

**APPENDIX E**  
**Survey Introduction**

**ONE TIME SURVEYS**

Questionnaire to be divided into following sections:

Appendix E1	Essential Questionnaire
Appendix E2	Disease Progression Survey (ALSFRS)
Appendix E3	Follow-up Questionnaire - Demography
Appendix E4	Follow-up Questionnaire - Lifestyle Factors
Appendix E5	Follow-up Questionnaire - Environmental Factors
Appendix E6	Follow-up Questionnaire - ALS-associated and Clinical Factors

General Instructions (on a separate screen before starting the survey)

**How to fill in answers:**

- Please read each survey question carefully and answer to the best of your knowledge.
- Answers to questions come in several formats:
  - Radio button and drop-down selections allow only one input per question.
  - Check box selections allow multiple answers per question.
  - Text boxes allow you to type in an answer. Text box entries are identified as an empty box or selection labeled “Other (specify)”.
- Some questions within each survey will appear “grayed-out” because of your answer to an earlier question. These questions do not apply to you and you can continue onto the next survey question or page.

**How the system works:**

- When Essential Questionnaire (Appendix E1) and the first assessment of ALS-related functional status (Appendix E2, Disease Progression survey) is completed and submitted, it'll be followed by set of additional questions (Appendix E3 – E6) asking for more detailed information regarding your demography, lifestyle, environmental, and ALS-associated factors. Follow-up questions are based on the responses from the Essential Questionnaire.
- Based on the selection of response either in the Essential Questionnaire or the Follow-up Questionnaires, there may be subsequent questions to complete.
- Each time you go to the next page of a survey your answers to the previous page are saved.
- You are given the option to save and quit a survey at anytime. Once you decide to save and quit the survey responses are saved and you can finish the survey later.

- At the end of each survey, you are given the option to review and change your answers. You can also print a copy of your answers. Once you submit your answers, you will not be able to change or print them later.
- There is no time limit to take surveys. However, if you stay logged in and do not work on the survey an alert will display. You will be informed that your session will time out if no further activity takes place.

***The purpose of this questionnaire is to obtain some general information about your demography, as well as information on lifestyle, environmental, and ALS-associated factors.***