

BASELINE TELEPHONE FOLLOW-UP

1 Background and Rationale

The follow-up telephone call will be administered between examinations in order to: a) update tracking information, b) ascertain interim hospitalizations, nursing home stays and new cardiovascular events, c) document changes in social relations and contact persons since the last contact, and to d) assess the extent to which respondents experienced any major life disruptions in the previous six months.

2 Definitions

2.1 Time Frame Life events questions are asked of occurrences that may have happened in the last six months prior to the questionnaire, or since the participant's Baseline Clinic Visit.

2.2 Spouse/Partner Questions about a person's spouse/partner, include both married spouses and unmarried partners who live together and have an intimate relationship.

2.3 Specific Life Events Questions

Q 4 Moving -- changing houses, apartments, or rooms(s) within the same residential care unit.

Q 17 Caring -- defined by participant.

Q 18 Significant change in personal finances -- a major change in income status (e.g. retirement, new employment, social security benefits, retirement benefits) or a major increase in debt or expenses.

Q 19 Very close friend or close family member -- defined by the participant.
Serious accident or illness -- one which required bed rest or hospitalization.

Q 21 Relationship -- a bond or communication between two people.
Significantly worse -- defined by the participant.

Q 23 Other important things -- events not previously covered which are significantly different from the participant's normal routine. For example: loss of a pet, taking a major trip/vacation, having problems with neighbors, etc.

3 Methods

3.1 The Follow-Up Telephone Call is administered by a CHS certified interviewer.

The average time for administration is 10 minutes. However, if the participant wishes to prolong the conversation, the interviewer will continue the call in the interest of maintaining good rapport with the participant.

- 3.2 Communication involving Events: Prior to your first attempt at contacting the participant, it is important to check with your site's Events Coordinator regarding the possibility of death or any recent changes in health status of the participant. Knowledge of and sensitivity to these issues will aid in collecting information from the participant more smoothly and help eliminate any awkwardness that may be caused by ignorance of the situation. If the participant is unable to provide the information him/herself, be aware that the form may be filled out by the designated proxy. Procedures are outlined in subsection 3.10 of this manual.

If you discover during the Follow-Up Telephone Interview that an unreported event has taken place, record as much information regarding the event as possible. This includes physician diagnoses of CHS end-points and any hospitalization (see Questions 10 through 12 below). This information should then be forwarded on to the Events Coordinator so that proper Events procedures may follow.

- 3.3 Attempts to contact the participant should be continued for up to three months following the initial contact date of the Follow-Up Telephone Call. Every attempt should be made to locate and speak to the participant him/herself. If it becomes apparent that the participant will be unavailable for the next three months or three months of contact attempts are unsuccessful, the interview will be forfeited.

When the interview will not be administered, YOU MUST CONTACT THE COORDINATING CENTER and provide the reason for the missing data. The following are valid reasons that will be coded into the CHS database:

- death
- refusal
- can't locate
- in hospital
- out-of-town
- Other, specify.

Additional guidelines regarding death or refusal are given below.

- 3.4 Introductory Script

Questions 1 through 3 deal with the script used to introduce the interview.

- Question 1 - (script): Hello, this is (your name) from the Cardiovascular Health Study. May I please speak with (participant's name)?

- Code "1 - Participant answers" if the participant him/herself answers or comes to the phone. Then skip to Question 2.
- Code "2 - Participant not in" if participant is not at home or unavailable to answer the phone. Follow-up with person who answered the phone by asking when would be a good time to reach the participant. Enter day and time that is suggested.
- Code "3 - Participant deceased" if you are informed that the participant has died. If possible, ask the following questions to ascertain if an Informant Interview is required:
 - Has CHS been notified? If yes, has an interview with a family member been conducted?
 - Did the participant die in the hospital?
 - What was the cause of death?

If the death occurred

- out-of-hospital or
- in-hospital with a cardiovascular cause,

an informant interview is required (if not already conducted). If possible, conduct or schedule the interview now.

■ Question 2 - Did you receive our letter?

- Code "1 - Yes" if the participant answers that s/he has received the letter.
- Code "2 - No" if the participant cannot recall receiving a letter. Then follow with script:

I'm sorry you didn't receive our letter since it told about this telephone call. We told you when you came to the CHS clinic for your examination that we would be calling you in about six months. Six months have now passed and we are calling to say hello and to find out how you have been since we last saw you. Do you have a few minutes to speak on the phone now?

■ Question 3 - Interview

Record the result of initiating the interview:

- Code "1 - Interview started" if the participant agrees to begin the interview. Fill in the time of day (hour, minute, and am or pm) at which the interview begins.
- Code "2 - Participant refuses interview" if the participant refuses to be interviewed even after attempts to reschedule. Check with your supervisor to determine if another call may help in persuading compliance. If it is determined that the refusal is final, write in the reason for the refusal in the space provided.
- Code "3 -Participant wants to reschedule interview" if the current time is not convenient for the interview and another time is requested. Record the date and time of the rescheduled interview in the space provided.

3.5 Tracking - Question 4

Refer to the specific Participant Tracking Information Sheet. Verify the participant's name and address as listed on the sheet. If the participant notes that a change in address has occurred during the last six months (or since his/her Baseline Clinic Visit), record this on the Telephone Interview form and document changes on the Tracking sheet. If the participant has moved, ask if the move has taken place during the last month. Record the response on the form.

3.6 Changes in Health Status - Questions 5 - 14

- Question 5 - Would you say, in general, your health is (read the alternatives and code response given):
 - "Excellent", Code 1
 - "Very Good", Code 2
 - "Good", Code 3
 - "Fair", Code 4
 - "Poor" , Code 5
 - Code "9 - Refused/Don't Know" if participant refuses to answer or doesn't know.
- Question 6 - How would you say your health compares to other persons of your age? Would you say your health is (read the alternatives and code response given):
 - "Better than others your age?" - Code 1
 - "About the same as others your age?" - Code 2
 - "Worse than others your age?" - Code 3
 - Code "9 - Don't Know" if participant doesn't know the answer.

- Question 7 - How does your health compare to when we saw you in (state month participant visited the clinic for CHS Baseline exam)? Would you say your health is (read alternatives and code response given):
 - "Better", Code 1
 - "About the same", Code 2
 - "Worse", Code 3
 - Code "9 - Don't Know" if participant doesn't know.

- Question 8 -During the past two weeks, how many days have you stayed in bed all or most of the day because of illness or injury? Do not include days in a hospital or nursing home.
 - Record the number of days participant cites, from 00 to 14.
 - If none (00), skip to Question 10.

- Question 9 - What illness caused you to stay in bed?
 - Don not read responses to participant, but code in response that best describes answer given.
 - Choose from the following alternatives:
 - Heart attack/heart failure
 - Diabetes
 - Arthritis
 - Stroke
 - Mental illness
 - Cold or flu
 - Cancer
 - Injury
 - General fatigue or weakness (including old age)
 - Lung disease, emphysema, bronchitis
 - Other (specify)
 - Don't know

- Question 10 - Now I would like to find out if you had any major changes in your health since we saw you in (month participant visited clinic). Have you been told by a physician that you had:
 - For each of the following, code "1 -Yes" if the participant states that a physician has diagnosed him/her since our last contact with the participant. Code "2 - No" if the response is no.

- Heart failure or congestive heart failure
 - Stroke or cerebrovascular accident
 - Transient ischemic attack or TIA or silent stroke
 - Myocardial infarction or heart attack
 - Angina pectoris or chest pain due to heart disease
 - Intermittent claudication of pain in your legs from a blockage of the arteries.
- If the participant answers "Yes" to any of the diagnoses in Question 10 (above), ask for the name, address and telephone number of the physician who diagnosed the event.
 - Information on any diagnosis not already reported to the Events Coordinator should be forwarded for Events data collection efforts.
- Question 11 - Have you stayed overnight as a patient in a hospital since we saw you in (month participant made clinic visit).
- Code "1 - Yes" if participant states that s/he has been hospitalized; code "2 - No" if s/he has not.
 - If participant responds "No", skip to Question 13.
- Question 12 - Please tell me the reason you were admitted, the name and location of the hospital, and the month and year you were a patient for each time you stayed overnight in a hospital.
- For each hospitalization, record the reason, name/city/state of hospital and month/year of stay in the spaces provided.
 - You may record information for up to five hospitalizations on the form itself. If there have been more than five stays, complete the remaining information on a Hospital Supplement Form.
 - If a hospitalization was reported, remind the participant of CHS investigation into events by stating the following:

As explained at your original clinic visit, records of these hospitalizations will be checked for medical information that may apply to the CHS study.
 - Information on any hospitalizations not already reported to the Events Coordinator should be forwarded for Events data collection efforts.
- Question 13 - Have you stayed overnight as a patient in a nursing home or

rehabilitation center since (month participant made clinic visit)?

- Code "1 - Yes" if participant states that s/he has stayed overnight in a nursing home or rehabilitation center; code "2 - No" if s/he has not.
 - If participant responds "No", skip to Question 15.
- Question 14 - Please tell me the reason you were admitted, the name and location of the nursing home, and the month and year you were a patient for each time you stayed overnight in a nursing home or rehabilitation center.
- For each stay, record the reason, name/city/state of nursing home and month/year of stay in the spaces provided.
 - You may record information for up to five separate stays on the form itself. If there have been more than five, complete the remaining information on a Nursing Home Supplement Form.
 - If a nursing home stay was reported, remind the participant of CHS investigation into events by stating the following:

As explained at your original clinic visit, records of these nursing home or rehabilitation center admissions will be checked for medical information that may apply to the CHS study.

3.7 Life Events

- Questions 15 to 23 - The Life Events Questionnaire consists of nine questions in addition to the one regarding moving (Question 4).
- Script - "I am now going to ask you about a number of events that commonly happen in people's lives and that can affect your health. In some cases, I will ask whether the event has happened to your or a member of your family during the past six months. In other cases, I will ask only whether it happened to you. When I ask a question about your spouse, I am referring to both married spouses and unmarried partners who live together. Please respond "yes" if the event happened and "no" if it didn't."
 - Read each question from the form.
 - Check the response on the form.
 - When the participant refuses to answer the question, check "9 - Unknown".

- If the participant reports any other changes that have happened in the past six months, record the specific event(s) in Question 23.
- Definitions for terms used in the questionnaire are as indicated under "Definitions" above. These should be provided when the participant asks for clarification.

3.8 Proxy and Contacts Tracking

- Questions 25 and 26 request verification of the proxy and contacts (Contact 1 and Contact 2) previously provided to CHS.
 - For current information, go to the hard copy of the Participant Tracking Information Sheet.
 - Changes should be made directly onto the Participant Tracking Information Sheet.
- Question 27 - Do you plan to be out of the area 6 months from now?
 - Code "1 - Yes" or "0 - No".
 - If the participant is planning to be out of the area, it is important to ascertain if the relocation will be permanent or temporary. Temporary relocations include vacations, business, trips, alternate (e.g. summer) residences, or other travel. Code "1 - Permanently" or "2 - Temporarily out of the area".
 - If the participant is moving out of the study area permanently, ask for the address and telephone number of the new residence. If this level of detail is not known as yet, record the general area into which the participant will be relocating.
 - If the participant is only leaving the area temporarily, record the month and year in which s/he will return. Ask him/her to please call CHS to make an appointment for the annual visit upon his/her return.

3.9 Closing

- Question 28 - Closing script: "Thank you very much for answering these questions. I enjoyed talking with you. Please call us if you move or if you should have to go to a hospital or nursing home, even if you have moved from the area. You are always welcome to call collect. I look forward to talking with you and seeing you in the CHS clinic during your annual visit six months from now."

- Question 29 - Record the time (hour and minutes) at which the interview ended.
- Question 30 - If another participant is scheduled to be interviewed, ask to speak with him/her. If the individual is not in or it is not a convenient time for him/her, reschedule the interview for another time. If the participant agrees, begin the interview using another Follow-Up Telephone Interview form.
- Following each interview, record your Interviewer ID Number and date of the interview in the spaces provided on the bottom of each form.

3.10 Proxy Procedures

In the event that a participant is physically incapacitated (e.g. comatose, hearing impaired, etc.), no longer able to function cognitively, or unable to be contacted during the telephone follow-up period, the interview may be conducted with the participant's proxy. For the Year One Follow-Up Telephone Interview, the following guidelines apply:

- The person who is interviewed must be the proxy named on the Participant Tracking Information Sheet. If the proxy has changed, information on the new proxy must be entered on the sheet.
- Instruct the proxy to answer for the participant (to the best of his/her knowledge) in lieu of the participant responding him/herself. If the proxy does not know the answer, "Don't Know" or "Unknown" is to be recorded rather than a guess. Also, keep in mind that the participant's name or "him/her" should replace "you" in the specific questions where appropriate.
- There is currently no variable on the form to indicate that the interview was completed by a proxy. You must contact the Coordinating Center with the name, ID Number and reason for using the proxy so that this information may be entered directly into the database. Future version of the Follow-Up Telephone Interview form will provide a field to collect this information.