**Chapter 5**

**Appointment Documents and Forms**

**This chapter outlines the appointment documents and forms needed for the pre-visit planning.**

LLFS assessments can be conducted in the participants' homes or in the Field Center's clinic space. Occasionally, visits are conducted in hotels, offices, or another location of choice. Although most visits are conducted in the participant's home, a map and directions to the specific field center should be provided whenever the participant opts to an in-clinic visit.

For returning participants, we will send a study-wide Newsletter discussing our plans for Visit 3. We will alert them to expect a call from us for either an Annual Telephone Follow-up or Visit 3, but everyone will be contacted in 2020.

Once a returning or new participant has agreed to Visit 3 based on the protocol outlined in Chapter 2, an appointment will be made for each individual to be seen in-person, either at the participant's home, another agreed upon location, or at the field center clinic. Additionally, some families will prefer to be seen together in one location while others will prefer to be seen at separate locations. The study staff will take into consideration the size of the home and number of participants seen to ensure there is sufficient space to see any family who wants to be seen together. We should be as flexible as possible in order to accommodate each participant's reasonable preferences for time, day and location of the visit. Weekend or evening visits may be requested and granted at the discretion of each Field Center's PI and his/her staff.

After the LLFS in-person appointment is made, the instructional letter (*see Appendix at end of this chapter*) is sent to each scheduled participant preferably 2 weeks before the scheduled in-person visit. If a visit is scheduled with less advance notice, the visit packet should be express mailed. The purpose of this letter is to remind the participant of the date/time/location of the visit as well as to provide all necessary instructions regarding the visit.

To prepare the letter, first the participant's name will be inserted at the top of the page on the line provided. Next, the day of the week, date of the appointment and time will be jotted down on the lines provided. A copy of the consent form is sent in advance for review as well as several panels that can be self-administered in this packet. The participant should complete the panels before their appointment as field personnel will collect them during the in-person visit, checking for completeness before leaving the home.

The specifics for the visit are then outlined for each participant so that s/he will be made aware of the preparations that need to be made for the visit.

Participants are asked to fast for at least 8 hours prior to the visit and no more than 16 hours. Participants with diabetes should limit fasting to 12 hours. Visits should be scheduled to accommodate these fasting limits or if not possible, venipunctures should be arranged through other arrangements (e.g., ExamOne or local lab). Participants are encouraged to drink water beforehand but asked to take nothing else aside from their medications.

Next, new participants are asked to have available a copy of the documentation used to verify their age, such as a birth certificate, passport, military record, marriage license.

The participants are asked to have available all medication containers for medications that they have taken in the past two weeks available for the examiner. It is stated that this includes both prescription and over-the- counter medications including vitamins, cold or allergy medications, aspirin, eye drops, nicotine (gum and e-cigarettes), creams and salves, and any other medications.

Participants are encouraged to take any medications that they normally take the day of Visit 3. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).

It is suggested the participants wear loose, comfortable clothing and shoes or have a pair of shorts available. This will help the examiners conduct the more physical assessments.

Next, participants are reminded to have their eyeglasses available if they need them to read. If they have a hearing aid, they are reminded to wear it for the visit.

Additionally, they are reminded to have a cane or walker available during the visit if they use any of these devices.

Lastly, field center staff should make a reminder phone call to the participant the day before the visit (or on the Friday before if a Monday visit) to address any questions and reconfirm the appointment.

Study Panels to be included in the Reminder Packet – Returning Participants:

* Panel 2 - Sociodemographics
* Panel 3 – Physical Function and ADLs
* Panel 4 – Personal History
* Panel 5 – Medical History
* Panel 20 – IADLs
* Panel 22 – Dietary History

Study Panels to be included in the Reminder Packet – New Participants:

* Panel 14 – Participant Contact Information
* Panel 2 - Sociodemographics
* Panel 3 – Physical Function and ADLs
* Panel 4 – Personal History
* Panel 5 – Medical History
* Panel 20 – IADLs
* Panel 19 – Health Habits
* Panel 22 – Dietary History

Please follow instructions in the corresponding MOP chapters for inserting dates and highlighting sections of panels for important skip patterns according to protocol.

**Chapter 1: Appendix 1a**



***A Collaborative Study, Including:***

Boston University Medical Center

Columbia University

University of Pittsburgh University of Southern Denmark

Washington University School of Medicine

***Sponsored by:***

National Institute on Aging

**Self-Administered Questionnaires**

**QUESTIONAIRE INSTRUCTIONS**

Date:

Dear :

Thank you for agreeing to participate in the Long Life Family Study (LLFS). In preparation for your in-person visit, please complete the enclosed questionnaires by yourself, without the help of other family members. LLFS staff will review these questionnaires for completeness during your in-person visit.

If you have any questions, please call at . Thank you again for your assistance in this important research project. We look forward to talking with you.

Sincerely,

**Chapter 1: Appendix 1b**



***A Collaborative Study, Including:***

Boston University Medical Center

Columbia University

University of Pittsburgh University of Southern Denmark

Washington University School of Medicine

***Sponsored by:***

National Institute on Aging

**Proxy/Study Partner/LAR Questionnaires**

**QUESTIONAIRE INSTRUCTIONS**

Date:

Dear :

Thank you for agreeing to be a proxy/study partner/LAR in the Long Life Family Study (LLFS). In preparation for the in-person visit, please complete the enclosed questionnaires without the help of other family members. LLFS staff will review these questionnaires for completeness during your in-person visit.

If you have any questions, please call at . Thank you again for your assistance in this important research project. We look forward to talking with you.

Sincerely,

**Instructions for Long Life Family Study Visit**

**(Sample Form – Visit Instructions for Visit 3 – Returning Participants)**

Dear \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_:

Your Long Life Family Study In-Person visit is scheduled for:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_/ \_\_\_ / \_\_\_\_\_\_ at \_\_\_\_\_\_:\_\_\_\_\_\_ AM/PM

 Day of Week Month Date Year Time

**Please be sure to review these instructions for your upcoming visit since they are very important for your visit’s success. This visit will take approximately 3-4 hours.**

**In preparation for your visit, please complete the enclosed questionnaires by yourself, without the help of another person. The LLFS Research Team will review these questionnaires for completeness during your in-person visit.**

* Please **FAST** (take nothing by mouth except water and medications) for at least 8 hours prior to your appointment and **drink plenty of water before your visit**.
* On the day of your visit, please take any medications as prescribed. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).
* Have all containers for prescription and over-the-counter medications that you have taken in the past two weeks available. This includes vitamins, cold or allergy medications, aspirin, eye drops, creams and salves, and any other medications.
* Please wear loose, comfortable clothing (or have a pair of shorts available) and wear shoes that are suitable for walking.
* Have your eyeglasses available for reading, if needed. If you have a hearing aid, please wear it.
* If you use aids to get around, such as a cane or walker, please be sure to have them available during your visit.

If you have any questions or concerns with this scheduled visit, **please call us toll-free at [XXX-XXX-XXXX].** We look forward to seeing you!

**Instructions for Long Life Family Study Visit**

**(Sample Form – Visit 3 Instructions for Proxy Visits)**

Dear \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_:

The Long Life Family Study In Person visit for \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_is scheduled for:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_/ \_\_\_ / \_\_\_\_\_\_ at \_\_\_\_\_\_:\_\_\_\_\_\_ AM/PM

 Day of Week Month Date Year Time

**Please be sure to review these instructions for your family member’s upcoming visit since they are very important for the visit’s success. This visit will take approximately 3-4 hours.**

**In preparation for this visit, please complete the enclosed questionnaires on behalf of your family member participating in the Long Life Family Study. The LLFS Research Team will review these questionnaires for completeness during this in-person visit.**

* Please have your family member **FAST** (take nothing by mouth except water and medications) for at least 8 hours prior to this appointment. Have them **drink plenty of water before the visit**.
* On the day of their visit, please have them take any medications as prescribed. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).
* Have all containers for prescription and over-the-counter medications that you have taken in the past two weeks available. This includes vitamins, cold or allergy medications, aspirin, eye drops, creams and salves, and any other medications.
* Please have your family member wear loose, comfortable clothing (or have a pair of shorts available) and wear shoes that are suitable for walking.
* Have their eyeglasses available for reading, if needed. If they wear a hearing aid, please wear it.
* If your family member uses aids to get around, such as a cane or walker, please be sure to have them available during this visit.

If you have any questions or concerns with this scheduled visit, **please call us toll-free at [XXX-XXX-XXXX].** We look forward to seeing you!

**Instructions for Long Life Family Study Visit**

**(Sample Form –Visit Instructions for New Enrollees)**

Dear \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_:

Your Long Life Family Study In Person visit is scheduled for:

\_\_\_\_\_\_\_\_\_\_\_\_\_\_ \_\_\_\_\_\_\_\_/ \_\_\_ / \_\_\_\_\_\_ at \_\_\_\_\_\_:\_\_\_\_\_\_ AM/PM

 Day of Week Month Date Year Time

**Please be sure to review these instructions for your upcoming visit since they are very important for your visit’s success. This visit will take approximately 3-4 hours.**

**In preparation for your visit, please complete the enclosed questionnaires by yourself, without the help of another person. The LLFS Research Team will review these questionnaires for completeness during your in-person visit.**

* Please **FAST** (take nothing by mouth except water and medications) for at least 8 hours prior to your appointment and **drink plenty of water before your visit**.
* Please have available a copy of the documentation that you use to verify your age, such as a birth certificate, passport, military record, marriage license. We will need to see it at your visit.
* On the day of your visit, please take any medications as prescribed. These include pills, dermal patches, eye drops, creams, salves, and injections (including insulin).
* Have all containers for prescription and over-the-counter medications that you have taken in the past two weeks available. This includes vitamins, cold or allergy medications, aspirin, eye drops, creams and salves, and any other medications.
* Please wear loose, comfortable clothing (or have a pair of shorts available) and wear shoes that are suitable for walking.
* Have your eyeglasses available for reading, if needed. If you have a hearing aid, please wear it.
* If you use aids to get around, such as a cane or walker, please be sure to have them available during your visit.

If you have any questions or concerns with this scheduled visit, **please call us toll-free at [XXX-XXX-XXXX].** We look forward to seeing you!

**Instructions for Long Life Family Study Visit**

**(Sample Form – Telephone Interview Returning Participants)**

Date:

Dear :

Thank you for agreeing to continue to participate in the Long Life Family Study (LLFS). By helping us understand longevity, you can help to improve the health of future generations.

It has been at least 3 years since you and your family members were last seen in-person.  We have been keeping up with you by phone or mail and have been tabulating the changes in your health over time.

Enclosed is a copy of the consent form for this third visit. Please read it carefully and if you have questions, please call at .

Approximately a week after we send you the consent information, we will call you to ask if you have any questions related to the consent document and either perform your LLFS interview or schedule your LLFS interview for a later date which we will coordinate. This interview will take about 1 hour and 30 minutes. We will ask you questions related to your current and past medical history, daily living activities, health habits, physical activity, your ability to process and recall information and your current medications. **Please gather all of your current medications, both prescription and over-the-counter that you have taken in the last 2 weeks and have them available during our telephone visit.**

During this interview we will also discuss arrangements to complete a blood draw if you are willing.

If you have any questions, please call at . Thank you again for your assistance in this important research project. We look forward to talking with you.

Sincerely,

Long Life Family Study Staff

**Instructions for Long Life Family Study Visit**

**(Sample Form – Telephone Interview for New Participants)**

Date:

Dear :

Thank you for agreeing to participate in the Long Life Family Study (LLFS). LLFS is an international project that is studying families who have several members who have reached very old age. With your help, we are hoping to learn why some people live until a very old age and why some families maintain their health far longer than the average family. By helping us understand longevity, you can help to improve the health of future generations.

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Enclosed is a copy of the consent form for this third visit. Please read it carefully and if you have questions, please call at .

Approximately a week after we send you the consent information, we will call you to ask if you have any questions related to the consent document and either perform your LLFS interview or schedule your LLFS interview for a later date which we will coordinate. This interview will take about 1 hour and 30 minutes.. We will ask you questions related to your current and past medical history, daily living activities, health habits, physical activity, your ability to process and recall information and your current medications. **Please gather all of your current medications, both prescription and over-the-counter that you have taken in the last 2 weeks and have them available during our telephone visit.**

During this interview we will also discuss arrangements to complete a blood draw.

If you have any questions, please call at . Thank you again for your assistance in this important research project. We look forward to talking with you.

Sincerely,

Long Life Family Study Staff

**Instructions for Long Life Family Study Visit**

**(Sample Form – Telephone Return Packet Letter)**

Date:

Dear :

Thank you for agreeing to be a part of the Long Life Family Study (LLFS). LLFS is an international project that is studying families who have several members who have reached very old age. With your help, we are hoping to learn why some people live until a very old age and why some families maintain their health far longer than the average family. By helping us understand longevity, you can help to improve the health of future generations.

It has been at least 3 years since you and your family members were first examined for this study.  We have been keeping up with you by phone or mail and have been tabulating the changes in your health over time.  The repeat examination that we have proposed will include physical measurements such as blood pressure, strength, walking, and cholesterol and glucose levels along with interview questions on your health, energy level, sleep and physical activity.

Recently we mailed you a packet of information that we asked you to complete and return. To date, we have not received this information. If you did not receive the packet or need another one to be sent, please contact us. We would appreciate hearing from you. If you have changed your mind about being a part of the Long Life Family Study please let us know.

If you have any questions or concerns, please contact \_\_\_\_\_ at or at . We look forward to hearing from you. Together we can discover the secrets of a long and healthy life.

Sincerely,

Long Life Family Study

**Instructions for Long Life Family Study Visit**

**(Sample Form – 'Unable to Contact You' Letter)**

Date:

Dear :

A while ago you agreed to participate in the second in-person visit for the Long Life Family Study (LLFS). To date, I have not been successful in reaching you. If you are still interested in being part of this important international study of longevity I can be reached at (insert staff e-mail and phone number). For your convenience our toll free number is 1-888-333-6327. To refresh your memory, I have enclosed information about the study or you can visit our website at [www.longlifefamilystudy.](http://www.longlifefamilystudy.)wustl.edu. If you have changed your mind about being a continuing part of LLFS it is important for us to know this as well. If we do not hear from you, I will plan to contact you in two weeks. Please keep in mind that we will be continuing to schedule appointments over the next few months.

If you have any questions or concerns, please feel free to contact at or at . I look forward to hearing from you. Together we can discover the secrets of a long and healthy life.

Sincerely,

(Insert staff name) Long Life Family Study

**Instructions for Long Life Family Study Visit**

**(Sample Form – 'Unable to Contact for Visit 3' Letter)**

Date:

Dear :

Thank you for your continued participation in the Long Life Family Study (LLFS). By helping us understand longevity, you can help to improve the health of future generations.

It has been at least 3 years since you and your family members were last seen in-person. In this next phase of the study, we would like to perform another evaluation in-person or by video. This is important for the study because we then have the opportunity to perform some very important measures and to see if anything has changed since we last saw you. Of course it is also wonderful for us that we can visit with you in person or virtually!

To date, I have not been successful in reaching you. If you are still interested in being part of this important international study of longevity, I can be reached at [insert staff e-mail and phone number]. For your convenience our toll free number is [insert toll-free line]. To refresh your memory and to find out what we have been learning, you can visit our website at www.longlifefamilystudy.wustl.edu. If you have changed your mind about being a continuing part of LLFS it is important for us to know this as well. If we do not hear from you, I will plan to contact you in two weeks.

I look forward to hearing from you. Together we can discover the secrets of a long and healthy life.

Sincerely,

(Insert staff name)

Long Life Family Study