



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 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. It is okay if you say No.

Why we are doing the study

Researchers often find out about people by asking questions. The answers to those questions can help improve the health and health care of people living in the United States. So that we know which questions to ask, we first try to talk to different people about their lives. If you agree to take part in this study, we will talk with you about your life and about difficulties you may have doing everyday things. What you say will help us to decide what questions we ask of everyone. In the future, we may also look at your interview along with interviews from other studies to make sure we understand the kinds of difficulties people have.

What will happen if you take part

An interviewer from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) will talk with you. The interviewer will ask you about your life and your experiences. You will also be asked to fill out a form about who you are as a person.

The interview will last no more than 75 minutes. We will give you \$50.

You may choose not to answer any question for any reason. If you don't 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, staff, who are allowed to work on the project, may watch or listen to your interview. This will help them learn about the experiences of people like you.

If you have questions about how the study works, contact send us a letter at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782. You can also send her an email at recruitmentteam@cdc.gov.

Why we ask to record your interview

We would like to video and audio record your interview. The recording allows us to carefully study what you told the interviewer. At the end of this form you will be asked to say if you agree for us to record the interview. If you agree, you can still ask us to stop the recording at any time, and we will turn off the recording machine. If you stop the recording, we will ask you if you will allow us to keep the part already recorded, but you can say No. When the interview is finished, you may watch or listen to the recording.

If you agree for us 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 who are allowed to work on the project will be able to watch or listen to the recording in a secured room. The recorded video of the interview will be destroyed at the end of the project unless you agree to let us keep it longer.

You may decide at any time after the interview that you don't want us to keep your recording. Contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

How we keep your information safe

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

Audio and video recordings are stored in a locked room or saved with 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 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.

Your name or other personal information that would identify you will not be used when we discuss or write about this study. However, people working on this study or those viewing the recordings 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.

The benefits and risks of taking part

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

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 \$50.

[Include if conducting an interview at a mutual location] 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, we suggest you choose a place that is private so that you will feel comfortable answering any questions. We will protect any materials that contain your personal information and take them immediately 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 Ethics Review Board (ERB) 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 # [Note: The protocol number will be inserted into the form once 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.

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 study at the NCHS offices.

- Yes
- No

IF YES:

I allow NCHS to keep my video recording for future work on the difficulties people have in their everyday lives. I also allow NCHS to play my video recording to internal NCHS staff. I understand that the recording of my interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- 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 study at the NCHS offices.

- Yes
- No

IF YES:

I allow NCHS to keep my audio recording for future work on the difficulties people have in their everyday lives. I also allow NCHS to play my audio recording to internal NCHS staff. I understand that the recording of my interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- Yes
- No

Respondent Signature

Print name

Date

The Public Health Service Act provides us with the authority to do this research (42 U.S.C 242k). Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks.

Public reporting burden for this collection of information is estimated to average 75 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 CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS H21-8, Atlanta, GA 30333, ATTN: PRA (0920-0222).

OMB #0920-0222; Expiration Date: 01/31/2026



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Purpose of the Research

Researchers often find out about people by asking questions. Sometimes these questions are included in a national survey or in administrative data systems. The information collected is used to help develop programs to improve the health and health care of people living in the United States. It is important that we make sure that we are asking the right questions. Therefore, we try to talk to different people about their relevant experiences in life. If you agree to take part in this study, we will talk with you about health matters and about difficulties the adult under your care may have doing day-to-day activities. In the future, we may also study your interview along with interviews from other projects. This will teach us about the different kinds of problems people have and make sure we are capturing those problems with our questions.

Procedures

An interviewer from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) will talk with you. The interviewer will ask you about any difficulties the person in your care has in life. You will also be asked to provide some background information about yourself, such as your age and gender.

The interview will last no more than 75 minutes. We will give you \$50.

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, authorized researchers, who are working on the project may [watch or listen to] the interview.

If you have questions about how the project works, contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

Recordings

We would like to video and audio record your interview. The recording allows us to more carefully study what you told the interviewer. At the end of this form, you will be asked if you are willing for the interview to be recorded. If you agree, you may still ask to stop the recording at any time, and we will turn off the recording 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 or listen to the recording.

If you agree for us 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 authorized researchers who are working on the project will be allowed to watch or listen to the recording in a secured room. In accordance with the CCQDER Data Storage and Access Policy, upon project completion, the video of the interview will be destroyed. Audio recordings will be retained for a minimum 2 years and may be used for question evaluation research that is not directly related to this project.

You may decide at any time after the interview that you don't want us to keep a recording of the interview. In this case you may contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

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 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 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 interview. You may also stop at any time and still receive the full \$50.

Conducting an interview at a mutual location²

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 # [Note: The protocol number will be inserted into the form once CDC IRB 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.

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 this topic. I also allow NCHS to play my video recording to internal NCHS CCQDER staff. I understand that the recording of my interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- 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 this topic. I also allow NCHS to play my video recording to internal NCHS CCQDER staff. I understand that the recording of my interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- Yes
- No

Respondent Signature

Print name

Date

¹The Public Health Service Act provides us with the authority to do this research (42 U.S.C 242k). Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks. ²This paragraph will be included in the consent form for those interviews conducted offsite.

Public reporting burden for this collection of information is estimated to average 75 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 CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS H21-8 Atlanta, GA 30333, ATTN: PRA (0920-0222).

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Hyattsville, Maryland 20782

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 they will be asked to do. You can choose to allow them to take part in the study or not. If you choose to allow them to take part, you will need to sign this form. The person under your care will also have an assent form to read and sign if they choose to take part in the study.

Purpose of the Research

Researchers often find out about people by asking questions. Sometimes these questions are included in a national survey or in administrative systems. The information collected is used to help develop programs to improve the health and health care of people living in the United States. It is important that we make sure that we are asking the right questions. Therefore, we try to talk to different people about their relevant experiences in life. If you permit the person under your care to take part in this study, we will talk with him/her about health matters and about difficulties he/she may have doing day-to-day activities. In the future, we may also study his/her interview along with interviews from other projects. This will teach us about the different kinds of problems people have and make sure we are capturing those problems with our questions.

Procedures

An interviewer from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) will talk with the person legally under your care. The interviewer will ask him/her about any difficulties he/she may have in life. You will also be asked to provide some background information about yourself such as your age and gender.

The interview will last no more than 75 minutes. We will give him/her \$50.

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, authorized researchers, who are working on the project may [watch or listen to] the interview.

If you have questions about how the project works, contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

Recordings

We would like to video and audio record the interview. The recording allows us to more carefully study what the person legally under your care told the interviewer. At the end of this form, you will be asked if you are willing for the interview to be recorded. If you agree, the person legally under your care can ask to stop the recording at any time, and we will turn off the machine. If the recording is stopped, we will ask your consent to retain the portion already recorded.

If you agree for us 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 authorized researchers who are working on the project will be allowed to watch/listen to the recording in a secured room. In accordance with the CCQDER Data Storage and Access Policy, upon project completion, the video of the interview will be destroyed. Audio recordings will be retained for a minimum 2 years and may be used for question evaluation research that is not directly related to this project.

You may decide at any time after the interview that you don't want us to keep a recording of the interview. In this case you may contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

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 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 or his/her 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 direct benefits to you or the person in your care 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 \$50.

Conducting an interview at a mutual location²

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 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 # [Note: The protocol number will be inserted into the form once approval has been received]. 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. I understand that while I may grant consent for him/her to participate, he/she also will be given the choice to provide assent to participate or not.

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 this topic. I also allow NCHS to play the video recording of the person under my care to internal NCHS CCQDER staff. I understand that the recording of the interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- 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 this topic. I also allow NCHS to play the audio recording of the person under my care to internal NCHS CCQDER staff. I understand that the recording of the interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- Yes • No

Legally Authorized Representative's Signature

Print name

Date

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**Informed Assent Form for
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[Name of LAR _____] says you can take part in a research study. This 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. Someone who knows that you have agreed to take part will also sign the form as a witness.

Why are we doing the study

We often find out about people by asking questions. The answers to those questions help improve the health of people living in the United States. If you agree to take part in this study we will talk with you about your life and about how easy or hard it is for you to do everyday things. What you say will help us to choose what questions to ask of everyone in the future.

What will happen if you take part

An interviewer from our center will ask you about your life and experiences.

The interview will last no more than 75 minutes, and we will give you \$50.

You may choose not to answer any question for any reason. It's okay if you tell the interviewer that you don't want to answer a question. The interviewer will move on to the next one. You may also tell the interviewer to stop at any time.

While the interview is going on, staff, who are allowed to work on the project, may watch or listen. This will help them learn about the experiences of people like you.

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Recordings are stored in a locked room or saved with a password. 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 a few of our 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. However, people working on this study, or those viewing the recordings, 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.

The benefits and risks of taking part

There are no benefits from taking part in this study.

The possible risks of taking part in this study are very small. We will take all possible steps to protect your information. 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 \$50.

If you have any questions about this study, please call the office of the Ethics Review Board (ERB) at the National Center for Health Statistics. The toll-free is 1-800-223-8118. Please leave a brief message with your name and phone number. Give them this number: Protocol # [Note: The protocol number will be inserted into the form once approval has been received]. Someone will call you back as soon as possible.

Please Read and Sign Below if You Agree

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

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- Yes • No

IF YES:

I allow NCHS to keep my video recording for future research on the difficulties people have in their everyday lives. I also allow NCHS to play my video recording to internal NCHS staff. I understand that the recording of my interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- Yes • No

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- Yes • No

IF YES:

I allow NCHS to keep my audio recording for future research on the difficulties people have in their everyday lives. I also allow NCHS to play my video recording to internal NCHS CCQDER staff. I understand that the recording of my interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- Yes • No

Participant Signature

Print name

Date

Witness Signature

Print name

Date

¹The Public Health Service Act provides us with the authority to do this research (42 U.S.C 242k). Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks. Public reporting burden for this collection of information is estimated to average 75 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 CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS H21-8, Atlanta, GA 30333, ATTN: PRA (0920-0222).

OMB #0920-0222; Expiration Date: 01/31/2026

Attachment 5e: Adult informed consent for self-report interviews (conducted virtually)



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 Virtual 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 read this entire form. It's okay if you choose not to take part.

Why we are doing the study

Researchers often find out about people by asking questions. The answers to those questions can help improve the health and health care of people living in the United States. So that we know which questions to ask, we first try to talk to different people about their lives. If you agree to take part in this study, we will talk with you about your life and about difficulties you may have doing everyday things. What you say will help us to decide what questions we ask of everyone. In the future, we may also look at your interview along with interviews from other studies to make sure we understand the kinds of difficulties people have.

What will happen if you take part

An interviewer from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) will talk with you through Zoom video. The interviewer will ask you about your life and your experiences. You will also be asked to for some additional information about who you are as a person.

The interview will last no more than 75 minutes. We will give you \$50 [in cash / electronic gift card].

You may choose not to answer any question for any reason. If you don't 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, staff, who are allowed to work on the project, may watch or listen to your interview. This will help them learn about the experiences of people like you.

NCHS keeps the information safe that we collect, process and store on our systems. However, NCHS cannot secure and protect your personal devices, such as personal computer or smart phones, used to complete the interview.

If you have questions about how the study works, Contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

Why we ask to record your interview

We would like to video and audio record your interview. The recording allows us to carefully study what you told the interviewer. If you agree, you can still ask us to stop the recording at any time, and we will turn off the

recording machine. If you stop the recording, we will ask you if you will allow us to keep the part already recorded, but you can say No. When the interview is finished, you may watch or listen to the recording.

If you agree for us 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 who are allowed to work on the project will be able to watch or listen to the recording. Following our office policy¹, when the study is done, the video recording will be destroyed. The audio recording of your interview will be kept for as long as it is of interest to researchers (a minimum of two years).

You may decide at any time after the interview that you don't want us to keep your recording contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

How we keep your information safe

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

Audio and video recordings are stored in a locked room or saved with 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 information.

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

Your name or other personal information that would identify you will not be used when we discuss or write about this study. However, people working on this study or those viewing the recordings 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.

The benefits and risks of taking part

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

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 \$50.

NCHS protects all information we collect, process and store on our systems as required by Federal regulations, Executive Orders, and NCHS confidentiality statutes. However, NCHS cannot protect your own computing devices, such as your computer or smart phone, used to complete the NCHS interview.

There is a place to call if you have any questions about this study. It is the office of the Ethics Review Board (ERB) 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 # [Note: The protocol number will be inserted into the form once approval has been received]. Your call will be returned as soon as possible.

¹CCQDER Data Storage and Access Policy

²The Public Health Service Act provides us with the authority to do this research (42 U.S.C 242k). Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks.

Public reporting burden for this collection of information is estimated to average 75 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 CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS H21-8, Atlanta, GA 30333, ATTN: PRA (0920-0222).

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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 Proxy-Report Interviews
One-on-one Virtual 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 read this entire form.

Purpose of the Research

Researchers often find out about people by asking questions. Sometimes these questions are included in a national survey or in administrative data systems. The information collected is used to help develop programs to improve the health and health care of people living in the United States. It is important that we make sure that we are asking the right questions. Therefore, we try to talk to different people about their relevant experiences in life. If you agree to take part in this study, we will talk with you about health matters and about difficulties the adult under your care may have doing day-to-day activities. In the future, we may also study your interview along with interviews from other projects. This will teach us about the different kinds of problems people have and make sure we are capturing those problems with our questions.

Procedures

An interviewer from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) will talk with you through Zoom videoconferencing software. The interviewer will ask you about any difficulties the person in your care has in life. You will also be asked to provide some background information about yourself, such as your age and gender.

The interview will last no more than 75 minutes. We will give you, \$50 [in cash/electronic gift card and activation code]. If you the person you are caring for is interviewed for the study, they will also receive \$50 for participating].

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, authorized researchers, who are working on the project may [watch or listen to] the interview.

If you have questions about how the project works, contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

Recordings

We would like to video and audio record your interview. The recording allows us to more carefully study what you told the interviewer. If you agree, you may still ask to stop the recording at any time, and we will turn off the recording 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 or listen to the recording.

If you agree for us 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 authorized researchers who are working on the project will be allowed to watch or listen to the recording. In accordance with the CCQDER Data Storage and Access Policy, upon project completion, the video of the interview will be destroyed. Audio recordings will be retained for a minimum 2 years and may be used for question evaluation research that is not directly related to this project.

You may decide at any time after the interview that you don't want us to keep a recording of the interview. In this case you may contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

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 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 or password protected. 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 direct benefits to you 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 \$50. NCHS secures all information we collect, process and store on our systems as required by Federal regulations, Executive Orders, and NCHS confidentiality statutes. However, NCHS cannot secure and protect your personal computing devices, such as personal computer or smart phones, used to complete the NCHS interview.

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 # [Note: The protocol number will be inserted into the form once CDC IRB approval has been received]. Your call will be returned as soon as possible.

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used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks.

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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

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 to allow him/her to take part, you will need to read this entire form. You may complete the form electronically or return a paper copy before the scheduled interview.¹ The person under your care will also have an assent form to read and sign.

Purpose of the Research

Researchers often find out about people by asking questions. Sometimes these questions are included in a national survey or in administrative systems. The information collected is used to help develop programs to improve the health and health care of people living in the United States. It is important that we make sure that we are asking the right questions. Therefore, we try to talk to different people about their relevant experiences in life. If you permit the person under your care to take part in this study, we will talk with him/her about health matters and about difficulties he/she may have doing day-to-day activities. In the future, we may also study his/her interview along with interviews from other projects. This will teach us about the different kinds of problems people have and make sure we are capturing those problems with our questions.

Procedures

An interviewer from the Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) will talk with the person legally under your care with Zoom videoconferencing software. The interviewer will ask him/her about any difficulties he/she may have in life. You will also be asked to provide some background information about yourself such as your age and gender.

The interview will last no more than 75 minutes, and we will give him/her \$50 [in cash/electronic gift card and activation code].

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, authorized researchers, who are working on the project may [watch or listen to] the interview.

If you have questions about how the project works, contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

Recordings

We would like to video and audio record the interview. The recording allows us to more carefully study what the person legally under your care told the interviewer. At the end of this form, you will be asked if you are willing for the interview to be recorded. If you agree, the person legally under your care can ask to stop the recording at any time, and we will turn off the machine. If the recording is stopped, we will ask your consent to retain the portion already recorded.

If you agree for us 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 authorized researchers who are working on the project will be allowed to watch/listen to the recording. In accordance with the CCQDER Data Storage and Access Policy, upon project completion, the video of the interview will be destroyed. Audio recordings will be retained for a minimum 2 years and may be used for question evaluation research that is not directly related to this project.

You may decide at any time after the interview that you don't want us to keep a recording of the interview. In this case you may contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

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 or his/her name or other personal facts.

Materials with personal facts (such as names or addresses) are also stored in a locked room or password protected. 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 direct benefits to you or the person in your care 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 \$50. NCHS secures all information we collect, process and store on our systems as required by Federal regulations, Executive Orders, and NCHS confidentiality statutes. However, NCHS cannot secure and protect your personal computing devices, such as personal computer or smart phones, used to complete the NCHS interview.

If you have any questions about this study, please call the office of the Ethics Review Board (ERB) 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 # [Note: The protocol number will be inserted into the form once approval has been received]. 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. I understand that while I may grant consent for him/her to participate, he/she also will be given the choice to provide assent to participate or not.

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. I also allow NCHS to play the video recording of the person under my care to internal NCHS CCQDER staff. I understand that the recording of the interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- 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. I also allow NCHS to play the audio recording of the person under my care to internal NCHS CCQDER staff. I understand that the recording of the interview will be kept for as long as it is of interest to researchers (a minimum of two years).

- Yes
- No

Legally Authorized Representative's Signature

Print name

Date

¹This form will be converted into a fillable and signable PDF for virtual interviews.

²The Public Health Service Act provides us with the authority to do this research (42 U.S.C 242k). Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks.

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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 CDC/ATSDR Reports Clearance Officer; 1600 Clifton Road, MS H21-8, Atlanta, GA 30333, ATTN: PRA (0920-0222).

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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

**Informed Assent Form for
One-on-one Virtual Interviews**

[Name of LAR _____] says you can take part in a research study. This 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 read this entire form. Someone who knows that you have agreed to take part will also sign the form as a witness.

Why we are doing the study

We often find out about people by asking questions. The answers to those questions help improve the health of people living in the United States. If you agree to take part in this study we will talk with you about your life and about how easy or hard it is for you to do everyday things. What you say will help us to choose what questions to ask of everyone in the future.

What will happen if you take part

An interviewer from our center will ask you about your life and experiences. The interviewer will use Zoom to talk with you.

The interview will last no more than 75 minutes, and we will give you \$50 [in cash/electronic gift card and activation code].

You may choose not to answer any question for any reason. It's okay if you tell the interviewer that you don't want to answer a question. The interviewer will move on to the next one. You may also tell the interviewer to stop at any time.

While the interview is going on, staff, who are allowed to work on the project, may watch or listen. This will help them learn about the experiences of people like you.

If you have questions about how the project works, contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

Why we ask to record your interview

We would like to video and audio record your interview. The recording allows us to carefully study what you told the interviewer. If you say it's okay to record, you can still tell us to stop the recording at any time. If you stop the recording, we will ask you if you will allow us to keep the part already recorded, but you can say No. When the interview is finished, you can watch or listen to the recording.

If you say it's okay for us to record the interview, we will keep it in a locked room, in a secure storage cabinet or on a password-secured computer that is not connected to the internet. Only staff who are allowed to work on the project will be able to watch or listen to the recording. Following our office rules¹, when the study is done, the video recording will be destroyed. The audio recording of your interview will be kept for as long as it is of interest to researchers (a minimum of two years).

You may decide at any time after the interview that you don't want us to keep your recording. Contact us by mail at NCHS, Room 5470, 3311 Toledo Rd., Hyattsville, MD 20782, or by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your interview will be immediately destroyed.

How we keep your information safe

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

Recordings are stored in a locked room or saved with a password. 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 or password protected. Only a few of our 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. However, people working on this study, or those viewing the recordings, 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.

The benefits and risks of taking part

There are no benefits from taking part in this study.

The possible risks of taking part in this study are very small. We will take all possible steps to protect your information. 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 \$50.

NCHS protects all information we collect, process and store on our systems as required by Federal regulations, Executive Orders, and NCHS confidentiality statutes. However, NCHS cannot protect your own computing devices, such as your computer or smart phone, used to complete the NCHS interview.

If you have any questions about this study, please call the office of the Ethics Review Board (ERB) at the National Center for Health Statistics. The toll-free is 1-800-223-8118. Please leave a brief message with your name and phone number. Give them this number: Protocol # [Note: The protocol number will be inserted into the form once approval has been received]. Someone will call you back as soon as possible.

¹CCQDER Data Storage and Access Policy

²The Public Health Service Act provides us with the authority to do this research (42 U.S.C 242k). Assurance of Confidentiality: We take your privacy very seriously. All information that relates to or describes identifiable characteristics of individuals, a practice, or an establishment will be

used only for statistical purposes. NCHS staff, contractors, and agents will not disclose or release responses in identifiable form without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 U.S.C. 242m(d)) and the Confidential Information Protection and Statistical Efficiency Act or CIPSEA (44 U.S.C. 3561-3583). In accordance with CIPSEA, every NCHS employee, contractor, and agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you. In addition to the above cited laws, NCHS complies with the Federal Cybersecurity Enhancement Act of 2015 (6 U.S.C. §§ 151 and 151 note) which protects Federal information systems from cybersecurity risks by screening their networks.

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