

Attachment 4: Adult Informed Consent



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 One-on-one Interviews

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

The purpose of the National Survey of Long-Term Care Providers (NSLTCP) is to collect and provide nationally representative statistical information about the supply and use of paid, regulated long-term care (LTC) providers in the United States. NSLTCP is intended to enable efficient monitoring of the dynamic, diverse, and evolving field of paid, regulated LTC and to help address the nation's information needs to inform future LTC policy.

The Collaborating Center for Question Design and Evaluation Research at the National Center for Health Statistics is conducting a study to evaluate the NSLTCP. It is important that the questions make sense, are easy to answer, and that everyone understands the questions the same way so that the information produced by the survey is valid and reliable.

The questions that we are working on today are about administrative data in long-term care facilities.

Your interview will help us improve the NSLTCP. In the future, we may also study your interview along with interviews from other projects. This type of study will teach us about the different kinds of problems people have in answering survey questions and filling-out data collection forms. This study will help us write better questions and design better data collections forms in the future.

Procedures

An interviewer will ask you about your experiences completing the NSLTCP. The interviewer will also ask you about your opinions of the form.

The interview will last no more than 60 minutes, and we will give you \$100. You will also be asked to fill out a personal information sheet.

You may find that some of the questions we are testing are sensitive. You may choose not to answer any question for any reason. If you do not want to answer a question, say so, and we 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 Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) and the Division of Healthcare Statistics, who are working on the project may listen to the interview.

If you have questions about how the project works, contact Ms. Karen Whitaker by phone at (301) 458-4569, or by mail at NCHS, Room 5448, 3311 Toledo Rd., Hyattsville, MD 20782.

Recordings

We would like to audio record your interview. 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 interview recorded. If you agree, you may still ask to stop the recording at any time, and we will turn off the machine. If you decide to stop recording, we will ask your consent to retain the portion already recorded. When the interview is finished, you may listen to the recording.

If you agree to record the interview, we will keep it in a locked room either in a secure storage cabinet or on a password-secured computer that is not connected to the internet. Only researchers from the (CCQDER) and the Division of Healthcare Statistics working on the project will be allowed to listen to the recording in a secured room. When in use all recordings will be in the safe keeping of a staff person from the (CCQDER).

At the end of the interview, we may ask you for special permission to play the recording in a more public setting. 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 agree to this special permission, we will not allow anyone other than staff working directly on this project to listen to the recording.

Privacy

We are required by law¹ to tell you what we will do with the recording. We must also tell you how we will protect your privacy.

Audio 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 CCQDER 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 or those viewing the audiovisual recording, however, may recognize you or your voice.

If you have questions about National Center for Health Statistics privacy' laws and practices, contact the NCHS Confidentiality Office by phone at 888-642-4159 or 301-458-4601, or by email at nchsconfidentiality@cdc.gov.

Benefits and Risks

There are no 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 interview. You may also stop at any time and still receive the full \$100.

In order for you to take part in the study today, we agreed to meet at this location. Meeting at this location is your choice. However, you are urged to choose a place that is private so that you will feel comfortable answering the questions. We will protect any materials that contain your personal information and transport them to the National Center for Health Statistics.

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 #2016-16-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 research study.

I allow NCHS to audio record my interview. I also allow NCHS to play my audio recording to other people working on this project on-site at NCHS CCQDER.

- 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

Respondent Signature

Print name

Date

¹The 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(d)) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).