Natural	Sleep-related	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	SIDS #% (#)
	Accident (non-sleep related)	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	External Causes #% (#)
	Homicide	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	
Natural	Prematurity	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)
	Congenital Anomalies	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)
	Infection / Disease	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)
	Complications (pregnancy/delivery)	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)	#% (#)
TOTAL		#	#	#	#	#	#