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Cognitive Interview Protocol - HINTS V - CYCLE 1

Thank you for agreeing to come in today. Let me tell you a little about Westat and what we're going to do today.

Westat is a research company that conducts research on many different topics, under contract with many different organizations. This particular project is for the National Institutes of Health, specifically, the National Cancer Institute. Westat has been contracted to conduct a survey about how adults in the United States get information about health, and other related topics such as their attitudes and behaviors regarding health. For this survey we will be sending questionnaires out in the mail to thousands of people nationwide.

At this stage we are still developing the questionnaire and trying to figure out how to make it as easy as possible for people to understand and fill out correctly. So that is what you'll be helping us with - I'll have you look at and fill out the questionnaire to see what your reaction is to it, and what difficulties you have with it.

Before we get started, I want to let you know that everything we cover in the interview will be kept private - only the few people actually working on the project will have access to the information you share with us. If there are any questions you don't want to answer that is perfectly fine - We're really more interested in how you interpret the questions.

ATTACHMENT F: INTERVIEW PROTOCOL

If it's OK with you, I would like to tape our conversation, just so that I can review it later when we're analyzing all the interview data.

IF NECESSARY: And finally, some of our colleagues from the National Cancer Institute are here today - behind the mirror - to observe and see for themselves how the questions work.

CONSENT FORM: *Here is a form I must ask you to look over and sign - it basically covers the points I've just gone over with you and indicates you have agreed to take part (ONE COPY FOR RESPONDENT, ONE COPY FOR US)*

ATTACHMENT F: INTERVIEW PROTOCOL

So let's move on. I'd like you to fill it out the best you can, but let me say a few things first...

- *I'd like you to read aloud as you go along – just read the question and whatever your answer is. I'm going to be filling in your answers on my copy.*
- *As much as possible, just read and respond to this the way you think you normally would if you were at home doing this on your own. Again, some people might read practically every word they see, while others might be inclined to skip stuff here and there – just do whatever feels right to you.*
- *Please share whatever reactions come to mind while you're filling it out. We're especially interested in knowing about things that confuse you, such as when you're not quite sure what a question is asking you – just let me know when that happens.*
- *Finally, we'll pause now and then to discuss something about a question – I might ask you to tell me why you answered the way you did, or ask you to tell me in your own words what you think the question is asking.*

ANY QUESTIONS?

HAND RESPONDENT THE QUESTIONNAIRE.

INTERVIEWERS, PLEASE NOTE:

- Fill out your copy of the questionnaire as the respondent says his/her answers – it will help with the probing.
- When respondents miss a skip instruction let them proceed and on their own unless they appear confused by a question not applying to them. When this happens, point out the skip instruction and show them where to go next. If appropriate, probe on what happened at the skip instruction initially.
- Observe carefully and probe as appropriate for potential misinterpretations, inability to recall, failures to answer, missing response choices, or anything else that may result in response error. Clues to look for include taking a long time to answer, having to read a question more than once, changing one's answer, and body language (e.g., *I noticed it took you longer to answer that question than most of the other questions here – what were you thinking about there?* OR *I noticed you got a funny look on your face when you read that question – can you tell me what that was about?*)
- **In general, do your probing once the respondent has completed the section.** Focus the respondent on a question by saying something like *“Let’s talk about question B6.”* The main exception is when a respondent is showing clear difficulty/confusion with a question – in that case, probe immediately.

QUESTIONNAIRE SECTION B (USING THE INTERNET TO FIND INFORMATION)

Have respondent answer entire section before probing

B1-B2: Do not probe

B3:

Can you tell me about the different ways you access the internet?

-Confirm that this aligns with their answers to B2 as well]

Probe any NA responses or if they mark Daily or Sometimes for g - Other

B4:

Only probe if their answer seems inconsistent with B5 (Basic cell phone + Uses App; I don't have any + Uses App)

B5:

IF YES – How did you come up with your answer? Can you tell me about the apps that you are referring to? What are they called? Do you use them?

IF NO, DK or DO NOT HAVE... - Tell me what you were thinking about when you answered this question. Have you heard of 'apps'?

B6a,b,c:

IF YES - How did you come up with your answer?

IF ALL ARE NO – Confirm whether or not they use the apps – if they do then try and determine how they use them.

B7:

IF YES – How did you come up with your answer? What did you use? When did you use it?

-Are they referring to the same thing as B5 & B6?

IF NO or DK – How did you come up with your answer? Can you say in your own words what this question is asking?

IF B5 ≠ B7 – If not apparent, try and determine the difference between the answers

IF B5 = B7 - If not apparent, Do you think B7 and B5 are asking about the same thing or different things?

B8:

IF YES – Can you tell me about your answer?

IF NO – What does it mean to 'share health information from the monitoring device...' ?

IF DK – How did you come up with your answer? Can you say in your own words what this question is asking?

B9-B10: Do not probe.

ATTACHMENT F: INTERVIEW PROTOCOL

B11: IF YES-Tell me about your answer.

IF NO- Have you ever done this before? What kind of text messages might you receive from a healthcare provider?

QUESTIONNAIRE SECTION C (YOUR HEALTH CARE)

Have respondent answer entire section.

C1-C6: Do not probe

C7a-f:

IF YES: *For each of these that you answered Yes to, Can you tell me about your answer?*

IF NO: [choose 2 or 3] *Can you say in your own words what ___ is asking about? Have you ever experienced any of these?*

QUESTIONNAIRE SECTION D (MEDICAL RECORDS)

Have respondent answer entire section.

Before retrospective probing – *This section is called ‘medical records’– what do you think of when you see the term ‘medical record’?*

D1: Do not probe unless they express confusion

D2:

Can you say in your own words what this question is asking? Do you have a doctor that you see most often? How often?

IF YES – *How do you know that they maintain your medical information in a computerized system?*

IF NO – *How do they maintain your medical records?*

D3:

IF YES – *Can you tell me about your answer? What specifically did you request to send? Where did you request that it be sent?*

IF NO – *Can you say in your own words what this question is asking? Have you ever requested that your medical record be sent electronically?*

D4:

IF NO or DK – *Can you tell me about your answer?*

D5:

ATTACHMENT F: INTERVIEW PROTOCOL

IF YES – *Can you tell me about your answer? What specifically were you given access to? What does it mean to be given ‘direct access’...?*

IF NO – *Can you say in your own words what this question is asking? Have you ever been given access to test results from a lab? What does it mean to be given ‘direct access’...?*

D6:

Only probe if there’s confusion

D7a-b:

What does your “health care provider” mean? What does your “health insurer” mean?

IF YES - *Can you tell me about your answer? What were you offered access to? [medical record? lab results? Something else?]*

IF BOTH = NO - *Who offered you online access to your medical information?*

D7 SKIP: VERIFY THAT THEY NOTICED THE SKIP

D8:

IF >= 1 TO 2 TIMES- *Can you tell me about your answer? What does it mean to access medical information ‘1 time’?*

IF NONE - *Can you say in your own words what this question is asking?*

D9a-g:

IF YES – [choose 2 or 3] – *Can you tell me about your answer?*

IF NO – [choose 3 or 3] – *Can you say in your own words what this question is asking?*

D9 SKIP: VERIFY THAT THEY NOTICED THE SKIP

D10:

Probe for familiarity with the 3 types of access and the terms used (portal, software, personal health record)

Probe any response for meaning

D11:

Probe any response for meaning

Can you tell me about your answer? What information did you look at?

[IF THEY LOOKED AT > 1 TYPE OF INFO] Was all of it ____ to understand?

D12:

Can you say in your own words what this question is asking?

Probe any response for meaning

ATTACHMENT F: INTERVIEW PROTOCOL

D13a-g:

Probe for familiarity with terms used (clinical notes; immunization history)

Confirm that they're referring to their *online* MR.

IF YES - *Can you tell me about your answer?*

IF ALL = NO & D8 > None - try and determine what information they accessed.

IF DK - *Can you tell me about your answer?*

D14a-m:

Probe for familiarity with terms used (track goals; securely message)

IF YES - *For each of these that you answered Yes to, Can you tell me about your answer?*

Confirm that activity was done *online*

Confirm whether they're double counting any behaviors in different answers

IF ALL = NO & D8 > None - try and determine what they did with their OMR.

IF DK - *Can you tell me about your answer?*

D15a-c:

Probe any Yes response for meaning

IF YES - Confirm that activity was done *electronically*

IF NO - Could you provide an example of someone doing each of these activities?

IF DK - *Can you tell me about your answer?*

D16: Tell me about your answer.

D17- D19: Do not probe unless they express confusion

D20:

Can you say in your own words what this question is asking?

Probe any Yes response for meaning.

Confirm that they noticed the clause 'with a medical/behavioral/disability/other condition'

Confirm that they didn't double count anyone (for example, their Mother as a parent and a close family member)

D21:

How did you come up with your answer? What types of activities did you include when coming up with your answer? How easy or difficult was it to answer this question?

IF D20 > 1 PERSON: Is this the total number of hours for all people, or for just one person? An average for all people?

ATTACHMENT F: INTERVIEW PROTOCOL

D22:

Can you say in your own words what this question is asking? How easy or difficult was it to answer this question?

Probe for familiarity with terms used (Alzheimer's; orthopedic/musculoskeletal; chronic conditions; neurological/developmental issues; acute conditions)

IF they selected > 1 person in D20 – *How did you decide which care-recipient to answer on behalf of?*

IF MULTIPLE SELECTIONS: Confirm that they didn't double count any condition in multiple categories erroneously

D23:

IF they selected > 1 person in D20 – *How did you decide which care-recipient to answer on behalf of?*

D24:

How did you come up with your answer?

Confirm that they understand difference between a & b.

SECTION E (MEDICAL RESEARCH)

Administer entire section

E1:

Probe as needed to get a sense of respondents' understanding of 'genetic test' as defined in this question. Note any signs of confusion or difficulty and probe as needed.

E2:

Probe any endorsed response for meaning.

E3:

Confirm whether the respondent has heard of all of these types of test.

Probe any endorsed response for meaning.

SKIP TO SECTION N AND ADMINISTER N10 – N19

N10:

Can you say in your own words what this question is asking?

ATTACHMENT F: INTERVIEW PROTOCOL

So now that you've looked at and answered all these questions, let me ask you something. When we conduct surveys we worry about people starting to fill out the questionnaire, but then getting bored or perhaps even irritated by the questionnaire, and thus not finishing it and sending it back to us.

- *If you had been doing this at home on your own, how do you think you would have handled this questionnaire once you began answering it?*

- *Were there any questions that stick out in your mind in this questionnaire, for any reason? You can take a minute and glance through the questionnaire if you want to. IF NEEDED - For example,*
 - o anything that seemed kind of irrelevant or unimportant?*
 - o Anything that seemed particularly important for National Cancer Institute or policy makers to know?*
 - o Anything that seemed a bit too personal or sensitive to ask about?*
 - o Anything that seemed difficult to answer?*
 - o Anything else about the questionnaire that you think we should think about?*

INTERVIEWERS: If there is any time left, check with observers to see if they have any additional questions for this respondent. If not, thank the respondent and dismiss (give them their incentive and have them sign the receipt).