

APPENDIX E1 ESSENTIAL QUESTIONNAIRE

Form Approved
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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	1 2 9	Have you participated in any ALS research studies? Yes No Don't know	
2	S17_Q07A	1 2 9	Are you interest in participating in any ALS research studies? Yes No Don't know	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
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 12 th grade	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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:	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
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:	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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_0		ENTER:	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	1			
	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:	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
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:	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			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	
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		2	No	
		9	Don't know	
14			Did you ever drink caffeinated beverages? (Check all that apply)	DOWN; Combines 5 into one question
	S13_Q01	0	No	
		1	Espresso or espresso drinks (i.e. Latte, Americano)	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			Mountain Dew®) GO TO: APPENDIX E 4.4	
15	S18_Q01	6	Don't know	DOWN; Combines 7 into one question
		0	No	
	S18_Q02	1	Football	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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
	S14_Q01	0	No	
		1	Childhood injuries GO TO: APPENDIX E 4.5	
	S14_Q02	2	Car accident or moving vehicle GO TO: APPENDIX E 4.5	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	DOWN;



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			resulted in the following? (Check all that apply)	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			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)	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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)	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		7	Unemployed GO TO: APPENDIX E 5.1	
	S2_Q01_01	8	Other (specify) ENTER:	
20	S3_Q01	0	Were you ever a member of the armed forces? (Check all that apply) No	DOWN; S3_Q01
	S3_Q02A	1	Army	
	S3_Q02B	2	Navy	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	DOWN;



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			you ever had a job where you worked with the following pesticides ? (Check all that apply)	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	S9_Q04	4	GO TO: APPENDIX E 5.2/5.2.3 Rodenticides	
	S9_Q05	5	GO TO: APPENDIX E 5.2/5.2.4 Fumigants	
		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



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		0	No	question
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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	S9_Q12	5	GO TO: APPENDIX E 5.2/5.2.9 Formaldehyde	
	S9_Q16	6	GO TO: APPENDIX E 5.2/5.2.10 Other chemicals	
		7	GO TO: APPENDIX E 5.2/5.2.11 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



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	S9_Q15	5	Metal dust or fume GO TO: APPENDIX E 5.2/5.2.16	
		6	Don't know	
25		0	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) No	DOWN; S10_Q01 Combines 5 into one question



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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
	S11_Q02	0	No	
		1	Glazing pottery/ceramics GO TO: APPENDIX E 5.3/5.3.12	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
			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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	S8_Q06	3	<p>GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY</p> <p>Within ¼ miles of agricultural area sprayed with pesticides/herbicides</p> <p>GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY</p>	
		4	<p>Don't know</p> <p>GO TO: APPENDIX E 5.4 RESIDENCE HISTORY SURVEY</p>	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
28b	S8_Q07	1 2	Was this your current or most recent residence? Yes 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



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		0	No	across 15 questions
	S6_Q03M1 – M3	1	Mother GO TO: APPENDIX E 6.1	
	S6_Q03F1 – F3	2	Father GO TO: APPENDIX E 6.1	
	S6_Q06S1 –	3	Sister	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	S3		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		0	that was diagnosed as ALS. 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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		5	GO TO: APPENDIX E 6.2 Breathing muscles	
		6	GO TO: APPENDIX E 6.2 All over my body	
		7	GO TO: APPENDIX E 6.2 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



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
	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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
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	



ITEM	VARIABLE CODE	RESPONSE	DESCRIPTION	BURDEN
		3	Don't know	
34			GO TO: APPENDIX E2 Disease Progression Questionnaire	



