



HCHS/SOL Question by Question Instructions, Annual Follow-Up Forms, Year 7 (FE7/FS7), Version A

I. Background

The purpose of the year seven follow-up phone interview for HCHS/SOL is to document medical events occurring since the six annual follow-up interview, maintain and update cohort contact information, and to ascertain vital status. The year seven follow-up interview is to be conducted by telephone in either English or Spanish. The interview should occur approximately 84 months after the baseline examination. Future annual follow-up interviews (contact year 8 onwards) will continue to occur approximately every 12 months from that same baseline anniversary date. The timing of the annual follow-up interviews is described in more detail in Manual 16, Follow-up available on the HCHS/SOL website.

NOTE: **AFTB** should be utilized for Year 7 interviews. All new Year’s 4, 5 and 6 should use version AFTB as well. Please refer to AFTB QxQ for instructions on details on the version B of the AFT.

II. Missing items/Forms Data entry protocol

AFU Year 7 will be recorded in the new HCHS/SOL data management system that is called CDART2. In this new system each section of the AFU-7 form needs to be entered individually. The system does not have an AFU year “formset” which automatically links a series of forms together. Instead, each group of forms for year 7 will be present in a folder identified with the AFU year number. CDART2 Missing items report located at the end of each form will assist data in identifying missing values. The missing item report will not query for values that are not required. Use the CDART2 “Field Status” to code missing values.

Paper form vs. CDART reference:

AFU-7 Paper form Section Headings	CDART2 form Mapping and question #'s
Section A-Vital Status	GHE1 to GHE2
Section B-Hospitalization	HOE3 to HOE4f
Section C-Self Reported Conditions	OPE5 to OPE9b7
Sections D, E and F not used in Year 7	Q10 to Q48 will not be present in CDART since sections not used
Section G-Contact InformationTracking	CIE49 to CIE66

III. Special Coding Procedures

A. “Soft Refusals” vs “Hard Refusals”

Definitions:

Hard-refusal- occurs when participant that clearly states that he/she does not want to be called ever again for any HCHS/SOL study related matter.

Code: hard refusals are coded as: “**Contacted and refused interview**” GHE-Q1= 2

Soft-refusal- is a case where the participant says they are not available for an interview at the time of call, but does not directly state that they do not want to be contacted ever again. They may even propose an alternate day/time which fails to be completed by the time their contact window closes for the year.

Code for GHE: “**Contacted and alive, agrees to interview**” GHE-Q1= 1, proceed to set forms HOE, OPE, EVE, and MEE as missing. Complete CIE form; if you cannot obtain actual information from the participant, allow the form to be completed with previous year information.

Code for AFTverB: Use AFT-ver B for all AFU interviews for Year 4, 5, 6, 7. If the participant does not complete the interview in the year window, and they were contacted, proceed to code the AFTB-Q5=4 “Contacted, Interview partially complete or rescheduled”.

B. Alternate Respondent/Designated Respondent/Proxy

There has been some confusion with the various terms use for a person that is well informed and is able to answer some basic questions on the participant’s health at the time of the AFU interview. The terms “Alternate Respondent/ Designated Respondent/ Proxy” describe the same relationship when defined as a well-informed, mature individual who can answer health related questions on behalf of an HCHS/SOL cohort member if the participant is not available, or is unable to provide the information. A family member or other person who shares the participant’s household or knows him/her well may qualify as an alternate respondent, if sufficiently well informed about the participant’s health and use of health care. The circumstances in which an alternate respondent is needed are outlined in MOP 03-Retention Manual, and MOP 16-Follow-up Manual.

If you are able to find a well-informed individual that would fit the description stated above, you can proceed with the AFU by assigning GHE-Q1=3. If the person contacted cannot provide accurate information on the health of the study participant GHE-Q1=4 (Other respondent contacted, reported alive.) Remember that we would like to obtain as much information as possible on the participants’ health, and that it can be a staff member judgment call to deem the person contacted to be used as an “Alternate Respondent/ Designated Respondent/ Proxy.” Once you have selected the correct code the AFU skip patters will guide you in the questions you can ask about the participant’s health. If your “Alternate Respondent/ Designated Respondent/ Proxy” is unable to answer any allowed questions, you would need to set them as permanently missing.

C. Case Study Coding

Study Case 1- See appendix 1.

Study Case 2- See appendix 2.

IV. Annual Follow-Up Procedures

A. Timing of the follow-up interview

The target date of the year seven follow-up phone interview is the seven-year anniversary of the participant's baseline interview at the field center. For example, if the participant's baseline visit interview was on October 1, 2008, then the target date for the year seven follow-up interview is October 1, 2015. The initial call for annual contacts is to be made no more than three weeks (21 days) before the target date. Ideally, the annual follow-up interview takes place as closely as possible to the participant's seven-year follow-up target date. However, it may require repeated attempts to contact the participant before an interview can be completed. All efforts should be used to complete the year seven follow-up interview no later than 6 months after the target date. If for some reason contact is not made within 6 months after the participant's follow-up target date, the year seven annual follow-up will be set to missing. The year seven follow-up interview form should be used when the participant's Year 7 anniversary occurs. This procedure is described in more detail in Manual 16.

B. Performing the Interview

General Instruction

Probing is appropriate technique to seek further information, provoke further discussion along a certain line of thought or explanation, or to question the respondent. In general, and unless specifically countermanded in the QxQ instructions of the interview, probing is appropriate when an answer is unclear, incomplete, inconsistent or no response is given. The best and most frequently employed probe is silence. In a silent probe, the interviewer pauses or hesitates and waits for the participant to answer. What appears to be dead time to the interviewer may represent the participant's review of a lifetime of events. Other types of probing include the following methods:

- **repetition** of the original question
- **channeling** ("tell me more about...")
- **clarification** ("exactly what was the date you went to the emergency room?")
- **elaboration/continuation** ("what happened next?")
- **encouragement** ("I see, um, huh, hmmm")
- **completion** ("anything else?"; "can you tell me anything more about that?")

C. Interviewing for the first time (previous AFU's not completed)

For participants that we are able to find for the current contact year, but have not completed previous year's interviews, the questions for the AFU-interview need to be framed stating "Since the last time we contacted you... have you, been to hospital etc." If the participant did not complete any follow up interview but participated in V2 exam, you will frame the questions from the last annual follow up contact or baseline visit (visit1 participation). Annual follow up interviews are always framed from baseline exam.

It is important that you capture the hospitalization admission dates for item HOE-Q4b. If the participant is not able to provide a full date for the event, try to get at least a partial date such as the month and year of their hospital or emergency department visit. This will assist the Medical-Records-Acquisitions team when they request medical records.

V. Question by Question Instructions

Once the interviewer established contact with someone on the phone, the interviewer begins the interview by reading the following introduction script:

“Hello, my name is (insert your name), and I am calling to follow up with (insert name of participant) about the Hispanic Community Health Study/Study of Latinos a health study in which s/he is currently enrolled. Is s/he available?”

Section A GHE (General Health Section for data entry begins here.)

Q1 Participant status

If the participant is not available, try to establish a convenient time to call back to talk to him/her by saying:

“When would it be convenient to call back? Thank you. I will call again.”

If the interviewer establishes that they are talking to the participant, follow up by saying the following:

Hello, *(participant name)*, this is *(interviewer name)* with the Hispanic Community Health Study / Study of Latinos. I’m calling to see how you have been since your last telephone interview and to update our SOL records. Do you have a few minutes to speak on the phone?

If the participant response that they are willing and able to complete the interview, record CONTACTED and ALIVE for Q1 and thank them for agreeing to speak with you. Then quickly but gently follow up by introducing the interview in the following way:

We’d like to gather information about your general health and about specific medical conditions that you may have had in the past year. I will ask you some questions about your health since the last telephone interview with you on *(date of last follow-up call)*. I want you to focus on what happened from *(date of last follow-up call)* until today. Then GO to Q2.

If the participant responds that they either not able or willing to complete the interview go to question 49.

“When would it be convenient to call back?..... Thank you. I will call again.”

When an HCHS/SOL participant cannot speak on the telephone with an AFU interviewer, but can respond to questions through an intermediary or has an alternate respondent, a limited number of the questions on the AFU form are administered. If it is not possible to conduct the full interview, VITAL STATUS question 1 (GHE), HOSPITALIZATIONS questions 3, 4-4f (HOE), and TRACKING (CIE) questions 49-65a are the most important.

If the HCHS/SOL participant is incapable of speaking on the telephone with an AFU interviewer, and is also NOT capable of responding to the questions even through some other intermediary, the HCHS/ SOL interviewer goes to question 49.

Likewise if the status of the participant is unknown also go to question 49.

If the interviewer establishes that the participant is DECEASED, the interviewer offers condolences. Record this information in Q1 (5=(Not contacted, reported deceased). Then the interviewer gently collects and records the date and the location (city, state, and country) of the death in the space provided (Q1a-b).

Q1a What was the date of death?

Collect and record date of death.

Q1b Where did the death occur?

Collect and record cite, state, and country where the death occurred.

Q1c Do you know if (decedent's name) was hospitalized or visited an emergency room for any reasons since (date of last contact) and his/her death?

If the informant responds "NO", thank the respondent, expressing condolences for their loss, and END THE INTERVIEW.

If the informant responds "YES", the interviewer gently goes to "Section B (HOE) Hospitalizations and Emergency Room Events" (Questions 3-4). The interviewer modifies Q3 slightly to ask if the decedent (using his/her name) had been hospitalized or seen in an emergency room since his/her SOL phone call date (see Q3). If the informant responds "NO" or "UNSURE" to Q3, the interviewer concludes the interview at that point by again expressing condolences and saying goodbye. If the informant is not comfortable answering Q3, record UNSURE and end the interview by once again expressing condolences and saying goodbye (see death investigation protocol in the Follow-up Manual).

If the informant responds "YES" to Q3, then the interviewer continues through to Q4e until all hospitalizations and emergency room visits have been reported. Use probing techniques, if necessary, to try to capture hospitalization admission dates. If the person does not remember, try to at least capture the month/year, do not leave the field entirely blank (e.g. 03/==/2012 is better than ==/==/2012). Use bracketing interviewing techniques if necessary to narrow down a date range. When there are no more hospitalized or emergency room visits to report, record "NO" for Q4e, and end the interview by expressing their condolences and saying goodbye (see death investigation protocol in the Follow-up Manual.)

General Health

Q2 Since our last telephone interview with you on (date),, would you say, in general, your health is Excellent, Very good, Good, Fair, or Poor?

Read the question, gently stressing the time frame, and pausing slightly between each of the response categories. Read all six categories, and record the participant's selection. When necessary, re-read the question for clarification.

Section B Hospitalized and Emergency Department Events

(HOE screen for data entry begins here.)

The goal of this section is to record all the episodes where the participant was admitted to the hospital or seen at an emergency department. Although the more technically correct term for an emergency medical facility is "emergency department", the most commonly used term will likely be

“emergency room”. For the purpose of this section, consider an emergency department and emergency room as equivalent.

For the purpose of this section, admission to the hospital includes any stay in the hospital even if it is not overnight or less than 24 hours. Visits to a physician’s offices or clinics located in a hospital should not be recorded as an admission to the hospital. Outpatient visits should not be included as either hospital admissions or emergency department visits.

Begin this section by introducing this section. Take care to clearly communicate that the time focus of the question is since the last SOL study contact with the participant.

“The following questions are about any hospitalizations or visits to an emergency room you may have had Since our last telephone interview with you on (date).”

Q3 Since our last telephone interview with you on (date), have you at any time been admitted to a hospital or seen in an emergency room?

This question asks the participant to recall hospitalizations in acute or chronic care facilities, such as hospitals. It also asks the participant to recall visits to an emergency room. Stress that if there were several hospitalizations or emergency room visits since their last telephone interview on (date) that you would like to ask some question about each of these separately, starting with the first occurrence since their last telephone interview.

If the participant or alternate responds “No” then this section will be skipped. If the participant responds that they are unsure, probe to find out if there is anything in the question that the participant didn’t understand. If the participant is still unsure, or if using an alternate respondent who is uncertain, then record “UNSURE” and this section will be skipped. If the participant or alternate respondent answers that the participant has been admitted to the hospital or seen at an emergency room then go to Q4.

“The next few questions are about one event, if there were more than one we would like to talk about each one separately, let’s start with the first event since our last telephone interview with you on (date).”

Q4 Was this visit to the emergency room only, a hospital admission only, or a visit to the emergency room that resulted in being admitted to the hospital?

This question asks the participant to identify whether the event was a visit to an emergency room, or a hospital admission or both. If a participant reports that s/he went to an emergency room, which led to an admission to the hospital, then record this as BOTH. If a participant went to an emergency room and then was released, record this response as EMERGENCY ROOM. If the participant indicates that s/he was admitted to a hospital without first going to the emergency room, record HOSPITAL ADMISSION.

Q4a What was the main reason for going to the (insert emergency room or hospital) that day? (Check one and do not read choices)

This question asks the participant to recall the nature of this episode. When asking the question, be sure to insert the appropriate response from question 4 above. For example, if the participant responded to Q4 by saying they went to an emergency room for several hours and then were sent home, insert the phrase “emergency room” into these questions (“What was the main reason for going to the emergency room?”). Do not read the responses. Listen to what the participant describes and record the category that is the best match. If there is no obvious match with items 0-7 or 9, record OTHER (response 8) and record the reason in the space provided

under “specify”. If the participant reports that a hospitalization or emergency room visit was for several reasons, record the one that fits any of the categories listed (0-7 or 9). For example, if the participant reports that they called 9-1-1 because of chest pain and dizziness that led to a fall and cut on their head, record CHEST PAIN (response 1). In many cases, the participant will not use the terms listed in questions 4a. If it is not possible to select a main reason from the participant’s first response, consider gently probing to gather enough information to make a reasonable categorization of the main reason for this event (e.g. “Can you tell me more about this event?”). If no additional information is forthcoming, record OTHER and specify the exact description of the episode provided by the participant.

Q4b What was the date of this event?

Collect and record the approximate date of the visit. This should be the first date of the event. For example if a person reports being hospitalized for 3 days, record the date of the first day. Stress that what you are seeking is the approximate date of the first event since their last telephone interview. If there are several events that have occurred since their last telephone interview, explain that you would like to take each of these in order. If you are unable to obtain an exact date, try to enter at least a month and year (e.g. 06/==/2012).

Q4c What is the name of the medical facility?

Collect the name of the hospital or emergency room visited for this reported event.

Q4d What is the address of this medical facility?

Collect the address of the hospital or emergency room visited for this reported event, including city and state.

Q4e For clarification or our records, under what name is this record?

This question asks for the participant to clarify under which name is the record. Since HCHS/SOL will be attempting to locate the record, it is important for the interviewer to discern the exact names used for the admission or visit to the emergency room.

Q4e1 First Name

Q4e2 Second Name

Q4e3 Last Name

Q4e4 Second Name

Q4f Were you admitted to a hospital or seen at an ER at any other time since your last SOL telephone interview?

This question asks for the participant to recall if there was another episode that led to them being hospitalized or seen at an emergency room since their last telephone interview. If a participant reported that they went to an emergency room and then were admitted to the hospital the same day as a continuation of the emergency room visit (Q4 above equals BOTH), do not consider the hospitalization as a separate event from the emergency room visit.

Section C Out-Patient Self-Reported Conditions (OPE Section for data entry begins here.)

In this section we seek information about specific conditions that led seeking and receiving medical attention as an outpatient. For the purposes of this section, outpatient treatment is defined as episodes other than a hospital admission or care in an emergency room. This section applies to visits to a doctor's office or a non-emergent medical care facility. Start this section out by saying the following introduction:

"Now I would like to ask you about conditions that may have resulted in you seeing a doctor or health profession at a clinic or doctor's office, but not actually being admitted to the hospital or visiting an emergency room."

By asking "Since our last interview with you has a doctor or health professional said...", we are interested in identifying *newly* occurring, or *newly* diagnosed conditions. If a participant responds by saying "Yes, my doctor told me that I have chronic bronchitis and I have had this for several years" the response to this question (question 5) is No. If the answer provided by the participant to questions in Section C suggests to the interviewer that this may not be a condition that has newly occurred since the last AFU interview, the participant is asked to clarify whether this is the first time a physician has said that she/he has this condition. Only new diagnoses of a condition since the last contact with the participant are recorded as Yes.

Q5 Since our last telephone interview with you on (*date*), has a doctor or health professional told you that you had emphysema, chronic bronchitis, or chronic obstructive pulmonary disease (COPD)? This does not include doctor's visits for tuberculosis or TB.

This question asks the participant to recall whether in the past year since their SOL telephone interview they had a diagnosis of COPD in an outpatient setting. **Be careful to stress that this does not include doctor visits for tuberculosis.**

It is likely that a doctor or health professional used other terms such as emphysema or chronic bronchitis. If the participant indicates they had such an event, the interviewer moves on to ask specific questions about this episode. If the participant denies any outpatient diagnoses of COPD, emphysema or chronic bronchitis then the interviewer skips to Q6.

Q5a-c This series of questions is intended to collect information about specific tests that might have been done in conjunction with the outpatient visit for COPD emphysema or chronic bronchitis. Introduce the series of questions 5a-c by asking the following:

"Did your doctor or healthcare professional order any of the following tests to help make the diagnosis?"

Q5a Breathing test or pulmonary function test?
Collect and record whether a breathing test or pulmonary function test was ordered or performed. For the purposes of this question, if a test was ordered and attempted but not completed this is sufficient to record YES to questions 5a.

Q5b Chest X-ray?
Collect and record whether a chest X-ray was ordered or performed. For the purposes of this question, if a test was ordered and attempted but not completed this is sufficient to record YES to questions 5b.

Q5c CT Scan of your chest?

Collect and record whether a computed tomography (CT) scan of the chest was ordered or performed. For the purposes of this question, if a test was ordered and attempted but not completed this is sufficient to record YES to questions 5c.

- Q5d** Were you told by a doctor or health professional that you were having an attack, worsening or an exacerbation of your emphysema, chronic obstructive pulmonary disease (COPD), or chronic bronchitis?

The purpose of this question is to determine if the recalled episode was actually an exacerbation of their emphysema, chronic obstructive pulmonary disease (COPD), or chronic bronchitis. It is likely that the term “exacerbation” may not be well understood by the participant. Take time to clearly communicate the terms “attack” and “worsening”. For the purpose of this question, any attack, sudden onset, increase in severity, or increase in frequency of symptoms is sufficient to record YES.

- Q5e** Did the doctor or health care professional prescribe a change in your medication, such as increasing your inhalers, oxygen or pills for your lungs or prescribing a steroid pill for your lungs?

The purpose of this question is to collect information that helps in determining if the recalled episode was an exacerbation. A change in medication in response to an acute event is evidence of a true exacerbation of the condition. Collect and record if the participant had their medication changed as a result of this episode.

- Q6** Since our last telephone interview with you on (date), has a doctor or health professional told you that you had asthma?

This question asks the participant to recall whether in the past year since their last SOL telephone interview they had a diagnosis of asthma in an outpatient setting. If the participant indicates they had such an event, the interviewer moves on to ask specific questions about this episode. If the participant denies any outpatient diagnoses of asthma then the interviewer skips to Q7.

- Q6a-c** This series of questions is intended to collect information about specific test that might have been done in conjunction with the outpatient visit for asthma. Introduce the series of Q6a-c by asking the following:

“Did your doctor or healthcare professional order any of the following tests to help make the diagnosis?”

- Q6a** Breathing test or pulmonary function test?

Collect and record whether a breathing test or pulmonary function test was ordered or performed. For the purposes of this question, if a test was ordered and attempted but not completed this is sufficient to record YES to Q6a.

- Q6b** Chest X-ray?

Collect and record whether a chest X-ray was ordered or performed. For the purposes of this question, if a test was ordered and attempted but not completed this is sufficient to record YES to Q6b.

- Q6c** CT Scan of your chest?

Collect and record whether a computed tomography (CT) scan of the chest was ordered or performed. For the purposes of this question, if a test was ordered and attempted but not completed this is sufficient to record YES to Q6c.

Q6d Were you told by a doctor or health professional that you were having an attack, worsening or an exacerbation of your asthma?

The purpose of this question is to determine if the recalled episode was actually an exacerbation of their asthma. As previously, it is likely that the term “exacerbation” may not be well understood by the participant. Take time to clearly communicate the terms “attack” and “worsening”. For the purpose of this question, any attack, sudden onset, increase in severity, or increase in frequency of symptoms is sufficient to record YES.

Q6e Did the doctor or health care professional prescribe a change in your medication, such as increasing your inhalers, oxygen or pills for your lungs or prescribing a steroid pill for your lungs?

The purpose of this question is to collect information that helps in determining if the recalled episode was an exacerbation. A change in medication in response to an acute event is evidence of a true exacerbation of the condition. Collect and record if the participant had their medication changed as a result of this episode.

Q7 Since our last telephone interview with you on (date), has a doctor or health professional told you that you had diabetes or high sugar in the blood?
If the answer is No or the participant is UNSURE, then go to Q8.

Q7a Did the doctor recommend any new or different treatments?
The purpose of this question is to determine whether or not the participant was treated for this reported diabetes. If treatments such as medications were recommended but the participant didn’t actually obtain and/or take the medications record YES. If the answer is No or the participant is UNSURE, then go to Q8.

Q7b What treatment was recommended?
Do not read the response options. Listen to the participant’s response and prompt if necessary for understanding. Record the treatments in the category that is most appropriate. If you are not sure whether a recalled treatment fits into a category, record other and specify the treatment in the space provided.

Q8 Since our last telephone interview with you on (date), has a doctor or health professional told you that you had high blood pressure or hypertension?
If the answer is No or the participant is UNSURE, then go to Q9.

Q8a Did the doctor recommend any new or different treatments?
The purpose of this question is to determine whether or not the participant was treated for this reported high blood pressure or hypertension. If treatments such as medications were recommended but the participant didn’t actually obtain and/or take the medications record YES. If the answer is No or the participant is UNSURE, then go to Q9.

- Q8b** What treatment was recommended?
Do not read the response options. Listen to the participant's response and prompt if necessary for understanding. Record the treatments in the category that is most appropriate. Select all that apply. If you are not sure whether the recalled treatment fits into a category, record other and specify the treatment in the space provided.
- Q9** Since our last telephone interview with you on (date), has a doctor or health professional told you that you had high blood cholesterol?
If the answer is No or the participant is UNSURE, then go to Q49.
- Q9a** Did the doctor recommend any new or different treatments?
The purpose of this question is to determine whether or not the participant was treated for this reported high blood cholesterol. If treatments such as medications were recommended but the participant didn't actually obtain and/or take the medications record YES. If the answer is No or the participant is UNSURE, then go to Q49.
- Q9b** What treatment was recommended?
Do not read the response options. Listen to the participant's response and prompt if necessary for understanding. Record the treatments in the category that is most appropriate. Select all that apply. If you are not sure whether a recalled treatment fits into a category, record other and specify the treatment in the space provided.

Thank you so much for answering these questions. We greatly appreciate your participation in the SOL study. Now, I'd just like to make sure our records are up to date.

[EVE section for data entry screens begins here] Not Present in Year 7

D. SELF REPORT OF EVENTS [Q10-22; not present in Y6]

[MEE section for data entry screens begins here] Not Present in Year 7

E. MEDICATIONS [Q23-44a.; not present in Y6]

F. Q45-48 [not present in Y6] Not Present in Year 7

Section G Participant Tracking (CIE section for data entry begins here.)

Begin this section by gently stating the following:

"Thank you so much for answering these questions. We greatly appreciate your participation in the SOL study. Now, I'd just like to make sure our records are up to date.

Current tracking information from SOL database will be displayed on the screen. Read the following statement before confirming contact information:

English

*"It is very important for this study to be able to reach you in the future. Although you provided your contact information at the time of your visit, in order to keep our records up **to date please provide** us with your current home address. All information you give us is strictly confidential and will not be shared with anyone else".*

Spanish:

“Es sumamente importante para este estudio que en el futuro podamos comunicarnos con usted. Entendemos que usted dio su información de contacto en su visita al centro, pero para mantener nuestros archivos al día necesitamos confirmar su información actual. Toda información que usted nos provea se mantendrá en estricta confidencialidad y no será compartida con ninguna otra persona o entidad.”

Q49 – 49.J.1 Current home address

Confirm participant’s current home address, updating the information as necessary.

Q50 Primary Phone Number

Confirm participant’s primary phone number, updating the information as necessary.

Q50a Confirm what type of phone is.

Q51 What is the best time of day to reach you at this number?

Confirm and/or record the best time of day to reach the participant at this number.

Q52 Secondary phone number

Confirm and/ or collect and record the participant’s secondary phone number.

Q52a Confirm what type of phone is.

Q53 What is the best time of day to reach you at this number?

Confirm and/or record the best time of day to reach the participant at this number.

Local Contacts Information changes for Year 7:

For year 7 local contact information has been streamlined to require only needed information. The paper form has the fields not required grayed out. CDART2 will not display those questions as the system is used.

Q54 Local contact1 name (primary contact)

Confirm and/or collect and record the name of a local contact person

Q55 Relationship

Relationship of contact person has with the participant.

Q55a: Is this an ARE Contact?

This question is looking to record if this person has been assigned as an Alternate designated contact in the ARE form by the participant. Or if by the definition described in Section B, of this document, can be identified as a “Alternate Respondent/Designated Respondent/Proxy”.

Q56 -56.J.1 Current home address of primary contact (local contact 1)

Confirm and/or collect and record the address of this local primary contact person.

Q57 Telephone (local contact 1)

Confirm and/or collect and record the telephone number of the local primary contact person.

Q57a, collect information on type of phone.

Q58 – 61.e Local contact 2 name (secondary contact)

Confirm and/or collect and record the name of a secondary local contact person.

Q59 Relationship

Relationship of contact person has with the participant.

Q59a Is this an ARE contact?

This question is looking to record if this person has been assigned as an Alternate designated contact in the ARE form by the participant.

Q60 – 60.J.1 Current home address of secondary contact (local contact 2)

Confirm and/or collect and record the address of this local secondary contact person.

Q61 Telephone: (local contact 2)

Confirm and/ or collect and record the telephone number of the local secondary contact person.

Q61a Define what type of phone is.

Q62 – 66.e Local contact 3 name

Confirm and/or collect and record the name of an additional local contact person.

Q63 Relationship

Relationship of contact person has with the participant.

Q63a Is this an ARE contact?

This question is looking to record if this person has been assigned as an Alternate designated contact in the ARE form by the participant.

Q64 – 64.J.1 Current home address of secondary contact (local contact 3)

Confirm and or collect and record the address of this additional local contact person.

Q65 Telephone (local contact 3)

Confirm and/or collect and record the telephone number of the local secondary contact person.

Q65a Define what type of phone is.

Q66 Name of physician or other health care provider (HCP)

Record name and address for participant's physician or health care provider (HCP).

Section H. END OF THIS PORTION OF THE ANNUAL FOLLOW-UP CALL

“Thank you for answering the questions about your health. We wish to continue to stay in touch with you and will be contacting you again next year”

Appendix

1. Case Study 1: After repeated attempts interviewers are unable to connect with the participant. Interviewers keep talking to the participants' mother and leaving messages. Before the interview window closes the participant's mother completes the interview via proxy.

The GHE should be coded =3 (designated respondent contacted, reported alive), in this case the mother of the participant would be likely to know about enough personal health items to answer the interview. Complete as much information as you can in the GHE/GHS and HOE/HOS. The OPE/OPS, Self-report of Events, should not be answered by the family member in this context. All the contact tracking information should be updated as expected in the CIE/CIS, try to capture as much contact information as possible.

2. Case Study 2: The interviewer calls the participant and the participant's daughter answers the phone. The participant's daughter is also the designated "Alternate Respondent", consents to performing the interviews as a proxy, and reports that she is now taking care of the participant full time due to advance Alzheimer's. The interviewer completes the interview with the Alternate Respondent and notes that from now on all future interviews will be completed with the Alternate Respondent and participant should not be called.

Since the daughter is the full-time caretaker for someone who is cognitively impaired and has provided consent, she can answer everything for the participant. All sections (forms) for the AFU questionnaire would be completed.