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### Cognitive Interview Protocol - Cycle 4

*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.*

*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. (And finally, some of our colleagues from the National*

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*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)*

*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.

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### 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 B1-B9.

Do not probe B1-B7.

B8: Tell me what you were thinking about when you answered this question. What does it mean to track or manage your health? If yes, tell me about the apps that you use? How often do you use them? How long have you used them?

B9: What is this question asking about? Probe on each item in the list with “You answered [yes/no] to item [a-d], what were you thinking about when you answered that question?”

B9a: If yes, what health related goal were you thinking about? Tell me about the app that you use.

B9b: If yes, how did the app affect your decision?

B9c: What does it mean to change your approach to maintaining your health?

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B9d: If yes, tell me more about this.

### **QUESTIONNAIRE SECTION C (YOUR HEALTH CARE)**

Have respondent answer C1-C5.

C3: What is this question asking about? What is a health exchange or marketplace? What have you heard about healthcare.gov?

C4: Can you tell me how much your monthly premium is?

C5: How do you know if your premium is subsidized or not?

Skip to C13

C13: What is this question asking about? Probe about two items in the list where the respondent indicates that they have experienced discrimination. "Tell me more about the discrimination you faced when ..."

C13e: If [a little, some, a lot] tell me about the discrimination you faced when getting medical care. If [Not at all] how would someone be discriminated against when getting medical care?

### **QUESTIONNAIRE SECTION D (MEDICAL RECORDS)**

Have respondent answer D9-D15

D9: What is this question asking about? If yes, tell me about when you were given online access to your medical record.

D10: What does this statement mean to you?

D11: What is this question asking about? What is a secure website?

D12: What does your "health care provider" mean? What does your "health insurer" mean?

D13: Tell me about the last time you accessed your medical record. Why did you need to do this?

D14-D15: If yes, why did you need to access a family member's medical record?

### **SECTION E (MEDICAL RESEARCH)**

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E1: Immediately after E1: “Tell me in your own words what you think E1 is asking about.”  
Probe as needed to get a sense of respondents’ understanding of ‘clinical trials’ as defined in this question. Note any signs of confusion or difficulty and probe as needed.

E2: You marked ‘yes’ for (subitem). Tell me more about the kind of information you got from (subitem). If marked “some other source” - Tell me about the other source you marked here.

E3: - If ‘yes’ - Tell me about the clinical trial you participated in. (What was the trial about? How did you get involved in it? How long was the trial?)

E4: What is this question asking about?

E8: Tell me about your answer to these two questions. Give an example of research where patients try an experimental new medication. Give an example of research where two or more medications are compared to see which works best. Are these two types of research the same or are they different? How so?

E9a: What does patient engagement in medical research mean to you? How did you come up with your answer?

E9b: If yes, tell me about how you engaged in this type of research?

E10: How did you come up with your answer?

E11: What does citizen led research mean to you?

E11a: If yes, where have you heard about citizen led research?

E11b: If yes, where have you worked on citizen led research?

E12: How did you come up with your answer?

E13: What is this question asking about?

E14: If yes, what study are you thinking about? If no, what is this question asking about?

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**QUESTIONNAIRE SECTION L (SCREENING FOR CANCER)**

Administer L10 and L11

L10: What is this question asking about? What medical tests and exams to check for early signs of cancer came to your mind? In your own words who do you trust to provide recommendations about when to check for cancer? Probe on each item in the list with “how did you come up with your answer?”

L10d: “What is the news media?”

L11: You answered \_\_\_\_\_ to the (first, second, etc.). How did you come up with your answer?

**QUESTIONNAIRE SECTION M (YOUR CANCER HISTORY)**

Administer entire section.

M14: What is this question asking about? How did you choose your answer?

M15-M18: How did you come up with your answer?

**QUESTIONNAIRE SECTION N (BELIEFS ABOUT CANCER)**

Administer N6-N12

N8: How did you come up with your answer?

N9: What is this question asking about?

N11: How did you come up with your answer?

**FINAL SUMMARY PROBE (IF YOU HAVE TIME)**

*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?*

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- *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).