

Consent Form and Authorization for School Nurses

Sponsor / Study Title: Centers for Disease Control and Prevention / School Nurse Led Combating Chronic Absenteeism Process

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KEY INFORMATION

This purpose of this study is to collect information about student chronic absenteeism related to health reasons, activities carried out by schools, especially school nurses, for health-related chronic absenteeism, and the outcomes of those activities. Students who are chronically absent from school due to health concerns is a growing concern across the country.

- Common health conditions include chronic conditions (i.e. asthma, diabetes, depression), social determinants of health, and undiagnosed conditions whose symptoms make it difficult to attend school ([Healthy Schools Campaign, 2016](#)).
- It has been thought that myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) may account for a high proportion of students with overwhelming fatigue and dizziness that lead to students being chronically absent or even school withdrawal. Post-acute sequelae of SARS-CoV-2 infection (the clinical term for what has been known as Long COVID) and ME/CFS show a significant overlap in symptoms.
- School nurses (SNs) are at the frontlines of student health. They already use their nursing expertise and proximity to vulnerable students to proactively identify and document student health concerns and assist families in getting the care that they need.
- The purpose of this project is to implement a process to guide school nurses in the identification and management of students who are chronically absent for health concerns, with particular emphasis on students who may be at risk for ME/CFS.
- The process includes school nurses obtaining a list of students who are chronically absent or officially withdrawn from school due to health reasons. School nurses will then reach out to these students and their families using some guided questions to identify the health concerns and determine if the students may be at risk for ME/CFS. The school nurse will use the information to identify ways to assist in addressing the health issues so that student can return to school. De-identified, combined data will then be submitted to a national data platform.

- By implementing the process in your district, you as the school nurse will have an opportunity to address the needs of students who are chronically absent so that the students can get the assistance they need to return to school.
- Implementing the process may necessitate changing how you track students for health reasons.

Please read this form carefully. Take your time to ask as many questions about the project as you would like. If you decide to take part in this project, you must sign your name at the end of this form and date it.

BACKGROUND AND PURPOSE

You were selected to participate in this study because you were 1) selected by your district who has agreed to be part of this effort, 2) your main assignment in school nursing is with the general student population, and 3) you work in a school that has students who are chronically absent or withdrawn from school due to health concerns. The purpose of this research study is to:

- Implement a school nurse led chronic absences review process to identify students who are chronically absent from school due to health concerns;
- Evaluate the usability of a national data platform to report de-identified chronic absence data and subsequent school nurse care coordination activities; and
- Analyze preliminary data for any effects of implementing the school nurse led chronic absences review and care coordination activities on school attendance and chronic condition (including ME/CFS) identification.

About 24 districts will be enrolled in this study over the course of three years. From those districts up to 50 school nurses may be asked to participate.

WHAT WILL HAPPEN DURING THE STUDY?

Your participation in this study will last at least one year. The time it takes to participate in this project will depend on the number of students who are chronically absent and the complexity of their situation. Submission of data and reporting worksheets will take approximately 20-30 minutes to complete.

Throughout the study the following procedures will be followed:

- Before participation of the districts can begin, the participants must sign and date the informed consent.
- Identify students who are chronically absent
- Identify students who are chronically absent for health reason (or suspected to be health reasons).
- Outreach to students and their families
- Identify reason(s) for absences/withdrawal
- Initiate care coordination and continue nursing process (and work with other school staff as appropriate)

- Develop nursing plan for each chronically absent student
- Evaluate care plan (at time interval determined in care plan)
- Submit data to national platform
- Evaluate overall process
 - At the end of each year the district and research team will discuss and decide together if the data collection and school nurse care coordination process will be expanded to include additional school nurses (or schools) in the district
- Every other month during the school year you will participate in a phone call with school nurses from other districts who are implementing the process as well.
 - Each call will be less than an hour and be used to answer questions or clarify the process.

EXPECTATIONS

Participation in this project includes assisting your district in completing an assessment of what you and your district currently do related to chronic absenteeism. You will then follow the data collection and school nurse care coordination process for the implementation time period (August 2023 – October 2024). At the end of each school year (as well as a mid-program check) you will provide written feedback on your experience, as well as participate in focus groups with other school districts participating in the process. In addition, you will share combined, de-identified data on the process followed.

To evaluate the usability of the data platform, you will also submit combined, de-identified data related to the number of students with chronic conditions, chronic absenteeism, school health workforce, and health office visits to pilot the national data platform.

RISKS

No other foreseeable risks of discomforts to the participants are expected. No personally identified health information will be collected for the study.

ALTERNATIVES TO PARTICIPATION

This study is for research purposes only. The only alternative is to not participate in this study.

BENEFITS

The direct benefit for you participating in this project is increased knowledge regarding how to track and address the needs of students who are chronically absent or have withdrawn from school due to health reasons. In addition, the experience may help other school nurses because the information gained from this evaluation will be utilized in tweaking the process for a national guidance manual other districts may follow. Any new important information that is discovered during the implementation and analysis will be shared with your district.

COMPENSATION FOR PARTICIPATION

The district will be paid \$2000 each year the district participates in piloting the data collection and care coordination process and submitting data into the national platform. How this money will be used will be decided internally by the district. In addition, costs for travel and lodging for school nurses to participate in face-to-face focus groups will be covered by NASN at standard government reimbursement rates. Travel expenses will be paid for upfront as much as possible; reimbursements for any costs not able to be paid upfront will be provided within 30 days of receipts. If you have any questions regarding your compensation for participation, please contact your district.

CONFIDENTIALITY

All data will be provided in de-identified, combined form. Information provided in the reporting worksheets and focus groups regarding the chronic absences review and care coordination process will remain confidential and will only be reported as group data with no identifying information. The information will be kept on a password protected, secure computer server. The information collected from the face-to-face meetings will be kept in a locked storage cabinet and only those directly involved with the research will have access to them. After the research is completed, the notes will be destroyed.

The de-identified, data submitted to the national data platform will not be reported out except in combined form with other district participants. However, if the number is smaller than 7 the number will not be reported. Information on the national data platform includes you and your school's names. The Investigator, the sponsor or persons working on behalf of the sponsor, and under certain circumstances, the Department of Health and Human Services and the Institutional Review Board (IRB) will be able to inspect and copy confidential study-related records which identify you by name and/or email. This means that absolute confidentiality cannot be guaranteed. This information will only be seen by the research team and will not be used in any reports or made public. If your district decides to be listed as a demonstration sites in the guidance manual, you will have the option to decide if you would like your name listed as a participating nurse or if you would prefer to stay anonymous.

WHOM TO CONTACT ABOUT THIS STUDY

During the study, if you have questions, concerns or complaints about the study, please contact the Investigator at the telephone number listed on the first page of this consent document.

An institutional review board (IRB) is an independent committee established to help protect the rights of research subjects. If you have any questions about your rights and/or concerns or complaints regarding this evaluation study, contact:

- By mail:
Study Subject Adviser
Advarra IRB
6940 Columbia Gateway Drive, Suite 110
Columbia, MD 21046
- or call **toll free:** 877-992-4724
- or by **email:** adviser@advarra.com

Please reference the following number when contacting the Study Subject Adviser:
Pro00032437

VOLUNTARY PARTICIPATION / WITHDRAWAL

You and your district’s decision to participate in this study and project is voluntary. You may choose to not participate or you may withdraw from the study for any reason without penalty, loss of benefits, or to your employment in the district or any future involvement with NASN. However, please note that any information collected up to the point of your withdrawal cannot be removed from the study.

NASN or the sponsor, can stop you or your district’s participation at any time without your consent for the following reasons:

- If you or your district fails to follow directions for participating in the study;
- If the study is canceled; or
- For administrative reasons.

FUNDING

This project was funded through contract by the Centers for Disease Control and Prevention to the National Association of School Nurses (Contract #75D30121C12121).

CONSENT

I have read and understand the information in this informed consent document. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I voluntarily agree to have the district participate in this study and project until I decide otherwise. I do not give up any of my district’s legal rights by signing and dating this consent document. I will receive a copy of this signed and dated consent document.

School Nurse’s Printed Name

School Nurse’s Signature

Date

Printed Name of NASN representative

Signature of NASN representative

Date