



HCHS/SOL Annual Follow-Up Interview Annual Follow-Up Tracking Form – AFT – QxQ

Updated on 3/25/2025

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-Retention and-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.

General Instructions

The record of contacts with the study participants is logged on the annual follow-up tracking form AFT. AFT-version-C 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.

Question by Question Instructions

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 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
I	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.
P	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.
T	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.
M	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/ no action taken. Contact has not started.
1	Tracing is defined as no contact has been successful with any source or participant. Will continue to try to find a valid source or participant until a final determination can be made. Enter the final determination in the last occurrence of the form.
2	Contacted, AFU interview completed with participant.
3	Contacted, AFU interview completed with alternate designated respondent (ADR) . It is permissible to complete the vital status (GHE1-1c), hospitalization information (HOE/S), and contact information (CIE/S) portions of the interview using an ADR. For detailed information, see Appendix 2 below.
4	Contacted, AFU interview partially complete or rescheduled . If the interview is interrupted, use this interim code to track interviews in progress. Also use this code if the participant is contacted and agrees to interview but wishes to reschedule to another time. Make an attempt to schedule a follow up call.
5	Contacted, AFU interview refused . 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.

Code	Description
	<p>A hard refusal to complete current year AFU does not affect participant eligibility for future AFU years.</p> <p>If the participant insists that they do want to be contacted anymore for AFU, complete a V3 ICT new occurrence. Set ICT0c=2 and ICT1=0.</p> <p>If the participant withdraws consent for all further contact from the study, complete a WTD form.</p>
6	Reported alive, will continue to attempt contact with participant this year. An informant or alternate designated respondent (ADR) has told you the participant is alive and may have verified their contact information. AFU staff will continue attempting to contact participant to complete the interview.
7	Reported alive, contact not possible this year. Similar to the code above with the exception that all means for direct contact with the participant have been exhausted.
	If only an informant is reached, GHE1-1c and CIE form should be completed. See Appendix 2 for details.
8	Reported deceased . This code should be based on reliable knowledge that can be verified through a vital records check.
9	Unknown vital status. If nothing is known about the location or vital status of the participant and all methods have been exhausted during the AFU 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, (6) Reported alive will continue to contact

Terminating Codes: (2), (3) Contacted and interview Complete, (4) Interview partially complete or rescheduled (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

<i>GHE(S)B1</i>	<i>AFTB5</i>
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.

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. Definition of Proxy, Alternate designated respondent, Informant

Proxy

Person authorized to act on behalf of an adult not capable of giving consent, thus allowing them to participate in HCHS/SOL. Also known as legally authorized representative (LAR).

- Usually a spouse, adult child, or adult sibling.
- May serve as alternate designated respondent depending on how familiar they are with participant's health history.
- In some cases, very well-informed proxy may be able to complete the entire AFU interview on behalf of the participant. Otherwise, the proxy may complete the GHE/S, HOE/S, and CIE/S forms (as the designated alternate respondent), or just the GHE/S and CIE/S forms as a non-designated informant.

Alternate Designated Respondent (ADR)

- ADR = someone the participant identifies who is well informed on their health history and can answer questions **on behalf** of the participant. Usually, a spouse or adult child.
- ADRs are identified as such in form CIE/S Q 55a, 59a and 63a.
- The interview can be completed with the ADR *if*:
 - The participant is unable to complete the interview due to cognitive impairment (usually in this case, the ADR is also the proxy/LAR)
 - The FC is unable to reach the participant after multiple attempts
- A close family member may know dates of hospitalizations/ER visits as they were likely to accompany them but may not have a detailed knowledge of the participant's overall medical history. Or they might, especially if acting as a caregiver for the participant.
- May respond to questions on GHE/S, HOE/S, and CIE/S forms (and in some cases, OPE/S form)

Informant (non-designated)

(Other) Informant = someone who knows participant and can answer some questions **about** the participant.

- In this case, can provide information about whether the participant is alive or not, and if not, some preliminary information about their death that the AFU/endpoints team can use to find out more details (Form GHE/S Q1 to 1b3).
- May respond to questions on GHE/S and CIE/S forms only
- However, may or may not also be proxy for participant.
- If participant reported alive, continue to attempt to contact the participant, proxy or ADR to complete the interview.

Special Situations

- In the case where participant is deceased (GHE/S Q1) and the answer to Q1c "Do you know if participant was hospitalized or went to the emergency room" is yes, either designated alternate respondent OR non-designated informant should attempt to respond to Q3 and Q4 of HOE/S form.
- If cannot reach participant after repeated attempts, designated alternate respondent should complete as much of HOE/S form as possible but not OPE/S form.
- However, if designated alternate respondent also acts as proxy, and is taking care of participant full time due to their cognitive decline, they may complete the OPE/S questions.

Summary of Expected Forms

Expected forms:	GHE/S	HOE/S	OPE/S	CIE/S
Participant	Yes	Yes	Yes	Yes
Designated alternative respondent (ADR)	GHE1 (and 1a-1c if deceased)	Yes	Only if ADR is full-time caregiver	Yes
Non-designated informant	GHE1 (and 1a-1c if deceased)	Only if reported deceased	No	Yes