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National Amyotrophic Lateral Sclerosis (ALS) Registry

Comment On: ATSDR-2022-0004-0001

National Amyotrophic Lateral Sclerosis (ALS) Registry 2022-21219

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Comment on FR Doc # N/A

Submitter Information

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Organization: The ALS Association

General Comment

See attached file(s)

Attachments

ALS Association - National ALS Clinic and Biorepository Registry Comments 11.23.22



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Via Docket Submission

November 23, 2022

Jeffrey M. Zirger, PhD
Information Collection Review Office
Centers for Disease Control and Prevention
1600 Clifton Road NE, MS H21-8
Atlanta, Georgia 30329

Re: National Amyotrophic Lateral Sclerosis (ALS) Registry (OMB Control No. 0923-0041, Exp. 01/31/2023)—Revision—Agency for Toxic Substances and Disease Registry (ATSDR); Docket No. ATSDR-2022-0004

Dear Dr. Zirger:

The ALS Association appreciates the opportunity to submit comments regarding the Agency for Toxic Substances and Disease Registry's (ATSDR) proposed revision for the National ALS Registry (Registry).

Established in 1985, The ALS Association (Association) is the only national nonprofit organization fighting ALS on every front. The Association is the world's largest philanthropic funder of ALS research and provides care services to over 20,000 Americans with ALS and their families. Until ALS is cured, our goal is to make ALS a livable disease for all.

The Association has led ALS community efforts to advance the Registry since its inception. The following views are offered to continue to strengthen the role of the Registry in preventing ALS and developing specific strategies to reduce the devastating toll the disease takes on individuals and their care partners.

ATSDR proposes three changes to the Registry:

1. “[B]ased on feedback from patients, caregivers, researchers as well as the National Center for Health Statistics (NCHS) Collaborating Center for Questionnaire Design and Evaluation Research, ATSDR proposes to restructure the original five-minute survey modules to make them more user-friendly and easier to navigate for patients.”

Association comment: To increase survey completion, the Association strongly recommends ATSDR offer financial incentives to survey participants. This is a well-established tactic for improving complete response rates and should be incorporated in the Registry program for this purpose and to recognize the efforts required from people living with ALS.

Further, the Association strongly endorses efforts to reduce burdens on people with ALS and their care partners. ALS places an incredible strain on the physical, psychosocial, and financial resources; both on individuals with ALS and their families. It is critical the Registry surveys be both efficient and focused on important questions.

The Association supports the reorganization of the Registry surveys into the core or “essential” questionnaire and supplemental modules. In addition, it is important that the modules be regularly evaluated and discontinued if no longer necessary for specific research purposes so that new questions may be posed with emphasis on prevention-related strategies. The Association strongly urges ATSDR to more rapidly translate the knowledge gained through this data collection and analysis into specific interventions, including in collaboration with other public (e.g., National Institutes of Health) and private partners.

2. “ATSDR proposes to release state level data as four-year rolling averages for ALS incidence, prevalence, and mortality. Case counts for the four-year moving average will only be released for states with more than 16 ALS cases and is consistent with United States Cancer Statistics practices where cases or deaths are small and tend to have poor reliability.”

Association comment: The Association agrees that state level ALS data will be an important step forward for both the surveillance and research functions of the Registry. This is consistent with broader CDC reporting approaches for specific disease conditions and promises insights to drive development of prevention interventions. We encourage ATSDR to undertake this reporting upgrade at the earliest possible time and to make the data fully available to the public.

We also encourage the Registry to report data with as much detail as ethically possible. The threshold of 16 cases over a 4-year moving average is very conservative and limits the utility of the data in two ways. First, 4-year averages make the Registry much slower at detecting trends, and second, the high case threshold makes it harder to serve our more rural states. We ask that the Registry work harder to make their data, and the significant contributions of people with ALS, more useful in the fight to end ALS.

3. "ATSDR aims to achieve more complete ALS case ascertainment by adding several new data sources, including state ALS registries, non-profit ALS organizations, national ALS multidisciplinary clinics affiliated with academic research institutions and hospital systems, and health insurance companies and neurologists."

Association comment: The Registry benefits from a robust array of reliable data sources that can be utilized to improve accuracy, engage more people with ALS, and energize research activities. The Association both endorses the integration of more data sources and is prepared to have a material role in encouraging this participation as we have in prior Registry recruitment and development efforts. Here again, the Association emphasizes both the data collection and the research aspects of the Registry so that new sources also might become more fully engaged in both areas. ATSDR should have a Registry strategy that is deeply integrated with these organizations that directly serve people with ALS.

Thank you for considering these comments. We appreciate the efforts the Registry is making to improve data collection and its applications. We encourage the Registry to keep working to advance the science of ALS prevention and translate it into reductions in ALS incidence. We would be pleased to address any concerns and look forward to learning the outcome of the proposed Registry revision.



Dr. Neil Thakur
Chief Mission Officer
The ALS Association

OUR VISION: Create a world without ALS.



OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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