ATTACHMENT 3B CMV Focus Group Discussion Guide

Exploratory Focus Group Discussion Guide: CMV

Purpose Statement: To assess knowledge, attitudes and beliefs of mothers to CMV and explore reactions to CMV message frames and preventive guidelines.

I. Introduction (10 minutes)

- a. THANK RESPONDENTS FOR ATTENDING, BRIEFLY INTRODUCE SELF.
- b. GROUND RULES
 - ASSURANCE THAT INFORMATION WILL BE KEPT SECURE
 - HONESTY/OK TO DISAGREE
 - TAPING/TWO-WAY MIRROR
 - SPEAKING ONE AT A TIME
 - RESTROOM
 - ETC.
- c. [GO AROUND THE ROOM AND ASK RESPONDENTS TO INTRODUCE THEMSELVES] Can you please tell me your first name and the names and ages of your children?

II. Knowledge and Awareness about CMV (5 minutes)

Let's start with talking about some of the things women who are pregnant think or worry about.

- a. What are some things pregnant women worry about for their babies?
- b. How many of you have heard of cytomegalovirus, or CMV?
 - IF YES, PROBE: What have you heard? Where or from whom did you hear about CMV?

■ IF NO, PROBE: What do you think CMV is?

READ DESCRIPTION OF CMV¹/ PROVIDE HANDOUT/ SHOW BULLET POINTS ON FIJP CHART:

- Cytomegalovirus, or CMV, is a virus that can cause serious birth defects. Most people who catch CMV do not know it because they do not get sick. However, a pregnant woman can pass the virus to her unborn baby (this is called congenital CMV). About 1 in 750 babies will have birth defects caused by congenital CMV. This is similar to the number of babies born with Down syndrome, fetal alcohol syndrome, or spina bifida. Babies with congenital CMV may have hearing loss, vision loss, or intellectual disability (mental retardation).
- The most common way a pregnant woman catches CMV is by getting an infected child's urine or saliva in her eyes, nose, or mouth. Pregnant women can also get infected through sexual contact with an adult who has CMV. The chance of catching CMV through casual contact is very small.

III. Beliefs about CMV risk and exposure [10 minutes]

Given what you have just been told about CMV, what are your initial thoughts or impressions?

- a. Since everyone here is either pregnant or planning to have another baby in the next year or so, how worried are you about CMV?
 - PROBE: Tell me about that. What are some reasons you are/are not worried about CMV?
- b. Now let's take a step back and think about the different ways pregnant women can be exposed to CMV. As we discussed earlier, CMV can be spread through a child's urine or saliva, as well as by sexual contact. Currently, research shows that getting a child's urine or saliva in their eyes, nose, or mouth is a more serious source of infection for pregnant women than sexual contact. So, today, we will focus on that. What are some of the different ways you could get a child's urine, either from your own child or someone else's in your eyes, nose, or mouth? [Note responses on easel pad]

¹ Information provided here is from the CDC one-pager on CMV. It does not include a discussion on prevention methods, since that will be discussed later in the focus groups.

For each way or transmission route cited:

- PROBE: How often does that happen? Compared to other ways you might get urine in your eyes, nose, or mouth, does this happen more often?
- c. Now let's think about getting a child's saliva in your eyes, nose, or mouth. What are some of the different ways you could get a child's saliva in your eyes, nose, or mouth?

For each way or transmission route cited:

PROBE: How often does this happen? Compared to other ways you might get saliva in your eyes, nose, or mouth, does this happen more often?

[For African-American groups only].

Research has shown that CMV infection is higher among African-Americans and Hispanics. This may be because they have a greater chance of being exposed to an infected person. Another possibility is that certain behaviors or ways the disease could spread are more common in these communities.

- d. Thinking about other African-American mothers you know and how CMV is spread from children to pregnant women, are any of the ways the disease could spread, or behaviors that we have just talked about, <u>more common</u> in the African-American community? If so, which ones and why?
- e. Are there any that you think are less common? If so, which ones and why?
- f. Do you think that there are other ways that mothers in our community might be at risk of CMV that we haven't talked about yet? For example, are there other ways that African-American mothers might be exposed to children's urine or saliva? If so, what are they?

IV. Attitudes about CMV prevention [15 minutes]

CDC has some guidelines for preventing CMV. [DISTRIBUTE/READ CDC'S CMV PREVENTION GUIDELINES]

- > Do not put things in your mouth that have just been in a child's mouth. For example:
 - Food
 - Cups or silverware
 - Toothbrush
 - Pacifier
- > Kiss young children on the forehead or cheek rather than the lips
- Wash your hands with soap and water, especially after:
 - Changing diapers
 - Feeding a child
 - Wiping a child's nose or mouth

 Touching a child's toys, pacifier, or other objects that have the child's saliva or urine on them
 If you do not have soap and water, use an alcohol-based hand sanitizer.

- a. What are your initial reactions to these guidelines?
 - PROBE: What comes to mind? Do these guidelines seem realistic?

- b. In your opinion, which of these guidelines would be hard for you to do?
 - What makes it hard?
 - What would make it easier for you to do some of these things?
- c. Which of these guidelines would be easiest to do? Why?
- d. How likely do you think you are to follow these guidelines during your pregnancy?
 - PROBE: What would motivate you, or women like you, to follow the guidelines?
- e. What are the benefits to following these guidelines?
- f. What are the costs? (What makes this difficult? What makes this hard to do?)
 - PROBE: What would you have to give up? What would happen if you didn't following these guidelines during your pregnancy?
- g. CMV prevention message might make some moms feel like their child is a threat to their unborn baby. How do you think knowing about and practicing these guidelines would affect your interaction with your child?
- h. Let's talk for a minute about the "kissing" guideline. What did you think about the way that guideline is worded? Is it easy to understand?
 - Kiss young children on the forehead or cheek rather than the lips

Here are some different ways to present that guideline. [DISTRIBUTE ALTERNATIVE WORDING TO KISSING GUIDELINE]:

- ➤ Avoid contact with saliva when kissing a young child.
- Kiss your toddler on the forehead instead of the mouth to avoid contact with saliva. We all love our kids but we don't need to love their germs.

PROBE: Out of the two different versions of this guideline, which of these do you like best?

V. Prevention Message Frames [20 minutes]

The CDC thinks it is important to tell women that congenital CMV is a serious condition they may be exposed to during pregnancy, and that they can prevent infection. They want to motivate pregnant women to take steps to prevent CMV and they want to do this without scaring them. I'd like to get some of your opinions about these different ideas. [DISTRIBUTE CONCEPT A]

CONCEPT A: [CMV IS A SEVERE CONDITION][5 minutes]

- Congenital CMV is a very serious condition
- Some babies born with congenital CMV develop disabilities such as hearing loss, vision loss, or mental disability
- > Congenital CMV is one of the most common causes of birth defects.
- Mark was born with congenital CMV. By nine months old he still could not crawl and did not respond to his name. We had his hearing checked and found out that he had some hearing loss in both ears. As he grew older, Mark also had some trouble walking. Despite these problems, he is now a happy eight year old boy who loves to play video games and laugh.
 - a. Please point out any words or sentences that you do not understand.
 - a. How would you describe the main message of these statements?
 - b. Which of these statements, if any, grab your attention?
 - c. Which statements, if any, do you dislike?
 - PROBE: What are some reasons for that?
 - d. Which of these statements do you like best?
 - PROBE: What are some reasons for that?
 - e. Who do you think these messages are intended for?
 - PROBE: Women like you? Other people?
 - f. How do you think pregnant women will react to statements that focus on the health effects of CMV?
 - PROBE: Will it scare them? Will it turn them off? Will it make them pay more attention?
 - g. Do you have any other comments about these statements?

Ok, now we are going to look at some different statements. [DISTRIBUTE CONCEPT B]

CONCEPT B: [CMV IS COMMON] [5 minutes]

- CMV is the most common congenital infection
- Each year 30,000 babies are born with CMV
- ▶ 1 in 150 babies are born with congenital CMV infection

- ▶ 1 in 750 babies has a disability due to congenital CMV
- Each year 5,500 babies develop disabilities due to congenital CMV
- Congenital CMV causes as much disability in children as Down syndrome, fetal alcohol syndrome, or spina bifida
 - a. Please point out any words or sentences that you do not understand.
 - b. How would you describe the main message of these statements?
 - c. Which of these statements, if any, grab your attention?
 - d. Which statements, if any, do you dislike?
 - PROBE: What are some reasons for that?
 - e. Which of these statements do you like best?
 - PROBE: What are some reasons for that?
 - f. Who do you think these messages are intended for?
 - PROBE: Women like you? Other people?
 - g. What do you think about the statements that talk about the numbers of babies affected by CMV?
 - PROBE: Do the numbers make sense, are they easy to understand? Why or why not?
 - PROBE: How do the numbers make you feel? Scared? More at risk? Less at risk? Why?
 - PROBE: How do you think pregnant women will react to the numbers?
 - *h.* Do you have any other comments about these statements?

And here is a final set of statements I'd like your feedback on. [DISTRIBUTE CONCEPT C]

CONCEPT C: CMV IS PREVENTABLE [5 minutes]

- Congenital CMV is preventable
- You can protect your baby from congenital CMV

A pregnant woman can prevent transmission of CMV by washing hands often and avoiding contact with a young child's urine or saliva

- Studies show that pregnant women can prevent CMV infection by following a few basic prevention guidelines
- Prevent CMV infection when you are pregnant by:
 - Not putting things in your mouth that have just been in a child's mouth. For example: food, cups or silverware, toothbrush, pacifier.
 - o Kissing young children on the forehead or cheek rather than the lips.
 - Washing your hands with soap and water, especially after changing diapers, feeding a child, wiping a child's nose or mouth, or touching a child's toys, pacifier, or other objects that have the child's saliva or urine on them.
 - a. How would you describe the main message of these statements?
 - b. Which of these statements, if any, grab your attention?
 - c. Which statements, if any, do you dislike?
 - PROBE: What are some reasons for that?
 - d. Which of these statements do you like best?
 - PROBE: What are some reasons for that?
 - e. Who do you think these messages are intended for?
 - PROBE: Women like you? Other people?
 - f. Do you have any other comments about these statements?
 - g. Of the three different message concepts we just looked at: CMV is severe, CMV is common, and CMV is preventable, which do you think would be the most effective for women like you?

VI. Review of CMV materials [10 minutes]

Now I'm interested in getting some of your general feedback about a draft factsheet CDC is working on. Please take a few minutes to read it and underline anything you find confusing. [DISTRIBUTE CMV FACTSHEET AND ALLOW TIME TO READ]

a. What are your general thoughts about the factsheet?

■ PROBE: What do you like about it?

PROBE: What do you not like about it?

b. Was it easy to read and understand?

- c. What, if anything, did you find confusing? [DISCUSS WHAT PARTICIPANTS UNDERLINED]
- d. What do you think about the layout and design?
 - PROBE: What did you think about the pictures?
- e. Where would you expect to see a factsheet like this?
 - PROBE: How likely would you be to pick up a factsheet like this? Tell me about that.
- f. Is there any other information about CMV that should be included here?

VII. Communication Preferences [5 minutes]

Let's continue talking about where mothers like you get information about pregnancy, parenting, and health.

- a. What are some of the people and places you turn to for information about pregnancy, parenting, and health?
- b. What are some people and places you would trust for information about CMV?
 - PROBE: What about a government health agency like CDC?
- c. There are many ways to get information about CMV to parents like you. A brochure is only one simple way to do that. Tell me about other formats you think would be effective at getting the message out?
 - PROBE: What about the social media, Facebook, Twitter, etc.?
- d. What about prenatal classes?
- e. Which formats would be most effective for educating other women about CMV?

VIII. Conclusion [5 minutes]

To wrap up, we have one final exercise.

[DISTRIBUTE POSTCARD PAPER] Given everything we've talked about today, please take a minute to write a brief postcard (2 or 3 sentences) to a mom like you telling her the most important things she should know about CMV.

[FALSE CLOSE: CHECK FOR ADDITIONAL QUESTIONS FROM OBSERVERS]

Thank you!