



HCHS/SOL Question by Question Instructions, Annual Follow-Up Form, Year 1 (AFE/AFS), Version A

I. Background

The purpose of the year one follow-up phone interview for HCHS/SOL is to document medical events occurring since the baseline visit, maintain and update cohort contact information, and to ascertain vital status. The year one follow-up interview is to be conducted by telephone in either English or Spanish. The interview is to occur approximately 12 months since the baseline clinic visit. Future annual follow-up interviews (contact years 2 and 3) are to occur approximately 12 months since last contact. The timing of the annual follow-up interviews is described in more detail in Manual 16, Follow-up available on the HCHS/SOL website.

II. Annual Follow-Up Procedures

A. Timing of the follow-up interview

The target date of the year one annual follow up interview is the one-year anniversary of the participants initial clinic visit. For example, if the participant's initial clinic visit was on October 1, 2008, then the target date for the year one follow-up interview is October 1, 2009. The initial call for annual contacts is to be made no more than three weeks before the target date. Ideally, the annual follow-up interview takes place as closely as possible to the participant's one-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 that year one follow up interview no later that 6 months after the target date. If for some reason contact is not made until after 6 months post the participants follow-up target date, the year one annual follow-up will be set to missing and the year two follow-up interview form should be used. 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 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") and completion ("anything else?"; "can you tell me anything more about that?").

III. 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. (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 (SOL). I’m calling to see how you have been since your visit to our center 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 since your visit to our center. I will ask you some questions about your health since your center visit on (date of center visit). I want you to focus on what happened from (date of center visit) until today.” Then GO to Q2.

If the participant responds that they either not able or willing to complete the interview at the time of the call, try to establish a time to call back by saying:

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

If the interviewer establishes that the participant is DECEASED, the interviewer offers condolences. Record this information in Q1d (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 (data of center visit) 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 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 clinic visit 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. 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 your SOL center visit 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. 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. Out patient 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 SOL center visit.

*“The following questions are about any hospitalizations or visits to an emergency room you may have had since your SOL center visit on *(date)*.”*

Q3 Since your SOL center visit 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 SOL center visit, that you would like to ask some question about each of these separately, starting with the first occurrence since the SOL center visit.

If the participant response “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, then record “UNSURE” and this section will be skipped. If the participant responds that s/he has been admitted to the hospital or seen at an emergency room then go to Q4.

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, 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). 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 SOL center visit. If there are several events that have occurred since their SOL visit, explain that you would like to take each of these in order.

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 of 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 another time since your SOL center visit?

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 SOL visit. 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."

Q5 Since your SOL center visit 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 visit 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.

5a-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 your SOL center visit 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 SOL visit 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 tests 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 your SOL center visit 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 your SOL center visit 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. If you are not sure whether a recalled treatment fits into a category, record other and specify the treatment in the space provided.

Q9 Since your SOL center visit 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 Q10.

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 Q10.

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. If you are not sure whether a recalled treatment fits into a category, record other and specify the treatment in the space provided.

Section D. Medications (MEE section for data entry begins here.)

This section asks the participant about medications they are currently taking. For the purpose of this question, “currently” refers to the past two weeks. Begin this section with the following transition statement, gently stressing the time frame, as “the past two weeks”.

“Now I would like to ask about the prescription medications you currently use. By that I mean in the past two weeks. Can I ask you to bring all the prescription medications you are currently taking to the telephone?”

Q10 (Interviewer: Do not ask) Does the participant have medications to report?

If the participant does not have any medications to report (NO) or refused to answer (PARTICIPANT REFUSE) then go to Section E.

Q11-30 Please read the names of all the medications prescribed by a doctor. This includes pills, liquid medications, skin patches, inhalers, and injections. Please do not include over the counter medications unless prescribed by a doctor. (If asked, repeat gently that currently taking applies to medications taken in the past two weeks.)

Begin by typing the medication name in the space provided. The table will pull up possible answers for you fill in the name. Select (by highlighting and pressing <enter>) the correct name from the list provided. The “Code” field will be filled once the medication name is selected with a medication code number up to 10 characters long. You will not be able to edit this field. If your medication is not in the look-up table, press <ESC> and you will return to the empty field where you may type the medication name in the name field, but no code will be allowed. Ignore any dosage or frequency information listed in the medication lookup table. If you enter a medication and/or code incorrectly, you may delete the medication name and then record a ‘blank’ entry from the look up table. If there is no code corresponding to a medication, use the ‘blank’ entry to leave the code field empty.

Collect and record the strength of the medication as well as the units. If the participant does not know the strength or units, leave this blank.

After the participant has reported all their current medications, GO to Section E.

Section E. 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.

Q31 Current tracking information from HCHS/SOL database will be displayed on the screen. Read the following statement before confirming contact information:

“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 in strictly confidential and will not be shared with anyone else”.

Q31 Current home address

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

Q32 Primary Phone Number

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

Q33 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.

Q34 Secondary phone number

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

Q35 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.

Q36 Local contact name (local contact 1)

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

Q37 Local contact 1 relationship

Confirm and/or collect and record the relationship to the participant of this local (primary) contact person.

Q38 Current home address of primary contact (local contact 1)

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

Q39 Telephone (local contact 1)

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

Q40 Local contact 2 name

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

Q41 Relationship (local contact 2)

Confirm and collect and record the relationship to the participant of this local (secondary) contact person.

Q42 Current home address of secondary contact (local contact 2)

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

Q43 Telephone: (local contact 2)

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

Q44 Local contact 3 name

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

Q45 Relationship (local contact 3):

Confirm and/ or collect and record the relationship to the participant of this additional local contact person.

Q46 Current home address of secondary contact (local contact 3)

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

Q47 Telephone (local contact 3)

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

Q48 Participant's personal physician or other health care provider (HCP) (name and address)

Collect and record the name and address of the participant's personal physician or other health care provider, making sure to include city and state.

Section F. Closing

Close this portion of the interview by saying the following:

"Thank you for answering the questions about your health. Now we would like to continue with the call by asking you some questions about the food that you eat."

GO to FPQ opening script