

## **Attachment 4: CCQDER Data Storage and Access Policy**

### **Background**

Cognitive Interviewing Methodology is a question evaluation method that examines the way in which survey questions perform. It offers a detailed depiction of the meanings and processes used by respondents to answer survey questions. This method provides insight into data quality as it is able to examine question validity and item response error. Within the Federal statistical system, cognitive interviewing methodology is a commonly used method for developing and evaluating survey questions. The Collaborating Center for Questionnaire Design and Evaluation Research (CCQDER) at the National Center for Health Statistics (NCHS) conducts numerous cognitive interview studies for sponsors both within and outside of the center.

In keeping with standard practice for cognitive interview studies, cognitive interviews (as well as focus group discussions) conducted by the CCQDER are video and/or audio recorded. These recordings serve as the raw data that lead to the analytical findings of each project. Importantly, recordings allow for an evidence-based approach for question evaluation and design. While both video and audio recordings are valuable as raw data, video is the richest format for data as it includes both verbal and nonverbal reactions to interviewer questions. While audio is limited to pure verbal interactions, video provides additional means to understand any confusion or to explore reactions otherwise missed through audio alone.

After the recordings are used for analytical purposes, they retain their qualitative value in three particular areas. Recordings: 1) foster transparency by providing evidence of analytic findings; 2) allow for the sharing of the methodological process with data users; and 3) may provide data for future question design research without additional burden to the public. Ideally, recordings of interviews should be maintained in their original format for as long as they retain this qualitative value.

However, the benefits of retaining recordings must be balanced with the risk of disclosure that exists as long as recordings of interviews are kept. The likelihood and implications of disclosure vary depending on media format as well as the type of respondent and interview topic. For example, video recordings are susceptible to identification of respondents through either facial or voice recognition, while audio recordings are vulnerable only through voice recognition. Additionally, disclosure of some topics and types of respondents may have more serious consequences for respondents. Therefore, interviews conducted with youth or those that cover topics of illegal behavior, for example, may merit added steps to minimize risk of disclosure. Thus, when assessing risk and determining data storage requirements, it is necessary to consider a variety of factors at the project and/or interview level.

In regards to the storage of interview recordings, The Office of Management and Budget stipulates in Guideline A.5.1 of the statistical policy directive, Standards and Guidelines for Cognitive Interviews:

A plan is prepared to store the raw data according to an agencies' record management schedule. If not available, a schedule for storing raw data for specified length of time based on the nature of the data and project should be developed. Each agency has the legal responsibility to safeguard respondent identity and personally identifiable information, and should treat all data according to their stated security and confidentiality procedures.

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This document delineates the NCHS plan for housing the raw data from its question evaluation studies in order to minimize risk of disclosure. In doing so, the policy specifies the procedures for both the storage of and access to CCQDER recordings of interview and focus group discussions, and data from personal information sheets. Storage and access pertain to 1) the permitted retention time for interviews, 2) the required media format for storage, and 3) the persons permitted access.

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### Terms and Definitions

*CCQDER*, the Collaborating Center for Question Design and Evaluation Research, refers to the NCHS question evaluation research program.

*QDRL*, the Question Design Research Laboratory, refers to the secured facility housing the infrastructure that supports the collection, processing and maintenance of question evaluation data. CCQDER manages the QDRL with the support of contracted staff, or non-Federal employees. QDRL contract staff are permitted access to QDRL data within the confines of the QDRL.

*CCQDER Interviews* are those interviews conducted and recorded by CCQDER staff as well as those conducted by non-federal employees contracted by CCQDER. Contracted interviewers have access to only their recorded interviews until turning them over to CCQDER (should they be conducted outside the QDRL).

### Policy Objectives

The objectives of the CCQDER data storage and retention policy are:

- To maintain recordings in the optimal useable format for as long as the interview continues to hold relevance and has qualitative value for likely use in federal question evaluation research projects or activities.
- To identify interviews that have confidentiality risks based on elevated privacy concerns.
- To minimize confidentiality concerns by specifying rules for which persons are permitted access to interview recordings.
- To minimize confidentiality concerns by stipulating the terms of regular review and disposal of each interview recording stored within the QDRL.

### Factors for Determination of Retention Status

An interview's retention status pertains to 1) retention time: how long a recorded interview will be stored, 2) media format: the media format used to store a recorded interview, and 3) authorized viewers: the persons permitted access a recorded interview. An interview's Retention Status is determined by several project and interview-level factors. Thus, each interview has its own individual retention status independent of the other interviews within the same project. An interview's retention status is based on the type of consent agreed upon by the respondent and whether the interview is considered to be a restricted interview based on the type of respondent or the interview topic. The retention status matrix (presented in the table below) describes all possible retention status levels and stipulates the retention time, media format, and permitted access for each retention status category. (See Attachments A, C and D, revised informed consent and special consent forms. Note: attachment labels A, C and D correspond to their designations in the original package.)

#### 1. Type of Consent

**Basic informed consent:** In order to participate in CCQDER research, each respondent must provide basic informed consent to be interviewed and to have the interview recorded. The informed consent statement that each respondent reads and signs indicates that the respondent's participation is voluntary and that the respondent can terminate the interview at any time without forfeiting any compensation that may have been promised

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(based on the study design of the particular project). This basic informed consent also specifies that CCQDER, QDRL contractor staff, and other project-specific collaborators and survey staff may be able to view interview recordings. Finally, the basic informed consent statement discloses that voice and facial identifiers will remain on the recording and acknowledges that the respondent may be recognized by anyone who views or listens to a recording in the course of working on the project. If a respondent does not agree to these terms, they will receive the incentive, but the interview will not be conducted.

**Future use consent:** In addition to basic interview consent, respondents are asked for consent to retain their interviews for future use. This future use consent allows for the respondent's data (the raw data of the recorded interview) to be used in future research that is directly related to the survey questions discussed in the interview but that is not necessarily related to the project the data was originally collected for. If a respondent does not grant consent for future research, the interview is conducted and the recording is maintained only through the conclusion of the project (determined by the submission of a final report or similar product).

**Special Consent:** Finally, respondents may also be asked to provide "Special Consent." The current special Consent allows interviews to be shown outside of the QDRL and/or to audiences other than CCQDER, QDRL contractor staff, and project-specific collaborators. Special consent specifies use at conferences and trainings as well as viewing within the QDRL by researchers who are not CCQDER staff or contractors. Special Consent is obtained from an adult respondent after the interview is completed by having the respondent read and sign the Special Consent for Expanded Use of Video and Audio Recordings form. Special Consent is not requested of those respondents who opt out of the future research consent and respondents under the age of 18.

## 2. Restricted Interviews:

Another factor that determines an interview's retention status is whether the interview is labeled as *restricted* or not. Restricted interviews are those that carry more serious implications associated with disclosure and which require enhanced data retention and storage protections. There are three types of *restricted* interviews:

- a. Child self-report: Recorded interviews of respondents under age 18 years, or minors, are designated as restricted.
- b. Adult proxy for Child: A proxy-respondent is a respondent who answers on behalf of another person. Recorded interviews of adult proxy-respondents who are answering on behalf of a minor (under the age of 18 years).
- c. The topic of interview is about illegal behaviors: Recorded interviews pertaining to illegal behaviors committed by the respondent, or a proxy are considered restricted. A designation is made between those projects with interview questions that ask respondents to report illegal behaviors verses those that do not. Illegal behaviors, including but not limited to illegal drug use and impaired driving, are those that are clearly defined by law and are punishable if disclosed. Because of the subjectivity of theoretically "sensitive" topics and because respondents provide informed consent based on the disclosed interview topic, interviews on behaviors that some may deem as embarrassing, or disconcerting are not restricted.

Restricted interviews, defined by the terms above, require enhanced protections for data storage and retention. Interviews that are given the restricted designation are stripped of video upon project completion by designated CCQDER staff and maintained only in audio format. The

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audience for restricted interviews is limited, and they are reviewed more frequently by the CCQDER Director and CCQDER project-specific staff to determine whether the interview continues to have qualitative value for use in federal question evaluation research projects or activities.

#### **Retention Status of Personally Identifiable Information Collected from the Respondent Data Collection Sheet During the Recruitment and Screening Processes**

During the recruitment and screening processes, CCQDER staff ask potential respondents to complete a “Respondent Data Collection Sheet” that requests personally identifiable information (PII) including gender, age, marital status, race, highest level of education, current employment status, and total household income. This information is also requested from persons who have been screened for a study but are deemed ineligible to participate. This could occur for various reasons, including not meeting project-specific eligibility criteria such as age or life experience; if enough participants with similar characteristics have already completed interviews; if a person cannot enter a Federal Government facility for any reason and is not willing to schedule an off-site interview; if an interview cannot be scheduled within the project timeline; and for studies that are only conducted virtually, if a person does not want to appear on camera for any reason, or does not have a computer, tablet, or cellphone with internet access.

CCQDER collects and stores this PII in a database for two reasons: (1) to describe (in aggregate form only at the end of the study) the characteristics of study participants for a final report that is usually posted online in Q-Bank; and (2) to build a recruitment database for potential future recontact, specifically, to ask if they would be willing to participate in upcoming research studies they may be eligible for. Respondents who complete interviews and ineligible respondents are told (during the appropriate exit script) that their PII will be kept for up to 5 years. They are told this information may be removed at any time if they change their mind and are given a phone number and email address for a point of contact to have it removed. This information (5-year retention period and point of contact) is included on the Informed Consent and Screening Script.

## Retention Status Categories

As stated above, an interview's retention status pertains to 1) the persons permitted access to the recording, 2) the required media format for its storage, and 3) the permitted retention time for its recording. These categories are stipulated by the project and interview-level factors discussed above and are demarcated within the Retention Status Matrix presented below.

1. **Viewing Access:** The determination regarding the persons who are eligible to view a recording and under which circumstances. There are 7 potential audiences:

With basic consent

- a. Internal project related: CCQDER and QDRL contractor staff viewing within the QDRL related to a specific project.
- b. Collaborator: Shown by CCQDER staff, inside the QDRL, for researchers collaborating on the specific project as named in the consent. This type of audience is relevant through the duration of the project. In the chance that a respondent chooses to terminate the interview, collaborators are permitted to view recorded interviews only; they are not permitted to watch live interviews.
- c. Project specific training: Shown by CCQDER staff, outside of the QDRL, to interviewers who will be conducting interviews for the specific project. This type of audience is relevant only when a project is running.

With future use consent

- d. Internal research related: CCQDER and QDRL contractor staff viewing within the QDRL related to general question evaluation research rather than to a specific project.

With both future use and special consent

- e. Conferences: Shown by CCQDER staff, outside of the QDRL, to a general audience of conference attendees.
- f. Classroom Training: Shown by CCQDER staff, outside of the QDRL, to students learning to conduct cognitive interviewing studies.
- g. Research Interests: Shown by CCQDER staff, inside the QDRL, to researchers not associated with a specific project but who have a viable question-evaluation research purpose for accessing specific interviews.

2. **Stored Data Format:** Recordings may be stored as either video with audio or audio-only. The CCQDER has a routine set of administrative, technical, and physical measures to safeguard video and audio recordings. The QDRL LAN is not located on either the NCHS or CDC LAN, and the QDRL LAN is inaccessible to others (not CCQDER personnel/QDRL contractors) inside or outside NCHS. Storage of video and audio recordings on the QDRL LAN are protected through use of passwords and carefully restricted access. Only authorized personnel are allowed access to video and audio recordings and only when their work requires it. Personnel holding proper

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passwords may access the QDRL LAN through their QDRL Computer Desk Top which is hardwired to the QDRL LAN (but which is not connected to any other network). When recordings are shown outside of the secure QDRL area, they are transported and stored on encrypted thumb drives.

3. **Data Retention Period:** Data retention specifies length of time the recording may be retained. The data retention period for recordings of interviews that do not have consent for future use is until the completion of the project (upon completion of a final product or final sponsor briefing). Upon project completion, these non-retained recordings will be destroyed by designated CCQDER staff. For those interviews being maintained for future use, the data retention period for storing the interview recording will begin after the conclusion of each project (upon completion of a final product or final sponsor briefing). Restricted recordings will have an initial retention period of 2 years after project completion, and non-restricted recordings will have an initial retention period of 5 years after project completion. After the initial retention period, the recordings will be re-evaluated by the CCQDER Director to determine relevance, ongoing usefulness, and qualitative value for likely use in question evaluation research. If it is determined by the CCQDER Director in conjunction with CCQDER project-relevant staff that there is no valid reason to retain the recording, it will be destroyed by designated CCQDER staff. If the interview continues to be of value (defined as ongoing use by research staff, topic relevance, likely use for federal questions evaluation research), reassessment of the recording will occur again in either 2 years (for restricted interviews) or 5 years (for unrestricted interviews).

#### Interview Retention Status Matrix

| Retention Status Categories            | With Special Consent*                                                                                                                                                                                                                               |                                                                                                                                                                                                    | Without Special Consent**                                                                                                           |                                                                                                                                     | No future use consent^ |
|----------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------|------------------------|
|                                        | Unrestricted Interview                                                                                                                                                                                                                              | Restricted Interview+                                                                                                                                                                              | Unrestricted Interview                                                                                                              | Restricted Interview+                                                                                                               |                        |
| <b>Viewing Audience</b>                | <ul style="list-style-type: none"> <li>Internal project related</li> <li>Collaborator</li> <li>Project specific training</li> <li>Internal research related</li> <li>Research Interests</li> <li>Conferences</li> <li>Classroom Training</li> </ul> | <ul style="list-style-type: none"> <li>Internal project related</li> <li>Collaborator</li> <li>Project-Specific Training</li> <li>Internal Research Related</li> <li>Research Interests</li> </ul> | <ul style="list-style-type: none"> <li>Internal project related</li> <li>Collaborator</li> <li>Project-Specific Training</li> </ul> | <ul style="list-style-type: none"> <li>Internal project related</li> <li>Collaborator</li> <li>Project-Specific Training</li> </ul> | NA                     |
| <b>Stored Data Type</b>                | Video or Audio                                                                                                                                                                                                                                      | Audio only                                                                                                                                                                                         | Video or Audio                                                                                                                      | Audio only                                                                                                                          | Destroyed              |
| <b>Data Retention Reviewing Period</b> | Assessed every 5 Years                                                                                                                                                                                                                              | Assessed every 2 Years                                                                                                                                                                             | Assessed every 5 Years                                                                                                              | Assessed every 2 Years                                                                                                              | NA                     |

**\*Interviews for which special consent has been obtained**

**\*\*Interviews for which special consent was not obtained either because it was not asked (minors or designated projects) or because special consent was not granted by the respondent**

**^Interviews with no future use consent are not maintained.**

**+Restricted interviews consist of interviews conducted with minors, adult proxy for minors, and/or those pertaining to illegal behavior (i.e., self-reported or proxy reported).**

### **Protocol for Determination, Maintenance and Safeguarding of Interview Recordings**

Each interview will receive a retention status based on both respondent and project level considerations and defined within the Retention Status Matrix. IRB packages will denote whether a project falls into the restricted or unrestricted designation. If the research requires a different policy than indicated by the matrix, a justification will be provided at that time.

All consent forms presented to the respondent at the beginning of the interview will disclose the eligible viewing audience, the recording type as well as the terms for data retention for the particular project. Informed consent documents contain the sentence “When the interview is finished, you may watch/listen to the recording.” If after viewing or listening to the recording, the respondent rescinds his/her earlier consent to be recorded or to have his/her recording retained the recording is destroyed. If a respondent chooses to terminate the interview, they will be asked for consent to retain the completed portion of the interview. If the respondent does not grant consent, the interview will be destroyed. Respondents are also given a copy of the form, containing information about how to contact the CCQDER Laboratory Manager, the NCHS Ethics Review Board Chair, and the NCHS Confidentiality Officer.

In cases where Special Consent is requested, the respondent is asked for Special Consent at the end of the interview and after receipt of remuneration. The special consent statement discloses the audience and retention terms specific to the particular project. If the respondent grants Special Consent, he/she is told that if for any reason they change their mind, they should contact the laboratory manager by calling or writing to change the status of the recording. If a respondent does not grant Special Consent, the respondent is informed that the recording will only be seen or heard by CCQDER staff, QDRL contractor staff working as designated agents on behalf of the CCQDER, or direct study collaborators, which is described in the initial informed consent form.

Each interview recording will be assigned a unique identifier, which specifies the respondent, the project and the retention status of the particular recording. The unique identifier will be assigned by the lab manager immediately after the interview when the recording is saved. With this approach, the status will always be attached to the recording.

After the analysis has been conducted at the conclusion of each project (as determined by the submission of a final report or similar product), interviews with no future use consent or special consent will be destroyed. Additionally, restricted interviews determined to be stored as audio-files will be stripped of video. The period of data retention will commence from the time of this distinction and reviewed according to their retention classification. Assessment of recordings

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will be every 2 to 5 years (depending on the particular review period) using the QDRL Outlook Calendar.

Recordings that are shown outside of the QDRL will be temporarily transported and stored on an encrypted thumb drive which is only accessible by the specific CCQDER researcher to which it was issued. The warning, "Recording of this material is prohibited," will be included in presentation materials (e.g., PowerPoint or presentation slides) when recordings are shown outside of the QDRL, for example as part of conference presentations.

At roughly a month in advance of the 2- or 5-year review period, interviews will be evaluated on the criteria of 1) current research using the project data since last review 2) current relevance of questions evaluated and 3) qualitative value for likely use in question evaluation research. If any of the 3 criteria are met, the interview will be kept with a renewed retention period and re-evaluated every 2- or 5- years according to the assigned retention status. Rationales for retaining interviews must be attached to each interview media file to serve as an audit trail. A report documenting the number of interviews retained and destroyed will be produced annually by CCQDER staff.

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](mailto:recruitmentteam@cdc.gov) to request removal.

After adoption of the current data retention and storage plan, all recordings of interviews that were conducted prior to the implementation of this policy, were identified and assessed according to the current policy.