

Chapter 5A: 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

QUESTIONNAIRE INSTRUCTIONS

(those only doing Mailed Questionnaires in additional for Annual Follow-Up)

Date: _____

Dear _____:

Thank you for agreeing to participate in the Long Life Family Study (LLFS). Enclosed is the informed consent document for Visit 3 along with several questionnaires. Please:

1. Read and sign the consent form
2. Complete the enclosed questionnaires by yourself, without the help of other family members
3. Return all documents in the enclosed envelope. LLFS staff will review these questionnaires for completeness.

If you have any questions at all, please call _at _____. Thank you again for your assistance in this important research project. We look forward to hearing back from you!

Sincerely,

Chapter 5A: 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

QUESTIONNAIRE INSTRUCTIONS

(those only doing Mailed Questionnaires in additional for Annual Follow-Up)

Date: _____

Dear _____:

Thank you for agreeing to be a proxy/study partner/LAR in the Long Life Family Study (LLFS). Enclosed is the informed consent document for Visit 3 along with several questionnaires. Please:

1. Read and sign the consent form
2. Complete the enclosed questionnaires by yourself, without the help of other family members
3. Return all documents in the enclosed envelope. LLFS staff will review these questionnaires for completeness.

If you have any questions at all, please call _at _____. Thank you again for your assistance in this important research project. We look forward to hearing back from you!

Sincerely,

Chapter 5A – Appendix 2a



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

Instructions for Long Life Family Study Visit (Sample Form – Telephone Visit 3 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 following the changes in your health over time.

Enclosed is a copy of the consent form. Please read it carefully and if you have questions, please call _____ at _____. Once your questions have been answered, follow instructions on the post-it notes for where to sign. Please also complete the **Contact Information sheet** and the **enclosed questionnaires by yourself without help from other family members and return them** along with your **signed consent form** in the addressed-stamped envelope provided, within 5 days of receiving this letter.

After we receive your signed consent form, we will call you to schedule an interview. This interview may take up to 1.5 hours. 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. Also please wear your glasses and hearing aids (if applicable) on the day of your interview.**

During this telephone visit 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 Research Team

Chapter 5A – Appendix 2b



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

Instructions for Long Life Family Study Visit (Sample Form – Telephone Visit 3 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.

Enclosed is a copy of the consent form. Please read it carefully and if you have questions, please call _____ at _____. Once your questions have been answered, follow instructions on the post-it notes for where to sign. Please also complete the **Contact Information Sheet**, the **enclosed questionnaires by yourself without help from other family members**, and a **copy of the verification of your birth date and return them** along with your **signed consent form** in the addressed-stamped envelope provided, within 5 days of receiving this letter.

After we receive your signed consent form, we will call you to schedule the Telephone Interview. This interview may take up to 1.5 hours. 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. Also please wear your glasses and hearing aids (if applicable) on the day of your interview.**

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 Research Team

Chapter 5A – Appendix 3a



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

Instructions for Long Life Family Study Visit (Sample Form – Video Visit 3 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 last had a more in-depth visit. We have been keeping up with you by phone or mail and have been following the changes in your health over time.

Enclosed is a copy of the consent form. Please read it carefully and call _____ at _____ so that we can review it together. I will answer your questions and walk you through how to fill out this form. Please also complete the enclosed questionnaires and return them along with your signed consent form in the addressed-stamped envelope provided.

After we receive your signed consent form, we will call you to schedule a Video Visit 3. This interview may take up to 2 hours. 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 video visit. Also please wear your glasses and hearing aids (if applicable) on the day of your video visit.**

During this video visit 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 Research Team

Chapter 5A – Appendix 3b



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

Instructions for Long Life Family Study Visit (Sample Form – Video Visit 3 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.

Enclosed is a copy of the consent form. Please read it carefully and call _____ at _____ so that we can review it together. I will answer your questions and walk you through how to fill out this form. Please also complete the enclosed questionnaires and return them along with your signed consent form, and a copy of the verification of your birth date in the addressed-stamped envelope provided.

After we receive your signed consent form, we will call you to schedule the Video Visit. This visit may take up to 2 hours. 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 video visit. Also please wear your glasses and hearing aids (if applicable) on the day of your video visit.**

During this video visit 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 Research Team

Chapter 5A – Appendix 4



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

Instructions for Long Life Family Study Remote Blood Draw Box

The contents of this box will be used to collect and ship your biologic (blood/saliva) samples to the LLFS central laboratory at the University of Minnesota.

Directions for how to freeze and prepare the box before your blood draw will take place during your remote Visit 3 (Telephone or Video).

Participants are asked to **fast for at least 8 hours prior** to the blood draw and **no more than 16 hours**. Participants with *diabetes* should **limit fasting to 12 hours**.

Participants are encouraged to drink water beforehand but asked to take nothing else aside from their medications.

If you have questions, please call _____ at _____.

Thank you again for your assistance in this important research project.

Sincerely,

Long Life Family Study Research Team

Chapter 5A – Appendix 7



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

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). We have been unsuccessful at re-contacting you via phone since your agreement to participate.

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,

(Insert staff name)
 Long Life Family Study

Chapter 5A – Appendix 8



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

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 video 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. 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

Chapter 5A – Appendix 9



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

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