

Attachment 2– Adult informed consent for in-person and virtual focus groups



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 In-person focus groups

You are being asked to take part in a research study. This consent form tells you about the study and what you will be asked to do. You can choose to take part in the study or not. If you choose to take part, you will need to sign this form.

- **Purpose of the Research**

The National Center for Health Statistics (NCHS) uses surveys and other tools to collect information on the health and wellbeing of Americans. Findings from these surveys and other research efforts help to develop programs to improve the health and health care of people living in the United States.

One important aspect of the work at NCHS is understanding how the public understands our data and the language they and health care providers use regarding public health topics. It is important that the products we release—including reports and data visualizations—make sense to the people who will use and consult them. To do this, NCHS conducts tests exploring how our data is understood for the surveys it sponsors and for other survey programs. If you agree to take part in this test, we will ask you to participate in a focus group where you and others will discuss how you understand and talk about topics such as growth charts and obesity. This focus group will give us insight into how to improve visualizations and user guides for products such as the growth charts.

Procedures

A member of the CCQDER research team, either a staff member or a contracted interviewer from Research Support Services (RSS), will lead you and a group of other participants in a discussion. A variety of topics will be covered, and the facilitator will do his or her best to make sure everyone in the group has an equal opportunity to contribute to the discussion.

The focus group will last no more than 90 minutes, and we will give you \$150. You will also be asked to fill out a personal information sheet. The information sheet will be stored on a secure server and only NCHS researchers (and NCHS contractors) working on the study will have access to the sheet. Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email recruitmentteam@cdc.gov to request removal.

You may choose not to participate in any section of the focus group for any reason. If you do not want to answer a question the facilitator poses, say so, and they will move on to the next participant or question. You may also stop participating at any time.

While the focus group is going on, researchers from the National Center for Health Statistics and its contractors who are working on the project may watch or listen to the focus group.

If you have questions about how the project works, contact CCQDER by email at recruitmentteam@cdc.gov.

Recordings

We would like to video and audio record this focus group. The recording allows us to more carefully study and improve the products. At the bottom of this form, you will be asked if you are willing to have the focus group 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 focus group is finished, you may watch/listen to the recording.

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If you agree to record the focus group, 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 NCHS and its contractors who are 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. In accordance with the CCQDER Data Storage and Access Policy, upon project completion, the video of the focus group will be destroyed. Audio recordings will be retained for a minimum of 5 years and may be used for topic evaluation research that is not directly related to this project.

You may decide at any time after the focus group that you don't want us to keep a recording of the focus group. In this case, you may contact CCQDER by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your focus group 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 on a password secure server and will be kept up to five years in a locked room. Only CCQDER staff has access to this material. Any hardcopies of these materials will be destroyed upon completion of the focus group. Project related information will be stored in our database for up to five years, located on password protected and secure server. You may decide at any time after the focus group that you don't want us to keep your information. In this case, you may contact CCQDER by email at recruitmentteam@cdc.gov to request removal. When CCQDER receives your request, your personal information and recording of the focus group will be immediately destroyed.

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 focus group. You may also stop at any time and still receive the full \$150. For you to take part in the study today, we agreed to meet at this location. We will protect any materials that contain your personal information and transport them to the National Center for Health Statistics.

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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 Project ID-7505. 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 video record the focus group. I also allow NCHS to play my video recording to researchers from NCHS and its contractors 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 clinicians understand and talk about topics such as growth charts and obesity. I also allow NCHS to play my video recording to internal NCHS CCQDER staff.

I understand that the recording of the focus group will be kept for as long as it is of interest to researchers 5 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). 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 90 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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Adult Informed Consent Form for Virtual Focus Groups

You are being asked to take part in a research study. This consent form tells you about the study and what you will be asked to do. You can choose to take part in the study or not. If you choose to take part, you will need to read this entire form.

- **Purpose of the Research**

The National Center for Health Statistics (NCHS) uses surveys and other tools to collect information on the health and wellbeing of Americans. Findings from these surveys and other research efforts help to develop programs to improve the health and health care of people living in the United States.

One important aspect of the work at NCHS is understanding how the public understands our data and the language they and health care providers use regarding public health topics. It is important that the products we release—including reports and data visualizations—make sense to the people who will use and consult them. To do this, NCHS conducts tests exploring how our data is understood for the surveys it sponsors and for other survey programs. If you agree to take part in this test, we will ask you to participate in a focus group where you and others will discuss how you understand and talk about topics such as growth charts and obesity. This focus group will give us insight into how to improve visualizations and user guides for products such as the growth charts.

- **Procedures**

This focus group will be conducted virtually through videoconferencing software. 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 focus group.

A member of the CCQDER research team, either a staff member or a contracted interviewer from Research Support Services (RSS), will lead you and a group of other participants in a discussion. A variety of topics will be covered, and the facilitator will do his or her best to make sure everyone in the group has an equal opportunity to contribute to the discussion.

The focus group will last no more than 90 minutes, and we will email you the link to your [\$150 electronic gift card with activation code to access funds]. You will also be asked demographic questions from a personal information sheet. This information will be stored on a secure server and only NCHS researchers (and NCHS contractors) working on the study will have access to the sheet. Your information will be kept for up to 5 years and you can decide at any time to be removed from our database. Email recruitmentteam@cdc.gov to request removal.

You may choose not to participate in any section of the focus group for any reason. If you do not want to answer a question the facilitator poses, say so, and they will move on to the next participant or question. You may also stop participating at any time.

While the focus group is going on, researchers from the National Center for Health Statistics and its contractors who are working on the project may watch or listen to the focus group.

If you have questions about how the project works, contact CCQDER by email at recruitmentteam@cdc.gov.

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- **Recordings**

We would like to video and audio record this focus group. The recording allows us to more carefully study and improve the products. If you agree, you may still ask to stop the recording at any time, and we will stop recording. If you decide to stop recording, we will ask your consent to retain the portion already recorded.

If you agree to record the focus group, we will keep it on a password-secured computer that is not connected to the internet. Only researchers from NCHS and RSS contractors who are 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. In accordance with the CCQDER Data Storage and Access Policy, upon project completion, the video of the focus group will be destroyed. Audio recordings will be retained for a minimum of 5 years and may be used for evaluation research that is not directly related to this project.

You may decide at any time after the focus group that you don't want us to keep a recording of the focus group. In this case, you may contact CCQDER by email at recruitmentteam@cdc.gov. When we receive your request, the recording of your focus group 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 on a secure server located in a locked room and 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.

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- **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 focus group. You may also stop at any time and still receive the full [\$150 electronic gift card]. 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 focus group.

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 Project ID-7505. Your call will be returned as soon as possible.

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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 90 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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