

IN-DEPTH INTERVIEWS WITH WOMEN AFFECTED BY THE ZIKA VIRUS INTERVIEW GUIDE

INTRODUCTION AND CONSENT

Thank you for participating in the interview today. This is [name] from RTI International. My colleague [name] is also on the phone.

The purpose of our conversation today is to learn about your experiences since you were told you had the Zika virus infection during your pregnancy. This study is supported by the Centers for Disease Control and Prevention, or CDC, a federal government health agency, and the March of Dimes, a nonprofit organization dedicated to preventing birth defects.

The study will help the CDC and the March of Dimes learn about mothers' experiences and needs. The study will help the CDC and March of Dimes to develop information and services mothers and families need when they learn their baby has been exposed to the Zika virus during the mother's pregnancy. By "exposed" to the Zika virus, I mean the mother had Zika infection during pregnancy and the baby may have been infected too.

By sharing your experiences and ideas, you can help other mothers who had the Zika virus infection during pregnancy. We appreciate your time and participation!

[Moderator to verbally review consent form]

Do you have any questions before we begin?

SECTION 1. INITIAL CONCERNS

Let's start with talking about your healthcare during your pregnancy.

1. Can you tell me about any healthcare you got during your pregnancy?

Probe:

- Where did you go for your healthcare during pregnancy? Was this a private doctor's office, a clinic, a hospital, or someplace else?
- When did you start getting healthcare during your pregnancy?
___ months into pregnancy

Was there one main OB/GYN or other health professional you saw throughout your pregnancy? Yes No Don't know

Now I would like to talk about when you first learned that you had been infected with the Zika virus during your pregnancy. I know some of this may be hard to talk about, so please take your time and let me know if any question makes you uncomfortable.

2. Can you tell me when and how you first learned that you had been infected with the Zika virus during your pregnancy?

Probe:

- Who told you about it? (obstetrician/gynecologist [OB/GYN] other healthcare professional?)
- When were you first told (for example, during your pregnancy), at birth or after birth?
 - o If during pregnancy: When, during your pregnancy, were you told?
- What do you remember about that conversation?
- Were you given any information at that time about how your baby might be affected? By "affected," I mean whether your baby might have any health or development problems because of Zika.

Yes No Don't know

3. Before you learned that you had been infected with the Zika virus, had you heard anything about it?

Yes No Don't know

Probe:

- What had you heard about Zika?
- Where you heard about Zika?

- Thinking back to when you first learned that you had Zika virus infection during your pregnancy, what concerns did you have at that time?

[Interviewer, check “mentioned” if respondent mentions the topic and “not mentioned” if respondent does not mention the topic. Capture comments about each topic.]

Probes:	Mentioned	Not mentioned
That I would miscarry		
That baby would be infected too		
Possible health effects on your baby (for example, vision, hearing, brain)		
What kind of healthcare your baby would need		
Other services your baby might need		
What to expect regarding your baby’s growth and development		
The costs of healthcare for your baby, health insurance coverage, out-of-pocket costs		
Problems you might have getting health care for your baby (e.g., concerns about eligibility due to immigration status)		
Impact on you and your family (for example, stress or financial impact)		
What you and your family can do to support your baby’s health and development		
Other (specify)		

- What would you say you were *most* concerned about at that time?

SECTION 2. TRANSITION FROM PRENATAL CARE

- While you were pregnant, what (if anything) did your OB/GYN [or other health professional] share with you about possible effects of the Zika virus on your baby’s health?
- While you were pregnant, what did your OB/GYN [or other health professional] share with you about the types of screening, tests or other healthcare your baby would need once born?

Probe:

- Any tests of screening that would be needed
- Need to be checked by any specialists
- Recommendations about where to get care

8. Did your OB/GYN [or other health professional] give you any information, documents, or records to share with the baby’s pediatrician?

- Yes No Don’t know

[Interviewer, check “mentioned” if respondent mentions the topic and “not mentioned” if respondent does not mention the topic. Capture comments about each topic.]

If Yes , what kinds of information, documents, or records?	Mentioned	Not mentioned
Your health records?		
Records from your baby’s birth?		
Information about the Zika virus?		
A letter to the baby’s doctor?		
Other (specify)		

9. Sometimes OB/GYNs give mothers a document (referred to as Pregnancy Registry Reminder Card in VA) to share with the baby’s doctor. The document has information about the mother’s pregnancy, the birth, and about the Zika virus. Did your OB/GYN give you anything like this?

- Yes No Don’t know

Probe: [If yes]

- What information was included in the document?
- When did your OB/GYN give it to you?
- What did you do with it? Probe:
 - Read the information
 - Gave to the baby’s doctor
 - Shared with friends or family
- In what ways (if any) was the document helpful?

[If no]

- Would something like this have been helpful? In what ways?
- What information would you like to have on the document?
- Would you like to have the document on paper, online, or in another way?

10. What did your OB/GYN [or other health professional] do or say that was most helpful to you in preparing for the birth of your baby?

11. What else could your OB/GYN [or other health professional] have done that would have been helpful?

SECTION 3. INFORMATION AND RESOURCES

12. Since you learned your baby was exposed to the Zika virus while you were pregnant, what questions have you had about your baby's health and development?

Probe:

- How have you tried to get answers to your questions? (Look online? Talk to a doctor? Talk to friends or family?)

13. [You mentioned that your OB/GYN had/had not given you information to share with your baby's pediatrician (refer to response to Q. 8)] Did a doctor [or other health professional] provide you with any other information or resources?

Yes No Don't know

[If yes]

- 13a. Who shared information or resources with you?

- OB/GYN
- baby's doctor
- specialist
- other health professional
- social worker
- family
- friend
- an organization
- other

- 13b. When did they share information or resources with you?

- during your pregnancy
- within the first month or so after the birth of my child
- more than a month after the birth of my child
- other

- 13c. Have any doctors or health professionals shared any written materials (for example, pamphlets), told you about a website, or something else?

- Websites (probe if CDC, March of Dimes, American Academy of Pediatrics, Department of Health, other)
- Print materials
- Other resources (for example, milestone tracker)
- Referral to an organization
- Referral to a support group

14. [Ask about each specific information/resource mentioned in previous discussion] What do you remember about [info/resource]?

Probe:

- What types of information did it have?
- In what ways was it useful or not useful to you? Tell me why you think that. How could it have been more useful?
- Would you say the information was trustworthy?

Tell me why you think that.

- Was the information in English or in another language? In what language would you have liked to have the information?
- Would you say it was easy or difficult to understand the information? What would have made it easier to understand?

15. Overall, would you say you got the information you needed about your baby's healthcare?

Probe:

- Which kinds of tests would be needed? Specialists? Schedule for appointments?

16. What other information or resources would have been helpful to you and your family when you first learned your baby was exposed to the Zika virus while you were pregnant?

17. How would you like to get information and resources?

Probe:

- From a doctor or other health professional
- Look online
- Talk to family and friends
- Talk to another mother

SECTION 4. BABY'S HEALTHCARE

Now I would like to ask your baby's healthcare.

18. Could you please tell me your baby's date of birth so we will know how old s/he is?

19. Is there one pediatrician or other doctor or health professional who has regularly cared for your baby since birth?

Yes

No

Don't know

[If yes]

- What type of doctor or other health professional?

[If no]

- Have you changed doctors since your baby was born? What were the reasons for this?

20. How well do the different doctors and other health professionals involved in your baby’s care seem to work together?

Would you say: very well somewhat well or not well?

Probe:

- In what ways do they seem to work well together well?
- In what ways do they seem not to work together well?

21. Would you say there is one doctor or other health professional who is in charge of your baby’s care overall? Yes No Don’t know

Probe *[If yes]:*

- Which type of doctor or other health professional?
- In what ways is this doctor/ other health professional in charge?
- What did they do to coordinate or plan your baby’s care?

[If no]

- Would you like to have one doctor or other health professional in charge overall? Yes/No/Not sure
- In what ways would that be helpful?

Now I’m going to ask you if your baby has experienced any health problems related to Zika. These questions may be especially sensitive. Please take your time, and let me know if you’d like to stop or skip any question.

22. Has your baby been diagnosed with any health problems caused (or possibly caused) by the Zika virus? What types of health problems?

[Interviewer, check “mentioned” if respondent mentions the topic and “not mentioned” if respondent does not mention the topic. Capture comments about each topic.]

	Mentioned	Not mentioned
Smaller than expected head size		
Problems with brain development		
Feeding problems, such as difficulty swallowing		

Hearing problems		
Seizures		
Problems with vision		
Problems with joints (pain, problems movement)		
Problems with muscle strength, tone		
Other (specify)		

[If participant reports baby has one or more health problems related to Zika]

23. How did you learn about this/these health problems?

Probe for each problem mentioned:

- Who told you about the health problem?
- When did you learn about the health problem?
- What did they say about the health problem?

24. Has your baby had any special tests related to this/these problems?

Probe for each problem:

- Blood test
- Vision
- Head ultrasound
- Eye exam
- Hearing
- Other

25. How old was your baby when s/he had this/these tests? (Probe for each test)

26. From your understanding, what were the reasons for this/these tests?

Probe for each test:

- What were the results of the tests? What did they show?

27. What have you been told about your baby's healthcare needs for this/these problems?

Probe for each problem:

- Who has discussed this with you?

- What have they discussed (for example, the need for tests or to see a specialist)?

28. Has your baby been referred to any specialists for this/these problems?

Probe for each problem:

- Ophthalmologist (eye doctor)
- Neurologist (doctor focused on the brain)
- Endocrinologist (doctor focused on the baby's metabolism; that is, how your baby converts food into energy)
- Hearing specialist
- Geneticist
- Infectious disease specialist
- Developmental specialist
- Other

[If participant does not report any health problems related to Zika]

29. What have you been told about your baby's healthcare needs?

Probe:

- Who has discussed this with you?
- What have they discussed (for example, the need for check-ups, tests, or to see a specialist)?

30. Has your baby been referred to any specialists?

Probe:

- Ophthalmologist (eye doctor)
- Neurologist (doctor focused on the brain)
- Endocrinologist (doctor focused on the baby's metabolism; that is, how your baby converts food into energy)
- Hearing specialist
- Geneticist
- Infectious disease specialist
- Developmental specialist
- Other

31. From your understanding, what were the reasons for being referred to a specialist(s)?

32. Has your baby had any special tests?

Probe:

- Blood test
- Vision
- Head ultrasound
- Eye exam
- Hearing
- Other

33. When did your baby have these tests? (Probe for each test)

34. From your understanding, what were the reasons for the test(s)?

Probe for each test:

- What were the results of the tests? What did they show?

35. What, if any, challenges have you faced in getting the healthcare your baby needs?

	Mentioned	Not mentioned
Don't know where to go for different types of care		
Don't know where to go for different health problems		
Difficulty getting appointments		
Specialists not available in area		
Health insurance doesn't cover costs		
Out-of-pocket costs high		
Care is time consuming		
Work and family responsibilities get in the way		
Language barriers		
Concerns about eligibility for health care		
Other (specify)		

[If participant reports baby has one or more health problems related to Zika]

- What, if any, challenges have you faced getting healthcare for *[health problem]*

36. To what extent do you feel your baby's doctors are knowledgeable about caring for a baby who was infected by the Zika virus? Would you say they are:

- very knowledgeable
- somewhat knowledgeable or
- not at all knowledgeable?

What makes you say that?

[If participant reports baby has one or more health problems related to Zika]

- How knowledgeable do you feel they are they about caring for a baby with [health problem]? Would you say they are:
 - very knowledgeable
 - somewhat knowledgeable or
 - not at all knowledgeable?

What makes you say that?

37. Thinking about your baby’s healthcare overall, how satisfied are you with the care? Would you say you are:
- very satisfied
 - somewhat satisfied or
 - not at all satisfied?

Probe: Tell me more about why you think that.

SECTION 5. EARLY INTERVENTION AND OTHER SUPPORT SERVICES

Ask questions in this section if participant reports baby has one or more health problems related to Zika

Now I would like to talk about other services for your baby.

38. Has a nurse visited your family at home (called a home visiting program)?

(If yes) Probe:

- How did you learn about this program?
- About how often did the nurse come?
- What kinds of things did the nurse do during home visits (e.g., check baby, discuss care for baby)?
- What (if anything) did you like about the home visits? In what ways were they helpful?
- What (if anything) did you not like?

38. Have you heard of any other services or programs that could help with your baby’s development? Yes No Don’t know

Probe:

Have you heard about early intervention programs? Sometimes called infant and toddlers’ programs? Yes No Don’t know

- Where did you hear about services and programs?

39. Was your baby referred to an early intervention program (or other program or service)? Yes No Don’t know

Probe:

- Who referred your baby?
- What is your understanding about why your baby was referred?
- What are the reasons you decided your baby should or should not participate in the early intervention (or other) program?

40. *[If participating in an early intervention or other program]* What has been your experience with the program?

Probe:

- What types of services are provided?
- What do you like or not like about the program?
- What has been most helpful?
- Have there been any challenges (for example, transportation or location)?
- Do you have to pay for the services or programs?

41. Are there other types of services or programs you would like to help your baby's development? Yes No Don't know

Probe: What other types of services would you like?

42. Are there other types of support or programs that would be helpful to you and your family?
43. Have you ever met any other mothers who were infected with the Zika virus during their pregnancy, either in-person or online (e.g., online support group)?

Probe:

- Would it be helpful to talk with other mothers? Tell me more why you think that?

SECTION 6. SOCIAL SUPPORT AND FAMILY SUPPORT SERVICES

Now I would like to ask about the support you may have gotten or not gotten from friends, family, and others.

44. How have your friends and family reacted to you being exposed to Zika during pregnancy? s

Probes:

- Did anyone react in a way that surprised you?
- Did anyone react in a way that made you feel bad? Or uncomfortable?

Ask questions 45 -47 only if participant reports baby has health problem(s) related to Zika

45. How has having a baby with health problems from the Zika virus affected you and your family?

Probe:

- How has it affected family life?
- Has it impacted your work/employment?
- Change in relationships with friends, family, other people you know?
- Change in how social you are?
- What, if anything, has been hard for you and your family?
- What would have been helpful for you and your family?

46. How has having a baby with health problems from the Zika virus affected you emotionally?

Probe:

- What emotions have you experienced? What, if anything, has been hard for you emotionally?
- What would have been helpful for you in coping with your emotions?

47. How much support have your friends, family, and other people you know given you?

Probe:

- How have they supported you?
- What has been most helpful?
- What other kinds of support would you like to have?

Ask all participants

48. As you have described, this has been a very [stressful, difficult, confusing, complicated, etc.] time for your family. What has been most helpful to you along this journey? What has been the biggest challenge?

49. What recommendations do you have for other mothers and families who have a baby who may be affected by the Zika virus?

SECTION 7. DEMOGRAPHICS AND WRAP-UP

Thank you very much for your time today and for sharing your story. Before we end today, we have a few last questions about you.

50. What is your age?

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 Years

51. Are you Hispanic or Latino?

- Yes
- No

52. What is your race? Do you consider yourself to be... (Select all that apply)

- White
- Black or African American
- Asian
- Native Hawaiian or other Pacific Islander
- American Indian or Alaska Native
- Other

53. Which one of the following best describes your current employment status?

- Employed for wages
- Self-employed
- Out of work
- Homemaker

- Student
- Retired
- Unable to work

54. What is your marital status?

- Never married
- Married
- Living with partner
- Divorced
- Separated
- Widow/Widower

55. How many children under 18 live in your house? What are their ages?

- None
- 1 child child #1 age
- 2 children child #2 age
- 3 children child #3 age
- 4 children child # 4 age
- 5 children child #5 age

56. What is the highest level of school you completed or the highest degree you received?

- Never attended school or only attended kindergarten
- Grades 1 through 8 (Elementary)
- Grades 9 through 11 (Some high school)
- Grade 12 (High school graduate) or GED
- Some college, no degree
- Associate degree (AA or AS)
- Bachelor's degree - BA, BS (College graduate)
- At least some graduate or professional school
- Graduate or professional degree

57. Which of the following income categories best describes your total annual household income from all sources in 2017?

- Less than \$10,000
- \$10,000 to under \$30,000
- \$30,000 to under \$50,000
- \$50,000 to under \$70,000
- \$70,000 to under \$110,000
- \$110,000 or higher

58. What type of health care coverage do you use to pay for your baby's medical care?

- Private insurance coverage

- Medicaid or Medical Assistance
- Children's Health Insurance Program (CHIP)
- Military, CHAMPUS, TriCare, or the VA
- Indian Health Service
- None
- Other (specify)

59. Which best describes your home?

- A trailer or mobile home
- A house
- An apartment
- Something else (specify)

[Provide information on how they will receive incentive]

We have some informational resources about how the Zika virus may affect your baby and ways to support your baby. Would you like us to send these resources to you?

The CDC may be interested in talking with you again in the future to learn about your experiences as your baby grows. Would you be willing to be contacted again? There is no obligation. If we contact you again in the future, you can decide at that time whether you want to participate.