

Appendix B. Data collection guide for the RAMP-UP* mixed-modality qualitative study
*Research around Medication Use during Pregnancy – User Perspectives

Intro: To get started, I'd like to ask you for a general introduction. **Please tell me how many children you have, their ages, and when you are thinking about or planning for another pregnancy.**

Then, I'd like draw on your general experiences as a mom. I'd like to know about social norms around how women can or should think about their health and health care during pregnancy.

Q1. From your experience, what makes for a "safe" or "responsible" pregnancy in the US, in terms of what society expects of women? **In other words, what are the things a pregnant woman "should do" as a responsible expectant mother?**

- 1a. You may have mentioned some norms or expectations around medication use in pregnancy, but if not, I'd like to hear more about what you heard or observed in relation to medication use during pregnancy. **What "should" pregnant women do when it comes to medication use?**
- 1b. Continuing on that theme - What if we think about preventive medicine, like vaccines? **How are vaccines or other preventive medicines viewed the same or differently than medications for illness or symptoms during pregnancy?** If there's a difference, why do you think that's so?
- 1c. I'm going to guess that some of these ideas have already come up, but I will ask specifically: If you consider the flipside of the first question, what is considered "unsafe" or "irresponsible" behavior during pregnancy? **In other words, what are things that a pregnant woman "shouldn't do" as an expectant mother?**

Q2. If you think about all of these social norms "should/shouldn'ts" for pregnant women above, **how did you learn about these expectations?**

- 2b. **How do you feel about these social norms?** (Did you feel pressured by them? Did you disregard them? Did you embrace them/identify with them?)

Q3. Let's move from the bigger picture of expectations to how this affected you and your behavior during pregnancy. If you think about these norms that you have raised and then **think back to your most recent pregnancy, what was the riskiest or least safe thing you did?**

- 3a. **How did you feel about doing the "risky" or "unsafe" thing you mentioned in the previous question?** Did you think about it before or after?

Q4. For this question, I'd like to know about **what you did if you had a cold or other health concern during a previous pregnancy.** We talked about social norms around medication use, but did your personal views, feelings, and/or decisions about taking medicine differ from when you were not pregnant? In other words, **did you handle cold symptoms or another health concern while pregnant the same way you would have if you weren't pregnant?** Give us examples or explain your thinking.

- 4a. Did it make a difference whether the medication was over the counter or prescription?
- 4b. How did you feel about your decision to take/not take medicine?

4c. If you took medicine, how does that compare to the “riskiest” thing that you did during pregnancy?

Q5. You likely already know that there are many recommended preventive treatments for women during pregnancy for conditions such as whooping cough and flu. It sounds like (according to 1d) you followed all of your doctor’s recommendations for vaccinations during pregnancy. **Could you describe which vaccines (and other preventive actions) you considered and how you decided to take them?**

Q6. Okay, thanks for hanging with me to this point. Let’s switch gears now and talk a bit about Zika. I am guessing you have heard about the Zika virus and the serious risks it can pose to fetuses in the womb. Specifically, when pregnant women get Zika virus, their children can be born with small brains (microcephaly) associated with problems with how they think and move as well as other serious birth defects. It also probably can cause miscarriage and stillbirth. Zika is usually caused by a mosquito bite but it also can be caused by having sex with someone who has Zika.

Given what you know about Zika and its consequences, what types of risk do you worry about from contracting Zika, specifically?

Q7. Earlier you mentioned your current plans to try for another pregnancy. **If Zika were to start spreading more widely here in the US, and here in North Carolina, how would that affect plans for your next pregnancy?**

7a. **What might you do differently? Why?**

Q8. Earlier I asked about your thoughts on vaccine use in pregnancy. There are currently vaccines under development to help prevent Zika infection.

Imagine that researchers and doctors developed a vaccine *that was safe and effective in early testing*, but they needed to continue the research with pregnant women specifically, in order *to learn about appropriate dosing* for a pregnant body. **Would you consider participating in that research while pregnant?** [This would likely involve receiving the vaccine while pregnant and then waiting a few hours for follow-up blood testing.] **Why or why not?**

8a. **What would be your main considerations or determining factors?**

8b. **What if the vaccine were only available in a research context, because it had not been approved yet? How might that affect your decision?**

Q9. Imagine now that there were a new vaccine that did have early approval for use during pregnancy to help prevent Zika. **Would you get that vaccine during your next pregnancy? Why/not?** Would it matter how prevalent Zika was in the US? Would it matter how prevalent Zika was in NC?

9a. **How would you compare the risks of getting a newly developed vaccine to the risks of contracting Zika?** In other words, which risk is more threatening? How would you weigh or balance these perceived risks? Try to explain your thinking or give examples of the things you would consider.

Q10. If we think beyond vaccines for Zika, **what kinds of information or medical services would make you feel more comfortable or safer in planning your next pregnancy**, particularly if Zika were more common in NC next summer? How would what you have suggested help you feel more comfortable or safer?

- 10a. **What if there were new/better data on the likelihood that Zika would cause birth defects?** Why might this help you – or not?
- 10b. **What if they could improve the accuracy of tests that could diagnose Zika?** Why might this help you – or not?
- 10c. **What if they could improve doctors' ability to diagnose Zika-related problems in a fetus, in utero?** Why might this help you – or not?

Okay, so now on to the series of questions about how Zika intersects with beliefs about abortion, and then we'll move on to research funding priorities.

Q11. The Zika epidemic has raised debates about termination of pregnancies based on diagnosis of fetal anomalies (problems with a baby's development) in the womb. You have already stated your general position on abortion on the demographic form at the beginning. Our intent with the next several questions is to determine how and why the case of Zika might influence thoughts on abortion and abortion policy. Your answers may reflect what you would consider for yourself or what you would advocate more generally for pregnant women, or both.

In general, how does the scenario of Zika change or modify your thoughts about termination of pregnancy?

Q12. Sometimes it is very difficult to diagnose microcephaly or other severe issues before birth. For instance, you might know you have Zika, but your doctor can't tell you for sure whether or not your baby would have problems, or how bad they would be. **Would you consider a diagnosis of Zika alone to be a point/justifiable reason for ending a pregnancy?** (Remember, you can answer for yourself and/or from a broader policy perspective.)

- 12a. A bit more specifically, in your opinion, **should diagnosis of microcephaly** (small, abnormal brain development) **or other severe Zika-related birth defects be considered a point/justifiable reasons for terminating a pregnancy?**
- 12b. Sometimes problems like microcephaly and other severe birth defects can't be detected until later on in pregnancy, after the 20th week. **Would this affect your feelings about whether late-term abortion should be an option?**
- 12c. I'm going to guess that you've already touched on this in your previous responses, but **if you were confronted with a diagnosis of Zika yourself, would you consider termination of the pregnancy?** Why/not? Under what conditions?
- 12d. If you would at all consider it, **how certain would you want to be that there was microcephaly or another severe problem before deciding to end the pregnancy?**

Thanks for discussing that sensitive topic of abortion candidly. We'll switch topics for the final set of questions. I'd like to ask you about where you think Zika funding should go.

Q13. There is currently funding for medical research into Zika. We have talked here mostly of prevention in the form of a vaccine, but there may be other prevention strategies, or early diagnosis tests, or even

treatments that could be developed. **Where do you think the priority should be in terms of the focus of Zika research funding? Why?**

Q13a. Consider these options for research topics, and **comment on whether and why each is important (or not):**

- i. Making sure that there is a vaccine that women can get before pregnancy
- ii. Making sure there is a safe vaccine for pregnant women who do not get vaccinated before pregnancy
- iii. Finding ways to be more sure about whether a pregnant woman has Zika or not
- iv. Making sure there is a treatment for women who do get Zika during pregnancy

Are there other priority areas for research around Zika and pregnancy?

Q13b. If you consider the same options, **how would you rank them in terms of priority, from highest to lowest?** (you can either re-arrange them below or just put their numbers in a list here)

What about your top priority earns it that ranking? In other words, why is the one you selected as most important “most important” in your view?

We've done it! We made it through a lot of questions on preventive medicine and Zika during pregnancy and I'm so appreciative of your time and responses! Do you have any lingering questions or comments you'd like to add? Anything else you have thought about in relation to this topic that I haven't asked about or that you think is important to share?

Thank you!