

Formative Research to Support Active Surveillance of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Among Schoolchildren

Generic Information Collection Request under OMB No. 0920-1154

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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 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 for this pilot study, the respondent universe consists of frontline school nurses and school district representatives from a small number of US school districts. Six school district pilot sites in four states (1 in Massachusetts, 1 in Florida, 2 in Michigan, and 2 in Utah) will participate in this project. These districts, which are located in a variety of settings—urban, suburban, and rural-- have been chosen so that the field test is conducted under different conditions that may affect outcomes. These specific states were chosen because they are known to be states where physicians experienced in caring for patients with ME/CFS practice.

2. Procedures for the Collection of Information

Three types of data will be collected on six forms for this pilot project: 1) data on health-related chronic absenteeism and school withdrawal (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).

In each of the 6 pilot sites, one frontline school nurse will identify children who are chronically absent or who have withdrawn from school, as well as children with ME/CFS and other chronic conditions. 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. The participating school nurses will gather data on children and schools from administrative (Attachment B) and school health records and from outreach to students who may have ME/CFS and their families (Attachment A). School nurses will field test a newly developed electronic data collection tool designed by NASN to record aggregate data on their school and its students for submission to NASN on a quarterly basis. 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, are starting to be implemented across the nation as schools start in August and September 2020. These modifications have presented challenges to the usual method of tracking chronic absenteeism and school withdrawal 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 upcoming 2020-21 school year. Even with the COVID-related changes in school operations, the school nurses are expected to follow up on children to identify and document chronic health problems that are interfering with school participation and have been provided guidance on the Attendance Works website: (<https://www.attendanceworks.org/chronic-absence/addressing-chronic-absence/monitoring-attendance-in-distance-learning/>).

Self-administered, online surveys will be used to collect data on technical assistance and training needs from the six participating school nurses (Attachment C) and from a data coordinator in each of the fifty states (Attachment D). These data will be analyzed for use by NASN to fine-tune the methods and data collection tool used in pilot, and to develop a plan for support of a future national rollout of the piloted approach, if scale up is to be undertaken. NASN staff will facilitate three focus groups of approximately 1.5 hours each for the six respondent school nurses, 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 report submitted to CDC. Finally, school district administrators for each of the six pilot 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 \$2000 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

This collection of information does not involve statistical methods.

The CDC staff below will provide oversight of this pilot project and receive summary reports from NASN, the contractor collecting the data.

CDC Staff

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

Chronic Viral Disease Branch
Division of High Consequence Pathogens and Pathology
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Contractor

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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