

School-Based Active Surveillance (SBAS) of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Among Schoolchildren

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Supporting Statement B

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This collection of information does not involve statistical methods. The purpose of the collection is to further field test and refine an approach for surveillance of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS). Statistical generalizations will not be made from the information collected.

1. Respondent Universe and Sampling Methods

For all but one data collection form in this project, the respondent universe consists of frontline school nurses and school district representatives from U.S. school districts. Approximately 60 frontline school nurses serving students in kindergarten through twelfth grade (K–12) across 24 states will participate over the three-year project period. These districts, located in urban, suburban, and rural settings, were selected to ensure the field test is conducted under varied conditions that may influence outcomes. Some of the participating states were chosen because they are known to have physicians experienced in caring for patients with ME/CFS.

2. Procedures for the Collection of Information

Three types of data will be collected on six forms for Phase-4 of the project: 1) data on health-related chronic absenteeism (2 forms—Attachments A and B); 2) data on technical assistance and training needs (2 forms—Attachments C and D); and 3) data on feasibility and usability of the active surveillance process and electronic data collection tool (2 forms—Attachments E and F).

To test the active surveillance process, in each of the school district sites, frontline school nurses (for a total of 20 annually), who serve children in grades kindergarten through twelve (K-12), will identify children who are chronically absent, as well as children with ME/CFS and other chronic conditions. These nurses will test a newly developed electronic data collection platform designed by NASN to report to NASN quarterly on the process, including outreach to students who may have ME/CFS and their families (Attachment A). Because the coronavirus pandemic has led to educational modifications, including virtual learning, traditional learning, or hybrid models, the methods used for identifying children will vary. Where possible, children's physical presence at school will be monitored. Where schools are implementing hybrid or virtual learning models, alternative methods will be used to track chronic absenteeism and school withdrawal, as described in the paragraph below. One school nurse from each site will gather data on children and schools from administrative and school health records (Attachment B). NASN will remove any school or school district identifiers and share the de-identified, aggregated data with CDC at the end of the school year.

Educational modifications, including virtual learning, traditional learning, or hybrid models, made necessary by the COVID-19 pandemic, have been implemented across the nation. These modifications have presented challenges to the usual method of tracking chronic absenteeism by taking *physical* attendance. The National Association of School Nurses (NASN) has been collaborating with Attendance Works to identify alternative methods of tracking chronic absenteeism and school withdrawal. Essentially, these proposed methods will identify students who miss 10% or more of virtual or traditional learning opportunities by monitoring school engagement and turning in assignments. The flexibility afforded by these alternative methods is expected to allow data collection as planned for the next three school year.

Self-administered, online surveys will be used to collect data on technical assistance and training needs from the participating school nurses (Attachment C). School data coordinators in all 50 states, who will report on training and technical assistance needs relevant to school surveillance of chronic health conditions (Attachment D) even though they are not participating in other parts of the SBAS project. These data will be analyzed for use by NASN to fine-tune the methods and data collection tool used in this project, and to develop a plan for support of a future extended national rollout of the approach, if further scale up is to be undertaken. NASN staff will facilitate three focus groups of approximately 1.5 hours each for the school nurses who report quarterly on the surveillance process, in which the nurses will be asked questions (Attachment E) related to the feasibility and usability of the active surveillance process and data collection tool. The focus group conversations will be recorded by a notetaker. The notetaker may use a recording device as a backup in case the conversations need to be transcribed. Qualitative analysis methods will be used to identify themes from the focus group discussions. NASN will know the personal, school, and school district identities of the focus group participants, but will not report these to CDC. Only authorized persons at NASN will have access to the focus group notes, and they will not be transmitted to CDC, although themes will be summarized in reports submitted to CDC. Finally, school district administrators for each of the sites will be asked to complete the School District Feedback Form (Attachment F) one time by email or alternatively, a NASN staff member will administer the questions over the phone, depending on the administrator's preference. This information will be analyzed qualitatively and reported to CDC in summary form. NASN will transmit summary reports containing aggregated, de-identified data to CDC by email.

3. Methods to Maximize Response Rates and Deal with No Response

Monitoring response rates of the active surveillance data reporting will be done through conference calls on a regular basis with each school district, offering the opportunity to share strategies for improving response rates. Response rates will be reported to CDC on a monthly basis. An incentive of \$2,000 per year will be provided to the school districts to improve response rates for data reporting, survey completion, and focus group participation. Site visits from NASN staff to the school districts will help maintain school nurse involvement and may be used if involvement wanes.

4. Tests of Procedures or Methods to be Undertaken

No pre-tests are planned before the proposed data collection.

5. Individuals Consulted on Statistical Aspects and Individuals Collecting and/or Analyzing Data

CDC Staff

All CDC project staff can be reached at the following address and phone number:

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The following staff at NASN will collect and analyze the data and can be reached at the following address and phone number:

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