

Public reporting of this collection of information is estimated to average 1 hour 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 (xxx-XXXX).

WTCHP Impact Assessment and Strategic Planning
In-depth Interview Discussion Guide

60 minutes

20 stakeholders from 3 groups: NIOSH, Researchers, Research Users

Introduction and Consent (5 minutes)

[Send consent form in advance by email when confirming the interview and reference it here.]
First of all, thank you [NAME] for taking the time to speak with us about the World Trade Center Health Program.

My name is *** and I'm a *** at the RAND Corporation. My research focuses on ****. In case you aren't familiar with RAND, we are a nonprofit, nonpartisan, research organization. RAND's research and analysis addresses issues that affect people around the world including health, education, security, justice, and the environment, among many other areas.

The purpose of this 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 conduct an evaluation of the Program's translational research efforts, which we'll talk about in a few minutes. Your unique perspectives on the Program will help inform our recommendations to the Program on translating research findings into better care for Members.

Our conversation will last about 1 hour. We're going to discuss several topics related to your own experiences with the World Trade Center Health Program, and if you participated in one of the focus groups we held in ****, you'll notice that some of our questions build on what we discussed during those meetings. We'll start by sharing with you the key findings from a large systematic review of WTC research that we've recently completed, and ask for your reactions to those findings, then we'll cover some other topics like the impact of research, the translation of research into better care, the future of the WTCHP, and how stakeholders could and should be involved in setting program priorities.

[If relevant: As we did in the focus groups,] we'll first explain our procedures for protecting your privacy and then ask for your consent to participate and have this phone interview recorded. Then, at the end of our conversation, we'll ask you to fill out a brief, anonymous survey about yourself that should take less than a minute to complete.

RAND will use the information you provide during this discussion for research purposes only. We hope you will feel comfortable sharing your honest opinions based on your own experiences. There are no right or wrong answers. Your comments will not be attributed to you by name or by your organization.

This conversation will be recorded because we don't want to miss anything that you say. The recording will be transcribed (that is, written out) 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.

Do you have any questions about the purpose of this discussion, our privacy procedures, or anything else that I've mentioned so far?

Do you agree to participate and to be recorded?

[If yes, start the recording and note the start time. If the person does not consent, thank them for their time and end the interview].

Perspectives on the Evidence Map from the Systematic Review (15 min)

As part of this project, we reviewed over 1100 published articles, reports, white papers, and other documents about the health impacts of 9/11 in order to understand what *has* and *has not* been studied on this topic so far. We would like to get your perspectives on 3-4 of the key things that we found in this review. We'll ask you to reflect on each of them one by one. [Refer them to the document that they had received prior to the interview where they can find the figures, notionally, a PDF that was emailed to them upon confirmation of the interview. Tailor the findings from the evidence review to the type of stakeholder that is being interviewed; either provide results verbally or in diagrams or visual aids]

For each figure that represents a key finding most relevant to the particular stakeholder, ask the following question and probes:

- First of all, what questions do you have about this figure--can I clarify anything before we continue?
- What are your impressions of this finding? What strikes you?
 - o Probe: *is this surprising or what you would have expected? Why is that the case?*
 - o Probe: *In your opinion, is there anything about this result that impresses you? Concerns you?*
 - o Probe: *What is missing from this figure?*
 - o Probe, if relevant: *We're interested in exploring if what we've found in the systematic review aligns with [alternative: reflects] what stakeholders like you think is most important to study about the health effects of 9/11. In other words, are YOUR concerns reflected in this research? With that in mind, is there anything else you'd like to comment on about this finding?*

Proposed figures to discuss:

- *Topics that have been studied both overall and specifically by the WTCHP.*
- *Populations/sub-populations that have been studied.*

- *Types of studies that have been conducted (exposure assessments, interventional studies).*
- *Adherence to translational principles [define in the prompts to each figure]*
- *Evidence of WTCHP research's impact.*
- *For NIOSH and Researchers only, show side-by-side comparisons of the field overall and the WTCHP-funded research specifically for the figures above.*

Translation of Research and Impact (15 min)

The WTCHP aims to support research that will be used to make a difference in people's lives—this is what we mean by translation of research. There are three characteristics of translational research –specifically, research should be relevant, transparent, and useful. In this part of our conversation, we are interested in understanding how relevant the research is (meaning to what extent stakeholders are involved before research starts so the research addresses their concerns); we are also interested in how transparent it is, which involves communication and openness with stakeholders about how research is carried out; and finally, how useful the research is to support decisions made in the real world.

Relevance

- [For Research Users]: Knowing what you know about WTC-related research, do you think it's relevant to you and other [insert stakeholder type]? Why or why not? What research topics or types of studies are particularly relevant to you? [*Clarify if needed: Do you think the research relates to your concerns and interests as a STAKEHOLDER TYPE*]
- [For NIOSH and Researchers]: when you think about WTC-related research, what topics or types of studies are most relevant to you?

Transparency

- To what extent do you feel you understand **how** WTC research is carried out? If so, what has contributed to your understanding? If not, why not?
 - *Probe: Do you feel that how the research is being conducted is communicated appropriately to [your stakeholder group] and other stakeholder groups?*
- Earlier we showed you the results of our literature review and the key findings. Do you feel you have an understanding of **why** WTC research has been focused on certain areas [i.e., main topics, populations, study types]?
- Now we want to ask you about your familiarity with research **findings**. Could you describe for us your understanding of the most important findings that have come out of WTC research? If you are unfamiliar with any research findings, just let us know.

Usefulness

- In what situations has WTC-related research been useful [*start with the participant individually, then broaden to other stakeholders like them and other stakeholder groups*]? Why or why not?
 - *Probes/examples: treating your patients, issuing funding opportunity announcements, communicating with loved ones or work colleagues about health concerns/conditions, talking to your doctor, doing advocacy work,*

recommending certain health conditions for consideration for the list of covered conditions, implementing clinical protocols or making changes to your clinical programs and policies.

- [If interviewee provides a response, follow with]: in what other situations could WTC-related research be useful?
- [If none given], can you think of any situations in which WTC research could be useful to help you make decisions? [*provide a stakeholder-specific example if needed*].
- To what degree do you find WTC research to be accessible?
 - *Probe: Is it disseminated in venues that are relevant to you?*
 - *Probe: How can researchers make the results of WTC research more accessible and understandable to [you and others in your shoes/non-researchers]?*

One good way to assess all of this is to think about the extent to which research has helped people make decisions they need to make. We'd like to know whether and how WTC research has made a difference in the real world.

- Where or how do you think research on 9/11 and health has made an impact?
 - Specifically, to what extent do you think that the health and wellbeing of [program members/you/your patients, *depending on the stakeholder*] has improved as a result of research? Can you explain why or why not (*probes: increased knowledge about health conditions, better self-care or changes in care seeking, changes in how one delivers patient care, etc.*).
 - The other long-term goal of the research mission of the WTCHP is to improve response to future disasters [*clarify if needed: events like 9/11 and other disasters, whether natural or manmade*]. What are your thoughts on whether WTC-related research is contributing to that goal? Why or why not?

Looking Ahead: Future of the WTCHP and Strategic Planning (20 min)

This last set of questions has to do with the future of the WTCHP. The program is unique in that it has been funded by Congress out to 2090. There are certainly going to be a lot of changes we can't even imagine to healthcare and health in general, as well as disaster response between now and 70 years into the future.

Program challenges and opportunities

- What challenges might the WTCHP's research mission face over this timeframe?
 - Probe: What do you think might be the major challenges to sustaining a research program until 2090? (examples: engagement, momentum, uncertainty, others).*
- What opportunities might arise for WTCHP research? (*examples: research advances, data and technology advances, the passage of time allows for longer follow-up/offspring studies*).
- Can you think of any new or emerging research questions about 9/11 and health that could arise in the near or long term?
 - Probe/examples: genetic susceptibility, epigenetics, offspring studies, intergenerational effects of disasters, new models of health service delivery to affected populations.*

- [For Members]: Are there particular areas of research about 9/11 and health, or disaster response in general, or unanswered questions that you think might come up over time?

Program accomplishments

- From your perspective, what would you hope the WTCHP will have accomplished by 2090 when it's slated to end, in order to say that it has been a success?
- What questions would you hope to have answers to by 2090?
 - *Probes: questions on the health effects of 9/11; clinical care for 9/11 conditions; how to respond to future disasters.*

Program management

- What big-picture advice would you like to give to future NIOSH leaders about how they carry out the research mission of the WTCHP?
- Planning for the future of the program is an ongoing process. How do you think NIOSH might approach **planning** for the future of the WTCHP, including how they set funding priorities, make course corrections [*define if needed as: changing course if the program runs into challenges*], and respond to changes between now and 2090? [*provide examples if needed*].
 - [For research users only:] How are you involved in planning for the future of the program?
 - How would you like to see [name their stakeholder community] be involved in planning for the future of the program?
 - At what stages of the process? [*provide examples if needed*].

Concluding Questions and Wrap-up (3 min + 2 min demographic survey)

We've come to the end of the interview. Thank you very much for sharing your perspectives with us today. Is there anything else we didn't cover?

[Concluding statements, next steps and when results will be shared, and instructions on completing the brief online demographic survey].