



# HCHS/SOL Question by Question Instructions

## Annual Follow-Up Forms Years 10-11-12-13

Updated on 12/8/2021

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### Background

The purpose of the yearly follow-up phone interviews for HCHS/SOL is to document medical events occurring every year from the Baseline examination (visit 1). These annual follow-up interviews maintain and update cohort contact information and ascertain vital status. The follow-up interviews are to be conducted by telephone in English or Spanish. Annual follow-up interviews will continue to occur approximately every 12 months from the baseline (visit 1) anniversary date. The timing of the annual follow-up interviews is described in more detail in Manual 3-Retentionand-Follow-up (formerly Manual 3 and Manual 16) available on the HCHS/SOL website.

Forms for AFU Years 10-13 include AFT (Annual Follow-Up Tracking, English only), GHE/S (General Health Status), HOE (Hospitalization and Emergency Department Events), OPE (Outpatient Self-Reported Conditions), and CIE (Contact Information Update).

**Note on using designated respondent:** Before initiating an AFU interview, HCHS/SOL personnel should review records from the last completed interview with the participant. If the previous interview was conducted with an alternate respondent due to participant’s cognitive impairment, the alternate respondent should again be contacted to schedule the follow-up interview. Historic alternate respondent information (if available) can be obtained from the CIE(S) form from the previous year.

### Annual Follow-up Tracking Form (AFT)

The record of contacts with the study participants is logged on the annual follow-up tracking form AFT. AFT-version-B is available in CDART under the English **form group** version for each AFU Contact Year. Each contact **or contact attempt** should be entered as a new occurrence of the form. Remember to choose the last occurrence of the form to provide a final (terminating) status code.

Note that monthly progress reports on follow-up will be distributed to the Steering Committee and on semi-annual basis to the Observational Study Monitoring Board (OSMB) using the information that comes from the AFT and other forms in the database.

### Administrative Information

- Q0a. Completion date = “data entry date”:** Enter date when the data was entered in the system. If the data entry was made from the paper form, it may be different than the date of the contact call.
- Q0b. Enter 3-digit HCHS Staff ID number** of person doing the data entry, which is not always the person that made the contact call.
- Q0c. Interview mode:** Select the way in which the interview was performed (phone or in person). Interview mode has some special coding. See Appendix 1 **Special Coding for AFT0c and AFT0d (Administrative Information)** for details.
- Q0d. Interviewer Location:** Select the location of the interviewer (staff location) when the interview was done (clinic or home visit). Interview location has some special coding. See “Special Coding” section (below) for details.

### Contract Tracking Results

- Q1. Date:** Enter actual date contact was attempted or made (date of call).
- Q2. Time:** Enter the time of contact either using a 24-hour clock format or specifying AM/PM.
- Q3. AM/PM:** In CDART this information is captured in Q2.
- Q4. Notes:** this is a free form text field to record details important for other staff, or your next call.

In the final occurrence of the ATF for the contact year, if unable to complete interview, use this field to identify the ‘Barrier to Participation’, code description in table below. Only enter the **Letter** code, use the notelog for comments. If the barrier to participation is not clear, probe the participant to obtain clarity. If probing is not an option, use your best judgement to enter a code. These codes will allow the CC to do concise code retrieval for analysis on barriers to participation.

### Barrier to Participation Codes Description Table

Code	Description	Details
<b>I</b>	Incentive not sufficient	Use this code if participant expresses that the incentive provided does not compensate for time of interview. If participant gives any excuse that shows lack of interest in the study, probe for further information.
<b>P</b>	Permanently Institutionalized	Use this code if the contacted person reports that the participant is institutionalized, and the respondent is not willing to answer questions related to the participant’s health.
<b>T</b>	Time of interview too long	Use this code if participant expresses that they do not have time and requests multiple times to be called back later.
<b>M</b>	Moved to another country no way of contacting participant	Use this code if the contacted person reports that the participant has moved to another country, they do not have contact information for the participant, and are not willing to answer questions related to the participant’s health. Before using this code, confirm if person contacted can serve as a proxy informant.

- Q5. Status Results code#:** These codes serve to indicate the contact tracing stage from early tracing through to completion of the interview. They also serve to indicate whether a respondent reports participant as alive, deceased, or unknown vital status.

**Results Description Table**

Code	Description
0	Pending contact/ <b>no action</b> taken. Contact has not started.
1	Tracing is defined as <b>no contact has been successful</b> with any source or participant. Will continue to try to find a valid source or participant until a final determination can be made. <b>Enter the final determination in the last occurrence of the form.</b>
2	Contacted, AFU <b>interview completed</b> with participant.
3	Contacted, AFU <b>interview completed with proxy or informant</b> . It is permissible to complete the vital status, general health, hospitalization information, and contact portions of the interview using an informed proxy.
4	Contacted, AFU interview <b>partially complete or rescheduled</b> . If the interview is interrupted, use this interim code to track interviews in progress. <b>Also use this code if the participant is contacted and agrees to interview but wishes to reschedule to another time.</b> Make an attempt to schedule a follow up call.
5	Contacted, AFU <b>interview refused</b> . A hard refusal must be accepted graciously. Try to keep the options open for subsequent contact years by not pressing so hard that the participant withdraws consent to contact. <b>A hard refusal to complete current year AFU does not affect participant eligibility for future AFU years.</b> <b>If the participant insists that they do want to be contacted anymore for AFU, complete a V3 ICT new occurrence. Set Q0c=2 and Q1=0.</b> If the participant withdraws <b>consent for all further contact</b> from the study, complete a V3 ICT new occurrence. <b>Set Q0c=2, Q1=0, and Q8=0.</b>
6	Reported <b>alive, will continue to attempt contact</b> with participant this year. An informant or proxy has told you the participant is alive and may have verified their contact information. <b>AFU staff will continue attempting to contact participant to complete the interview.</b>
7	Reported <b>alive, contact not possible</b> this year. Similar to the code above with the exception that all means for direct contact with the participant have been exhausted.
8	Reported <b>deceased</b> . This code should be based on reliable knowledge that can be verified through a vital records check.
9	<b>Unknown</b> vital status. If nothing is known about the location or vital status of the participant and all methods have been exhausted during the AF contact window, then use this code.

**Final Code (Terminating code)**

Each contact with the participant should be entered in a new occurrence of the form. The last occurrence of the form should have the final (terminating) code. If the final code is entered in any other occurrence, the record would show as open or incomplete. Please ensure that the final code is present in the **Last Occurrence** of the form.

**Interim Codes:** (0) Pending, (1) Tracing, (4) Interview partially complete or rescheduled, (6) Reported alive will continue to contact

**Terminating Codes:** (2), (3) Contacted and interview Complete, (5) Contacted interview refused, (7) Reported alive and interview not possible this year, (8) Reported deceased, (9) Unknown vital status.

## **Final Code Match Reference Table**

Use this reference table to make sure your GHE(S)1 and AFTB5 have matching final (terminating) codes.

**GHE(S) and AFT code  
reference Mapping**

<b>GHE(S)B1</b>	<b>AFTB5</b>
1	2 or 4
2	5 Final code
3	3 Final code
4	6 or 7
5	8 Final code
9	9 Final code

**Q6.** Staff ID: 3-digit HCHS/SOL staff ID code of person making contact.

## **Section A. GHE(S) (General Health Status)**

[Q1-2 present for years 10, 11, 12 13]

**Q0a.** Enter the date of AFU interview.

**Q0b.** Enter staff ID.

**Introduction:** Interviewer reads one of the following scripts:

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

Spanish: Buenos días/Buenas tardes/Buenas noches, mi nombre es (interviewer name), y estoy llamando para hablar con (participant name) para un seguimiento acerca del Estudio sobre la Salud de la Comunidad Hispana / Estudio de Latinos (SOL), un estudio sobre la salud en el cual él/ella está registrado(a) actualmente. ¿Puedo hablar con él/ella?

**Q1.** Participant status

### **Scenario #1: Participant is not available:**

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

English: "When would it be convenient to call back? ..... Thank you. I will call again."

Spanish: ¿Cuándo sería conveniente llamarlo(a) nuevamente? Gracias. Volveré a llamar.

Set GHE(S)1=4

In AFT form set AFT5=6 (Reported alive, continue to attempt contact this year)

If multiple attempts are made to contact the participant without success and AFU window will close soon, the interview may be completed with an alternate respondent. See Scenario #5 below.

**Participant contacted:**

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

**English:** *“Hello, (participant name), this is (interviewer name) with the Hispanic Community Health Study / Study of Latinos (SOL). We can’t thank you enough for the contributions that you are making in the understanding of Hispanic/Latino health. 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?”*

**Spanish:** *Buenos días/Buenas tardes/Buenas noches, (participant name), mi nombre es (interviewer name) y trabajo para el Estudio sobre la Salud de la Comunidad Hispana / Estudio de Latinos (SOL). Estamos muy agradecidos por su contribución al entendimiento de la salud hispana (latina). Estoy llamando para ver cómo ha estado desde la última entrevista telefónica que le hicimos y para actualizar nuestros registros del estudio. ¿Tiene unos minutos para hablar por teléfono?*

**Scenario #2: Participant contacted, agrees to interview now:**

**Set GHE(S)=1** (Participant contacted and alive, agrees to interview). 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.”*

**Spanish:** *Nos gustaría obtener información acerca de su salud en general y acerca de condiciones médicas específicas que puede haber tenido durante el último año. Le haré algunas preguntas acerca de su salud desde que le hicimos la entrevista telefónica el (date of last follow-up call). Quisiera que se concentrara en lo que pasó desde el (date of last follow-up call) hasta el día de hoy.*

**Go to Q2**, then complete forms OPE(S), HOE(S), and CIE(S) with participant.

**Set AFT5=2** (Contacted, interview completed w/ Cohort Member)

**Scenario #3: Participant contacted, not available for interview now:**

**Set GHE(S)1=1** (Participant contacted and alive, agrees to interview). Go to **Q49** to confirm contact information. Try to complete as much of CIE(S) as possible.

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

**Spanish:** *¿Cuándo sería conveniente llamarlo(a) nuevamente? Gracias. Volveré a llamar.*

**Set AFT5=4** (Contacted, interview partially complete or rescheduled)

Continue attempting to reach participant until interview is completed. If AFU window is closing soon and participant cannot be reached, but a non-designated (other) respondent can be reached, interview can be completed with a non-designated participant (see Scenario #7). If interview cannot be completed before the AFU window closes, code as a “soft refusal” (see **Appendix 2** for details).

**Scenario #4: Participant contacted and refuses to complete interview (hard refusal):**

**Set GHE(S)1=2** (Participant contacted and refused interview).

**Go to Q49.** Try to complete as much of the CIE(S) as possible.

**Set AFT5=5** (Contacted, interview refused)

A hard refusal to complete this year's AFU interview is not necessarily the same as a hard refusal to participate in future AFU interviews or other HCHS study components. If participant withdraws consent to participate in future AFU interviews, or if they withdraw consent for all forms of contact from the study, create a new ICT occurrence and update accordingly. If possible, try to keep the window open for contact in future years and for invitations to future participation in exam visits and ancillary studies. See **Appendix 2** for information on soft and hard refusals and withdrawals.

**Scenario #5: Designated respondent contacted, participant reported alive:**

A designated respondent (or alternate respondent) is defined as a well-informed, mature individual who can answer health-related questions on behalf of an HCHS/SOL cohort member. A designated respondent may complete the AFU interview on behalf of the participant if the participant is unable to complete the interview due to cognitive impairment, or if the participant cannot be reached during the AFU window. The alternate informant may be designated as such in the prior year's CIE(S) form. See Manual of Procedures 3: Retention and Follow-up for more information on assessing the need for an Alternate Informant.

If designated respondent is contacted but participant may still be reached for interview:

- **Set GHE(S)1=3** (Designated respondent contacted, reported alive).
- Complete CIE(S) form to the extent possible. This may be updated later during interview with participant.
- **Set AFT5=6** (Reported alive, continue to attempt to contact this year)
- Continue to attempt to contact participant to complete AFU interview.

If designated respondent is contacted and participant is unable to complete the AFU interview due to cognitive impairment, OR AFU window is about to close, and participant still cannot be reached:

- **Set GHE(S)1=3** (Designated respondent contacted, reported alive).
- Complete the rest of the AFU interview to the extent possible. Priority is given to HOE(S) and CIE(S) forms. Do not complete the OPE(S) form unless it is clear that the alternate respondent has in-depth knowledge of the participant's medical care (for example, if the respondent is the participant's primary caregiver and medical proxy).
- CDART will "expect" the HOE(S) and CIE(S) to be at least partially completed, so if either of these forms cannot be at least partially completed, mark the form as permanently missing in CDART at the form level.

**Set AFT5=3** (Contacted, interview completed w/ Proxy/Informant)

See **Appendix 3 (Case Studies for Alternate Respondents)** for examples of scenarios where AFU interview may be completed with a designated respondent or proxy.

**Scenario #6: Non-designated respondent is reached and reports participant as alive.**

A non-designated respondent can be any respondent that can be reached who knows the participant but may or may not be a quality source of information about the participant's health or medical history. If non-designated respondent is reached:

- **Set GHE(S)1=4** (Other respondent contacted, reported alive)
- **Go to CIE(S)Q49.** Attempt to complete CIE(S) form to the extent possible.

- Do not attempt to complete HOE(S) or OPE(S) with the non-designated respondent.
- **Set AFT5=6** (Reported alive, continue to attempt to contact this year)
- Continue to attempt to contact participant to complete AFU interview.

If AFU window closes and neither participant nor designated respondent can be reached:

- **Set AFT5=7** (Reported alive, Contact not possible this yr.)

**Scenario #7: Designated or non-designated respondent reached; status of participant is unknown.**

**Set GHE(S)1=9** (Unknown)

**Go to Q49.** Attempt to complete CIE(S) form to the extent possible.

**Set AFT5=9** (Unknown vital status)

**Scenario #8: Designated or non-designated respondent reached, participant reported deceased.**

If the interviewer establishes that the participant is DECEASED, the interviewer offers condolences.

**Set GHE(S)1=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 (GHE(S) Q1a-b3).

**Q1a** What was the date of death?  
Collect and record date of death.

**Q1b** Where did the death occur?  
Collect and record city, 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 between (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(S)) Hospitalizations and Emergency Room Events" (Questions 3-4).

**Set AFT5=8** (Participant deceased)

## **Q2. General Health**

**This question is only enabled if completing interview with participant, i.e., GHE(S)1=1.**

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 **five** categories and record the participant's selection. If necessary, re-read the question for clarification.

## Section B. HOE(S) (Hospitalized and Emergency Department Events)

[Q3-4 present for Years 10, 11, 12, 13]

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 less than 24 hours and not overnight. 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.

When 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.

English: *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).*”

Spanish: *“La siguiente serie de preguntas trata sobre hospitalizaciones o visitas a la sala de emergencia en alguna ocasión desde su última entrevista telefónica el (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 questions about each of these separately, starting with the first occurrence since their last telephone interview.

If the participant or alternate responds “No” then the rest of 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 the rest of 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 was 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, 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.

An emergency room (ER) or emergency department (ED) for the purposes of this study is defined as a hospital department with a 24-hour ambulance bay where patients are treated for a variety of conditions and then sent home within a relatively short period of time. Generally, if a

participant has an “Emergency Room Only” visit, they will arrive at the ED, be seen by a physician, be diagnosed and/or treated, and be sent home in less than 24 hours. However, an ED visit stay can last as long as 48 hours. The participant may be moved from the ED to radiology or another department for testing, but they will be returned to the ED and sent home from there.

A “Hospital Admission Only” visit is when a participant is taken directly to a hospital room on an acute care unit that is not in or connected to the ED, is formally “admitted” to the hospital, and spends at least one night. This can occur as a direct admit from a doctor’s office or clinic or can occur for overnight care following planned surgery. An example is an overnight stay after placement of a pacemaker, where the patient presented to the surgery center from home, had the procedure, and was taken directly to a unit bed.

**Please note** that in the context of hospitalizations for HCHS, an “acute care unit” means a hospital unit/section where the patient is monitored and actively treated for their condition. Acute care units include intensive care, medical and surgical units, neurological units, etc.

Non-acute care units in a hospital include inpatient hospice and rehabilitation units. Non-hospital stays at outpatient hospice, rehabilitation, or skilled nursing care facilities, psychiatric hospitals or any other type of care facility that does not have an ambulance bay and ED department are not considered a hospitalization. Treatment received in a doctor’s office, walk-in clinic and outpatient/day surgery are not considered an ED visit or hospitalization. Answer “No” on Q4 if patient was admitted to any of these types of facilities or units or seen in an outpatient setting.

ED observation or “observation stays” are considered an “Emergency Room Only” visit.

A “Both” visit is when a participant arrives at the hospital and is seen in the ED first, then later transferred to a bed on an acute care unit and spends the night. This visit is considered “Both” an ED visit and a hospital admission.

If the participant confidently answers Q4, record their answer. If they are not sure if the visit was emergency department only or if they were admitted to the hospital, please gently probe to try and focus the answer. Did they stay in or near the emergency department (except for tests)? Were they taken on a gurney or wheelchair to another floor in the hospital with new nurses and doctors to their own (or a shared) room with a door? It may be possible to help clarify the nature of the visit in this way.

HCHS/SOL records the occurrence of all hospitalizations and all emergency department visits and captures the discharge diagnosis and procedure codes (ICD-9 codes) but only conducts detailed investigations for the selected kinds of medical events noted above.

**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 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.

**NOTE:** To record visits related to the novel coronavirus pandemic, if the participant indicates the reason for their visit was coronavirus or COVID, choose **new** answer option **10-COVID-19, COVID, SARS-CoV-2 or Coronavirus**. If the participant only reports shortness of breath or some other symptom but does not specifically say coronavirus or COVID, record their response as usual.

**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. OPE(S) (Out-Patient Self-Reported Conditions)

[Q5-9b8 present for Years 10, 11, 12, 13]

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:

English: *"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."*

Spanish: *"Ahora me gustaría preguntarle sobre condiciones que le hayan motivado a que vaya a ver a un doctor o un profesional de la salud en una clínica o un consultorio médico, pero sin tener que ser admitido(a) al hospital y sin tener que ir a la sala de emergencias."*

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.

*Close this section by saying:*

*"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." Proceed to section CIE(S) (Q49).*

## **Section D. Contact Information Update/Participant Tracking- CIE(S)**

**[Q49-66e; present for Years 10, 11, 12, 13]**

Begin this section by gently stating the following:

*English: "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."*

*Spanish: Muchas gracias por contestar estas preguntas. Apreciamos mucho su participación en el SOL. Ahora, quisiera asegurarme que nuestros registros están al día.*

**Interviewer:** 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 – 49j1** 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 it 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 it 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.

**Q54 – 54d Local Contact 1 Name (primary contact)**  
Confirm and/or collect and record the name of a local contact person

**Q55 Relationship**  
Relationship of contact person 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 definition can be identified as a "Alternate Respondent/Designated Respondent".

**Local Contacts Information changes:**

Local contact information has been streamlined to require only needed information. Below is a table to be used as a guide for all contact information data entry.

**Q56-56j1** Current home address of primary contact (local contact 1)  
Confirm and/or collect and record the address of this local primary contact person. [See table below for guide on data entry]. This table applies to all local contact information.

Address Component	HOW TO USE IT
<p><b>A1. PO Box, Box &amp;/or Route and Number</b></p> <p>Contact 1: 56a1. Contact 2: 60a1. Contact 3: 64a1.</p>	<p>Should include all relevant descriptors and numbers. e.g., "PO BOX" (post office box), "BOX", "R" (route), or "RR" (rural route).</p> <p>If the address is reported as "Route 16, Box 14-A": Enter: ROUTE 16 BOX 14 A.</p> <p>If the only address provided is a post office box, box &amp; / or route and number, complete item <b>[a1]</b>. Proceed to ask about the intersection or street closest to the home location and enter this information in items <b>[c2]</b>, described below. If a closest intersection is provided, enter "INTERSECTION" in upper case letters in item <b>[c2]</b>, then record the information about both of the two intersecting streets in the note log using item <b>[c2.]</b> format. If available, enter the name of the building at the street or intersection in item <b>[e1]</b>.</p>

Address Component	HOW TO USE IT
<b>B2 Street Number</b> Contact 1: 56b2. Contact 2: 60b2. Contact 3: 64b2.	<p>Are alphanumeric characters or character strings that may precede or follow the street number (item <b>[b2]</b>) and may be separated from it by a hyphen (-). Hyphens (-) should be dropped at data entry. For example, the "B" in B-21 East Main Street, would be entered in item <b>[b2]</b> as B 21.</p> <p>If the address includes "1/2" as in "21 ½ West Elm St", "1/2" is a number suffix since it comes after a number so that is how it would be recorded 1, /, 2 in the set of boxes.</p>
<b>C2. Street Name</b> Contact 1: 56c2. Contact 2: 60c2. Contact 3: 64c2.	<p>Refers to the name of the street, avenue, etc. If the address is reported as 21-B East Main Street, then "Main" would be entered into item <b>[c2]</b>. Digits should be used for entering numbered street names, e.g., for 1300 South Second Street, "2nd" would be entered in item <b>[c2]</b>.</p>
<b>C3. Street Name Type</b> Contact 1: 56.c3. Contact 2: 60c3. Contact 3: 64c3.	<p>Refers to the type of roadway used in the address. If the address is reported as 21-B East Main Street, then "Street" would be entered into item <b>[c3]</b>. Special reference needs to be made to street name type abbreviations, since these are frequently used in addresses and often reflect colloquial rather than standard abbreviations. You can find the standard U.S.P.S. abbreviations used for geocoding needed in HCHS/SOL in <a href="https://pe.usps.com/text/pub28/28apc_002.htm">https://pe.usps.com/text/pub28/28apc_002.htm</a>.</p>
<b>E1. Other</b> Contact 1: 56e1 Contact 2: 60e1 Contact 3: 64e1	<p>Enter additional address information. For example, name of building or location.</p>
<b>F1. City</b> Contact 1: 56f1 Contact 2: 60f1 Contact 3: 64f1	<p>In completing this item, only standardized abbreviations of city can be used. These are Brooklyn, CH, MI, and SD. All other names must be transcribed in full into the address entry panel, but to save time in transcribing cities, a look-up table of commonly encountered cities is provided in the DES. As is the case for other look-up tables in the DES, the table is displayed by placing the cursor on the field (<b>[f1] City</b> in this case) and pressing F4. Entering the first letters of a city will highlight the closest match in the table. After verifying that the appropriate city is highlighted in the table HCHS staff can double-click the mouse or press the &lt;Enter&gt; key to import the city name into the data field on the form. If the city is <i>not</i> included in the table, pressing the &lt;ESC&gt; key will clear the look-up table so that the full name of the city can be entered.</p>
<b>G1. County</b> Contact 1: 56g1 Contact 2: 60g1 Contact 3: 64g1	<p>Information for this item should not be problematic. If unavailable or suspect it can be compared to information in a look-up table.</p>
<b>H1. State</b> Contact 1: 56h1 Contact 2: 60h1 Contact 3: 64h1	<p>You can find the standard U.S.P.S. abbreviations used for two-character state abbreviations needed in HCHS/SOL in <a href="https://pe.usps.com/text/pub28/28apb.htm">https://pe.usps.com/text/pub28/28apb.htm</a></p>

Address Component	HOW TO USE IT
<b>I1. Country/Territory (Select code from list)</b> Contact 1: 56i1 Contact 2: 60i1 Contact 3: 64i1	See <b>Appendix 4</b> for codes.
<b>J1. Zip Code</b> Contact 1: 56j1 Contact 2: 60j1 Contact 3: 64j1	Should be relatively straightforward. If available, Zip code information in 5+4 format should be transcribed in full, since they are more informative.

**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 – 58d** 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 with the participant.

**Q59a** 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 definition can be identified as a “Alternate Respondent/Designated Respondent/Proxy”**.

**Q60 - 64j1** Current home address of secondary contact (local contact 2). Confirm and/or collect and record the address of this local secondary contact person. [See table above for guide on data entry].

**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 it is.

**Q62 – 62d** 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 **or if by definition can be identified as a “Alternate Respondent/Designated Respondent/Proxy”**.

**Q64 – 64j1** Current home address of secondary contact (local contact 3)

Confirm and or collect and record the address of this additional local contact person.  
[See table above for guide on data entry].

**Q65** Telephone (local contact 3)  
Confirm and/or collect and record the telephone number of the local contact person.

**Q65a** Define what type of phone it is.

**Q66-66e.** Name **and address** of physician or other health care provider (HCP)  
Record name and address for participant's physician or health care provider (HCP).

### 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. Special Coding for AFT0c and AFT0d (Administrative Information)

Some special situations have been presented by the Field Centers. Here is the description of special codes to be used for these two items in the form:

**Scenario 1.** Hybrid interview. At some field centers, a staff member performs a home visit and uses their cell phone to communicate with the participant.

**Coding:**

**AFT0c.** Interview mode = 1 phone

**AFT0d.** Interviewer Location = 2 home visit

This combination will capture the fact that the participant was visited at home, and that the interview was performed on the phone.

**Scenario 2.** Reminder letter contact. When the reminder letter is sent out there is no direct person-to-person contact with the participant. Please set the 'Field Status= Not applicable' for questions 0c and 0d. Use Notelog for comments as needed.

**Coding:**

**AFT0c.** Interview mode – set the 'Field Status= Not applicable'

**AFT0d.** Interviewer Location – set the 'Field Status= Not applicable'

## Appendix 2. Coding Soft Refusals, Hard Refusals, and Withdrawals

All pending interviews need to be closed at the end of a contact window. These instructions are for those cases where scheduling and completing the interview was incomplete after repeated attempts with the study participant and/or their alternates.

Below is the coding scheme by AFU year for the Hard-Refusals and Soft-Refusals using the following working definitions:

- **Hard refusal** occurs when participant **clearly states** that he/she does not want to complete the AFU interview this year.
- **Soft refusal** occurs when 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 for future AFU. They may even propose an alternate day/time which fails to be completed.

- **Withdrawal from AFU:** Occurs when participant clearly states that he/she does not want to be called ever again to complete the AFU interview. Update the ICT form accordingly.
- **Withdrawal from all future study contact:** Occurs when participant clearly states that he/she does not want to be called ever again for any HCHS-related reason. Update the ICT form accordingly.

### **How to Complete the Interview Forms for Hard vs. Soft Refusals:**

#### **Hard Refusals**

- Set GHE(S)1=2** (Contacted and refused interview)
- Set AFT5=5** (Contacted, interview refused)

#### **Soft Refusal (participant alive, but elusive)**

- Set GHE(S)1=1** (Contacted and alive, agrees to interview)
- Complete CIE(S) form; whenever possible.
- Set forms unable to be completed (HOE(S), OPE(S), EVE(S), and/or CIE(S) to missing).
- Set AFT5=4** (Contacted, Interview partially complete or rescheduled)

#### **Withdrawal from AFU:**

- Set GHE(S)1=2** (Contacted and refused interview)
- Set AFT5=5** (Contacted, interview refused)
- Create new ICT occurrence. **Set ICT0c=2 and ICT1=0.**

#### **Withdrawal from All Study Contact:**

- Set GHE(S)1=2** (Contacted and refused interview)
- Set AFT5=5** (Contacted, interview refused)
- Create new ICT occurrence. **Set ICT0c=2, ICT1=0, and ICT8=0.**

## **Appendix 3. Case Studies for Alternate Respondents**

1. Case Study 1: After repeated attempts interviewers are unable to connect with the participant. Interviewers keep talking to the participants' mother (a designated respondent) and leaving messages. Before the interview window closes the participant's mother completes the interview on behalf of the participant.

*Set GHE(S)1=3 (designated respondent contacted, reported alive. Complete as much information as you can in the HOE(S)/HOS and all the contact tracking information should be updated as expected in the CIE(S). Try to capture as much contact information as possible. The OPE(S)/OPS, Self-Report of Events, should not be answered by the family member in this context.*

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 advanced 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.*

## Appendix 4. Location Codes for Questions 49.I.1, 56.I.1, 60.I.1, 64.I.1

01	Afghanistan	48	Nicaragua
02	Anguilla	49	Norway
03	Antigua and Barbuda	50	Pakistan
04	Argentina	51	Panama
05	Aruba	52	Paraguay
06	Australia	53	Peru
07	Austria	54	Philippines
08	Bangladesh	55	Poland
09	Belgium	56	Portugal
10	Belize	57	Puerto Rico
11	Bolivia	58	Russia
12	Brazil	59	South Africa
13	Canada	60	Spain
14	Chile	61	Sweden
15	China	62	Switzerland
16	Colombia	63	United States
17	Costa Rica	64	Uruguay
18	Cuba	65	Venezuela
19	Czech Republic	66	Virgin Islands
20	Denmark	67	Other
21	Dominican Republic	99	Unknown/ refused
22	Ecuador		
23	El Salvador		
24	Finland		
25	France		
26	Germany		
27	Great Britain		
28	Greece		
29	Guam		
30	Guatemala		
31	Haiti		
32	Holland		
33	Honduras		
34	Hungary		
35	India		
36	Indonesia		
37	Iran		
38	Iraq		
39	Ireland		
40	Israel		
41	Italy		
42	Japan		
43	Korea		
44	Lebanon		
45	Malaya		
46	Mexico		
47	New Zealand		

