

Attachment E-1. Assurance of Confidentiality and Informed Consent for Cognitive Interviews



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service
National Institutes of Health
National Cancer Institute

OMB# 0925-xxxx
Expiry Date: xx/xxxx

Assurance of Privacy and Informed Consent for Interview to Test Survey Questions

You are being asked to take part in a research study, run by the National Cancer Institute, a part of the U.S. Federal government. This consent form tells you about the study and what you will be asked to do. The study is voluntary - you can choose to take part in the study or not to. If you choose to take part, you will need to sign this form.

Purpose of the Research

Surveys are used to collect information on the health and well being of Americans. Our surveys help to develop programs to improve the health of people living in the United States.

Before we conduct health surveys, we first test them with the help of people such as yourself. It is important that the questions make sense, are easy to answer, and that everyone understands the questions the same way. The National Cancer Institute, and its contractors, carry out these tests for our surveys. If you agree to take part in this test, we will ask you to answer the survey questions. Then, we will ask you to explain what you were thinking and how you came up with your answers. Our purpose is not to collect health information about you. Instead, we will test the questions to be used in a later survey.

The questions that we are working on today are about [FILL]. Your interview will show us how to improve these questions.

Procedures that we will use

An interviewer will ask you the survey questions that we are testing. Then, the interviewer will ask you to explain what you were thinking as you answered the questions. The interviewer will ask you if there were any words or questions that were confusing and if you understood what was being asked.

The interview will last no more than one hour, and we will give you \$50.

You may find that some of the questions we are testing are personal or sensitive. You may choose not to answer any question, for any reason. If you do not want to answer a question, just say so, and the interviewer will move on to the next one. You may also stop the interview at any time. While the interview is going on, researchers from the National Cancer Institute who are working with us on this project may [watch/listen to] the interview.

If you have questions about how the project works, contact Dr. Gordon Willis by phone at (301) 594-6652, or by mail at 6130 Executive Blvd, MSC 7344, EPN 4005, Bethesda, MD, 20892-7344.

Recording the interview

We would like to [video/audio] record your interview. The recording allows us to more carefully study how well the questions are working. At the bottom of this form, you will be asked if you are willing to have the interview recorded. If you agree, you may ask to stop the recording at any time, and we will turn off the machine. If you decide to stop taping, we will ask if we have your consent to keep the portion already recorded.

If you agree to record the interview, we will keep the recording in a locked room or in the safe keeping of a staff person from the National Cancer Institute who is working on this project. At the end of the interview, we may ask you, in writing, for permission to play the recording in another location. For example, the interview could be played at a conference or for students who want to learn how to write survey questions. If you do not give us this additional permission, we will not allow anyone other than staff working directly on this project to [watch/listen to] the recording.

Protecting information about you

Materials with personal facts (such as names or addresses) are not connected to the answers you give to the questions we are testing. Except for this form, all records we have that contain your name, telephone number, or other written information that could identify you will be destroyed after the interview. We will keep this form for one year after this study is completed, and will then destroy it.

Your name or other personal facts that would identify you will not be used when we discuss, or write about, this study.

If you allow recording of the interview, the recording will be stored in a locked room. The recording will not be labeled with your name or other personal facts.

Benefits and Risks

Other than the \$50 you receive, there are no other direct benefits from taking part in this study.

There are no known physical or psychological risks from taking part in this study.

Please check the boxes next the statements you agree to-

- I freely choose to take part in this research study.

I allow NCI to record my interview. I also allow NCI staff to play my recording to other people working on this project

- I do **not** allow NCI to record my interview.

Participant Signature

Print name

Date