



(Affix Label Here)

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

Date Form Filled Out:

d d M M M y y y y

(e.g., 10JUN2005)

Interviewer Code:

Circle Field Center Location:

BU CU DK UP

Circle Visit: <sup>1</sup>Visit 1 <sup>3</sup>Visit 2 <sup>4</sup>Visit 2 (New Participant)

Form Version Date: 17/06/2014

### LLFS Telephone Screener Visit 2 New Family Member (TS1a)

***Interviewer Note:*** To be kept in a confidential file separate from other data forms. Recommended resources: Panel 12 and known family pedigree.

***This interview entails calling a family member that has been identified and consented by the Proband or another previously screened family member.***

***Interviewer Script:*** Hi, my name is [insert your name here] and I am calling from [insert your institution here] about the LONG LIFE Family Study. We are attempting to learn why some families have more relatives living to a very old age than some other families. [Insert family member's name] told us that they spoke with you and that you are interested in learning more about participating in this family study. [Insert Proband's name] has lived a long life. That is why we are asking you to participate with [him/her] in an important international study of longevity. In addition to our university, this study is being conducted at two other American universities [insert names here], as well as at the University of Southern Denmark. Our goal is to find out what families with histories of long-lived individuals have in common. By participating in this study with your family members, you may have an opportunity to help improve the health of future generations.

We have already spoken with [insert Proband's name] about your family, but if it is okay with you, we have some questions we would like to ask you. Based on the telephone interview, some family members will be invited to participate in a more detailed part of this study. This would involve seeing you in person. You do not have to answer any questions that you do not want to. All information that I receive from you, including your name and any other identifying information, will be strictly confidential and kept in secure files. Your participation is voluntary; you do not have to answer these questions. This will take approximately 5 minutes. Is it okay to speak with you now?

1 ..... Yes  
 0 ..... No

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**Interviewer:** *If no, then ask: When would be a good day and time for me to call you back and discuss this family study?*

Day/Date: \_\_\_\_\_ Time: \_\_\_\_\_ AM/PM

1. Do I have permission to ask you some questions about yourself?

<sup>1</sup> .....Yes

<sup>0</sup> .....No

**Script:** *Thank you very much for speaking with me.*

**Interviewer:** *Now I would like to verify your contact information: (Pre-fill from Panel 15, FU questionnaire when possible)*

2a. Name: \_\_\_\_\_

**First Name**

**Middle Initial**

**Last Name**

2b. Home Address: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_ City State Zip Code

2c. What is your home telephone number?

( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_

2d. Is there another number to call that is better during the day? [If no, check here .]

( \_\_\_\_\_ ) \_\_\_\_\_ - \_\_\_\_\_

3. What is your age? \_\_\_\_\_ Years

4. What is your date of birth?

Day: \_\_\_\_\_ Month: \_\_\_\_\_ Year: \_\_\_\_\_

*(Example: May 6, 1904 should appear as 06 / 05 / 1904)*

5. What is your gender?

<sup>1</sup> .....Male

<sup>2</sup> .....Female

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***Interviewer:*** Be sure to determine the precise biological relationship; use the "other" category, as needed, for "half" relationships.

6. What is your relationship to \_\_\_\_\_ [name of Proband]?

- 1 .....Spouse
- 2 .....Sibling
- 3 .....Offspring
- 4 .....Grandchild
- 5 .....Niece  
If Niece, daughter of which Index Person? \_\_\_\_\_
- 6 .....Nephew  
If Nephew, son of which Index Person? \_\_\_\_\_
- 7 .....Other (Please Specify) \_\_\_\_\_

***Interviewer Script:*** Now I would like to ask you some questions about your general health and any serious medical conditions that you may have.

7. In general, how would you say your health is? Would you say it is...

- 5 .....Excellent
- 4 .....Very Good
- 3 .....Good
- 2 .....Fair
- 1 .....Poor
- D .....Don't Know
- R .....Refused

8. Do you have advanced cancer or a serious medical condition, such as one which requires oxygen or dialysis that would keep you from being able to participate in a home interview or a physical examination?

- 1 .....Yes, definitely physically unable   **End Interview (Script A below)**
- 0 .....No, definitely physically able       **Continue with Interview**
- D .....Maybe, Call back   **Date/Time:** \_\_\_\_\_

***Script A – End Interview:*** "Thank you so much for this information. We greatly appreciate the time and interest you have shown in our study. The information you provided is very important and will help us discover how some people and their families live to a very old age." **END OF INTERVIEW**

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

**Interviewer Script – for those continuing:** Before we continue, I want to ask you what is your understanding of the purpose of the LONG LIFE Family Study?

9a. Key elements (concepts), "family, long lived, research study" \_\_\_\_\_

\_\_\_\_\_  
\_\_\_\_\_

9b. **Interviewer:** Does the individual have a clear understanding of the purpose of the study?

1 .....Yes  
 0 .....No

**Go to Q9c**  
**End Interview (Use Script B Below)**

9c. **Interviewer:** Does a hearing, language barrier or other problem make the Sreenee unable to communicate with you?

1 .....Yes  
 0 .....No

**End Interview (Use Script B Below)**

**Script B – End Interview:** "Thank you so much for this information. We greatly appreciate the time and interest you have shown in our study. The information you provided is very important and will help us discover how some people and their families live to a very old age." **END OF INTERVIEW**

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**Script:** Thank you for answering our questions. The information you provided is very helpful. At this point, we would like to invite you to participate in an in-person visit so that we can gather more information about your health and find out what common traits are present in families with long-lived individuals. This interview can be scheduled at your convenience either in your home or at our clinic. During the visit, a trained clinical staff member will obtain medical and personal information about you. You will be asked to answer questions related to your current and past medical history, medication use, daily living activities, physical activity as well as your health habits. You will also be asked questions such as how many years of education you have had and where you were born and your occupation. Other questionnaires will include paper and pencil tests of your ability to process and recall information and a mood/personality assessment. With your permission, we will obtain measurements of your weight, height, waist circumference, heart rate, blood pressure and lung function. You will also be asked to perform some simple physical tasks such as standing up from of a chair, gripping an object to measure hand strength and walking a short distance to assess your physical function. Additionally, you will be asked to perform a series of movements to test your balance. You will be asked if we can collect a small blood sample. This examination can be completed in approximately 3-3.5 hours. We will use all this information to determine the different ways in which families can achieve long lives and successful aging. You may refuse to participate in any portion of the study.

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**Complete this Section when Family Eligibility Has Been Met:**

10a. Are you interested in participating in this study, including providing a blood sample?

1 .....Yes  
 0 .....No  
 D .....Don't Know (Pending) Specify: \_\_\_\_\_

**Go to Q10c**  
**Go to Q10b**  
**Call Back**

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10b. Could you please indicate your reason(s)? (*Please X all that apply; then End Interview using "End Interview Script" below*).

- 1 .....Not Interested
- 1 .....Not Enough Time
- 1 .....Unwilling to Provide Blood Sample
- 1 .....Not Well
- 1 .....Concern about Ability to Complete Examination
- 1 .....Privacy Issue/Concern
- 1 .....Unwilling to Contact Family Members
- 1 .....Lack of "Family" Interest
- 1 .....Other, Please Specify: \_\_\_\_\_

**End Interview Script:** *"Thank you so much for the information you have provided. We greatly appreciate the time and interest you have shown in our study. If you decide at a later date that you would like to participate in this family study, please contact me at XXX-XXX-XXXX. Thank you and good-bye." END OF INTERVIEW*

10c. Where would you like this visit to be conducted?

- 1 .....Home Visit     **Schedule appointment for in-person visit**
- 2 .....Clinic Visit     **Schedule appointment for in-person visit**
- 3 .....Other (Please Specify) \_\_\_\_\_

- **If applicable, schedule appointment for in-person visit.**
- **If "other" (i.e. distant visit), then read the following script: "We will follow-up with you in a few months, as we have yet to begin conducting distant visits."**
- **If phone visit is the only option, Go to Q10d.**

10d. Do you think you would be interested in participating in the study via a telephone visit?

- 1 .....Yes                     **Schedule Telephone Visit**
- 0 .....No                       **Answer Q10e; Read End Interview Script**

10e. **Interviewer:** If no, why not? \_\_\_\_\_

**End Interview Script:** *"Thank you so much for the information you have provided. We greatly appreciate the time and interest you have shown in our study. If you decide at a later date that you would like to participate in this family study, please contact me at XXX-XXX-XXXX. Thank you and good-bye." END OF INTERVIEW*

**For Proband Generation Only:**

11a. Do you have a living spouse?

- 1 .....Yes                     **Go to Q11b**
- 0 .....No                       **Go to End Interview Script**

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Participant Name Code: \_\_\_\_\_

11b. Is [he/she] the biological [father/mother] of any of your children?

- <sup>1</sup> .....Yes      **Go to Q11c**
- <sup>0</sup> .....No      **Go to End Interview Script**

11c. What is [his/her] age?      \_\_\_\_\_ Years      **Go to 11d**

11d. Does [he/she] live with you?

- <sup>1</sup> .....Yes      **Go to 11e**
- <sup>0</sup> .....No      **Go to 11e**

**Interviewer Only for 11e:**

11e. Does spouse live within 2-3 hours of the New York City, Boston, MA or Pittsburgh, PA field centers?

- <sup>1</sup> .....Yes      **Go to Q11f**
- <sup>0</sup> .....No      **Go to Q11f**

11f. Does your spouse have any living siblings over the age of 85?

- <sup>1</sup> .....Yes      **Go to Q11g**
- <sup>0</sup> .....No      **Go to Q11g**

11g. Would you be willing to ask your spouse if we can contact [him/her] to discuss participation in the study?

- <sup>1</sup> .....Yes      **Record Contact Information; read End Interview Script**
- <sup>0</sup> .....No      **Go to End Interview Script; Remind of Appointment**

**Spouse Contact Information:**

Relationship to Index Person: Spouse _____
Name: _____
Address: _____
Phone: _____ ( <input type="checkbox"/> Home <input type="checkbox"/> Work ) Best day/time to call: _____
E-Mail Address: _____
LLFS Proband (Family) ID #: _____

***End Interview Script:*** Would you be willing to ask your [brothers/sisters, aunts/uncles, nieces/nephews or cousins] if we can contact them to discuss the study and answer any questions they may have? May I ask who you plan to contact? First names only, please, and their relationship to [Insert Proband's Name Here].

**Note to Interviewer:** Record this information on Panel 12. I will call you back in a week or so to confirm that you spoke with these family members and they are interested in speaking with us.

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

**For Offspring Generation Only:**

12a. Do you have a living spouse?

1 .....Yes  
 0 .....No

**Go to Q12b**

**Go to *End Interview Script***

12b. What is [his/her] age? \_\_\_\_ \_\_\_\_ \_\_\_\_ Years

**Go to Q12c**

12c. Does [he/she] live with you?

1 .....Yes  
 0 .....No

**Go to Q12d**

**Go to Q12d**

**Interviewer Only for 12d:**

12d. Does spouse live within 2-3 hours of the New York City, Boston, MA or Pittsburgh, PA field centers?

1 .....Yes  
 0 .....No

**Go to Q12e**

**Go to Q12e**

12e. Would you be willing to ask your spouse if we can contact [him/her] to discuss participation in the study?

1 .....Yes  
 0 .....No

**Record Contact Information; read *End Interview Script***

**Go to *End Interview Script*; Remind of Appointment**

**Spouse Contact Information:**

Relationship to Index Person: Spouse \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ (  Home  Work ) Best day/time to call: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

LLFS Proband (Family) ID #: \_\_\_\_\_

**End Interview Script:** *"Thank you so much for the information you have provided. We greatly appreciate the time and interest you have shown in our study. If you decide at a later date that you would like to participate in this family study, please contact me at XXX-XXX-XXXX. Thank you and good-bye."* **END OF INTERVIEW**

**Interviewer Note:** *It is important that as the interviewer, you make all attempts to either obtain the information directly from Proband or obtain a designated Reporter. Without the PIF information, the value of the family to the Study will be compromised.*

Participant ID: \_\_\_\_\_

Participant Name Code: \_\_\_\_\_

**Reporter Information: Please complete the information below for the individual who will provide information for the PIF, if not Index Person.**

Have you informed this person about the LLFS study and what this will involve? <sup>1</sup> Yes <sup>0</sup> No

Is this individual willing to be contacted by our research group about participation? <sup>1</sup> Yes <sup>0</sup> No

Relationship to Index Person: \_\_\_\_\_

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Phone: \_\_\_\_\_ ( Home  Work) Best day/time to call: \_\_\_\_\_

E-Mail Address: \_\_\_\_\_

LLFS Proband (Family) ID #: \_ \_ \_ \_ \_