

Attachment 1: Focus Group Protocol

The Public Health Service Act provides us with the authority to do this research (42 United States Code 242k). All information which would permit identification of any individual, a practice, or an establishment will be held confidential, will be used for statistical purposes only by NCHS staff, contractors, and agents only when required and with necessary controls, and will not be disclosed or released to other persons without the consent of the individual or the establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).

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Form Approved OMB #0920-0222; Expiration Date: 07/31/2018

[NOTE: The focus group discussions will use the following protocol as a general guide. However, as is typical with focus groups, the moderator will allow the discussion to proceed naturally, and therefore the protocol may not be administered either completely or chronologically. Furthermore, as discussed in the 10-day letter, different groups will explore different materials.]

1. Introduction

Welcome. My name is _____. Before we start, I want to make sure that you understand who we are and why you're here. We are the Collaborating Center for Questionnaire Design and Evaluation Research in the National Center for Health Statistics at the Centers for Disease Control and Prevention (CDC) and our expertise is the design, refinement and testing of surveys.

2. Overview and Group Rules

Before we continue, I'd like to go over some general information, establish some ground rules for our focus group, and tell you about the confidentiality procedures we have in place.

I would like you to know that in our focus group today, you don't have to reveal anything that you are not comfortable revealing.

For purposes of the group discussion, we'd like you to pick a name that you would like to be called— a first name is fine, it doesn't even have to be your real name. [ASK THEM TO FILL OUT NAME CARDS.]

The consent form you just signed assures you that we will keep your information confidential. We would also like to ask everyone to treat this focus group as confidential. That is, if you learn anything private about another member of the group, we ask that you do not share this information with anyone outside of this room. Although we are required by federal law to keep information private, we cannot guarantee that everyone else will honor your privacy. All we can do is ask that people please agree to that. And again, you should never feel obligated to share any information that you are not comfortable sharing.

We are planning to [video/audio] record this focus group. This is for note-taking purposes in case we miss anything that was said. We will use the recording to double-check our notes and make sure they are complete. Only Center for Questionnaire Design and Evaluation Research staff will have access to the recordings.

One of the great things about this discussion is the “group dynamic” – ideas that one person raises will remind someone else of a related issue. That’s great, feel free to speak up. But please don’t interrupt each other. We ask that there be only one speaker at a time so that responses can be accurately recorded. You may have more or less to say about some topics than others, and that’s OK too.

Don’t feel like you have to agree or disagree with anyone in this room. We want to hear about your personal experiences and thoughts and it’s OK to disagree with someone else. But please be respectful of the opinions or experiences of others in the room.

Sometimes groups start talking about subjects that are off the main topic. That’s natural; but please don’t be offended if we steer the conversation back to the material we need to cover.

As a courtesy to everyone, please turn off cell phones. The focus group will last no longer than 90 minutes. We will not have breaks built into it, but should you need to go to the restroom during the focus group, please feel free to leave. However, I would appreciate it if you would go one at a time.

Does anyone have any questions before we get started?

3. Existing NHANES Protocol

- a. Participants will be shown the following NHANES contact materials and messages.
 - i. Advance Postcard (Appendix 8, pages 2-3)
 - ii. Advance Letter (Appendix 8, page 5)
 - iii. Example Refusal Letter 1 (Appendix 8, page 7)
- b. Moderators will probe participants on the messages that they believe each piece of material conveys.
- c. Moderators will also attempt to understand if the materials, and the messages each piece contains, work to either engage or deter the participants.
- d. Freelists: Respondents will be asked to freelist the following (which will be analyzed across all of the FG participants). Freelisting is a well-established social science method wherein participants are asked to write down all the things they can think of in a given social domain (i.e. the benefits of participating in NHANES). These individual-level lists can then be analyzed to find the most culturally-salient members of the domain.
 - i. Benefits of participating in NHANES
 - ii. Why they would not agree to participate in NHANES

4. Proposed NHANES Materials (Note that the Advance Postcard and Advance Letter are the same in both the Existing and Proposed materials—see pages 1-5 of both Appendices 8 and 9. We will only discuss the advance materials once. They are included in both appendices because we may choose to only discuss the proposed material in some focus groups—see for instance Protocol Structure 3 captured in the 10-day letter.)

- a. After going through the current materials and discussing them, participants will be shown the following proposed materials and videos
 - i. Advance Postcard (Appendix 9, pages 2-3)
 - ii. Advance Letter (Appendix 9, page 5)
 - iii. Example “Scratch-Off” Refusal Postcard (Appendix 9, pages 7-9)
 - iv. Example Text-Only Refusal Postcard (Appendix 9, pages 11-13)
 - v. Animated Video (https://youtu.be/Uv4K_DtvBgc)
- b. Again, moderators will probe participants on the messages that they believe each piece of material conveys.

- c. Moderators will also attempt to understand if the materials, and the messages each piece contains, work to either engage or deter the participants.
- d. Freelists: Respondents will be asked to freelist the following (which will be analyzed across all of the FG participants)
 - i. Benefits of participating in NHANES
 - ii. Why they would not agree to participate in NHANES

5. General Discussion

- a. After all the material has been shown and discussed, the moderators will conclude by circling back to points that participants had mentioned previously, as well as some or all of the following:
 - i. Beliefs and expectations of privacy and confidentiality from NHANES
 - ii. Benefits and challenges to participating in federal health surveys
 - iii. Importance of federal health statistics and data
- b. In addition to this general discussion, if any of the following areas have not been discussed during the groups, we will bring them up at this time:
 - i. The acceptability of receiving a “scratch-off” card from the government
 - ii. The general feelings of legitimacy when receiving similar material from the government
 - iii. How participants determine whether or not something they receive in the mail is a scam
 - iv. Interest in getting health information from NHANES as compared to from a doctor

6. Wrap-Up

OK. We are pretty much out of time. Does anyone have any last thoughts or questions? I want to thank all of you for coming today and sharing your opinions. The information you’ve shared today will be very useful in helping to improve how we reach out to people and ask them to participate in our surveys.