

STATEMENT OF PRIVACY: Collection of this information is authorized by The Public Health Service Act, Sections 411 (42 USC 285 a) and 412 (42 USC 285a-1.a and 285a1.3). The purpose of this data collection is to evaluate whether the survey questions are easy to understand. The results of the data collection will be used to improve the survey instrument. Rights of study participants are protected by The Privacy Act of 1974. Participation is voluntary, and there are no penalties for not participating or withdrawing from the study at any time. Refusal to participate will not affect your benefits in any way. The information collected in this study will be kept private under the Privacy Act and will only be seen by people authorized to work on this project. The report summarizing the findings will not contain any names or identifying information. Identifying information will be destroyed when the project ends.

NOTIFICATION TO RESPONDENT OF ESTIMATED BURDEN: Public reporting burden for this collection of information is estimated to average 90 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, 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 currently valid OMB control number.** Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to: NIH, Project Clearance Branch, 6705 Rockledge Drive, MSC 7974, Bethesda, MD 20892-7974, ATTN: PRA (0925-0589). Do not return the completed form to this address.

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 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)*

This survey will be mailed to a random sample of home addresses across the country. The only information we know when we mail the survey is the address, nothing else. We don’t know who lives at the address. Before we actually start talking about the questionnaire we’re developing, I’d like to get an understanding of how the mail is usually handled at your house. For example...

- *Who gets the mail, how does it get distributed, and so on?*
- *IF NEEDED: Who would probably look at this (POINT TO MAILING PACKAGE) first, in your household? (It won’t be addressed to any specific person, it will say something like “The Rockville Resident at...” and then the street address) (What would likely happen to it?)*

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 MAILING PACKAGE. PACKAGE INCLUDES:

- Cover letter
- A questionnaire

SURVEY PACKAGE:

NOTE ANY REACTIONS THAT R HAS: [So what are you thinking at this point?]

OBSERVATION: DID R READ THE COVER LETTER?

- R read letter completely and very carefully
- R read it completely but very quickly/not so carefully
- R read some of the letter
- R skipped most of the letter
- R basically ignored the letter

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 A (LOOKING FOR HEALTH INFORMATION)

A5: Tell me what you were thinking about when you answered that question.

A11h: Tell me about the last time you saw something about health and medical topics on Facebook or Twitter?

QUESTIONNAIRE SECTION B (USING THE INTERNET TO FIND INFORMATION)

B8i: Tell me about the last time you saw something about health and medical topics on Facebook or Twitter?

QUESTIONNAIRE SECTION C (YOUR HEALTH CARE)

C11: Tell me what you were thinking about when you answered that question.

QUESTIONNAIRE SECTION D (YOUR HEALTH, NUTRITION, AND PHYSICAL ACTIVITY)

D4: How did you come up with your answer?

D15-D19?: How did you come up with your answer? Was it easy or difficult to find the information you needed to answer this question?

D22b: What kind of hat are you thinking about? Can you describe it for me?

D26: What does personal control mean? Probe on the meaning of the subitems with "You answered _____ can you tell me what this means? Try to ask about at least one answer in each category.

D27-D29: Probe on the meaning of the subitems with "You answered _____ can you tell me what this means?" Try to ask about at least one answer in each category.

QUESTIONNAIRE SECTION E (PATIENT ACTIVATION):

E1-E4: [If always, usually, or sometimes] Tell me about the last time you did this. [If never or don't know] Have you ever done this?

E5: Probe with "Tell me about your answer" for two items in the list.

E6: Tell me about your answer to his question.

E7: What does it mean to "do your own research"?

E8: What does it mean to take an active role in your own health care?

E9: How did you come up with your answer? What condition are you thinking about?

E10: How did you come up with your answer?

E11: Tell me about the last time that you read this information.

E12: Tell me about the last time you brought a friend or relative to the doctor with you.

E13: Tell me about your answer.

E14: What is this question asking about?

E15: Tell me about your answer.

E16: How did you come up with your answer?

E24: Probe about the meaning each statement (e.g. What is this question asking about?)

QUESTIONNAIRE SECTION F (WOMEN AND CANCER)

No probing unless the respondent demonstrates confusion or difficulty.

QUESTIONNAIRE SECTION G (WOMEN AND CANCER)

No probing unless the respondent demonstrates confusion or difficulty.

QUESTIONNAIRE SECTION H (YOUR CANCER HISTORY)

H5: Immediately after H5: Tell me in your own words what you think H5 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.

H6: You marked 'yes' for (subitem) . Tell me more about the kind of information you got from (subitem).

H6: If marked "some other source" - Tell me about the other source you marked here.

H7, H8: - 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?)

H9: How did you come up with your answer?

QUESTIONNAIRE SECTION I (BELIEFS ABOUT CANCER)

I8: How did you come up with your answer?

I9: How did you come up with your answer?

I10: Probe about two of the items in the list where the respondent answered in different categories.

I11: How did you come up with your answer?

I14: Probe about two of the items in the list where the respondent answered in different categories.

I15: Probe about two of the items in the list where the respondent answered in different categories.

I16: Probe about two of the items in the list where the respondent answered in different categories.

I17: Probe about two of the items in the list where the respondent answered in different categories.

SECTION K (MEDICAL RESEARCH AND MEDICAL RECORDS)

K3: What are safeguards to protect your medical records?

K4: Tell me about your answer to this question.

K7: What is this question asking about?

SECTION L (TOBACCO PRODUCTS)

L9 – Take a look at L9. It mentions “electronic cigarettes, e-cigarettes and personal vaporizers”. Have you ever heard of any of those terms? Do they mean the same thing to you, or do you think of those as different from one another? Which term are you most familiar with, if any?

L17 – Let’s look at L17. In your own words, what is this question asking about? IF NEEDED – what do you think ‘do things to undo the harmful effects of smoking’ is getting at in this question? Does ‘protect against the effects of smoking’ mean the same thing, or is that different in some way? How?

L17 – Now let’s look at some of the subitems a- m. Do any of these items seem like they don’t belong in this question? Why/Not? Do any of these subitems seem very similar, maybe even overlapping? Are there any that are missing that we should include- things you’ve heard about as a possible way to undo the effects of smoking?

SECTION X (GENOMICS AND FAMILY HISTORY)

X3: Probe about the meaning of two of the items in the list.

X4: Tell me about your answer.

X6: Tell me what you were thinking about when you answered this question.

X7: What do you know about your family’s health history?

X10: What does it mean to share your family history information with a health professional?

X11: What do you think this question is asking about? IF NEEDED – What do you think of as behaviors? IF JUST THE EXAMPLES LISTED – Are there other things that come to mind as “health behaviors”? Were those things you thought about in answering this question?

X12: What is that asking about? What about the term ‘genetics’ can you give me your own version of a definition for that?

X11, 12: PICK TWO SUBITEMS WITH THE SAME RATING IN X11 AND X12 – Let’s take a look at letter (subitem). I noticed you marked (response) for both X11 and X12 for this condition. Tell me a little more about what your responses mean in each question. IF NEEDED – Does this mean that both health habits and genetic makeup contribute equally to whether or not a person gets (condition/subitem), or does either health habits or genetic makeup matter more, though they both contribute (response).

X13: What “health decision” were you thinking about?

X14: How did you come up with your answer?

X15: You answered yes to _____. Can you tell me more about this?

X16: You said you had heard of _____. Tell me what you know about _____.

X17: Tell me more about the research studies you were thinking about.

X18: Tell me about your answer to this question.

X19: Probe about at least two items in the list.

X20: What does it mean to work with researchers to plan a study for a medical condition that affects you? What came to your mind?

X22: Probe about the meaning of the two items.

X23: Probe about the meaning of the items.

SECTION O (YOU AND YOUR HOUSEHOLD)

No probing unless the respondent demonstrates confusion or difficulty.

FINAL SUMMARY PROBE

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).