Michigan Fetal Infant Mortality Review (FIMR) Maternal/Family Interview Guide



Purpose of the FIMR Maternal/Family Interview

The purpose of the FIMR maternal/family interview is to hear their story, to get their perspective on their loss, and to show them their community cares for them. The information gathered from the interview provides insight to what families are facing, health inequities, disparities, services provided, and community resources.

Resources to Help Prepare for Conducting Maternal/Family Interviews

- 1. National Center for Fatality Review and Prevention (NCFRP) Parental Interview Guidance
- 2. National FIMR (NFIMR) Manual
 - a. This resource is a guide to help new teams not just with maternal/family interviews, but the entire FIMR process
- 3. NCFRP Maternal Interview Training Module
- 4. NCFRP Sample Protocol for Contacting Mothers
- 5. NCFRP Recorded Webinar: "Bereavement Support for Families and Professionals"
 - a. Passcode: Support

Items to Bring to the Maternal/Family Interview

- 1. NCFRP Sample Maternal Interview Consent Form
- 2. Lock Box
- 3. Resources for the Family
 - a. Grief and Bereavement Resources
 - b. Community Resources Available
- 4. Questionnaire for Interviewer

Questions for the Maternal/Family Interview

At a minimum, FIMR teams should try to answer the following questions from the National Fatality Review Case Reporting System (NFR-CRS) (Section A5: FIMR Maternal Interview)² during the interview:

- 1. Does the mother expect to have any more children? (Y/N/U)
 - a. If yes, how many?
 - i. When:
- 2. Was the mother currently pregnant at the time of maternal/family interview? (Y/N/U)
 - a. If no, is she currently using birth control? (Y/N/U)
 - i. If yes, describe type of birth control:
- 3. How does the mother remember feeling about becoming pregnant?
 - a. Wanted to be pregnant sooner
 - b. Wanted to be pregnant later
 - c. Wanted to be pregnant then
 - d. Didn't want to be pregnant then or at any time in the future
 - e. Unknown
- 4. How does the mother describe the time just before her pregnancy?

- a. One of the happiest times of her life
- b. A happy time with a few problems
- c. A moderately hard time
- d. A very hard time
- e. One of the worst times of her life
- f. Unknown
- 5. Did the mother feel she had family or friends who could help with the infant at home? (Y/N/U)
 - a. If yes, specify who:
 - b. Note: A good follow-up question would be, "Was this discussed prior to delivery?" If yes, specify who was this discussed with:
- 6. In the months prior to the infant's death, how often did the mother feel that daily activities were overwhelming?
 - a. Never
 - b. Almost never
 - c. Sometimes
 - d. Fairly often
 - e. Very often
 - f. Unknown
- 7. In the months prior to the infant's death, how often did the mother say that she felt very sad?
 - a. Never
 - b. Almost never
 - c. Sometimes
 - d. Fairly often
 - e. Very often
 - f. Unknown
- 8. According to the mother, was the infant in the same room with someone who was smoking? (Y/N/U)
 - a. If yes, number of hours per day, maximum 24:
- 9. According to the mother, did she have a crib, Pack 'n Play, bassinet, bed side sleeper or baby box for the infant? (Y/N/U) *Notes: 1. The American Academy of Pediatrics (AAP) cannot make a recommendation for or against bed side sleepers, because there have been no studies. 2. The AAP recommends that babies sleep in a crib, bassinet, portable crib or play yard that conforms to Consumer Product Safety Commission (CPSC) standards. Currently, Baby Boxes do not meet the CPSC mandatory safety standards nor the U.S. ASTM (American Society for Testing & Materials) bassinet safety standards.
 - a. If yes, how often did the infant sleep in it?
 - i. Always
 - ii. Usually
 - iii. Half the time
 - iv. Occasionally
 - v. Never
 - vi. Unknown
- 10. Did the mother feel that her infant was ever treated differently or unfairly in getting services? (Y/N/U)

- a. If yes, for what reasons?
 - i. Race
 - ii. Culture/ethnic background
 - iii. Citizenship status
 - iv. Marital status
 - v. Type of insurance
 - vi. Ability to pay
 - vii. Other, specify:
 - viii. Unknown
- 11. How supportive was the father toward the mother during the pregnancy?
 - a. Not involved
 - b. Supportive
 - c. Unsupportive
 - d. Unknown
- 12. How satisfied was the mother with the father's contribution(s) toward her or the infant's financial support?
 - a. Very satisfied
 - b. Somewhat satisfied
 - c. Not satisfied
 - d. Unknown
- 13. Were any of the following identified as psychosocial or lifestyle problems experienced by the mother AT ANY TIME in her life, as a child herself, before or during pregnancy or while the infant was still alive?
 - a. Mother as a child (Y/N/U):
 - i. If yes, which one(s):
 - 1. Housing inadequate/homeless
 - 2. Food insecurity
 - 3. Mother treated violently
 - 4. Parents or caregiver with substance abuse problem
 - 5. Parents or caregiver problem drinkers
 - 6. Parents or caregiver with mental health problems
 - 7. Parental separation or divorce
 - 8. Incarcerated household member
 - b. Current (during pregnancy or after the birth) (Y/N/U):
 - i. If yes, which one(s):
 - 1. Disturbed mother/infant relationship
 - 2. Mother physical/developmental disability
 - 3. Husband/partner physical/developmental disability
 - 4. Mother employment/education needs
 - 5. Husband/partner employment/education needs
 - 6. Inadequate support system
 - 7. Mother or husband/partner felt "stereotyped" or profiled due to race, gender, class, etc.
- 14. Did the mother feel that she was ever treated differently or unfairly in getting services? (Y/N/U)

- a. If yes, for what reasons?
 - i. Race
 - ii. Culture/ethnic background
 - iii. Citizenship status
 - iv. Marital status
 - v. Type of insurance
 - vi. Ability to pay
 - vii. Other, specify:
 - viii. Unknown
- 15. During the mother's recent pregnancy, did the mother have others who would have helped her if a problem had come up? (For example, needed a ride to the clinic or needed to borrow money) (Y/N/U)
 - a. If yes, describe who would have helped (husband/partner, friend, mother/in-laws, other family, etc.)
- 16. Did the father experience any stressors during mother's pregnancy? (Y/N/U)
 - a. If yes, which one(s)?
 - i. Work or employment problems
 - ii. Problems with drugs or alcohol
 - iii. Money problems
 - iv. Housing problems
 - v. Emotional problems
 - vi. A death in the family
 - vii. Problems with children or other relatives
 - viii. Problems with the law
 - ix. Health problems
 - x. Other, specify:
 - b. Note: Additionally, it would be beneficial to ask, did mom have these stressors?
 - i. If yes, which one(s)?
- 17. Did the infant ever have an illness for which they weren't seen or treated? (Y/N/U)
 - a. If yes, what were the barriers?
 - i. Lack of money for care
 - ii. Limitations of health insurance coverage
 - iii. Lack of transportation
 - iv. No phone
 - v. Cultural differences
 - vi. Language barriers
 - vii. Couldn't get provider to take as a patient
 - viii. Multiple providers, not coordinated
 - ix. Couldn't get an earlier appointment

- x. Lack of childcare (other children)
- xi. Lack of family/social support
- xii. Services not available
- xiii. Distrust of health care system
- xiv. Unwilling to obtain care
- xv. Didn't know where to
 - go
- xvi. Other, specify:
- xvii. Unknown

Maternal/Family Interview Script

If you would like to review examples of the questions in a script format please review the <u>NFIMR Case</u> <u>Abstraction Book</u>. Also, for another example of a maternal interview script, please see Appendix G.

Additional Resources for the Maternal/Family Interview

Some FIMR teams want to collect additional information during the interview. For example:

- 1. Adverse Childhood Experiences (ACEs) Questionnaire
- 2. <u>NFIMR Data Abstraction Book</u> (for additional questions to ask during the interview)
- 3. Edinburgh Postnatal Depression Scale (EPDS) (Note: Be prepared to make a referral)
- 4. Maternal Interview Evaluation

These are not required for the maternal interview; however, some members of the Michigan FIMR Network incorporate these tools into their interviews.

References

- Fetal Infant Mortality Review Manual: A Guide for Communities. Washington, D.C.: American College of Obstetricians and Gynecologists, 2008. National Center for Fatality Review and Prevention Website. https://www.ncfrp.org/wp-content/uploads/NCRPCD- Docs/FIMRManual.pdf. Accessed August 14, 2019.
- 2. FIMR Report Form, National Fatality Review Case Reporting System. National Center for Fatality Review and Prevention; 2018. Accessed August 14, 2019.

Appendices

Appendix A: Jackson County Maternal/Family Interview Packet Sample

Appendix B: Oakland FIMR Maternal/Family Interview Consent Form

Appendix C: Adverse Childhood Experiences (ACEs) Questionnaire

Appendix D: Edinburgh Postnatal Depression Scale (EPDS)

Appendix E: Detroit Health Department FIMR Maternal Interview Evaluation

Appendix F: Michigan Pregnancy and Infant Loss Support Resources

Appendix G: Kalamazoo Maternal/Family Interview Script

Appendix A: Jackson County Maternal/Family Interview Packet Sample

Bereavement Packet Content List for Home Interviews Jackson County

Flyers:

- 1. Fetal & Infant Mortality Review
- 2. Tiny Purposes
- 3. Treasures in Our Heart
- 4. Adam Flyer

JCHD Home Interview Informed Consent Form

- 1. Home Interview form from NFIMR
- 2. Possibly: Home Interview Supplement: Baby's Health At Home
- 3. Possibly: Home Interview Supplement: Special SIDS Questions
- 4. Aces Questionnaire
- 5. MCHAT Questions

Edinburgh Postnatal Depression Scale (EPDS)

Resources:

1. Allegiance Grief Support Services Flyer 2016

Education:

1. JCHD Grieving Teaching Grid (For MIHP if doing bereavement support)

Additional Considerations:

- 1. Meijer Gift Card Visit Form
- 2. JCHD Reimbursement for Infant Death Bereavement Support Visits
- 3. Waiver of Ownership Agreement (JCHD requirement)
- 4. Customer Satisfaction Survey
- 5. Candle with saying attached with ribbon: In loving Memory

Never more than a thought away, loved and remembered

every day!

Updated 8/12/2019



OAKLAND COUNTY EXECUTIVE L. BROOKS PATTERSON

HEALTH DIVISION

Leigh-Anne Stafford, Health Officer (248) 858-1280 | health@oakgov.com

FETAL AND INFANT MORTALITY REVIEW HOME INTERVIEW CONSENT FORM

Purpose of the Study

Working to reduce fetal and infant deaths, a Fetal and Infant Mortality Review study is being conducted by the Oakland County Health Division (OCHD). By identifying why they occurred, future infant deaths may be prevented. Interviews with parents (or other family members) whose fetus or infant died will provide important information.

The interview will:

- include questions about your fetus/baby's death, your pregnancy, health, family, health care, and use of social services
- take place in your home
- be scheduled at your convenience and last about one (1) hour.

Participation is voluntary. You may decline answering any of the questions and may end the interview at any time without consequences to you or your family. There is no payment for participation.

Description of Potential Risk

There is no expected risk or injury as a result of participating in the study. However, the questions may be difficult for you. The interviewer can give you resources to help you cope with your fetus/baby's death.

Confidentiality of Records

All identifying information (i.e. name, health care provider, etc.) will be removed from the questionnaire before review. Staff and consultants involved in the study have signed oaths to protect confidentiality of participants.

NORTH OAKLAND HEALTH CENTER

1200 NORTH TELEGRAPH ROAD PONTIAC MICHIGAN 48341-0432 General Information 248-858-1280

Questions

Call David Roth, DrPH, BSN, RN, at 248-858-1378 for answers to questions about the study or the interview process.

Consent

- · I have read this form.
- I understand the purpose of and conditions for participating in the study.
- · I agree to an interview.
- I understand that confidentiality will be protected.

Name (please print):
Signature:
Date:
Interviewer's Name:
Interviewer's Signature:
Date:
All I Company of the Parish of Natural Ellin

Adapted from: Alameda/Contra Costa Perinatal Network FIMR Program, Oakland, CA.

SOUTH OAKLAND HEALTH CENTER 27725 GREENFIELD ROAD SOUTHFIELD MICHIGAN 48076-3663 General Information 248-424-7000

Adverse Childhood Experience (ACE) Questionnaire Finding your ACE Score ra hbr 10 24 06

While you were growing up, during your first 18 years of life:

1. Did a parent or other adult in the household often Swear at you, insult you, put you down, or humiliate you?	
Act in a way that made you afraid that you might be physically l Yes No	nurt? If yes enter 1
2. Did a parent or other adult in the household often Push, grab, slap, or throw something at you?	
Ever hit you so hard that you had marks or were injured? Yes No	If yes enter 1
3. Did an adult or person at least 5 years older than you ever Touch or fondle you or have you touch their body in a sexual water or	ay?
Try to or actually have oral, anal, or vaginal sex with you? Yes No	If yes enter 1
4. Did you often feel that No one in your family loved you or thought you were important or	or special?
Your family didn't look out for each other, feel close to each other. Yes No	ner, or support each other? If yes enter 1
5. Did you often feel that You didn't have enough to eat, had to wear dirty clothes, and ha	d no one to protect you?
Your parents were too drunk or high to take care of you or take Yes No	you to the doctor if you needed it? If yes enter 1
6. Were your parents ever separated or divorced? Yes No	If yes enter 1
7. Was your mother or stepmother: Often pushed, grabbed, slapped, or had something thrown at her	?
Sometimes or often kicked, bitten, hit with a fist, or hit with some or	mething hard?
Ever repeatedly hit over at least a few minutes or threatened wit Yes No	h a gun or knife? If yes enter 1
8. Did you live with anyone who was a problem drinker or alcoholic or very Yes No	who used street drugs? If yes enter 1
9. Was a household member depressed or mentally ill or did a household Yes No	I member attempt suicide? If yes enter 1
10. Did a household member go to prison? Yes No	If yes enter 1
Now add up your "Yes" answers: This is yo	ur ACE Score

Appendix C: Adverse Childhood Experience (ACE) Questionnaire Continued

Explanation of ACE scoring:

These 10 types of adverse childhood experiences¹ are:

ABUSE

- 1. Emotional Abuse
- 2. Sexual Abuse
- 3. Physical Abuse

FAMILY DYSFUNCTION

- 4. Incarcerated Relative
- 5. Mother Treated Violently
- 6. Mental Illness
- 7. Parental Divorce or Separation
- 8. Substance Abuse

NEGLECT

- 9. Physical
- 10. Emotional

For more information about ACE scores visit the Centers for Disease Control & Prevention's <u>Adverse</u> Childhood Experiences – Looking at How ACEs Affect Our Lives & Society infographic.¹

Reference:

1. Adverse Childhood Experiences Looking at How ACES Affect Our Lives & Society. Centers for Disease Control and Prevention Website.

https://www.michigan.gov/documents/mdhhs/Adverse Childhood Experiences Infographic-CDC 508995 7.pdf. Accessed October 4, 2021.

Appendix D: Edinburgh Postnatal Depression Scale (EPDS)

The Edinburgh Postnatal Depression Scale (EPDS) was created for screening purposes and does not diagnose depression. The screening tool consists of 10 questions and has scoring criteria. If there are plans to use the EPDS or another postnatal depression screen, FIMR Maternal/Family Interviewers should be prepared to make a referral to a licensed health care professional. You may find the EPDS and scoring information at. https://www.kdheks.gov/c-f/integration toolkits/EPDS Training Tip Sheet.pdf ²

In the past 7 days:

 I have been able to laugh and see the funny side of things

> As much as I always could Not quite so much now Definitely not so much now Not at all

2. I have looked forward with enjoyment to things

As much as I ever did Rather less than I used to Definitely less than I used to Hardly at all

*3 .I have blamed myself unnecessarily when things went wrong

Yes, most of the time Yes, some of the time Not very often No, never

4. I have been anxious or worried for no good reason

No, not at all Hardly ever Yes, sometimes Yes, very often

*5. I have felt scared or panicky for no very good reason

Yes, quite a lot Yes, sometimes No, not much No, not at all *6. Things have been getting on top of me

Yes, most of the time I haven't been able to cope at all

Yes, sometimes I haven't been coping as well as usual

No, most of the time I have coped quite well No, have been coping as well as ever

*7. I have been so unhappy that I have had difficulty sleeping

Yes, most of the time Yes, sometimes Not very often No, not at all

*8. I have felt sad or miserable

Yes, most of the time Yes, quite often Not very often No, not at all

*9 I have been so unhappy that I have been crying

Yes, most of the time Yes, quite often Only occasionally No, never

*10. The thought of harming myself has occurred to me

Yes, quite often Sometimes Hardly ever Never

EDINBURGH POSTNATAL DEPRESSION SCALE (EPDS) J. L. Cox, J.M. Holden, R. Sagovsky

From: British Journal of Psychiatry (1987), 150, 782-786.

Appendix D: Edinburgh Postnatal Depression Scale (EPDS) Continued

References:

- 1. J.L. Cox, J.M Holden, R. Sagovsky. Edinburgh Postnatal Depression Scale (EPDS). British Journal of Psychiatry (1987), 150, 782-786.
- 2. Edinburgh Postnatal Depression Scale Tip Sheet. Kansas Department of Health and Environment Website. https://www.kdheks.gov/c-f/integration_toolkits/EPDS_Training_Tip_Sheet.pdf. Accessed October 4, 2021.

Appendix E: Detroit Health Department FIMR Maternal Interview Evaluation



DETROIT HEALTH DEPARTMENT

Fetal and Infant Mortality Review (FIMR) Maternal Interview Follow-Up Evaluation

			rollow-op Evaluation				
1.	This Session kept m	y attention and p	resented me with helpf	ul information			
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		
2.	During my session I	was given the op	portunity to share infor	mation.			
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		
3.	I gained some insigh	nt about my pers	onal experience.				
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		
4.	Information present	ted was clear and	l concise.				
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		
5.	My overall impressi	on of the session	was positive.				
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		
6.	Based on the Sessio	on the Session, I could list ways that would contribute to my health and well-being.					
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		
7.	During my session, I	was connected t	to resources.				
	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree		

Appendix E: Detroit Health Department FIMR Maternal Interview Evaluation Continued



DETROIT HEALTH DEPARTMENT

	1 Strongly Disagree	2 Disagree	3 Neither Agree or Disagree	4 Agree	5 Strongly Agree
Comments	:				

Thank You!

Appendix F: Michigan Maternal, Pregnancy, and Infant Loss Support Resources

The MDHHS Fetal Infant Mortality Review (FIMR) program is pleased to announce the addition of the Michigan Maternal, Pregnancy, and Infant Loss Support Resources, which can be found here. With the tragic loss of a mother, pregnancy, or an infant, it is important that families receive grief and bereavement support during this extremely difficult time. As a provider, it may be difficult to know where to connect families for these services. This document offers resources to consider when connecting families to support services after experiencing a loss. For more information please visit www.michigan.gov/FIMR.

Appendix G: Kalamazoo FIMR Maternal/Family Interview Script

version 3, 10-15-16

Structure of Family Interview – Kalamazoo County FIMR

Pay attention to mother/fathers body language to gauge their comfort with question

Your job is to ask questions and listen (NOT to judge, NOT to be a therapist)

Introduce yourself, wear nametag, give business card

Review format of interview (length, can be multiple sessions, etc)

If others in room, ask for privacy.... (if possible, ask ahead of time, if want to be alone or have someone there)

Refer to baby by his/her name throughout the 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. 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

- Explain purpose
- Read, if necessary
- Signatures
- "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.

PREGNANCY

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

version 3, 10-15-16

If needed....

- a. In the year before you got pregnant, tell me about your life. PROBES.....
 - i. where were you living,
 - ii. how did you afford this living arrangement
 - iii. were you working
- b. Can you tell me about your experiences during this and previous pregnancies PROBES...
 - i. Have you ever been pregnant before
 - ii. Can you tell me about your experiences
 - iii. Did you have someone in your life to provide you with emotional support during the pregnancies
 - iv. What type of things did they do to make you feel supported
- c. Can you tell me how you felt when you realized that you were pregnant. PROBES...
 - i. How many weeks were you when you realized you were pregnant
 - ii. What did the father of the baby, family and friends say when they learned you were pregnant
 - iii. Did you feel you had someone to go to for information and questions
- d. What was your experience with medical insurance during your pregnancy. PROBES...
 - i. What kind of insurance did you have during your pregnancy
 - ii. Did you encounter problems with the insurance...what type of problems...were they resolved
- e. What were your experiences with health care services like during your pregnancy. PROBES...
 - i. Did you receive prenatal care.....where
 - ii. When did you start...did you get pnc as early as you wanted...what influenced the start of your pnc visits
 - iii. Did you miss any visits...why
- f. When you think back to your pregnancy, did you ever feel you were treated with less respect than other people or received poorer service than other people?
 - i. What about you healthcare; how were you treated by your doctor, the office and the hospital compared to other people?
 - ii. Why do you think you were treated differently?
 - iii. How did this affect you?
- g. Is there anything you wished you or your provider could have done differently
- E. Did anyone ever talk to you about mother-baby home visitation programs? What did they say?
 - a. Did you want to be part of the program?
 - b. Did you participate? Did anyone ever visit you?
 - i. If yes, how was that for you? How did the visits go?
 - ii. Did they visit you often enough? Did you want more, or want less?
 - iii. Did you like your home visitor? Did you trust them? Feel comfortable with them? Did they listen to what you had to say?
 - iv. Did they have good follow-through; could you depend on them?
 - v. Is there anything you wished your home visitor could have done differently
 - vi. If no, why not?

DELIVERY

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

FOB

- G. 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. How was he not...? If not, what do you wish he had done differently?

BABY, HOME

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

- H. 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...\$20 for diapers, food....watch 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?
- I. 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?
- J. Did your baby make it to his/her first well-baby check-up? How was that?
 - i. PROBE 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?

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- 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?
- a. When you think back to your baby's doctor visits, did you ever feel you were treated with less respect than other people or received poorer care than other people?
 - i. Why do you think you were treated differently?
 - ii. How did this affect you?
- b. 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...

DEATH, HOME

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

- K. 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?
- L. 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?
- M. 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
- N. 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?
- O. When you think back to that day, is there anything you wished you or any of the people involved could have done differently?

DEATH, HOSPITAL

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

- A. 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
- B. How were you treated? PROBES
 - a. How would you have wanted to be treated / What could have been done better

version 3, 10-15-16

- b. What was the most helpful for you
- c. What was the worst?
- C. When you think back to that day, is there anything you wished you or any of the people involved could have done differently?

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

RIGHT AFTER

- D. 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?
- E. 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?
- F. 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?
- G. 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?

POST-LOSS

- H. 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?
- I. 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?
- J. 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

version 3, 10-15-16

[REFER TO RESOURCE LIST OR CALL GRYPHON PLACE / 2-1-1]

- K. 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 YWCA/BATTERERS INTERVENTION....CPS CALL IF CHILD INVOLVED OR 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?

Different things help different people – some find relief talking to their family, others prefer a counselor, still others like support groups.

- L. 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?
- M. 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

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.

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 FOB'S VISIT OR HAVEN'T BEEN ABLE TO REACH HIM, USE THIS OPPORTUNITY TO TALK TO/CONTACT HIM.