

Attachment A- National ALS Registry Website Satisfaction Survey

1. I am a (select all that apply)
 - a. Person with ALS
 - b. Friend/Family member
 - c. Caregiver
 - d. Healthcare Professional
 - e. Researcher
 - f. Other _____

2. How did you learn about the National ALS Registry website (<https://wwwn.cdc.gov/als/>)?
 - a. Healthcare Professional (e.g. Physician, Nurse etc.)
 - b. Friend/Family member
 - c. News story
 - d. Internet search engine (e.g. Google, Yahoo, Bing etc.)
 - e. Referred by other website
 - f. Presentation or other event
 - g. Pamphlet, brochure, or other written material
 - h. ALSA (Amyotrophic Lateral Sclerosis Association)
 - i. MDA (Muscular Dystrophy Association)
 - j. Les Turner
 - k. Another ALS advocacy/support organization
 - l. Other _____

3. How often do you visit the National ALS Registry website?

ATSDR estimates the average public reporting burden for this collection of information as approximately 5 minutes per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data 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 collection of information unless it displays a currently valid OMB control number. Send comments regarding this burden statement or any other aspect of this collection of information, including suggestions for reducing this burden to CDC/ATSDR Reports Clearance Officer, 1600 Clifton Road, MS D-74, Atlanta, GA 30333, ATTN: PRA (0923-0047).

- a. First visit
 - b. Daily
 - c. 2 or more time per week
 - d. Weekly
 - e. 2-3 times per month
 - f. Rarely
4. I came to the National ALS Registry website to find information and resources for the following: Check all that apply
- a. To learn about the National ALS Registry
 - b. To learn about the Biorepository
 - c. To find a clinic near me
 - d. To learn about ALS Research
 - e. To learn about and/or participate in Clinical Trials or other types of studies
 - f. To learn about ALS continuing education and training modules
 - g. To order Registry materials (e.g. Registry guides, factsheets, infographics etc.)
 - h. Just curious
 - i. Other (please specify) _____
5. I was able to find what I was looking for? (If no, please specify what you were looking for.)
- a. Yes
 - b. No
- I could not find: _____
6. Which features of the National ALS Registry website do you find most useful (Check all that apply)
- a. Information about ALS, ATSDR and the Registry (Registry Resources)
 - b. Information for ALS researchers (ALS Research Resources)
 - c. Information about the Biorepository (ALS Biorepository)
 - d. Signing up for the ALS Registry (ALS Registry Enrollment)
 - e. Finding a nearby clinic (ALS Service Locator)
 - f. Learning about funded research (ALS Registry Research)
 - g. FAQs, patient guide, provider guide, contact etc. (Feedback and Help)
 - h. MMWR reports, surveillance reports, annual meeting reports etc. (ALS Reports)
 - i. Papers and articles about the Registry, ATSDR conference events etc. (Publications and Conferences)
 - j. Continuing Education Module (Education and Training)
 - k. National ALS Registry videos, podcasts, webinars etc. (Multimedia Tools)
 - l. Registry guides, fact sheets, infographics etc. (Ordering Registry Materials)

- m. Quick links to other ALS associations, trials and research (e.g. MDA, NIH, ALS Untangled etc.)

7. Please rate the following attributes of the National ALS Registry website

Rating Scale (1 = Very Dissatisfied; 2 = Dissatisfied; 3 = Neutral; 4 = Satisfied; 5 = Very Satisfied)

A. Layout/design	1	2	3	4	5
B. Quantity of content	1	2	3	4	5
C. Easy to find information	1	2	3	4	5
D. Meeting my needs	1	2	3	4	5
E. Quality of content	1	2	3	4	5
F. Clear Information	1	2	3	4	5
G. Overall Satisfaction	1	2	3	4	5

8. How likely are you to recommend the National ALS Registry website to a friend or patient in the future?

- a. Very likely
- b. Somewhat likely
- c. Neutral
- d. Somewhat unlikely
- e. Very unlikely

9. How likely are you to visit the National ALS Registry website again if you need more information?

- a. Very likely
- b. Somewhat likely
- c. Neutral
- d. Somewhat unlikely
- e. Very unlikely

10. What areas of the National ALS Registry website can we improve? (Select all that apply)

- a. Website design
- b. Social media promotion
- c. Registry Resources (videos, infographics, factsheets etc.)
- d. Research information
- e. Clinical trials information
- f. Ease of contacting the National ALS Registry
- g. Other _____

11. Did you register for the National ALS Registry?

- a. Yes
- b. No
- c. Not Applicable

12. (If selected yes to #11): Please rate:

Rating Scale (1 = Very Dissatisfied; 2 = Dissatisfied; 3 = Neutral; 4 = Satisfied; 5 = Very Satisfied)

A. Clear directions	1	2	3	4	5
B. The website responded as expected	1	2	3	4	5
C. Time to complete	1	2	3	4	5
D. Overall Satisfaction	1	2	3	4	5

13. Did you complete risk factor surveys?

- a. Yes
- b. No
- c. Not Applicable

14. (If selected yes to #13): Please rate:

Rating Scale (1 = Very Dissatisfied; 2 = Dissatisfied; 3 = Neutral; 4 = Satisfied; 5 = Very Satisfied)

A. Clear directions	1	2	3	4	5
B. The website responded as expected	1	2	3	4	5
C. Time to complete	1	2	3	4	5
D. Overall Satisfaction	1	2	3	4	5

15. Many items on our site will soon be translated into Spanish. Is there another language you think we should also use?

- a. Yes
What language? _____
- b. No

16. How old are you? _____

17. What is your race (select all that apply)

- a. American Indian or Alaska Native
- b. Asian
- c. Black or African American
- d. Native Hawaiian or other Pacific Islander
- e. White

18. What is your ethnicity?

- a. Hispanic or Latino
- b. Not Hispanic or Latino