

Appendix E: Community Leader Interview Script and Protocol

Following administration of informed assent/consent and questionnaire.

- This interview will be audio-recorded and last approximately one hour and a half.
- I'll open the interview by asking you some questions about your community, your personal involvement in the community, and for information about your identities as they relate to your community. I'll then ask you some questions about the types of health issues your community experiences before focusing on what health questions your community has and how your community addresses these questions; how you or members of your community share health advice, news, and other resources; and how your community uses health advice, news, and other resources to make changes or decisions.
- After these questions and about mid-way through the interview, I'll ask you to draw what I'm calling your community's "health information world." Here, you'll draw a picture of your community on a piece of paper along with the people, places, and things that provide health information to your community, receive health information from your community, and help your community to make health decisions. There's no right or wrong way to make this drawing.
- We'll then review your drawing together and I'll ask you some follow-up questions about it.
- I may take some notes during the interview. Following the interview, I will share my notes, a transcript of your interview, and a preliminary write-up of findings with you for you to review and comment on. Basically, I want to know if I got it right in capturing information related to your community.
- You do not have to answer any questions you do not want to and can stop the interview at any time.
- Do you have any questions before we get started?
- *Note to interviewer: Italicized words should be replaced with the name of the person's community (if applicable). If not, use "your community."*

Part 1. Open-ended Questions

Opening Discussion

1. Let's start by talking about the word "community." What does the word "community" mean to you?
2. Next, let's talk about *your community*. Please describe *your community*. Start wherever you'd like and include as much or as little detail as you'd like to.

Personal Involvement in Community

3. Now, I'd like to talk about you and your involvement in *your community*. Let's start by having you tell me a bit about yourself and how you came to create or join *your community*. Again, you can start wherever you'd like and include as much or as little detail as you'd like to.
4. Do you consider yourself a leader within *your community*? Why or why not?

Personal and Community Identity

5. I now want to talk a bit about your personal identities, as well as the identities of others in *your community*. Let's start with you. When describing yourself to others, what do you say?
6. Is there a difference between how you describe yourself to others and how you prefer to be described? If so, why?
 - a. Does this differ depending on to whom you are describing yourself? If so, how? Why?
7. Do you have any other important identities we didn't address that you think I should know about?
8. Now let's move onto *your community*. What are the potential identities you're *your community* members have in common?
9. Is there a difference between how you describe *your community* to others and how you talk about *your community* with other members? If so, why?
 - a. Does this differ depending on to whom you are talking? If so, how? Why?
10. Are there any other important identities *your community* members have that you think I should know about?

Community Health Issues

11. Let's shift gears and talk about the role or roles that health plays within *your community*. Tell me about them in as much or as little detail as you'd like.
12. What do *your community* members do to stay healthy?
 - a. What helps *your community* members be healthy?
13. What health issues do *your community* members experience?
 - a. What prevents *your community* members from being healthy?
14. What types of health questions or concerns does your community have?
 - a. How does your community deal with these questions or concerns?
 - b. What barriers or obstacles does your community experience when addressing these questions or concerns?
15. Who or what helps *your community* members the most in dealing with its health questions or concerns?
 - a. Does *your community* ever make changes or decisions based on this information?
 - b. Does *your community* ever pass this information along to someone else?
16. Does *your community* ever receive health advice, news, or resources it did not ask for?
 - a. Who or what provides them?
 - b. What does your community think of the advice, news, or resources?
17. From whom or what would your community never want health advice, news, or resources? Why not?
18. Does your community have any health questions or concerns that it hasn't found the answer to yet?
 - a. What do you think will happen with these questions or concerns? Will the community try to find answers in some way? Why or why not?
 - b. If not, what would need to change for the community to deal with these questions or concerns?

19. Is there any information that you wish your community had to address these questions or concerns that it doesn't?
20. Are there people who come to your community with health questions or concerns?
 - a. Why do they come to your community? What do you do when they come to you?
21. Has your community ever created a resource like a handout, website, or video to address other people's health questions or concerns?
 - a. What did your community create? What motivated your community to create the resource? For whom were the resources created?

Information Worlds Mapping

- *Participants will receive a handout to accompany this explanation.*
- Now I'm going to ask you to draw what we're calling your "health information world." You're going to draw *your community* on this piece of paper then add the people, places, and things that provide health information to *your community*, receive health information from *your community*, and help *your community* members to make health decisions.
- There is no right or wrong way to draw this health information world.
- Things to consider including in your information world:
 - How and where *your community* looks for answers when it has a health question or concern
 - How and where *your community* receives information about health questions and concerns it's not necessarily looking for
 - People *your community* shares health advice, news, and resources with, or creates health resources for
 - People, places, and things that help *your community* understand its health questions or concerns, or help them make decisions about their health questions or concerns
 - Health-related advice, news, and resources *your community* wants versus those it doesn't want
 - Ways or places *your community* stores or remembers information for later
 - Places – physical or virtual – where *your community* interacts with health information
- You can describe what you're doing as you draw or do it without talking.
- You can take whatever time you need to draw this, just let me know when you have finished. Then, I'm going to ask you about what you drew.

Information Worlds Mapping

22. I'd like to have you talk about your drawing. Can you explain to me what's going on in the drawing? If you've used abbreviations in your drawing it would also really help if you clarified the names for me. Also, if you notice that there's something missing on the map as we're talking – don't worry, you can draw it in.
 - a. ***As interviewee is describing their drawing, ask them to tell you more about specific sections of the map.***

- b. *Ask interviewee if they can provide examples as they are showing the drawing. For instance, if they show a drawing of news media and say that news media is where their community gets information, ask them to provide an example or memorable moment when their community got information from news media. What happened with it?*

Closing Questions

- Thank you again for taking the time to talk with me today. I now want to ask you a few closing questions to wrap up.
23. May I take your drawing to help me analyze data for my project?
 24. What do you think is important for researchers like me to know about the experiences of *your community* members in general? How about their health experiences?
 25. Are there any other further insights, opinions, or feelings that you would like to share?
 26. Are there any questions you think I should have asked that I didn't?
 27. Do you have any leaders you could recommend participating in this study? If so, what is the best approach to contacting them?
 28. Finally, do you have any members of your community that you could recommend to participate in a future study? If so, what is the best approach to contacting them?

Closing Information

- Thank you again for participating in this study. I am giving you a handout with my information. Please contact me with any questions you might have about the study, including its progress, follow-up questions about the data collected, etcetera. This handout also has contact information for our institutional review board (IRB). You can contact the IRB with any questions or concerns that you have about your rights as a study participant.
- Once I have a draft write-up of my findings, I want to send it to all study participants for review. Please note that you'll only be referred to using your pseudonym, or fake name, in all write-ups of the study results. When I provide you with the write-up, I'll ask you to comment on whether I got it right. In other words, how well did the write-up capture what you told me during the interview? In addition, I want to make sure that I'm protecting your confidentiality, so if I've included any information that you feel uncomfortable with, I want to know. Can you provide me with a preferred email address to send you this write-up?