Attachment 5 – Adult Informed Consent for Focus Groups

Description: dhhs_logo

**DEPARTMENT OF HEALTH & HUMAN SERVICES Public Health Service**

**Centers for Disease Control and Prevention**

**National Center for Health Statistics**

**3311 Toledo Road**

**Hyattsville, Maryland 20782**

**Adult Informed Consent Form**

**for Focus Groups**

You are being asked to take part in a research study. This consent form tells you about the study and what you will be asked to do. You can choose to take part in the study or not. 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. The surveys help to develop programs to improve the health and health care of people living in the United States.

Before health surveys are conducted, the questions are tested with people of different backgrounds. It is important that the questions make sense, are easy to answer, and that everyone understands the questions the same way. The National Center for Health Statistics conducts these tests for the surveys it sponsors and for other survey programs.

If you agree to take part in this test, you will be part of a discussion group about new questions for vaccination acceptance/confidence.

The discussion group will show us how to improve the questions for this survey. In the future, we may also study the group interview along with interviews from other projects. This type of study will teach us about the different kinds of problems people have answering survey questions. The study will help us write better questions in the future.

**Procedures**

A group leader will ask you to share your thoughts and ideas about the questions with other people in the group. You will not be asked your personal answers to the questions. We will ask you to pick a name and put it on a name tag. You do not have to use your real name.

The discussion will last 90 minutes, and we will give you $50. In order to receive the $50, you will need to fill out the attached cash payment receipt form. You will also be asked to fill out a personal information sheet.

You may leave the discussion group at any time. You may also choose not to discuss any question for any reason. While the discussion is going on, researchers from the Center for Questionnaire Design and Evaluation Research (CQDER) and the National Center for Immunization and Respiratory Diseases (NCIRD), who are working on the project may watch the discussion.

If you have any questions about how the project works, contact Karen Whitaker by phone at (301) 458-4569, or by mail at NCHS, Room 6330, 3311 Toledo Road, Hyattsville, MD 20782.

**Recordings**

We plan to video/audio1 record the discussion. The recording allows us to more carefully study and improve the questions. At the bottom of this form, you will be asked if you are willing to have the discussion recorded. When the discussion is finished, you or anyone in the group may watch/listen to the recording. Recording is essential for this project. If you do not wish to be recorded, you should not join the discussion. If you decide that you do not want to be recorded, you will still receive the full $50.

Recordings are kept in a locked room, either in a secure storage cabinet or on a password-secured computer that is not connected to the internet. When in use, all recordings will be in the safe keeping of a staff person from the CQDER.

At the end of the discussion, we may ask you for special permission to play the recording in a more public setting. For example, the discussion could be played at a conference or for students who want to learn how to write survey questions. If you do not agree to this special permission, we will not allow anyone other than the staff working directly on this project to [watch/listen to] the recording.

# Privacy

We are required by law2 to tell you what we will do with the recording. We must also tell you how we will protect your privacy.

Audio and video recordings are stored in a locked room or secured by a password. All recordings are labeled by a code number, date, time, and project title. The recording is never labeled with your name or other personal facts.

Materials with personal facts (such as names or addresses) are also stored in a locked room. Only CQDER staff has access to this material.

Your name or other personal facts that would identify you will not be used when we discuss or write about this study. People working on this project, however, may recognize you or your voice.

If you have questions about NCHS privacy laws and practices, contact Eve Powell-Griner, Ph.D., Confidentiality Officer at 1-888-642-4159.

# Benefits and Risks

There are no direct benefits from taking part in this study.

The possible risks of taking part in this study are minimal. We will take all possible steps to protect your privacy. You do not have to give us any information that you do not want to, and you can choose not to answer any question in the discussion. You may also stop at any time and still receive the full $50.

If you have any questions about this study, please call the office of the Research Ethics Review Board at the National Center for Health Statistics, toll-free at 1-800-223-8118. Please leave a brief message with your name and phone number. Say that you are calling about Protocol #2010-19-XX [Note: The amendment number will be inserted into the form once NCHS ERB approval has been received]. Your call will be returned as soon as possible.

**Please Read and Sign Below if You Agree**

I freely choose to take part in this discussion group.

When video recording is selected:

I allow NCHS to video record me. I also allow NCHS to play the video recording to other people working on this project either in the CQDER or in another location under the direct supervision of CQDER staff.

Yes No

IF YES:

I allow NCHS to retain my video recording for future research on how people react to survey questions and how survey questions can be hard to understand or hard to answer.

Yes No

When audio recording is selected:

I allow NCHS to audio record me. I also allow NCHS to play the audio recording to other people working on this project either in the CQDER or in another location under the direct supervision of CQDER staff.

Yes No

IF YES:

I allow NCHS to retain my audio recording for future research on how people react to survey questions and how survey questions can be hard to understand or hard to answer.

Yes No

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_\_\_

**Participant Signature Print name Date**

1Either video or audio will be selected.

2The 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) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).