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Appendix E (FGD Guide)

INDIVIDUALS WITH CONGENTIAL HEART DEFECTS:

Focus Group Discussion Guide

Background and Moderator Introduction 10 minutes

Hello and welcome to this discussion session. It's great to see you all. My name is <NAME>. I am an independent researcher and moderator with KRC Research. The sole sponsor of today's focus group is the Centers for Disease Control and Prevention (CDC). However, no one from CDC will be observing today's focus group.

Thank you for your willingness to participate in this conversation and share your experiences. The findings will help the CDC learn about the experiences of people with CHD, like yourselves, in getting both general healthcare and cardiac care, meaning medical care specifically for your heart. We also want to learn how we can help people with CHD get the cardiac care they need. You were selected to participate in this focus group discussion because you reported in our survey that you had not seen a cardiologist or other cardiac specialist in 3 or more years.

I'm a professional researcher, not a CDC employee or subject matter expert on health topics. My role is to facilitate our conversation for the next 90 minutes. Let me tell you a bit about it:

- There are no wrong answers. You may have different opinions. That's ok—all your experiences and opinions are important, and we want to hear from all of you.
- Since we are having these groups online, we will need to talk one at a time and let everyone have time to speak. Not everyone has to answer each question; however, it's important that everyone participates throughout this conversation.
- We will be showing you information on your screen to look at and respond to. If at any time you can't see the screen well or have difficulty hearing, let me know—we have a technician here who can help us with any technical issues.
- Please silence your cell phones and put away portable devices.
- If you need to step away from our discussion for any reason, you don't have to ask for my permission—just step away and come back as soon as you can.

Appendix E (FGD Guide)

Because privacy is important, I'm going to show you our Privacy Policy **[SHOW ON SCREEN AND READ]**

- We will protect your privacy for today's discussion, and nothing you say will be reported in association with your name.

- We will use first names only during this conversation. You may choose to use a nickname or any other name you prefer.

- Your participation is voluntary—you do not have to answer anything you are uncomfortable with.

- Like our technician who is with us today virtually but who you do not see, a few colleagues are also with me virtually to watch quietly and take notes.

- We are digitally recording today's discussion for transcribing purposes. Because we are speaking with other groups similar to this one, it is important for me to have an accurate record of today's conversation.

We ask that you not share any information, participants' comments, or participants' identities with others outside of this group.

Do you have any questions or concerns? **[PAUSE FOR QUESTIONS]**

Participant Introductions 5 minutes

Let's get started by going around and sharing:

- Your first or preferred name

- Where you live (state)

- Something fun you hope to do in the next few months

General Healthcare Experience 10 minutes

Let's start the conversation by discussing your experiences with healthcare. During this discussion, we will be talking about healthcare providers, and I wanted to take this time to explain what we mean by that.

  - Healthcare providers are any people you receive general healthcare from, this could include general or non-cardiac doctors, physician assistants, nurse practitioners, nurses, etc. Healthcare providers are also referred to as a healthcare team.

1. How often do you go to a healthcare provider for general check-ups?
   a. What about if you are sick?

2. Do you have a general healthcare provider that you see regularly? If so, what kind of provider?
   PROBES
   i. *Do you see an OB/gynecologist, primary care provider, family medicine, other?*

3. When you do see a healthcare provider, where do you usually go?
   PROBES
   i. *Do you go to a primary care clinic, urgent care, emergency room, other?*

4. How easy or difficult is it to ask your healthcare provider questions about your health care, treatments, or procedures?
   a. What makes it easy?
   b. What makes it difficult?

5. Have you ever had a conversation with a healthcare provider about your CHD?
   a. Who began the conversation (you or the healthcare provider)?
   b. What type of healthcare provider were they?
   c. What did you discuss during those conversations?
      PROBES
      i. *Did you/they ever discuss concerns regarding your CHD? What about your healthcare goals as a person living with CHD?*

6. If you have not personally discussed your CHD with any of your healthcare providers, why is that?

7. Have any of your healthcare providers ever discussed with you the need to get regular check-ups for your CHD or ever recommended you see a cardiac specialist about your CHD?

8. If so, what type(s) of providers discussed this with you? What did they discuss with you?

Cardiac Healthcare Experience 25 minutes

Next, we'll continue the conversation by focusing on your experiences with cardiac care specifically. We will also be talking about cardiac specialists, and I wanted to explain what we mean by that.

- Cardiac specialists are healthcare providers who focus specifically on or specialize in cardiac care, or care of your heart. For example, this could be a cardiac doctor also known as a cardiologist, or you might also see a physician assistant, or nurse practitioner that specializes in cardiac care.

9. When was the last time you received cardiac care or saw a cardiac specialist?

10. Did a cardiac specialist or doctor ever discuss with you the need to get check-ups for your CHD? Did they recommend that you continue receiving regular cardiac care?

11. Could you share your reasons for not receiving cardiac care since then?
    a. How did or does the prospect of seeking cardiac care make you feel?

12. Have you ever tried to get cardiac care, but couldn't?
    a. Can you describe any barriers you might have encountered related to getting cardiac care in the past?

13. What has been your experience, if any, with finding a clinic or doctor for your CHD?
    PROBES
    i. *How did you find the clinic or doctor for your CHD? Was it easy or difficult for you to find them?*

14. Can you share your past experiences, if any, with clinics that provide cardiac care?
    PROBES
    i. *Have you ever had any bad experiences with cardiac care? Have you had any good experiences? What happened? What did you do?*

15. What has been your greatest challenge, if any, in getting the care that you needed for your CHD?
    PROBES
    i. *Challenges getting care due to travel or distance, language barriers, lack of knowledge of the condition by your doctor, inability to find specialist care, hours of operations for healthcare providers, insurance coverage*
    ii. *For those of you that have insurance coverage, has that played a role in how and where you get care? How so?*

16. Have you ever experienced any potential problems or symptoms with your heart that you think might have been related to your CHD?
    a. Is there a reason why you haven't followed up with a cardiologist about this?

17. Have you faced any other challenges that resulted from not receiving cardiac care? If so, please describe.
    PROBES
    i. *Have you had issues getting medications you might have needed for your CHD? Have you had any health problems that might have been avoided (complications during pregnancy, emergency visits, etc.) if you had received cardiac care?*

Return to Cardiac Care 10 minutes

As we mentioned earlier, you have all been invited to this focus group because you have not been recently seen by a cardiac specialist to get a check-up on your heart.

One of our main goals for this focus group is to figure out how we can help people with CHD to get regular visits with a cardiac specialist. We want to start this next conversation by opening up the floor to ask:

18. Do you have any suggestions or advice on what would encourage people like yourselves to get regular cardiac care? Again, we welcome any thoughts, ideas, or suggestions.

19. Do you have plans to see a cardiac specialist in the near future?
    a. **IF YES:** If so, why?
    b. **IF NO**: If not, what would you need or find helpful to ensure you regularly visit a cardiac specialist for a check-up in the future, even if you aren't currently having problems with your heart?
    c. What, if anything, could a *cardiac specialist* do to encourage you to visit them regularly for a check-up?
    d. What, if anything, could your *general healthcare provider* do to encourage you to visit a cardiac specialist regularly for a check-up? This could be your primary care provider, OB, or any non-cardiac healthcare provider.
    e. What, if anything, could your *family* do to encourage you to visit a cardiac specialist regularly for a check-up?

20. Have you heard or seen any messages saying that people with CHD should receive lifelong cardiac care?
    PROBES
    i. *What do you remember about those messages? Did they motivate you to take any action or return to cardiac care?*

21. If not, would you feel reminded and encouraged to visit a cardiac specialist after hearing or seeing those messages?

22. Would learning about possible consequences of not receiving cardiac care make you more likely to get care? For example, learning that people with CHD who do not get regular care for their heart are three times more likely to eventually need heart surgery or other urgent interventions for their heart.
    a. What about hearing personal stories of people living with CHD?

Health Care Transition 10 minutes

Now, we want to get a better understanding of your experiences moving from your childhood (or pediatric) cardiac care into adult cardiac care. We also would like your thoughts on what would have been helpful to you during this period of transitioning to adult cardiac care, even if you personally did not receive regular cardiac care as a child. Your experiences or suggestions will help us better understand how to help children with CHD as they transition to adult cardiac care in the future. I will open this discussion by asking:

23. When you were younger, what kind of information, if any, did you receive from your doctors or nurses about the need for cardiac care throughout your life?

24. Did your caregiver/family discuss with you the need for cardiac care throughout your life?
    PROBES
    i. *If so, at what age did these conversations take place?*
    ii. *How did you feel about that conversation? Was it clear that lifelong cardiac care is important? Do you think anything could have been done to communicate the reasons more clearly?*

25. What role, if any, do you think your caregivers/families played in preparing you to transition from pediatric to adult cardiac care?

26. For those of you who received cardiac care when younger, when you were an adult, did you change to a healthcare practice that sees adults for cardiac care? When did that happen?

27. Did transitioning to adult care ever impact decision making in your daily life? Such as influencing where you might be able to live or your job?

28. Has anyone transitioned off of their parents' insurance? If so, did you have any difficulty making that transition?

29. Have you had challenges finding healthcare insurance as an adult? If so, what is the cause of those challenges?

30. Finally, do you have any suggestions or advice on what would have made the transition to adult care easier? What would you have liked to experience during this time? Again, we welcome any thoughts, ideas, or suggestions.

Cardiac Defect Information Sources and Knowledge 15 minutes

I'd like to turn our conversation to where you usually learn information about CHD.

31. Where do you learn about or get information about your CHD?
    PROBES
    i. *What is or was your primary source of information on your CHD?*
    ii. *If English is your second language, in what language do you receive your information on CHD?*

32. If you have a question(s) about your CHD, what sources do you use to answer those questions?
    PROBES
    i. *Is there a specific website you use or person you talk with?*

33. Are you aware of any other organizations, websites, or resources that provide information for people living with a CHD?
    PROBES
    i. *What are these organizations/websites/resources?*
    ii. *Can you describe the information they provide?*

34. Can you describe how you have used, if ever, the information provided by these sites or resources?
    PROBES
    i. *Did you use the information to learn more about your CHD?*
    ii. *Did you use this information to help you make decisions on the care you receive(d) for your CHD?*

35. Are you familiar with any recommendations for getting cardiac care for CHD? What recommendations do you recall?
    PROBES
    - *i. What kind of information have you received, if any, about recommended visits to a cardiac specialist?*
    - *ii. How old were you when you first learned this information? Was the information written/oral?*
    - *iii. Did you understand the information and have opportunities to ask any follow-up questions?*

36. Can you describe how you prefer, or would prefer, to receive information about your CHD and the recommended care for your CHD?

37. Think back to the moment you first learned you had a CHD. What was that moment like? How did you feel? What did you experience?
    a. Do you feel like you understood what it would mean to live with a CHD at this time? Or did you come to realize this at another time?
    b. How did you feel when you understood this?

Wrap Up 5 minutes

38. Is there any information you want to know that wasn't covered in our discussion today?

39. Is there anything you'd like to share that we haven't asked about in the focus group discussion around your CHD?

Thank you for your time!