**APPENDIX E1**

Form Approved

OMB No. 0923-0041

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**ESSENTIAL QUESTIONNAIRE**

ATSDR estimates the average public reporting burden for this collection of information as 6 minutes per response, including the time for reviewing instructions, searching existing data/information sources, gathering, and maintaining the data/information needed, and completing and reviewing the collection of information. An agency may not conduct or sponsor, and a person is not required to respond to a collection of information unless it displays a currently valid OMB Control Number. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Information Collection Review Office, 1600 Clifton Road NE, MS D-74, Atlanta, Georgia 30333; ATTN: PRA (0923-0041).

**Essential questionnaire is composed of the following sections:**

* Thirty-three items to complete upon registration to assess general information about the patient with ALS (Items 1-33).
* The first of 3 longitudinal assessment of disease progression to record ALS-related functional status at the time of registration (Item 34/APPENDIX E2).

**GO TO:** Upon selection of the response, more questions pertaining to the response will be followed upon completion of registration.

**ENTER:** Upon selection, patients are prompted to enter the response manually.

| **ITEM** | **VARIABLE CODE** | **RESPONSE** | **DESCRIPTION** | **BURDEN** |
| --- | --- | --- | --- | --- |
| 1 | S17\_Q07 |  | Have you participated in any ALS research studies? |  |
|  |  | 1 | Yes |  |
|  |  | 2 | No |  |
|  |  | 9 | Don't know |  |
| 2 | S17\_Q07A |  | Are you interest in participating in any ALS research studies? |  |
|  |  | 1 | Yes |  |
|  |  | 2 | No |  |
|  |  | 9 | Don't know |  |
| 3 | S1\_Q05 |  | Current marital status |  |
|  |  | 1 | Never married |  |
|  |  | 2 | Married |  |
|  |  | 3 | Separated |  |
|  |  | 4 | Divorced |  |
|  |  | 5 | Widowed |  |
|  |  | 6 | Living with partner |  |
| 4 | S1\_Q06 |  | Highest level of education attained |  |
|  |  | 1 | Did not complete High School; Less than 12th grade |  |
|  | S1\_Q06A |  | ENTER: |  |
|  |  | 2 | High school diploma or GED |  |
|  |  | 3 | Technical or trade school diploma |  |
|  |  | 4 | Some college credit |  |
|  |  | 5 | College degree (AA, BS, BA, etc) |  |
|  |  | 6 | Graduate School degree |  |
|  | S1\_Q06B |  | ENTER: |  |
|  |  | 7 | Other (specify) |  |
|  |  |  | ENTER: |  |
| 5 | S1\_Q07 |  | Do you consider yourself Spanish, Hispanic, or Latino/Latina? |  |
|  |  | 1 | No |  |
|  |  | 2 | Puerto Rican |  |
|  |  | 3 | Mexican, Mexican-American, Chicano |  |
|  |  | 4 | Cuban |  |
|  |  | 5 | Other Spanish, Hispanic (specify) |  |
|  |  |  | ENTER: |  |
| 6 | S1\_Q08 |  | What do you consider to be your race or ethnic group? (Check all that apply) |  |
|  | S1\_Q08A | 1 | White |  |
|  | S1\_Q08B | 2 | African American |  |
|  | S1\_Q08C | 3 | Native American/Alaskan Native |  |
|  | S1\_Q08D | 4 | Asian Indian |  |
|  | S1\_Q08E | 5 | Chinese |  |
|  | S1\_Q08F | 6 | Filipino |  |
|  | S1\_Q08G | 7 | Japanese |  |
|  | S1\_Q08H | 8 | Korean |  |
|  | S1\_Q08I | 9 | Vietnamese |  |
|  | S1\_Q08J | 10 | Other Asian (specify) |  |
|  | S1\_Q08J\_01 |  | ENTER: |  |
|  | S1\_Q08K | 11 | Native Hawaiian |  |
|  | S1\_Q08L | 12 | Guamanian or Chamorro |  |
|  | S1\_Q08M | 13 | Samoan |  |
|  | S1\_Q08N | 14 | Another Pacific Islander (specify) |  |
|  | S1\_Q08N\_01 |  | ENTER: |  |
|  | S1\_Q08O | 15 | Don’t know |  |
| 7 | S1\_Q09 |  | Country of birth |  |
|  |  |  | ENTER: SEE COUNTRY |  |
| 8 | S16\_Q01 |  | Please enter your ideas or thoughts regarding the factors that may have caused your ALS. |  |
|  |  |  | ENTER: |  |
|  | S16\_Q02 |  | Please enter any ideas about factors that may cause ALS in general |  |
|  |  |  | ENTER: |  |
| 9a | S1\_Q10A |  | Current height (ft) |  |
|  |  |  | ENTER: |  |
|  |  |  | **GO TO: APPENDIX E 4.1** |  |
| 9b | S1\_Q10B |  | Current height (in) |  |
|  |  |  | ENTER: |  |
|  |  |  | **GO TO: APPENDIX E 4.1** |  |
| 10 | S1\_Q11 |  | Current weight (pounds) |  |
|  |  |  | ENTER: |  |
|  |  |  | **GO TO: APPENDIX E 4.1** |  |
| 11 | S4\_Q01 |  | Have you ever smoked one or more cigarettes per day for 6 months or longer? |  |
|  |  | 1 | Yes |  |
|  |  |  | **GO TO: APPENDIX E 4.2** |  |
|  |  | 2 | No |  |
|  |  | 9 | Don't know |  |
| 12 | S4\_Q07 |  | Did you ever drink alcoholic beverages such as wine, beer and spirits at least once a month for 6 months or more |  |
|  |  | 1 | Yes |  |
|  |  |  | **GO TO: APPENDIX E 4.2** |  |
|  |  | 2 | No |  |
|  |  | 9 | Don't know |  |
| 13 | S5\_Q01 |  | Have you ever engaged in vigorous leisure-time physical activity for at least 10 minutes that caused heavy sweating or large increases in breathing or heart rate |  |
|  |  | 1 | Yes |  |
|  |  |  | **GO TO: APPENDIX E 4.3** |  |
|  |  | 2 | No |  |
|  |  | 9 | Don't know |  |
| 14 |  |  | Did you ever drink caffeinated beverages? (Check all that apply) | DOWN; Combines 5 into one question |
|  |  | 0 | No |  |
|  | S13\_Q01 | 1 | Espresso or expresso drinks (i.e. Latte, Americano) |  |
|  |  |  | **GO TO: APPENDIX E 4.4** |  |
|  | S13\_Q02 | 2 | Regular coffee |  |
|  |  |  | **GO TO: APPENDIX E 4.4** |  |
|  | S13\_Q03 | 3 | Hot or cold tea (i.e. black, green) |  |
|  |  |  | **GO TO: APPENDIX E 4.4** |  |
|  | S13\_Q04 | 4 | Highly caffeinated drinks (i.e. Jolt®, Surge®, Mountain Dew MDX®, Red Bull® or other energy drinks) |  |
|  |  |  | **GO TO: APPENDIX E 4.4** |  |
|  | S13\_Q05 | 5 | Regular soda (i.e. cola, Barq’s Root Beer ® or regular Mountain Dew®) |  |
|  |  |  | **GO TO: APPENDIX E 4.4** |  |
|  |  | 6 | Don’t know |  |
| 15 | S18\_Q01 |  | Have you participated in organized or professional sports? (Check all that apply) | DOWN; Combines 7 into one question |
|  |  | 0 | No |  |
|  | S18\_Q02 | 1 | Football |  |
|  |  |  | **GO TO: APPENDIX E 4.7** |  |
|  | S18\_Q07 | 2 | Hockey |  |
|  |  |  | **GO TO: APPENDIX E 4.7** |  |
|  | S18\_Q13 | 3 | Boxing |  |
|  |  |  | **GO TO: APPENDIX E 4.7** |  |
|  | S18\_Q16 | 4 | Soccer |  |
|  |  |  | **GO TO: APPENDIX E 4.7** |  |
|  | S18\_Q22 | 5 | Other sports |  |
|  |  |  | **GO TO: APPENDIX E 4.7** |  |
|  |  | 6 | Don’t know |  |
| 16 |  |  | Have you ever had an injury to your head or neck due to the following? (Check all that apply) | DOWN; Combines 5 into one question |
|  |  | 0 | No |  |
|  | S14\_Q01 | 1 | Childhood injuries |  |
|  |  |  | **GO TO: APPENDIX E 4.5** |  |
|  | S14\_Q02 | 2 | Car accident or moving vehicle |  |
|  |  |  | **GO TO: APPENDIX E 4.5** |  |
|  | S14\_Q03 | 3 | Falling or being hit or playing sports |  |
|  |  |  | **GO TO: APPENDIX E 4.5** |  |
|  | S14\_Q04 | 4 | Fights/Violence/Shaken |  |
|  |  |  | **GO TO: APPENDIX E 4.5** |  |
|  | S14\_Q05 | 5 | Explosion/Blast |  |
|  |  |  | **GO TO: APPENDIX E 4.5** |  |
|  |  | 6 | Don’t know |  |
| 17 |  |  | Have you ever received any electrical shock that resulted in the following? (Check all that apply) | DOWN; Combines 3 into one question |
|  |  | 0 | No |  |
|  | S14\_Q06 | 1 | Unconsciousness |  |
|  |  |  | **GO TO: APPENDIX E 4.6** |  |
|  | S14\_Q07 | 2 | Burn |  |
|  |  |  | **GO TO: APPENDIX E 4.6** |  |
|  | S14\_Q08 | 3 | Just the electrical shock |  |
|  |  |  | **GO TO: APPENDIX E 4.6** |  |
|  |  | 4 | Don’t know |  |
| 18 |  |  | What kind of health insurance or health care coverage do you have? Exclude private plans that only provide extra cash while hospitalized. If you have more than one kind of health insurance, please check the box next to each plan that you have. (Check all that apply) |  |
|  | S15\_Q01 | 1 | HMO |  |
|  | S15\_Q01\_01 | 2 | Private health insurance (non-HMO employer-sponsored) |  |
|  | S15\_Q01\_02 | 3 | Medicare |  |
|  | S15\_Q01\_03 | 4 | Medi- GAP (private insurance that supplements Medicare) |  |
|  | S15\_Q01\_04 | 5 | Medicaid |  |
|  | S15\_Q01\_05 | 6 | VA (Veteran’s Administration) |  |
|  | S15\_Q01\_06 | 7 | Other military health care (CHAMP, TRICARE, Department of Defense health plans) |  |
|  | S15\_Q01\_07 | 8 | Indian Health Service |  |
|  | S15\_Q01\_08 | 9 | State-sponsored health plan |  |
|  | S15\_Q01\_09 | 10 | Other government program (specify) |  |
|  | S15\_Q01\_10 |  | ENTER: |  |
|  | S15\_Q01\_11 | 11 | Other health insurance plan: (specify) |  |
|  | S15\_Q01\_12 |  | ENTER: |  |
|  | S15\_Q01\_13 | 12 | No health care coverage of any type |  |
|  | S15\_Q01\_14 | 13 | Don’t know |  |
| 19 | S2\_Q01 |  | What is your current employment status? |  |
|  |  | 1 | Full-time employed |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 2 | Part-time employed |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 3 | Retired |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 4 | Disabled |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 5 | Full-time student |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 6 | Homemaker |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 7 | Unemployed |  |
|  |  |  | **GO TO: APPENDIX E 5.1** |  |
|  |  | 8 | Other (specify) |  |
|  | S2\_Q01\_01 |  | ENTER: |  |
| 20 | S3\_Q01 |  | Were you ever a member of the armed forces? (Check all that apply) | DOWN; S3\_Q01 |
|  |  | 0 | No |  |
|  | S3\_Q02A | 1 | Army |  |
|  | S3\_Q02B | 2 | Navy |  |
|  | S3\_Q02C | 3 | Marines |  |
|  | S3\_Q02D | 4 | Air Force |  |
|  | S3\_Q02E | 5 | Reserves/National Guard |  |
|  | S3\_Q02F | 6 | Coast Guard |  |
|  |  | 7 | Don’t know |  |
| 21 | S3\_Q03 |  | Were you ever deployed to a war arena? (Check all that apply) | DOWN; S3\_Q03 |
|  |  | 0 | No |  |
|  | S3\_Q04A | 1 | World War II |  |
|  | S3\_Q04B | 2 | Korean Conflict |  |
|  | S3\_Q04C | 3 | Vietnam War |  |
|  | S3\_Q04D | 4 | Persian Gulf |  |
|  | S3\_Q04E | 5 | Afghanistan War |  |
|  | S3\_Q04F | 6 | Persian Gulf II |  |
|  | S3\_Q04G | 7 | Other (specify) |  |
|  | S3\_Q04G\_01 |  | ENTER: |  |
| 22 |  |  | Over your lifetime (at least 100 days or more), have you ever had a **job** where you worked with the following **pesticides**? (Check all that apply) | DOWN; Combines 5 into one question |
|  |  | 0 | No |  |
|  | S9\_Q01 | 1 | Herbicides |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.1** |  |
|  | S9\_Q02 | 2 | Fungicides |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.2** |  |
|  | S9\_Q03 | 3 | Insecticides |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.3** |  |
|  | S9\_Q04 | 4 | Rodenticides |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.4** |  |
|  | S9\_Q05 | 5 | Fumigants |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.5** |  |
|  |  | 6 | Don’t know |  |
| 23 |  |  | Over your lifetime (at least 100 days or more), have you ever had a **job** where you were exposed to the following **chemicals**? (Check all that apply) | DOWN; Combines 6 into one question |
|  |  | 0 | No |  |
|  | S9\_Q06 | 1 | Glues or adhesives |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.6** |  |
|  | S9\_Q07 | 2 | Solvents and degreasers |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.7** |  |
|  | S9\_Q08 | 3 | Unleaded gasoline |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.8** |  |
|  | S9\_Q10 | 4 | Unleaded paint |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.9** |  |
|  | S9\_Q12 | 5 | Formaldehyde |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.10** |  |
|  | S9\_Q16 | 6 | Other chemicals |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.11** |  |
|  |  | 7 | Don’t know |  |
| 24 |  |  | Over your lifetime (at least 100 days or more), have you ever had a **job** where you were exposed to the following **metals/metal work**? (Check all that apply) | DOWN; Combines 5 into one question |
|  |  | 0 | No |  |
|  | S9\_Q09 | 1 | Leaded gasoline |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.12** |  |
|  | S9\_Q11 | 2 | Lead paint |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.13** |  |
|  | S9\_Q13 | 3 | Soldering |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.14** |  |
|  | S9\_Q14 | 4 | Welding/brazing/flame cutting |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.15** |  |
|  | S9\_Q15 | 5 | Metal dust or fume |  |
|  |  |  | **GO TO: APPENDIX E 5.2/5.2.16** |  |
|  |  | 6 | Don’t know |  |
| 25 |  |  | Have you ever **personally** **handled** any of the following outside job (such as home or garden) for a potential exposure to **pesticides**? (Check all that apply) | DOWN; S10\_Q01  Combines 5 into one question |
|  |  | 0 | No |  |
|  | S10\_Q03 | 1 | Herbicides |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.1** |  |
|  | S10\_Q04 | 2 | Fungicides |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.2** |  |
|  | S10\_Q01/ S10\_Q02 | 3 | Insecticides |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.3** |  |
|  | S11\_Q09 | 4 | Gardening |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.4** |  |
|  |  | 5 | Don’t know |  |
| 26 |  |  | Have you ever **personally handled** any of the following outside job (such as home or garden) for a potential exposure to **chemicals**? (Check all that apply) | DOWN; Combines 7 into one question |
|  |  | 0 | No |  |
|  | S10\_Q05 | 1 | Pet tick/flea treatment (soaps, shampoos, dips, or powder) |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.5** |  |
|  | S11\_Q01 | 2 | Leatherwork |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.6** |  |
|  | S11\_Q03 | 3 | Oil-based painting |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.7** |  |
|  | S11\_Q05 | 4 | Woodworking |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.8** |  |
|  | S11\_Q06 | 5 | Car or tire repairing/restoring/oil change |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.9** |  |
|  | S11\_Q07 | 6 | Using glue to build wooden/plastic models |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.10** |  |
|  | S11\_Q08 | 7 | Developing photographs |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.11** |  |
|  |  | 8 | Don’t know |  |
| 27 |  |  | Have you ever **personally handled** any of the following outside job (such as home or garden) for a potential exposure to **metals**? (Check all that apply) | DOWN; Combines 9 into one question |
|  |  | 0 | No |  |
|  | S11\_Q02 | 1 | Glazing pottery/ceramics |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.12** |  |
|  | S11\_Q04 | 2 | Remodeling/paint scraping on homes built before 1960 |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.13** |  |
|  | S11\_Q010 | 3 | Soldering, welding, metal work |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.14** |  |
|  | S11\_Q011 | 4 | Outdoor hunting or shooting |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.15** |  |
|  | S11\_Q012 | 5 | Indoor range gun shooting |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.16** |  |
|  | S11\_Q013 | 6 | Bullet casting or reloading |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.17** |  |
|  | S11\_Q014 | 7 | Fishing with lead weights/sinkers |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.18** |  |
|  | S11\_Q015 | 8 | Knitting and jewelry making/Other hobbies (1) |  |
|  | S11\_Q15\_01 |  | ENTER: |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.19** |  |
|  | S11\_Q016 | 9 | Other hobbies (2) (specify) |  |
|  | S11\_Q16\_01 |  | ENTER: |  |
|  |  |  | **GO TO: APPENDIX E 5.3/5.3.20** |  |
|  |  | 10 | Don’t know |  |
| 28a |  |  | To the best of your knowledge, have you ever lived for more than 6 months in areas with following environment **AT BIRTH**? (Check all that apply) | DOWN; Combines 3 into one question |
|  |  | 0 | No |  |
|  | S8\_Q04 | 1 | Farm or ranch |  |
|  |  |  | **GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY** |  |
|  | S8\_Q05 | 2 | Private well as source of water |  |
|  |  |  | **GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY** |  |
|  | S8\_Q06 | 3 | Within ¼ miles of agricultural area sprayed with pesticides/herbicides |  |
|  |  |  | **GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY** |  |
|  |  |  |  |  |
|  |  | 4 | Don’t know |  |
|  |  |  | **GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY** |  |
| 28b | S8\_Q07 |  | Was this your current or most recent residence? |  |
|  |  | 1 | Yes |  |
|  |  | 2 | No |  |
|  |  |  | **GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY** |  |
| 29 |  |  | Has any member of your immediate biological family member diagnosed with ALS, Parkinson’s, or Alzheimer’s disease? (Check all that apply) | DOWN; Assess general family history across 15 questions |
|  |  | 0 | No |  |
|  | S6\_Q03M1 – M3 | 1 | Mother |  |
|  |  |  | **GO TO: APPENDIX E 6.1** |  |
|  | S6\_Q03F1 – F3 | 2 | Father |  |
|  |  |  | **GO TO: APPENDIX E 6.1** |  |
|  | S6\_Q06S1 – S3 | 3 | Sister |  |
|  |  |  | **GO TO: APPENDIX E 6.1** |  |
|  | S6\_Q06B1 – B3 | 4 | Brother |  |
|  |  |  | **GO TO: APPENDIX E 6.1** |  |
|  | S6\_Q06C1 – C3 | 5 | Children |  |
|  |  |  | **GO TO: APPENDIX E 6.1** |  |
|  |  | 6 | Don’t know |  |
| 30a | S17\_Q02 |  | In what part of the body did you first notice weakness that was diagnosed as ALS. |  |
|  |  | 0 | Not applicable |  |
|  |  | 1 | Speech and or swallowing muscles |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 2 | Arm or hand |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 3 | Neck, back or abdominal area |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 4 | Leg or foot |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 5 | Breathing muscles |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 6 | All over my body |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 7 | Don’t know |  |
| 30b |  |  | Before you noticed weakness that turned out to be ALS, did you experience any of the following? (Check all that apply) | DOWN; Combines 5 into one question |
|  |  | 0 | No |  |
|  | S17\_Q03A | 1 | Cramps or muscle spasm |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  | S17\_Q03B | 2 | Scattered muscle twitching |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  | S17\_Q03C | 3 | Difficulty swallowing |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  | S17\_Q03D | 4 | Problems with speech |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  | S17\_Q03E | 5 | Difficulty controlling bowels or bladder |  |
|  |  |  | **GO TO: APPENDIX E 6.2** |  |
|  |  | 6 | Don’t know |  |
| 31 |  |  | Have you ever used/had the following? (Check all that supply) | DOWN; Combines 5 into one question |
|  |  | 0 | No |  |
|  | S17\_Q05A | 1 | Wheelchair/Electric scooter |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  | S17\_Q05B | 2 | Breathing equipment (BiPap®) |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  | S17\_Q05C | 3 | Tracheostomy |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  | S17\_Q05D | 4 | Communication device |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  | S17\_Q05E | 5 | Hospice program |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  |  | 6 | Don’t know |  |
| 32 |  |  | Since you developed ALS, have you had any of the following? (Check all that apply) | DOWN; Combines 3 into one question |
|  |  | 0 | No |  |
|  | S17\_Q06A | 1 | Pneumonia |  |
|  | S17\_Q06B | 2 | Falls |  |
|  | S17\_Q06C | 3 | Blood clot |  |
|  |  | 4 | Don’t know |  |
| 33 |  |  | Are you currently taking or have you ever taken the following medication? (Check all that apply) | DOWN; Combines 2 into one question |
|  |  | 0 | No |  |
|  | S17\_Q04 | 1 | riluzole (Rilutek®) |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  | S17\_Q04A | 2 | edaravone (Radicava®) |  |
|  |  |  | **GO TO: APPENDIX E 6.3** |  |
|  |  | 3 | Don’t know |  |
| 34 |  |  | **GO TO: APPENDIX E2 Disease Progression Questionnaire** |  |