

Attachment E. Focus Group Discussion Guide

Protocol for WTCHP Members

Public reporting of this collection of information is estimated to average 2 hours per response, including the time for reviewing instructions and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a current valid OMB number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road NE, MS D-74, Atlanta, GA, 30033; ATTN: PRA (0920-XXXX).

Welcome, Ground Rules, Consent (10 minutes)

Thank you for joining us for this discussion of the World Trade Center Health Program.

My name is *** and I'm a *** at the RAND Corporation. For those of you who are not familiar with RAND, we are a nonprofit, nonpartisan, research organization that is committed to the public interest.

[Co-facilitator]: And I'm ****. I'm a *** at RAND.

The purpose of the discussion today is to hear your perspectives on the World Trade Center Health Program, and specifically, your thoughts on the Program's *research mission*. The World Trade Center Health Program contracted with the RAND Corporation to develop evidence that will the WTCHP in program planning and decisionmaking. Your unique perspectives on the Program will help inform our recommendations to the Program on translating research findings into better care for Members.

This meeting will last 2 hours. We're going to discuss several topics related to your experiences with the World Trade Center Health Program, starting with your thoughts on research and how research gets translated into patient care specifically; then focusing on the research topics that the Program has prioritized so far; then the use of research for different purposes; and finishing with your perspectives on the processes the WTCHP uses to achieve its research mission. In order to get through all of the questions we have in our allotted time, my colleague *** will help me move through the topics in a timely fashion. Please be aware that if we are running over time on any one question, we may have to move on to the next topic.

We'll first explain our procedures for protecting your privacy and then ask for your consent to participate and be recorded. Then, at the end of our meeting, we'll hand out a brief, anonymous survey about yourself that should take about a minute or less to complete.

RAND will use the information you provide during this focus group for research purposes only. We hope you will feel comfortable sharing your honest opinions based on your own experiences,

and there are no right or wrong answers. Participation is voluntary and you do not have to answer any question you are not comfortable answering. In our written reports, comments will not be linked to you or your organization. In conversations you may have outside of this focus group, we ask that you protect the privacy of others in this meeting. Please do not repeat anything that is said here so that feedback from other groups members is protected. Comments will not be attributed to a particular person or organization.

This meeting will be recorded because we don't want to miss anything that you say. The recording will be transcribed and the transcripts will be stripped of any information that could identify you later. After removing all identifying information from the transcripts, the recordings and the original transcripts will be destroyed.

Does anyone have any questions about the purpose of this focus group, our privacy procedures, or anything else that I've mentioned so far?

Now, I'll go around the room and ask you one by one for your consent to participate in this focus group and to be recorded.

[To each participant]: Do you consent to participate in this discussion and to be recorded?

[If everyone consents to participate and be recorded, start the recording and note the start time for the focus group. If anyone does not consent, ask that person to please excuse him/herself and wait until the individual has left the room before starting the recording.]

Focus Group Participant Introductions (10 minutes)

We're going to start with introductions so everyone knows who's [on the phone/in the room].

1. [Go around the room/phone] 1. Could each of you please describe what your specific role is in the program, or how you interact with the WTCHP?

The WTCHP and Research: Overview (15 minutes)

Thank you for those introductions.

The WTCHP carries out many different activities, including research.

2. . Why do you think that the WTCHP includes a research mission?

Probes

- Ideally:
 - o Who is using research?
 - o Who should be using the research?
 - o Who should be using the research?

- o How should the research be used?

The WTCHP has come up with a list of short-, medium-, and long-term outcomes that it aims to achieve through its research. [Show the slide and give a moment to think about the list]

3. What do you think about these outcomes?

Follow up questions:

- Is there anything that you would add to what's shown here?
- Any you would change or take away?

WTCHP Research Priorities (30 minutes)

Next, we'll discuss research that's supported by the WTCHP. The program has focused on several broad **research areas**, some of which were specified in the original Zadroga Act [the Act that established the WTCHP] and others that have emerged over time. The research areas include cardiovascular disease (or heart disease), cancer, mental health, and the others shown here: [show slide with the following topics as a word cloud to avoid ranking them, and provide a footnote defining which emerging conditions have been studied): adult mental health, cardiovascular disease, emerging conditions; note to moderator: includes Hepatitis C, autoimmune disease, cognitive function, kidney disease, among others; WTC youth, respiratory disease (or lung disease), and exposure assessment (or, what things in the environment people at the 9/11 site were exposed to). Give people 1 minutes to scan slide].

4. What do you think about this list of research topics?

Probes:

- Which of these topics are most relevant to you? And why?
- Which of these seem the most relevant to WTCHP leadership, or people who make policy decisions about the program itself? Why?
- What research areas do you think are missing from this list?

Now I'm going to show a slide that ranks the research topics by the amount of research funding that each has received from the WTCHP. [Show slide that ranks them as follows: 1. Respiratory disease, 2. Adult mental health, 3. Cancer, 4. WTC youth, 5. Cardiovascular disease, 6. Emerging conditions, 7. Exposure assessment].

5. What do you think about this ranking? And why?

Probes:

- What would you change? And why?

6. What are the most important questions about the health effects of the 9/11 attacks? And are these the questions being answered by the research the WTCHP supports?

Probes, some questions might include:

- What health conditions are more common among people exposed to the 9/11 attacks?
- How should [*survivors or first responders, depending on stakeholder group*] be screened and monitored over time for health effects of 9/11?
- How should [*survivors or first responders, depending on stakeholder group*] be best treated?
- What are the links between the 9/11 events and associated health conditions?
- What special groups should be studied in more detail, such as children and youth; pregnant women; elderly populations?

How research is communicated (45 minutes)

Thank you. Now that we've discussed some of the important research topics and questions, we'll now talk about the use of this research.

7. How have you learned about [for non-Members: stayed up to date on the latest] WTCHP research findings? How would you like to learn about WTCHP research in the future?

8. When research is first getting started, how are you hearing about it then? Provide specific examples if you can.

9. What is standing in the way of you being connected to WTCHP research?

10. What makes it possible for you to be connected to research?

Concluding Points and Demographic Survey (10 minutes)

That concludes our prepared questions for this focus group.

11. Before we wrap up, is there anything else that has come to mind during the course of this discussion, or important points about research within the WTCHP that you wanted to bring up?

Thanks to you all for taking time to participate in today's focus group. Your feedback has been incredibly informative and we appreciate your time. If you have any questions after we conclude, please email the study team at hiatt@rand.org. Finally, the timeline for this project spans the next few years or so. Some of you may be contacted in the future for follow-up questions. If you would prefer not to be contacted again for this project, please email us that as well. We'll present preliminary findings from this work to different communities involved in the World Trade Center Health Program during the course of the project, and you will all be notified when our final report to NIOSH is completed. One last request: we would be grateful if you could all fill

out a very brief, anonymous survey about yourself. Thanks again very much for participating and have a great rest of your day.