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

April 17, 2026

Supporting Statement A

Contact:
Thomas Daymude
National Center for Emerging and Zoonotic Infectious Diseases
Centers for Disease Control and Prevention
1600 Clifton Road, NE
Atlanta, Georgia 30329
Phone: (404) 553-3567
Email: qkh7@cdc.gov

Exhibits

Attachments

Attachment Designation	Document Description
A	Electronic Platform: Quarterly Chronic Absenteeism Data Reporting Form
B	Demographic Data Collection Points
C	Pilot Site Baseline Survey
D	Webinar 1 Feedback Form
E	Question Guide for Face to Face Evaluation Interviews
F	School District Feedback Form

- **Goal of the study:** The goal of this phase (termed Phase 4) is to increase the number of states, school districts, and school nurses involved in this project compared to the prior phases of the School-Based Active Surveillance (SBAS) project. Phase-4 continues to further expand the approach for surveillance of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) by building on and improving ongoing active surveillance of chronic conditions associated with absenteeism and school withdrawal among US schoolchildren, (grades kindergarten through twelve, K-12).
- **Intended use of the resulting data:** The data from the proposed project will be used 1) to fine-tune a new electronic data collection tool and active surveillance methods for school-level surveillance of chronic conditions, including ME/CFS; 2) to enhance technical assistance and training to support this surveillance activity; 3) to identify considerations for further scaling up the approach.
- **Methods to be used to collect data:** The methods will include usability testing of a new electronic surveillance data collection tool, field testing of the surveillance tool after modification guided by usability testing results, and online surveys and focus groups of users and potential users of the tool.
- **The subpopulation to be studied:** Respondents for the proposed data collection will be from U.S. school districts in states where physicians are interested or experienced in caring for patients with ME/CFS practice. School districts have been chosen to include urban, suburban, and rural areas. The respondents will be school nurses in the selected school districts, who will test the developed data collection tool and describe their needs and experiences related to this activity; administrators in the same school districts, who will describe the impact of the activity on their district; and school data coordinators in all 50 states, who will report on training and technical assistance needs relevant to school surveillance of chronic health conditions, including ME/CFS.
- **How data will be analyzed:** The data from the surveillance tool and online surveys will be analyzed using descriptive statistics; qualitative analysis methods will be used to identify themes from focus group interviews.

A. JUSTIFICATION

1. Circumstances Making the Collection of Information Necessary

The purpose of this submission is to request OMB authorization for extending the information collection, “School-Based Active Surveillance (SBAS) of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Among Schoolchildren.” We are requesting three years to complete the information/data collection. This request is to extend the prior phases that were under OMB Control No. 0920-1396.

The request is to involve more schools and refine data collection tools and methods for determining the frequency of ME/CFS among other currently monitored chronic health conditions associated with school absenteeism and school withdrawal among US schoolchildren (grades kindergarten through twelve, K-12). Collection of information on better-known conditions that school nurses have already been tracking, in addition to ME/CFS, will allow assessment of the quality of this surveillance approach.

ME/CFS is a complex, debilitating, chronic disease that involves several body systems and is hypothesized to contribute to chronic school absenteeism. The condition is characterized by reduced ability to perform pre-illness activities that lasts for more than six months and is accompanied by profound fatigue, which is not improved by rest. Additional symptoms include post-exertional malaise, cognitive impairment, dizziness, and lightheadedness. ME/CFS affects children and adolescents as well as adults. Less is known about the condition in children and youth because less research has been focused on this age group. A few studies have estimated the number of children affected by ME/CFS, but these estimates vary, and the studies have limitations. Information on how many children are affected by ME/CFS and the impact of their condition on school attendance is needed to raise awareness of ME/CFS and to plan for children’s health care needs. Recognizing this need, in January 2017, the Chronic Fatigue Syndrome Advisory Committee (CFSAC) of the U.S. Department of Health and Human Services (HHS) recommended that HHS educate educators and school nurses on how ME/CFS affects children and adolescents.

The National Association of School Nurses (NASN) has long promoted surveillance of health conditions affecting schoolchildren; however, ME/CFS was not included among the tracked conditions until 2018, when the SBAS project began. Although efforts to standardize data collection have been underway since then, there is still no nationwide electronic platform that enables school-level data entry. As a result, information on chronic conditions, absenteeism, and health concerns remains inadequate. This proposed project aims to address these gaps by implementing an electronic platform for school-based surveillance of chronic conditions linked to absenteeism and school withdrawal, including ME/CFS. Trained school nurses at participating sites have piloted an approach, and will continue refining it to proactively identify students affected by ME/CFS and other chronic conditions, while using the new tool to report aggregate, de-identified data to NASN. The project will evaluate active surveillance methods, the data collection tool, and associated training and technical assistance to inform considerations for national rollout.**.**

2. Purpose and Use of Information Collection

The purpose of this project is to test and refine an approach for school-based active surveillance (SBAS) of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) by building on and improving ongoing active surveillance of chronic conditions associated with absenteeism and school withdrawal among US schoolchildren (grades kindergarten through twelve, K-12). Thus far, the project has four phases. The pilot began in 2018 and Phase-3 was completed in 2025. During this period, an electronic data platform for the SBAS process was developed and pilot-tested on several schools for the SBAS process. The four phase (Phase-4) will focus on refining the SBAS process established in earlier phases and evaluating it across a larger number of schools to inform a potential national rollout. The Phase-4 consists of four main components: 1) **engage and educate nursing professionals** including school nurses, 2) **maintain and enhance the electronic data platform** for the active surveillance, 3) **increase nurse workforce** to help ensure students' health and data collection for the surveillance, and 4) **assess burden of ME/CFS** using data from Phase-4 for the school-based active surveillance. Data collection will be led by school nurses in participating districts. Information collection will include but not limited to: chronic conditions (e.g. asthma, diabetes, respiratory problems) as well as less-recognized conditions like ME/CFS, Long COVID, and other infection-associated chronic conditions and illnesses (IACCs). Additional data will capture characteristics associated with these conditions, including school absenteeism, withdrawal, and activity participation.

Several states already track data on chronically absent students, and many school districts have school nurses monitoring chronic conditions such as asthma, diabetes, and seizure disorders. However, this data collection is not standardized at school level. Adding ME/CFS to the list of chronic conditions tracked by school nurses could provide a more accurate estimate of how many schoolchildren have ME/CFS while also increasing awareness and knowledge of ME/CFS among school nursing professionals. Active surveillance could help communities identify students at risk of ME/CFS earlier, monitor trends, and proactively address the health needs of students and their families.

An environmental scan conducted by NASN found that the presence of school electronic health records, dedicated school health data coordinators, and data training significantly improved active surveillance outcomes. For this project, CDC will use an electronic data collection tool to enable standardized school-level data entry by trained school nurses at the participating sites. Standardizing data collection at the school level will allow data to be aggregated more easily at state and national levels, ensuring greater consistency compared to the current system, where data points are not consistently defined, collected, or reported across states. The results of this project will inform key considerations for scaling up the approach nationwide.

Over the next three years, school district sites from at least 24 states will participate in Phase-4 of this project. These states include some that were involved in earlier phases, as well as others that expressed interest after learning about this project through NASN members and publications. Several participating states have physicians that have experienced caring for patients with ME/CFS. School districts include urban, suburban, and rural areas. At least one frontline school nurse at each site will identify children who are chronically absent or have withdrawn from school, as well as children with ME/CFS and other chronic conditions by reviewing school records, including health records. Approximately 80 frontline school nurses are expected to participate during this phase. To date, 17 states have participated in previous SBAS phases: Alaska, Arizona, Delaware, Florida, Georgia, Illinois, Iowa, Kentucky, Maine, Massachusetts, Michigan, Montana, New Jersey, New York, Utah, Washington, and Wisconsin.

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

Data on Health-related Chronic Absenteeism and School Withdrawal

School nurse respondents will collect data on health-related school withdrawal and chronic absenteeism, which has been defined as missing more than 10% of a school year, or more than three days per month. This definition has been modified slightly because of operational changes related to the coronavirus pandemic. For this surveillance project, chronic absenteeism is defined as missing 10% or more of virtual and/or traditional learning opportunities. The data from this component of the project will be used to assess whether school nurses can provide accurate, useful information to track ME/CFS and other chronic health conditions associated with absenteeism and school withdrawal in schoolchildren, and to identify considerations for implementing this approach on a larger scale in the U.S. The surveillance information to be collected includes both data from the school health record and follow-up data from outreach to students who have ME/CFS symptoms. Collecting data on additional chronic conditions—including, but not limited to, asthma, diabetes, seizures, as well as less-recognized conditions like ME/CFS, Long COVID, and other IACCIs—will support assessment of data quality within the system. As more is known about these conditions, such information will also help establish benchmarks and improve the accuracy of surveillance estimates. Without standardized data entry at the school level--the approach that the proposed project is intended to test--information on ME/CFS and other chronic conditions in schoolchildren will continue to be limited, and the patchwork approach to current school surveillance will continue to be a barrier to a coordinated system that provides national data.

School nurses will enter and submit data related to chronic absenteeism and school withdrawal surveillance in an online data collection tool (Attachment A). This form includes the following aggregate data elements from each site: number of students chronically absent or withdrawn for any reason and for health reasons, number of families contacted for students with chronic absenteeism, number of undiagnosed students with symptoms related to ME/CFS, number of students referred to a provider for possible ME/CFS, types of nursing interventions, and nursing diagnoses for students who are chronically absent. Additionally, the school nurses will note the time needed to complete parts of this data collection tool. In addition, school nurses will electronically enter the number of enrolled students in the school, school level demographics, and school nurse workforce data as listed in the "Demographic Data Collection Points" document (Attachment B). The data entered in the platform will be reported by the school nurses to NASN quarterly, and NASN will send a summary to CDC at the end of the school year. The quarters are defined as follows: Quarter 1 (beginning of school year to November 30), Quarter 2 (December 1 to February 28), and Quarter 3 (March 1 to end of school year).

Data on Technical Assistance and Training Needs

Considering the variability between states in data collection infrastructure and practices and knowledge about ME/CFS, school nurses in the school district sites will be asked to complete an online survey

(Attachment C) on technical assistance and training needs before the sites start data collection on health-related chronic absenteeism and school withdrawal. The questionnaire is designed to provide a baseline understanding of the ME/CFS knowledge and information technology status and needs of each site. This information will be used by NASN to provide continued nursing education and technical assistance for school nurses and leaders to improve critical skills related to data collection and use. Without this information, NASN would not be able to provide appropriate support for the sites throughout the surveillance process.

The state data coordinator in each of the 50 states will be asked to complete a second online survey (Attachment D). This survey gathers feedback on the status of training and technical assistance needs relevant to the ongoing school surveillance of chronic health conditions, as well as the level of ME/CFS knowledge, awareness of activities related to ME/CFS and chronic absenteeism, and availability to participate in webinars. The data will be used to identify planning considerations for further scaling up the SBAS approach nationally, should the current phase be successful and further national rollout be determined to be feasible. Without these data from all 50 states, NASN would be missing critical information needed for planning for training and technical assistance related to surveillance of chronic conditions, including ME/CFS, among U.S. schoolchildren, to support a future extended national rollout of the approach.

Data on Feasibility and Usability of the Active Surveillance Process and Data Collection Tool

Data on the feasibility and usability of the surveillance process and data entry platform will be collected through three separate focus groups (each lasting about 1.5 hours) with the school nurses from the school district sites, conducted by a NASN facilitator. The interview guides for focus group interviews (Attachment E), are semi-structured, allowing for in-depth discussions. These questions are designed to elicit information about school nurses' experience working with students and entering data into the platform, how well the surveillance data entry platform guided their practice, and suggestions for improving this tool. Information collected through these semi-structured interviews may be used to gain insight into the experience school nurses have with the active surveillance process and to inform changes that may be needed in tools and procedures. The potential changes, best practices, and lessons learned will be documented so that they may be used to inform expanded national roll-out of the current approach, if the current phase is successful and additional national scale-up is determined to be feasible.

School district administrators for each of the school district sites will be asked to complete the "School District Feedback Form" (Attachment F). This form is designed to evaluate the feasibility of this school nurse-led surveillance process from the perspective of the school district representative. The answers will be used to adjust and revise the process. The form includes inquiries about the impact on the chronic absenteeism surveillance on the school districts, any changes that are needed for tracking purposes, and general insights and feedback. Successful school-based health surveillance requires the engagement of multiple organizational levels. Without the data from this form on the impact on school districts, NASN will be missing key considerations related to scaling up the approach.

3. Use of Improved Information Technology and Burden Reduction

Only the minimum amount of de-identified aggregate data about children who are chronically absent or withdrawn will be collected. An online electronic database platform will be used to facilitate entry of surveillance data by the school nurses, and online surveys will be used to assess the feasibility of the approach and to collect information about training technical assistance needs. Provision of electronic data collection software, training, and technical assistance will help to reduce the burden of data collection on school nurse respondents involved in this project. Automated edit checks will be built into the computer software programs as an additional quality control measure. This will eliminate the need for data cleaning associated with data entry and subsequent errors and will result in a reduction in the time to transfer the data itself. The use of an online survey may reduce the burden on respondents by improving comprehension and reducing the amount of time needed to complete the assessment.

4. Efforts to Identify Duplication and Use of Similar Information

We reviewed currently funded programs and did not identify potential areas of duplication. We are not aware of any department or agency that collects or maintains data on ME/CFS and other chronic conditions and school absenteeism. School nurses have collected information through NASN on other chronic diseases contributing to school absenteeism and school withdrawal, but not in a standardized way. They have not reported the data to the federal government, and ME/CFS has not previously been among the chronic diseases tracked.

5. Impact on Small Businesses or Other Small Entities

This data collection will not involve small businesses. All school district sites are public schools.

6. Consequences of Collecting the Information Less Frequently

The frequency of data collection from school nurses in the school districts is quarterly for data on health-related chronic absenteeism and school withdrawal, and a total of three times for focus groups on the feasibility and usability of the active surveillance process and data collection tool. Collecting this information less frequently would not allow evaluation, refinement, and re-evaluation of the data collection methods and tool. All other data collection will occur only one time.

7. Special Circumstances Relating to the Guidelines of 5 CFR 1320.5

This request fully complies with the regulation 5 CFR 1320.5.

8. Comments in Response to the Federal Register Notice and Efforts to Consult Outside the Agency

A. A 60-day Federal Register Notice was published in the Federal Register on February 11, 2026, vol. 091, No. 28, pp. 6219 . CDC received two public comments related to this notice.

B. The following ME/CFS experts have been consulted regarding this project:

Lucinda Bateman M.D.
Bateman Horn Center
24 South 1100 East, Suite 205

Salt Lake City, UT 84102
Email: support@batemanhornecenter.org
Tel.: 801-359-7400

Nathan Holladay MD, PhD865 E 4800 S Ste 160
Murray, UT 84107
Email: nbholladay@gmail
Tel.: 385-251-6028

Ruth Walkotten DO, MA
Walkotten Wellness Center
2947 Russell Rd.
Muskegon, MI 49445
Tel.: (231) 733-1989

Edward Conley MD
G-3494 Beecher Rd Suite A
Flint, MI 48532
Email: Conley@cfids.com
Tel.: 810.230.8677

No major unresolved problems were identified.

9. Explanation of Any Payment or Gift to Respondents

No incentive or gift will be given to respondents (school nurses).

10. Protection of the Privacy and Confidentiality of Information Provided by Respondents

The district school nurses will collect aggregated, de-identified data on the students' health and reasons for absenteeism/school withdrawal and report the data to NASN. NASN will collect the school nurse respondent's personal identifiers (first name, last name, school district) to allow for NASN's potential future analysis by school district. Before sending the data to CDC, NASN will remove the personal and school district identifiers. NASN will be conducting focus group interviews with the district school nurses and will know the identity of the nurses who participate, and which comments/responses are associated with a particular school nurse. However, data from focus group interviews will be reported to CDC without identifiers.

Focus group interviews will be conducted three times during the data collection, to gather information to guide local implementation of the project. The focus group conversations will be recorded by a notetaker. The notetaker may use a recording device as a backup for transcription purposes only. When the focus groups have been completed, the notes/transcriptions will be stored at NASN. The notes (or transcription) will be qualitatively analyzed for themes without the use of qualitative analysis software. Only authorized persons will have access to the notes, and they will not be transmitted to CDC.

School district administrators for each of the sites will be asked to complete the "School District Feedback Form" (Attachment F). NASN will be aware of the identity of the respondents. However, their responses will be shared with CDC only in aggregate form from all districts; no personally identifying information will be reported.

NASN will transmit summaries of data from this project without identifiers to the CDC team by email.

A Privacy Impact Assessment is included as part of this submission (Attachment G).

11. Institutional Review Board (IRB) and Justification for Sensitive Questions

Institutional Review Board (IRB)

NASN received IRB exemption determination for the protocol on January 13, 2022, through Advarra IRB (Attachment H).

Justification for Sensitive Questions

No sensitive questions are to be included.

12. Estimates of Annualized Burden Hours and Costs

A. Estimated Annualized Burden Hours

The estimate of annualized burden hours for this sub collection is 951 hours; details are provided in exhibit 12.A. Twenty frontline school nurses will assemble and enter data for a quarterly report regarding the active surveillance process (Attachment A) and participate in three focus groups to elicit feedback about the surveillance process (Attachment E). Assembling and entering data is estimated to take five hours each quarter; the three focus groups is expected to last for 1.5 hours each. Twenty lead nurses in the sites will enter demographic form data (Attachment B) once and complete one online survey (Attachment C) annually. The demographic form is estimated to take six hours to complete and the online survey is estimated to take 10 minutes. Eight school district representatives are expected to complete the School District Feedback Form (Attachment F) once, which is estimated to take 15 minutes. Fifty state data coordinators are expected to complete a one-time webinar feedback survey (Attachment D), which is estimated to take 15 minutes.

Exhibit 12.A Estimate of Annualized Burden Hours

Type of Respondent	**Form Name**	**No. of Respondents**	**No. Responses per Respondent**	**Avg. Burden per response (in hrs.)**	**Total Burden (in hrs.)**
Frontline School Nurses	Electronic Platform Quarterly Chronic Absenteeism Data Reporting Form	20	4	9	720
Frontline	Demographic Data	20	1	6	120

School Nurses	Collection Points				
Frontline School Nurses	Site Baseline Survey	20	1	0.2	4
Frontline School Nurses	Question Guide for Face-to-Face Evaluation Interviews	20	3	1.5	90
State Data Coordinators	Webinar 1 Feedback Form	50	1	0.3	15
School District Representatives	School District Feedback Form	8	1	0.3	2
TOTAL					**951**

B. Estimated Annualized Burden Costs

The annualized cost to respondents for the burden hours is estimated to be $35,505.89; details are provided in Exhibit 12.B.

The estimates of hourly wages were obtained from the Department of labor (Bureau of Labor Statistics Wage Data (https://www.bls.gov/ooh/healthcare/registered-nurses.htm). The median hourly wage for Registered Nurses is $37.31. Both Frontline School Nurses and State Data Coordinators correspond with this profile.

U.S. Bureau of Labor Statistics website states that Education Administrators for elementary and secondary schools have an annual median wage of $102,650. (https://www.bls.gov/oes/current/oes119032.htm#(4)An hourly wage is not provided on the website. Assuming a 40-hour work week, 52 weeks/year, the mean hourly wage is estimated as $49.35. School District Representatives correspond with this profile.

Exhibit 12.B Estimate of Annualized Burden Costs

Type of Respondent	**Form Name**	**Total Burden Hours**	**Hourly Wage Rate Dept of Labor**	**Total Respondent Costs**
Frontline School Nurses	Electronic Platform Quarterly Chronic Absenteeism Data Reporting Form	720	$37.31	$26,863.20
Frontline School Nurses	Demographic Data Collection Points	120	$37.31	$4,477.20
Frontline School Nurses	Site Baseline Survey	4	$37.31	$149.24
Frontline School Nurses	Question Guide for Face-to-Face Evaluation Interviews	90	$37.31	$3,357.90
State Data Coordinators	Webinar 1 Feedback Form	15	$37.31	$559.65

School District Representatives	School District Feedback Form	2	$49.35	$98.70
TOTAL				**$35,505.89**

13. Estimates of Other Total Annual Cost Burden to Respondents or Record Keepers

There are no costs to respondents other than their time to participate.

14. Annualized Cost to the Government

The annualized cost of this SBAS project is estimated to be $348,384, which is the cost of the contract with NASN.

Exhibit 14.A Estimate of Annualized Cost to Government per Activity

Expense Type	**Expense Explanation**	**Estimated Annualized Cost**
Contract	Contract funds to NASN	$348,384.01
TOTAL		**$348,384.01**

This phase of the project is anticipated to be completed by 2029. The estimated annualized contract cost to the federal government is $350K, with a total of $1.1 million over the three-year period of the SBAS project. These costs include activities related to information collection, system design and development, form production, travel, meetings, and data deliverables.

15. Explanation for Program Changes or Adjustments

This request seeks approval for a revision to the information collection under OMB Control No. 0920-1396 to support the expansion of Phase 4 of the SBAS project. The revision includes updates to Attachment A, adding new questions to the quarterly report to better capture elements of the school-based active surveillance process.

16. Plans for Tabulation and Publication and Project Time Schedule

All data collection will be completed by 2029. The following is a brief overview of the timeline for the proposed project.

Exhibit 16.A Project Time Schedule

Activity	**Time Schedule**
Data/information collection and reporting	0–16 months after OMB approval
Data cleaning and analysis	10–12 months after OMB approval
Preparation of final report(s) / manuscript	12-24 months after OMB approval
Manuscript publication	24-36 months after OMB approval

17. Reason(s) Display of OMB Expiration Date is Inappropriate

The display of the OMB Expiration Date is not inappropriate. The expiration date will not be displayed on the online or hard-copied forms, but it will be provided upon request.

18. Exceptions to Certification for Paperwork Reduction Act Submissions

There are no exceptions to the certification.

19. References

1. IOM (Institute of Medicine). 2015. Beyond myalgic encephalomyelitis / chronic fatigue syndrome: Redefining an illness. Washington, DC: The National Academies Press. Bauer L, Liu P, Schanzenback DW, and Shambaugh J.Reducing Chronic Absenteeism under the Every Student Succeeds Act. Brookings Institute. [Online] April 2018. [Cited: Feb 26, 2020.] https://www.brookings.edu/wp-content/uploads/2018/04/reducing_chronic_absenteeism_under_the_ every_student_succeeds_act2.pdf.

2. Jason L, Torres-Harding S, Njok M. The face of CFS in the US. CFIDS Chronicle 2006, 16-21. https://www.researchgate.net/publication/236995875_The_Face_of_CFS_in_the_US.

3. Jason L, Richman JA, Rademaker AW, et al. A community-based study of chronic fatigue syndrome. Archives of Internal Medicine 1999, 159(18):2129-2137.

4. Chalder T, Goodman R, Wessely S, Hotopf M, Meltzer H. Epidemiology of chronic fatigue syndrome and self-reported myalgic encephalomyelitis in 5-15 year olds: cross sectional study. BMJ 2003, 327:654–5.

5. Bell K, Cookfair D, Bell DS, Reese P, Cooper L. Risk factors associated with chronic fatigue syndrome in a cluster of pediatric cases. Reviews of Infectious Diseases 1991;13(Suppl 1):S32-8.

6. Geraghty KJ, Adeniji C. The importance of accurate diagnosis of ME/CFS in children and adolescents: A commentary. Front. Pediatr. 2019, 6:435.

7. Chronic Fatigue Syndrome Advisory Committee. Transcript for January 13, 2017 CFSAC meeting. [Online] Jan 13, 2017. [Cited: March 3, 2020.] https://wayback.archive-it.org/org-745/20181018061119/https://www.hhs.gov/sites/default/files/january-13-2017-transcript.pdf.

8. National Association of School Nurses. Environmental Scan: Current School-Based Active Surveillance Efforts. 2018.