

## Chapter 25-A

### Phase I: Participant Follow-Up

#### OVERVIEW

The purpose of the annual follow-up contact questionnaire is to provide a means to remain connected to the family as well as update vital status, functional status, health conditions and current contact information. Another aim of this annual follow-up is to inquire whether other family members are interested in participating in LLFS.

#### ADMINISTRATION

This form can be either telephone administered by study staff or mailed. If sent by mail and not returned, multiple efforts should be attempted to reach the participant by phone. If the participant is deemed unreachable, call the named contact on Panel 14, Contact Information. If the contact is not available, go to the next contact. If no follow-up information can be obtained, record an “N” in the data field for “Date Form Filled Out” on Panel 16, Follow-up Questionnaire, and the participant will be recorded in the dataset as missing. If a participant has been reported as deceased prior to annual follow-up, no phone call is necessary.

Annual follow-up will be conducted for at least three years within a one calendar month window (i.e., 2 weeks before or 2 weeks after) of the anniversary date that the in-person or telephone visit was completed. However, if the follow-up cannot be completed in that time, it is still best to ascertain the information out of the window than have missing data.

**Instructions to Interviewer(s):** There is no scripting on how to open up the conversation when you do the follow-up call. Refer to our general interviewing guidelines chapter of the MOP. A suggested opening would be to reintroduce yourself, thank them for their participation in LLFS and tell them the purpose of this call (to update their health history) and how long it will take (approximately 5-10 minutes). If you are asked by the participant how many other family members are participating in this study, you can answer provide a global answer (i.e., approximately 15 or whatever is accurate) but you are not permitted to provide names of those participating as it would be a HIPAA violation.

Prior to contacting the participant or mailing the form, please complete the two questions on the top of page 1, making certain that you check the appropriate follow-up contact (i.e., first, second, third year). In addition, pre-populate Questions 3a and 4a from Panel 14, Contact Information, for the first follow-up, and use the information obtained from this Panel for subsequent follow-up years.

If you are administering this questionnaire to a proxy, insert the participant’s name instead of stating “your” for all applicable questions.

**Question 1a:** Interview will mark this question based on information received when making the follow-up phone call. If deceased, go to Q1b. If the participant is living, continue to Question 2 with the participant or their DFR/Proxy.

**Question 1b:** If the participant is marked as deceased in Q1a, ask for date of death and record on the form. The interview is now complete. Please mark in the DES the status change to deceased for this individual.

**Question 2:** This question asks about the participant's current overall health. Read the question and the first 5 responses. Do not read the "Don't know" and "Refused" responses.

**Question 3a:** This question is self-explanatory. The past year refers to the period of time since the participant was seen for LLFS. Have that date available. If the answer is "yes", go to Q3b, if "no" go to Q4a.

**Question 3b:** Please record the number of times the participant was hospitalized since they were seen for LLFS. If at least one hospitalization, go to Q3c.

**Question 3c:** For each hospitalization indicated in Q3b, ask the participant or their proxy the date of the hospitalization and the reason. If there are more than three hospitalizations, please list them on a separate sheet. If the exact date of the hospitalization is unknown ask for their best estimate; if the date is unknown, indicate as such with a "D". Proceed to Q4a.

**Note:** Do not record the Code at the time of interview. The hospitalization codes need to be assigned after the phone follow-up. Refer to the table at the end of this chapter.

**Questions 4a-10b:** These questions ask about the participant's current functional status. Please note the skip patterns on this form. Refer to Chapter 11 for specific details on administration of these questions, including detailed information on the skip patterns. These questions are identical to those currently administered in Panel 3.

**Note:** *Questions 11 and 12 will not be completed by the University of Southern Denmark field center as this information is available in their public registers.*

**Question 11a:** Indicate whether the contact information on file is accurate, has changed or if a move is planned. If there is a change, complete Q11b; otherwise, proceed to Q12a.

**Question 11b:** Provide updated contact information here. If the participant or their proxy indicate a move, please remind them to call the Field Center (and provide the toll-free telephone number) to update us when they have the new information. Proceed to Q12a.

**Question 12a:** Confirm the contact person for the participant. If there are any changes, denote them on the form and go to Q12b.

**Question 12b:** Indicate if the contact person is enrolled in LLFS and go to Q12c.

**Question 12c:** Verify or change the address, phone, best time to call and email address of the contact person and go to Q12d.

**Question 12d:** Please check the appropriate relationship between the contact person and the participant (i.e., spouse, daughter, son, niece, nephew, etc.) and go to Q12e.

**Question 12e:** Please ask whether this individual has power of attorney and check the appropriate response. Proceed to Q13.

**Question 13:** If the interviewer has any additional information that they would like to record, do so in the field for Question 13. Proceed to Q14a.

**Question 14a:** Please identify the person completing this form. If it is the study participant, proceed to Q15, if it is the contact person for the participant or someone else, go to Q14b.

**Question 14b:** Indicate the relationship between the person completing this form and the study participant and proceed to Q14c.

**Question 14c:** Please mark the reason why someone other than the participant is completing this form. Proceed to Q15.

**Question 15:** Ask the participant or their designated family representative if there are any additional family members (brothers/sisters, sons/daughters/nieces/nephews, etc) that they may have spoken to that are now interested in participating in LLFS. If yes, ask for the name and contact information and record this information in the TS2 and proceed accordingly. Note: If this box is checked when returned by mail, study staff need to follow-up via telephone call to obtain the contact information for the interested family member(s). Interview is complete.

***End Interview Script:*** “Thank you very much for answering these questions. I enjoyed talking with you. Please remember to call us if you move or your mailing address changes. I look forward to speaking with you again at approximately the same time next year. Again, thank you for your ongoing interest in our study.”

## HOSPITALIZATION CODING

<b>(a) Heart Disease</b>	
Myocardial Infarction or Heart Attack	A1
Coronary Angioplasty or Coronary Artery Bypass Grafting (CABG)	A2
Heart Failure or Congestive Heart Failure	A3
Atrial Fibrillation/Pacemaker	A4
Deep Vein Thrombosis (or blood clots in legs) or Pulmonary Embolism (blood clot in lung)	A5
Rheumatic Fever or Heart Valve Problems	A6
High Blood Pressure	A7
Other	A8
<b>(b) Stroke</b>	
Stroke or Cerebrovascular Accident	B1
Transient Ischemic Attack (TIA) or Mini-Stroke	B2
Other	B3
<b>(c) Lung Disease</b>	
Asthma	C1
Chronic Bronchitis	C2
Emphysema or Chronic Obstructive Pulmonary Disease (COPD)	C3
Pneumonia	C4
Pulmonary Fibrosis	C5

Chest Surgery	C6
Other	C7
<b>(d) Arthritis</b>	
Arthritis of the Knees, Hips or Spine	D1
Other	D2
<b>(e) Endocrine/GI/Kidney</b>	
Diabetes	E1
Thyroid Disease	E2
Osteoporosis	E3
Chronic Liver Disease, Cirrhosis, or Hepatitis	E4
Kidney (Renal) Disease or Failure	E5
Other	E6
<b>(f) Neurological</b>	
Alzheimer's Disease or Dementia	F1
Parkinson's Disease	F2
Depression or Anxiety	F3
Other	F4
<b>(g) Cancer</b>	
Breast Cancer	G1
Blood Cancer, Leukemia, or Lymphoma	G2
Colon (Bowel) or Rectal Cancer	G3
Lung Cancer	G4
Malignant Melanoma	G5
Other Skin Cancer	G6
Esophageal Cancer	G7
Pancreatic Cancer	G8
Other Cancer	G9
Prostate Cancer	G10
Enlarged Prostate, not cancer	G11
<b>(j) Fractures</b>	
Hip	J1
Wrist or Forearm	J2
Spine	J3
Other	J4
<b>(k) Other Illnesses not listed above</b>	K1

\* *Note:* Items H and I from Panel 5 are not included because they are related to vision and hearing.