## Table of Contents

## 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.

**Note on using alternate designated respondent (ADR)**: 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 ADR due to participant's cognitive impairment, the ADR should again be contacted to schedule the follow-up interview. Historic ADR information (if available) can be obtained from the CIE(S) form from the previous year.

## GHE(S) (General Health Status)

**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/ADR 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 ADR. See Scenario #5 below.

**Participant or ADR contacted:**
If the interviewer establishes that they are talking to the participant or ADR, 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 our 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 back."*

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**).

**Scenario #4: Participant contacted and refuses to complete interview (hard refusal):**
    **Set GHE(S)1=2** (Participant contacted and refused interview).
    **Go to CIE(S)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: Alternate designated respondent contacted, participant reported alive:**
An alternate designated respondent (ADR) is defined as a well-informed, mature individual who can answer health-related questions on behalf of an HCHS/SOL cohort member. An ADR 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 ADR may be designated as such (or the equivalent ARE) 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 ADR.

If the ADR is contacted but participant may still be reached for interview:
- **Set GHE(S)1=**3 (Alternate 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 the ADR 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 (Alternate 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 ADR 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/ alternate designated respondent)**

    See *Appendix 3 (Case Studies for Alternate Respondents)* for examples of scenarios where AFU interview may be completed with an ADR.

**Scenario #6: Non-designated informant is reached and reports participant as alive.**
A non-designated informant can be any individual 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 informant is reached:
- **Set GHE(S)1=4** (Other informant contacted, reported alive). This can be changed later if the participant or ADR is reached.
- **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 informant.

- **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 ADR can be reached:
- **Set AFT5=7** (Reported alive, Contact not possible this yr.)

**Scenario #7: ADR or non-designated informant reached; status of participant is unknown.**
**Set GHE(S)1=9** (Unknown)
**Go to CIE(S)Q49.** Attempt to complete CIE(S) form to the extent possible.
**Set AFT5=9** (Unknown vital status)

**Scenario #8: ADR or non-designated informant 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** What city, state, and country 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 ADR or informant responds "NO", thank the respondent, expressing condolences for their loss, and END THE INTERVIEW.

If the ADR or informant responses "YES ", the interviewer gently goes to "Section B (HOE(S)) Hospitalizations and Emergency Room Events" (Questions 3-4).

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

**Scenario #9: Unable to reach participant, ADR, or informant and AFU window is closing.**
**Set GHE(S)1=9** (Unknown)
**Set AFT5=9** (Unknown vital status)

**NOTE: If participant passes away after AFU has been completed and the next AFU year is not available in CDART, complete a 2nd occurrence of GHE form in the latest AFU year. For example, if participant completed AFU Y16 and AFU Y17 is not available in CDART, complete a 2nd occurrence of GHE form in AFU Y16. Only the most recent AFU year will have the max occurrence allowed = 2 for GHE/S form.**
**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.

## Summary

| Scenario | Action |
|---|---|
| 1. Participant is not available | GHE1=4<br>AFT5=6<br>Continue to attempt to reach participant. |
| 2. Participant contacted, agrees to interview now | GHE1=1<br>AFT5=2<br>Complete GHE, HOE, OPE, and CIE. |
| 3. Participant contacted, not available for interview now | GHE1=1<br>AFT5=4<br>Complete CIE to extent possible. |
| 4. Participant contacted and refuses to complete interview (hard refusal) | GHE1=2<br>AFT5=5<br>Complete CIE to extent possible. |
| 5. 5a. ADR contacted, participant reported alive – FC will continue to try to reach participant | GHE1=3<br>AFT5=6<br>Complete CIE to extent possible.<br>Continue to attempt to reach participant. |
| 5b. ADR contacted, participant reported alive- participant cannot complete interview OR AFU window is closing | GHE1=3<br>AFT5=3<br>Complete HOE and CIE to extent possible. Complete OPE only if ADR has in-depth knowledge of participant's medical care. |
| 6. Non-designated informant is reached and reports participant as alive | GHE1=4<br>AFT5=6 (if will continue to contact) or AFT5=7 (if determined that contact is not possible this year)<br>Complete CIE to extent possible.<br>Continue to attempt to reach participant until window closes or it is determined that contact is not possible this year. |
| 7. Designated or non-designated respondent is reached; status of participant is unknown | GHE1=9<br>AFT5=9<br>Complete CIE to extent possible. |
| 8. ADR or informant reached, participant reported deceased | GHE1=5<br>AFT5=8<br>Complete GHE1b1-1c; HOE |
| 9. Unable to reach participant, ADR, or informant; AFU window closing | GHE1=9<br>AFT5=9 |

## 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**

| GHE(S)B1 | AFTB5 |
|---|---|
| 1 | 2 or 4 |
| 2 | 5 Final code |
| 3 | 3 Final code |
| 4 | 6 or 7 |
| 5 | 8 Final code |
| 9 | 9 Final code |

# Appendix 1. 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, including for AFU, a visit, or ancillary studies. Complete withdrawal (WTD) form.

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)
   Enter Withdrawal (WTD) form for participant

## Appendix 2. Case Studies for Alternate Designated Respondents/Informants

1. Case Study 1: After repeated attempts interviewers are unable to connect with the participant. Interviewers keep talking to the participants' mother (an alternate designated respondent/ADR) 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 (alternate 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 ADR, 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 ADR and notes that from now on all future interviews will be completed with the ADR 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.*