



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**

We are asking you to take part in a research study. This consent form tells you about the study and what we will ask you 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. If you say no, that is totally fine.

Purpose of the Research

Surveys are used to hear from people on how healthy and well they are. Surveys are made up of many questions that people answer. This information helps to improve the health and health care of people living in the United States.

Survey questions are first tested with different people. This makes sure the questions 1) make sense, 2) are easy to answer, and 3) that everyone understands the questions the same way. The National Center for Health Statistics does these tests for health surveys. If you agree to take part in this test, we will ask you to answer the survey questions. We will ask you to explain what you are thinking, and how you came up with your answers.

The questions we are working on today are about health. We will also ask questions about how easy or hard some things are for you. That will be things like learning new things, solving problems, and making decisions.

Your interview answers will show us how to make the questions better. In the future, we may also study your answers along with answers from other projects. This study will teach us about the different kinds of problems people have answering questions. The study will help us write better questions.

Procedures

This is how we will do things today. An interviewer will ask you a survey question. Then, the interviewer will ask you to explain what you are thinking as you answer the question. The interviewer will ask you if there are any words that are confusing and if you understand what is being asked. Then the interviewer will move on to the next question. At the end, you will also be asked to fill out a form about who you are as a person.

The interview will last no more than an hour. We will pay you \$40 for your time.

You can choose not to answer any question. 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.

Researchers working on the project may watch or listen to our interview. This will help them understand how to develop better questions. The researchers might be from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER), the Office of Analysis and Epidemiology (OAE), and the Department of Health and Human Services (HHS), Administration for Community Living (ACL), or the Administration on Intellectual and Developmental Disabilities (AIDD).

If you have questions about how the project works, contact Ms. Karen Whitaker by phone at (301) 458-4569, or send her a letter at NCHS, Room 5448, 3311 Toledo Rd., Hyattsville, MD 20782. You can also send her an email at KWhitaker@cdc.gov.

Recordings

We would like to video/audio¹ record your interview. The recording allows us to more carefully study and improves the questions. The bottom of this form asks if you give permission for us to record the interview. If you agree, you can still ask to stop the recording at any time, and we will turn off the machine. If you want to stop the recording, we will ask your permission to keep the part already recorded. When the interview is finished, you can [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 saved with a password. Only researchers from the CCQDER, OAE, and HHS/ACL/AIDD who work on the project will be allowed to [watch/listen to] the recording. They will have to do that in a secured room. When we use them, all recordings will be in the safe keeping of a staff person from our office (CCQDER). All recordings are labeled by a code number, date, time, and project title. The recording is never labeled with your name or other personal information.

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

We will not use your name or other personal information that would identify you when we discuss or write about this study. It is possible that people working on this project or viewing the recording may know 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 to you from taking part in this study except for helping us develop better questions.

The possible risks of taking part in this study are very small. 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. You can choose not to answer any question in the interview. You may also stop at any time and still receive the full \$40.

Conducting an interview at a mutual location³

We agreed to meet at this location so that you could take part in the study today. This location is your choice. We will protect all materials that contain your personal information and transport them to the National Center for Health Statistics.

There is a place to call if you have any questions about this study. It is the office of the Research Ethics Review Board at the National Center for Health Statistics. The toll-free number is 1-800-223-8118. Please leave a brief message with your name and phone number. Give them this number: Protocol #2016-16-30. Someone will return your call as soon as possible.

Please Read and Sign Below if You Agree

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

When video recording is selected:

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

- 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 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

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

³This paragraph will be included in the consent form for those interviews conducted offsite.



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Purpose of the Research

Surveys are used to collect information on the health and wellbeing 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, 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.

The questions that we are working on today are about an adult under your care. We will ask you about this person's health and difficulties he/she may have with day-to-day activities like learning new things, solving problems, and making decisions.

Your interview will show us how to improve the questions for this survey. 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 answering survey questions. The study will help us write better questions in the future.

Procedures

An interviewer will ask you some survey questions. 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 that were confusing and if you understood what was being asked.

The interview will last no more than 60 minutes, and we will give you \$40. 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), the Office of Analysis and Epidemiology (OAE), and the Department of Health and Human Services (HHS), Administration for Community Living (ACL), Administration on Intellectual and Developmental Disabilities (AIDD), who are working on the project may [watch/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 video/audio¹ 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 [watch/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, OAE, and HHS/ACL/AIDD working on the project will be allowed to [watch/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).

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 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 or audio 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 \$40.

Conducting an interview at a mutual location³

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 #2016-16-30. 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.

When video recording is selected:

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

- 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 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

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

³This paragraph will be included in the consent form for those interviews conducted offsite.



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Legally Authorized Representative Informed Consent Form

A person legally under your care is being asked to take part in a research study. This form tells you about the study and what he/she will be asked to do. You can choose to permit him/her to take part in the study or not. If you choose not to allow him/her to take part, you will need to sign this form. The person under your care will also have a consent form to read and sign.

Purpose of the Research

Surveys are used to collect information on the health and wellbeing 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 permit the person under your care to take part in this test, we will ask him/her to answer the survey questions. Then, we will ask him/her to explain what he/she was thinking and how he/she came up with his/her answers.

The questions that we are working on today are about health and difficulties he/she may have with day-to-day activities like learning new things, solving problems, and making decisions.

His/her interview will show us how to improve the questions for this survey. In the future, we may also study his/her 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

An interviewer will ask him/her some survey questions. Then, the interviewer will ask him/her to explain what he/she was thinking as he/she answered the questions. The interviewer will ask him/her if there were any words that were confusing and if he/she understood what was being asked.

The interview will last no more than 60 minutes, and we will give him/her \$40. You [He/she] will also be asked to fill out a personal information sheet.

He/she may find that some of the questions we are testing are sensitive. He/she may choose not to answer any question for any reason. If He/she does not want to answer a question, he/she can say so, and we will move on to the next one. He/she 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), the Office of Analysis and Epidemiology (OAE), and the Department of Health and Human Services (HHS), Administration for Community Living (ACL), Administration on Intellectual and Developmental Disabilities (AIDD), who are working on the project may [watch/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 video/audio¹ record his/her 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, he/she may still ask to stop the recording at any time, and we will turn off the machine. If he/she decides to stop recording, we will ask your consent to retain the portion already recorded. When the interview is finished, you may [watch/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, OAE, and HHS/ACL/AIDD working on the project will be allowed to [watch/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).

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 his/her 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 CCQDER staff has access to this material.

His/her name or other personal facts that would identify him/her will not be used when we discuss or write about this study. People working on this project or those viewing the audiovisual recording or audio recording, however, may recognize him/her or his/her 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 his/her privacy. He/she does not have to give us any information that he/she does not want to, and he/she can choose not to answer any question in the interview. He/she may also stop at any time and still receive the full \$40.

Conducting an interview at a mutual location³

In order for him/her 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 he/she will feel comfortable answering the questions. We will protect any materials that contain his/her 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 #2016-16-30. Your call will be returned as soon as possible.

Please Read and Sign Below if You Agree

- I allow the person legally under my care to take part in this research study.

When video recording is selected:

I allow NCHS to video record the person legally under my care’s interview. I also allow NCHS to play his/her video recording to other people working on this project on-site at NCHS CCQDER.

- Yes
- No

IF YES:

I allow(s) NCHS to retain his/her 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(s) NCHS to audio record his/her interview. I also allow NCHS to play his/her audio recording to other people working on this project on-site at NCHS CCQDER.

- Yes
- No

IF YES:

I allow(s) NCHS to retain his/her 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

Legally Authorized Representative’s 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(d)) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347).

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**Informed Assent Form for
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[Fill name of caretaker _____] says you can 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

One way that the National Center for Health Statistics learns about health in this country is to ask people questions on surveys. Before we do that, we want to test the questions out on people of different backgrounds. We are interested in learning how well the questions work. Whether they make sense, are easy or hard to answer. There is no right or wrong answer to these questions.

The questions that we are working on today are about health and difficulties you may have with day-to-day activities like learning new things, solving problems, and making decisions.

Procedures

An interviewer will read the survey questions and have you answer. Then, the interviewer will ask you some follow-up questions about how you came up with your answers. The interviewer will ask you if the questions were clear, and if any terms were confusing.

The interview will last no more than 60 minutes, and we will give you \$40.

You may find that some of the questions we are testing ask about sensitive issues. 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), the Office of Analysis and Epidemiology (OAE), and the Department of Health and Human Services (HHS), Administration for Community Living (ACL), Administration on Intellectual and Developmental Disabilities (AIDD), who are working on the project may [watch/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 6330, 3311 Toledo Rd., Hyattsville, MD 20782.

Recordings

We would like to video/audio¹ record your interview. The recording allows us to review what you said about 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 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 what we have already recorded.

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. When in use all recordings will be in the safe keeping of a staff person from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER).

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 CCQDER staff have 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.

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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 \$40.

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Please Read and Sign Below if You Agree

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

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

- 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 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

Participant Signature

Print name

Date

¹Either video or audio will be selected.

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