

2023

Enhancing School Health through Data Collaborations

A Guide for School Health Leaders and Decision-Makers



The Center for
**SCHOOL
HEALTH**
Innovation & Quality



Enhancing School Health through Data Collaborations: A Guide for School Health Leaders and Decision-Makers

The Center for School Health Innovation & Quality

December 2023

Suggested Citation: Lee, R. Y. & Maughan, E. D. (2023). *Enhancing School Health through Data Collaborations: A Guide for School Health Leaders and Decision-Makers*. The Center for School Health Innovation & Quality.

© 2023 The Center for School Health Innovation & Quality. May be reproduced and distributed with attribution for educational and noncommercial purposes only.

Contents

Acknowledgments.....	4
How to Use This Guide.....	5
Introduction	6
Current State of School Health Data-Sharing	16
Spectrum of Data-Sharing Possibilities	20
Decision-Making Process and Key Questions to Ask before Deciding to Participate	25
Commonalities of Successful Data-Sharing Partnerships.....	30
Common Barriers and Strategies to Sharing School Health Data	33
Moving Forward.....	37
Conclusion	38
Additional Resources	39
References.....	40
Appendix A. Understanding the Legality of Sharing School Health Data: Is It Legal to Share School Health Data?	41
Appendix B. Key Components of Successful Data-Sharing Agreements.....	46
Appendix C. Common Barriers and Strategies in School Health Data-Sharing	47
Appendix D. School Health Data-Sharing Exemplars.....	54

Acknowledgments

Funded by

Opportunity Labs Foundation Inc.

Authors

Rachel Y. Lee, PHD, RN

Postdoctoral Research Scientist, Columbia University

Erin D. Maughan, PHD, MS, RN, PHNA-BC, FAAN, FNASN

Executive Director, The Center for School Health Innovation & Quality

Associate Professor, George Mason University

Advisory Committee Members

Denise Chrysler, JD

Senior Advisor, Mid-States Regional Office

The Network for Public Health Law

Betty Sue Hinkson, MSN, RN-BC, NCSN

Utah School Nurse Consultant

Emily Kraus, MPH, PHD

Kraushold Consulting

David Lee, MPH, MBA

Senior Director, Product Development and Data Systems

Public Health Accreditation Board

Additional Reviewers

Andrew Buher

Founder and Managing Director

Opportunity Labs

Matthew Hickling, CPNP, MSN, RN

Medical Director

Lansingburgh Central School District

Alex Mays, MHS

Program Lead, Student Behavioral Health, Thriving Schools and Communities

Kaiser Permanente

Amanda Martinez, MPH, MSN, RN

NACDD Consultant

Mario Ramirez, MD

Managing Director

Opportunity Labs

Chanthini Thomas, BSN, RN

School Nurse

Katy Independent School District

How to Use This Guide

Purpose and Scope

This guide aims to provide school health services leaders with guidance to help in their data-sharing partnerships, ensuring they can do so with confidence and clarity. It aims to empower stakeholders to harness the full potential of school health data-sharing collaborations with non-school partners to improve the health and well-being of students.

Within this guide, we:

- ▶ Present an overview of the current state of school health data-sharing.
- ▶ Outline a range of potential data-sharing agreements and systems.
- ▶ Propose a decision-making framework along with the key considerations at each step.
- ▶ Showcase various successful data-sharing collaborations as practical examples and sources of inspiration.
- ▶ Discuss common challenges and potential strategies related to school health data-sharing.

Who Should Use This Guide?

This guide is intended primarily for school health services leaders and decision-makers, particularly school nurses, school health services managers, district¹ administrators, and other relevant stakeholders who engage with student health data.

What This Document is Not

While this guide offers an overview of the legal landscape around sharing school health data, it should not be used as legal advice. This guide should be used as a resource for gaining understanding and facilitating discussions, but not as a substitute for legal counsel.

“ This guide aims to provide school health services leaders with guidance to help in their data-sharing partnerships, ensuring they can do so with confidence and clarity.

¹ In this document, the term "district" is used to refer to the local education agency unit.

Introduction

What is School Health?

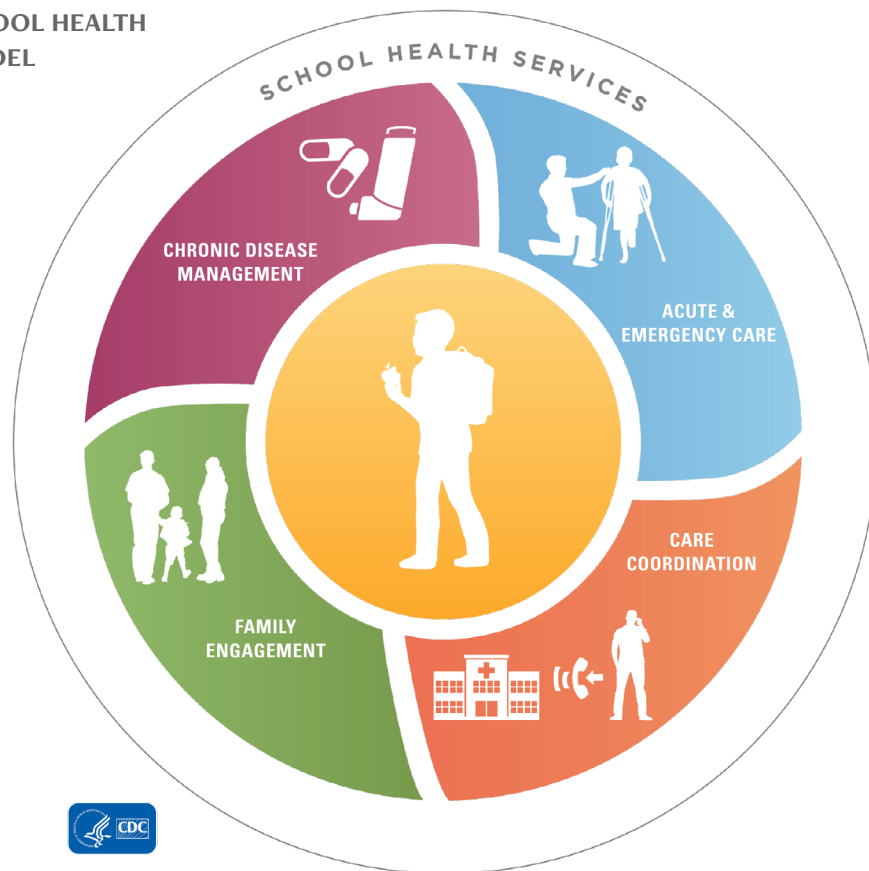
"School health" refers to a broad range of practices and services aimed at fostering students' health and well-being. The Centers for Disease Control and Prevention (CDC)'s [Whole School, Whole Community, Whole Child \(WSCC\) model](#) illustrates this holistic approach, considering both community and school factors impacting students' success and well-being.

This guide narrows its focus on the "school health services" element of comprehensive school health, most commonly overseen by school nurses (**Figure 1**). School health services manage students' chronic conditions, provide acute and emergency care, and coordinate with families, healthcare providers, and educators to ensure that students thrive inside and outside the classroom.²

While this guide focuses on health services, the term "school health data" encompasses a broader scope including information such as physical activities, behavioral patterns, and attendance. These types of data are not always collected by school nurses, but they provide important context for students' overall health and well-being. These various types of data underscore the unique value of school health data.

FIGURE 1. SCHOOL HEALTH SERVICES MODEL

Image Credit: [CDC](#)










² www.cdc.gov/healthyschools/schoolhealthservices.htm

What are School Health Data?

Currently, there is no standardized definition for the term "school health data." In the context of this guide, "school health data" is defined as a broad spectrum of information related to the health and well-being of students within a school or school district. We are primarily focusing on data collected and maintained by school nurses. This broad category includes, but is not limited to, various data points such as:

School Health Data



School Health Data Category		Brief Description / Examples
	Student Health Records	Health office visits, immunization records, medical histories, Medicaid data/healthcare coverage data, chronic conditions, referrals, medications, along with other acute and chronic health-related information commonly documented and/or maintained by school nurses or healthcare professionals.
	Physical Health Measures	Height, weight, vision, hearing, and other routine health screening measures.
	Mental and Emotional Health	Students' mental and emotional health information, including any diagnoses, counseling records, and assessment results.
	Health Behavior	Information about behaviors that can impact health, such as nutrition, physical activity, substance use, sexual behavior, and sleep habits.
	Accident and Injury Reports	Incidents or injuries that occur on school grounds or during school-related activities.
	Health Education and Services Utilization	Engagement and use of health education programs and health-related services offered within the school.
	Attendance and Academic Performance	Metrics on student attendance and academic performance which can also serve as indirect indicators of student health.

School Health is the Intersection of Education, Healthcare, and Public Health

School health is essentially a multi-sector concept. School health is at a unique intersection of education, healthcare, and public health sectors (Figure 2). It is essential to delve into how each sector's perspective contributes to the concept of school health to understand the complex nature of school health.

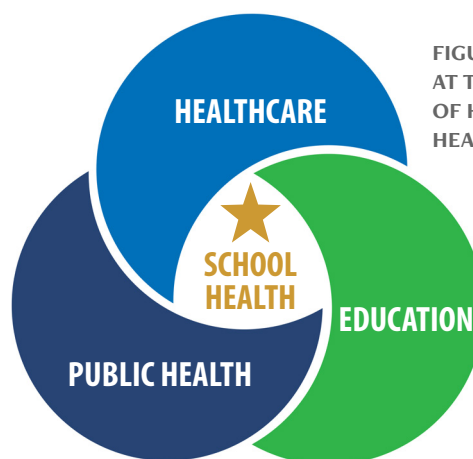


FIGURE 2. SCHOOL HEALTH AT THE INTERSECTION OF HEALTHCARE, PUBLIC HEALTH, AND EDUCATION

EDUCATION SECTOR: In schools, the health and well-being of students have a direct impact on their academic performance, and in turn, academic achievements are associated with health outcomes. The [Every Student Succeeds Act \(ESSA\)](#), the nation's K–12 education law, is an example of this interconnectedness. For example, ESSA highlights the critical importance of viewing student performance through a holistic lens by requiring schools to report their rates of chronic absenteeism (missing more than three days a month³). Chronic absenteeism serves not only as an indicator of academic engagement but also as a warning sign of potential health concerns. The issue of chronic absenteeism highlights the necessity of school health services in understanding and addressing the root causes, especially focusing on students with health conditions.

HEALTHCARE SECTOR: Schools serve as pivotal points for early detection, prevention, and management of various health issues of children and adolescents. School health services function as an integral extension of the healthcare system, orchestrating a spectrum of care, such as conducting routine health screenings, providing care for acute and chronic conditions, coordinating vaccinations, and addressing developmental or behavioral concerns.

PUBLIC HEALTH SECTOR: From a public health standpoint, schools provide a snapshot of community health trends, offering insights into various health metrics and potential outbreaks. Public health initiatives frequently target schools to implement wide-reaching programs, such as incorporating substance use prevention in school curricula or launching awareness campaigns about emerging health threats.

³ www.attendanceworks.org/chronic-absence/the-problem/



Legal Frameworks around School Health Data

Given the interconnected nature of school health, a clear understanding of the legal frameworks governing the management of student health data is important. Since school health data inherently pertain to "health," yet are collected and maintained within educational contexts, there are often confusion and ambiguity regarding their governance.

The [Family Educational Rights Privacy Act \(FERPA\)](#) is a federal law that regulates the confidentiality and exchange of information found in student education records within educational institutions.⁴ FERPA is applicable to all primary and secondary institutions that receive funds from the U.S. Department of Education. The [Health Insurance Portability and Accountability Act \(HIPAA\)](#) oversees data privacy and sharing in the healthcare sector. **However, in the context of school health data, FERPA takes precedence because HIPAA explicitly excludes education records protected under FERPA.**⁵

FERPA governs all "education records" of students, and this umbrella encompasses student health information. Whether it's health screening results, records of school nurse visits,

chronic conditions, or immunization data maintained by schools, FERPA treats them the same way it does academic data like grades or assessment scores. Under FERPA, school health data can be shared in three ways:⁶ 1) de-identified data, which removes student-specific identifiers, 2) data with personally identifiable information (PII) with parental or student consent, and 3) data disclosed under specific FERPA exceptions, such as the school official exception, studies exception, directory information, audit or evaluation, and health and safety exception.

In addition to FERPA, it is critical to consider state-specific regulations. Each state may have its own set of rules and guidelines for data-sharing in schools. State regulations frequently supplement, and in some cases supersede, federal laws and can have a significant impact on how school districts handle data-sharing. As a result, in addition to federal guidelines, school districts should consult with their state laws to ensure compliance with all applicable data privacy and sharing laws.

See [Appendix A: Understanding the Legality of School Health Data-Sharing](#) for more details and resources.

⁴ [20 U.S.C. § 1232g\(a\)\(4\); 34 C.F.R. § 99.3](#)

⁵ [45 C.F.R. § 164.103](#)

⁶ [34 C.F.R. § 99.3](#)






Why is Cross-Sector Data-Sharing Important?

Schools may wonder if navigating the complexities of school health data-sharing collaborations is worthwhile. There is an increasing acknowledgment of [social determinants](#)⁷ in shaping one's health outcomes across the lifespan, with elements like education, socio-economic status, and neighborhood conditions recognized as critical influencers of child health. In this context, schools, where these factors intersect, play a crucial role in child health.

The benefits and potential of cross-sector data-sharing became notably evident during the COVID-19 pandemic. The challenges presented by the pandemic highlighted the urgent need for coordinated efforts across education, healthcare, and public health sectors. The pandemic demonstrated that data-sharing can significantly enhance the efficiency, coordination, and overall quality of care, not just for individual students but for broader populations as well.⁸

What do Schools Gain from Data-Sharing Partnerships?

Data-sharing partnerships provide a variety of benefits, including the following:

 ENHANCED STUDENT HEALTH OUTCOMES <ul style="list-style-type: none">• Comprehensive Health Insights• Tailored Health Programs	 IMPROVED STUDENT ACADEMIC SUCCESS <ul style="list-style-type: none">• Data-Informed Strategies• Reduced Absenteeism	 STRENGTHENED COMMUNITY ENGAGEMENT & PARTNERSHIPS <ul style="list-style-type: none">• Collaborative Solutions• Enhanced Trust	 ENHANCED DECISION-MAKING <ul style="list-style-type: none">• Data-Driven Strategies• Predictive Analytics• More Efficient Use of Resources and Funds	 INCREASED FUNDING OPPORTUNITIES <ul style="list-style-type: none">• Grant Eligibility• Demonstrated Need
---	--	---	--	---

⁷ www.cdc.gov/about/sdoh/

⁸ Hyder et al. (2021). COVID-19 Surveillance for Local Decision Making: An Academic, School District, and Public Health Collaboration. *Public Health Reports*, 136(4), 403–412.

1 Enhanced Student Health Outcomes

COMPREHENSIVE HEALTH INSIGHTS:

By exchanging data with external partners, schools can gain a more comprehensive understanding of the health trends, needs, and issues affecting their students. The insights gained enable the early identification and address of health concerns, contributing to better health outcomes.

TAILORED HEALTH PROGRAMS:

Schools can develop and implement health programs and interventions specifically tailored to the unique needs of their students, based on insights gained from shared data.

2 Improved Student Academic Success

DATA-INFORMED STRATEGIES: With data shedding light on the direct link between health and academic success, schools are better equipped to craft educational strategies. Schools can promote student academic success by addressing specific health-related barriers through these strategies.

REDUCED ABSENTEEISM: Addressing student health issues promptly and effectively reduces absenteeism, enabling more consistent learning experiences and academic engagement.

3 Strengthened Community Engagement and Partnerships

COLLABORATIVE SOLUTIONS: Schools, healthcare providers, and community organizations can collaboratively devise solutions to address the broader determinants of health and education.

ENHANCED TRUST: Regular and transparent communication about data-sharing initiatives can build trust between schools and the community, building stronger relationships and collaboration.

4 Enhanced Decision-Making

DATA-DRIVEN STRATEGIES: Integrating diverse data sources provides a richer, more nuanced understanding of student needs, enabling more precise and effective decision-making.

PREDICTIVE ANALYTICS: Schools may utilize exchanged data for predictive analytics to anticipate issues and implement preemptive strategies, optimizing care quality and impact and resource allocation.

MORE EFFICIENT USE OF RESOURCES AND FUNDS: Using the knowledge gained from synthesizing and analyzing data, schools can pinpoint areas of highest need and allocate resources and funds more strategically. This targeted approach also plays a pivotal role in decreasing health disparities, ensuring all students have equitable access to essential health resources and services.

5 Increased Funding Opportunities

GRANT ELIGIBILITY: Enhanced data-sharing can position schools to meet the eligibility criteria for various grants, opening doors to additional funding opportunities.

DEMONSTRATED NEED: A robust data-sharing framework allows schools to demonstrate the needs and impact of their programs, strengthening their case for funding and support.

Reciprocity, Collaboration, and the Transformation of Data to Actionable Wisdom

Ideal data-sharing collaborations should not be viewed as one-sided endeavors. Instead, they should be recognized as a reciprocal process that bolsters collaboration, forming an interconnected network that benefits all participants. In line with the Data-Information-Knowledge-Wisdom (DIKW) model,⁹ shared data hold transformative potential that, when properly harnessed, can lead to actionable wisdom that profoundly impacts student health and well-being (Figure 3).

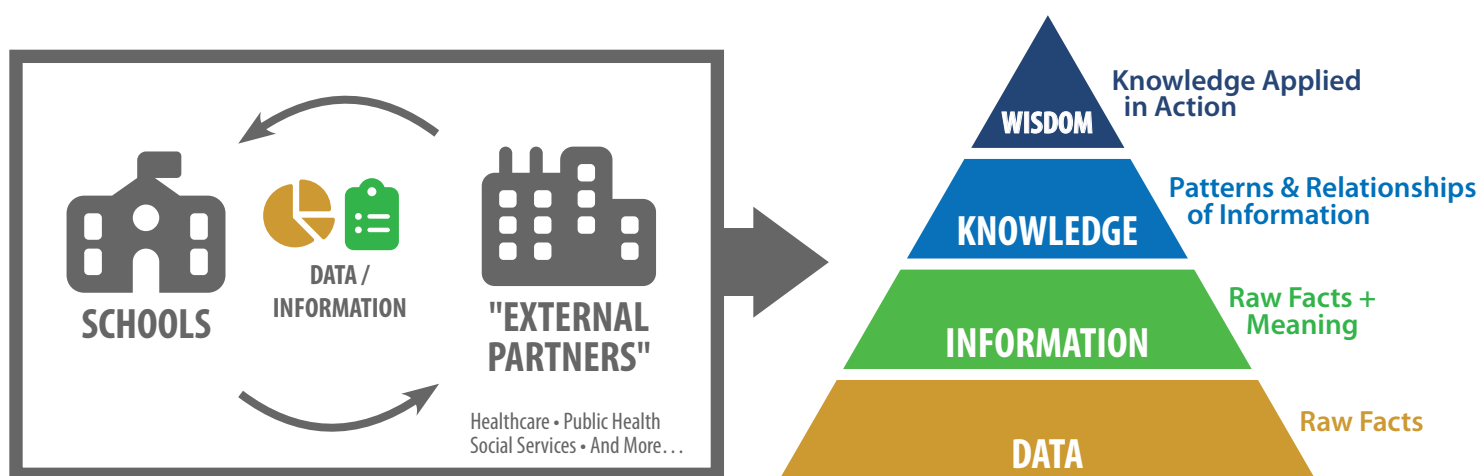


FIGURE 3. RECIPROCAL EXCHANGE OF DATA BETWEEN SCHOOLS AND EXTERNAL PARTNERS AND DATA-INFORMATION-KNOWLEDGE-WISDOM (DIKW)

Data consist of raw, context-less facts and elements.

Information is extracted when raw data are processed, organized, and interpreted to produce meaning. In the context of collaborative efforts to share school health data, "data" refer to the unprocessed information that the schools and their partners bring to the table, while "information" refers to the enhanced understanding they obtain from data as a group.

Knowledge emerges from interpreting, integrating, and understanding information.

Wisdom results from applying knowledge to actionable strategies.

⁹ Ackoff, R. L. (1989). From Data to Wisdom. *Journal of Applied Systems Analysis*, 16(1), 3–9.



To illustrate the above, let's explore a data-sharing collaboration between a school district and the local health department aimed at enhancing adolescent sexual health:

DATA

School nurses log records of student visits seeking advice or treatment related to sexual health concerns. They note a rise in general inquiries about STIs and requests for resources or counseling. At the same time, community health clinics also report an increase in STI tests among adolescents.

INFORMATION

When combined, the data suggest not only a potential increase in STIs but also heightened awareness or concern among students. While school nurses are noting more inquiries, the community health clinics are seeing a parallel rise in testing.

KNOWLEDGE

Delving deeper, shared insights reveal that specific schools or neighborhoods are more affected. Additionally, student feedback to school nurses indicates a lack of understanding about STIs or misinformation spreading in those areas. Community health data also identify a lack of youth-friendly resources or accessible clinics.

WISDOM

Collaboratively, schools and community partners can design a targeted intervention. Schools could introduce STI awareness campaigns, led by school nurses, focusing on debunking myths and providing accurate information. Community partners, informed by the data, could establish pop-up clinics in identified neighborhoods or schools, ensuring easier access to testing and treatment.

In essence, the transformative power of data-sharing, as exemplified above, can usher in substantial enhancements in student health and overall well-being. A collaborative data-sharing arrangement can allow school districts to both contribute and receive critical insights, benefiting their students and the wider community.

Case Study

Shared Data, Shared Solutions: A Community's Response to a Surge in Teen Pregnancy

In a mid-sized suburban town, the local high school's nurse began noticing an alarming uptick in pregnancies among very young teens, many of whom were less than 14 years old. When she communicated her concerns with the local community clinic, they also observed the surprising age of the pregnant teens and that many of the babies' fathers were over 20.

Yet, the issue didn't stop there. Despite the availability of a supportive program that allowed young mothers to continue their education while caring for their babies, many of these teens were choosing to drop out of school.

THE COLLABORATION: A COMMUNITY'S RESPONSE

Determined to understand and address the root of the issue, the school nurse and the community clinic spearheaded a collaborative initiative. They gathered a diverse group of stakeholders: educators, parents, youth leaders, local law enforcement, and the health department, which provided access to vital records.

Several insights emerged:

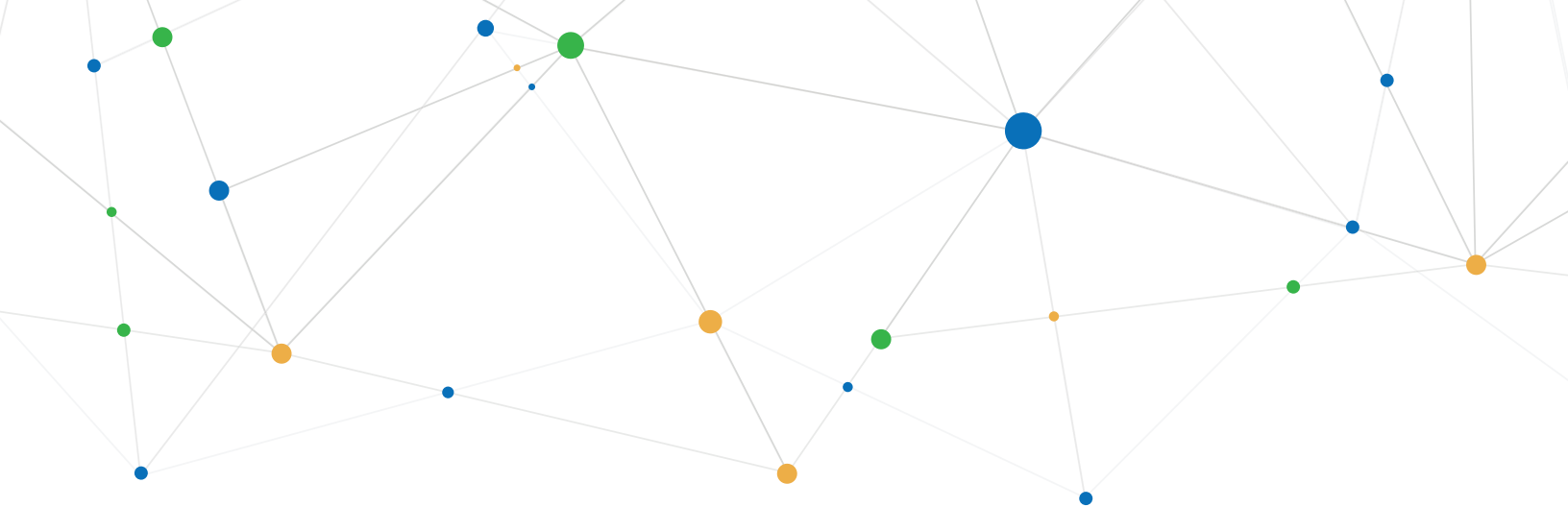
- **Cultural Context:** Many of these young girls were first-generation Americans. Their parents, while worried about their daughters, wanted them to integrate and believed that certain behaviors were part and parcel of fitting into their new society.
- **Knowledge Gap:** Many of these young girls hadn't yet undergone reproductive health education and lacked understanding about their own bodies and how to advocate for themselves in unsafe situations.
- **Gang Involvement:** The local police department shared that there was an emerging trend among local gangs, where girls to get pregnant was a form of initiation.

ACTION PLAN AND OUTCOMES

Recognizing the complexity of the problem, the community devised a multi-angle approach:

- **Education:** Comprehensive reproductive and sexual health education programs were enhanced in the school curriculum.
- **Resources & Support:** The community clinic offered birth control education, counseling, and additional resources, both pre-and post-pregnancy.
- **Gang Intervention:** In partnership with local community leaders, law enforcement launched initiatives to stop gang initiation rituals and provide other avenues and support to at-risk youth.

Thanks to this coordinated, data-driven approach, the town witnessed a significant reduction in teen pregnancies, illustrating the power of collaborative interventions based on shared insights. By fostering open dialogue and sharing insights across various community sectors, it becomes possible to generate actionable wisdom that can transform the health trajectories of our students.



National Initiatives Promoting Data-Sharing Partnerships

To illustrate the transition from recognition of necessity to action, [CDC's Data Modernization Initiative \(DMI\)](#),¹⁰ initiated in 2020, exemplifies the emphasis on holistic and integrated data systems. This initiative aims to modernize siloed data systems by transitioning to more interconnected, proactive health data networks emphasizing three core areas: 1) Data, 2) People, and 3) Policy.

Furthermore, the [National Healthy Schools Collaborative's 10-Year Roadmap](#), published in 2022, was developed by a diverse group of partners from education, public health agencies, community-based organizations, mental health professionals, and policy advocates, among others. One of the 10 priorities listed in this roadmap is to "improve data regulation, collection, transparency, privacy, and interoperability." Particularly, they call for establishing local data-sharing agreements to enhance collaborations between education, healthcare, and public health.

Challenges in School Health Data-Sharing

The intricate nature of cross-sector data exchanges resulting from differing regulatory guidelines and operational landscapes often makes establishing data-sharing partnerships challenging. Many school health services leaders find navigating these complexities to be overwhelming, in the absence of adequate support or clear guidance. Addressing this resource gap is critical for empowering schools to maximize the benefits of data-sharing collaborations while protecting student data. **This guide aims to help school health services leaders develop data-sharing partnerships with confidence and clarity.**

¹⁰ Centers for Disease Control and Prevention. (n.d.) [Data Modernization Initiative](#).

Current State of School Health Data-Sharing

School districts across the country manifest varied practices in school health data-sharing. This diversity in practice largely emerges from a combination of differences in resource availability, existing policies, technological infrastructure, and perceptions surrounding data privacy. While some districts have developed more robust infrastructures for data-sharing, others are in nascent stages. This section provides an overview of the current landscape of school health data-sharing, organized around the three core focuses of the CDC's Data Modernization Initiative: **Data, People, and Policy**.

Data

TECHNOLOGICAL DIFFERENCES BETWEEN SECTORS

The difference between the education and healthcare sectors extends to their data standards and systems. **Student information systems (SIS)** are commonly used in educational institutions to track academic and administrative data. Healthcare providers and systems, on the other hand, use **electronic health records (EHRs)** to document patient health information. While effective in their respective contexts, these systems are not inherently designed to talk to each other, introducing challenges in data-sharing. School nurses often use EHRs tailored for school health services, but these systems often lack integration capabilities with EHRs used in other healthcare settings. The differences in technological systems used and the lack of interoperability between them contribute to the complexity of data-sharing across sectors.

DIFFERING DATA MATURITY LEVELS BETWEEN DISTRICTS

The scope of school health data-sharing is also influenced by the varying data maturity levels across school districts. Data maturity refers to a district's capability to collect, manage, analyze, and use data responsibly. The level of data maturity can profoundly impact a district's ability to participate in data-sharing collaborations.

The [StriveTogether Data Maturity Model](#)¹¹ categorizes data maturity into two primary areas: 1) Data Quality/Technological Capacity and 2) Cultural and Socio-Political Context. The model breaks down the spectrum of data maturity into four levels: Lagging, Basic, Advanced, and Leading.

- **Data Quality/Technological Capacity** includes aspects such as data storage, collection, and privacy. A district with advanced data maturity would have accessible, integrated data storage, high-quality data collection processes, and robust privacy protection systems and protocols that adhere to FERPA and state regulations. It is crucial to understand that a district's technological infrastructure extends beyond mere data management. It profoundly impacts the district's data culture, internal decision-making processes, and even its ability to write grant applications and secure external funding.

¹¹ StriveTogether. (2017). [The StriveTogether Data Maturity Model: A Compass for Building and Advancing Data Infrastructure across Community Partners](#).

- **Cultural and Socio-Political Context:** This aspect reflects the internal and external attitudes and relationships toward data-sharing. It begins internally with "Partnership Buy-in," where both leadership and staff value the sharing and use of data. External "Partner Buy-in" would include the relationships between districts, students/parents, collaborating partners, and funders, all of whom have stakes in shaping data-sharing practices. The maturity of this context also hinges on "Transactional Factors," namely effective data use policies and competent staff to interpret and implement insights. A mature district, thus, not only values data internally but also cultivates a collaborative environment with its partners, supported by clear standards and skilled staff.

Lacking data maturity not only impedes the internal use of health data within the district but can also isolate the district from benefiting from external resources and collaborations. To address this, districts and school health leaders can actively seek to improve their data maturity by utilizing available resources such as:

- [Accountable Communities for Health: Data-Sharing Toolkit](#) from UC Berkeley Center for Healthcare Organizational Innovation and Research (CHOIR); and
- [The StriveTogether Data Maturity Model](#) from StriveTogether.

People

CULTURAL DIFFERENCE BETWEEN EDUCATION AND HEALTH

Because school health data are fundamentally "health" data but are collected and maintained within educational settings, there is confusion that often results in hesitancy to share such data. Education has historically emphasized the importance of student privacy and limited data-sharing, as educators prioritize confidentiality and maintain strict control over student information.¹² In contrast, the healthcare sector has evolved to become increasingly open to data exchanges to facilitate patient care and streamline billing processes. Moreover, public health is rapidly advancing its data management, transitioning from fragmented systems to more cohesive collaborative frameworks (e.g., CDC's Data Modernization Initiative (DMI)).

CONCERNS ABOUT DATA PRIVACY AND ENGAGING STAKEHOLDERS

The attitude toward student data privacy varies among districts, often shaped by the local communities' outlook toward schools sharing student data. Some districts and their surrounding communities maintain a reserved stance toward sharing student data, prioritizing student privacy. This atmosphere of caution can sometimes create hurdles for data-sharing initiatives, necessitating more substantial efforts to build trust and secure agreement for data-sharing. Schools will need to clearly communicate the benefits of data-sharing and the measures in place to safeguard student privacy to foster community buy-in.

continued on p. 19

¹² Makel, M. C., Hodges, J., Cook, B. G., & Plucker, J. A. (2021). Both Questionable and Open Research Practices Are Prevalent in Education Research. *Educational Researcher*, 50(8), 493–504.

Example

Let's illustrate data maturity with two hypothetical districts, "District A" and "District B."

District A is at the **leading** end of the data maturity spectrum. They utilize a school nursing EHR system that not only interfaces seamlessly with the student information system (SIS) but is also robust enough to receive and integrate additional data, when appropriate, providing a comprehensive view of students' academic success, health, and well-being. The EHR allows school nurses to efficiently document and access various health data, including health office visits, immunization records, routine screening results, essential student demographics, attendance, and information related to social determinants of health. They've developed a robust data governance framework that adheres to FERPA and state regulations and employed legal counsel, ensuring data privacy and security. They've also employed a dedicated data analyst who helps the district spot health trends, identify at-risk students, and evaluate the effectiveness of health programs.

As a result, District A can tailor interventions to meet the specific health needs of students, improving the overall health and academic outcomes in the district. With these elements, along with data-sharing agreements in place, District A can confidently share data with external partners such as local health departments and is better positioned to receive and integrate additional data from these partners, thereby enhancing their understanding and approach to student health and success.

District A benefits from the collective knowledge of partners and contributes insights by actively participating in data exchange. District A is enabling a collaborative effort where data turn into shared information, providing value and insights that can inform their work and strategy in student health and academic success through this mutual data exchange. Districts and their partners can learn about broader health trends, challenges, and best practices by integrating and analyzing these data. Finally, this collective wisdom has the potential to inform and shape health interventions, policies, and programs that will benefit students on a much larger scale.

District B, on the other hand, is on the **lagging** end of the data maturity spectrum. Student health data collection in District B might be inconsistent or even rely on outdated paper-based systems, revealing gaps and inaccuracies in student health records. Lacking a robust data governance framework, District B struggles with potential issues regarding data privacy and security, causing them to be unsure of how to comply with complex legal regulations.

Further, the absence of data analysis capabilities hinders District B from making data-informed decisions that could enhance student health outcomes. Their limited data capacity might restrict their understanding of prevalent health issues within their student population, making it challenging to develop effective health programs or interventions.

Due to these challenges, District B may be hesitant to share student health data with external partners, missing out on potential benefits that data-sharing collaborations can offer.

“ As we move toward a more cohesive health data ecosystem, it's crucial to find a balance: protect student privacy while maximizing the benefits of integrated data.

Concerns among parents, students, and community members can range from fears of personal data mishandling or misuse to worries about breaches of confidentiality, identity theft, or potential discrimination based on health or behavioral issues. These are real and significant concerns that underscore the cautious approach that should be taken toward data-sharing.

Sharing student data benefits not just the external partner organizations. When done correctly, data-sharing allows schools to promote student health and success more effectively. It is also critical for schools to inform families that any data containing personally identifiable information (PII) will be shared only with their consent.

Policy

REGULATORY DIFFERENCE

Navigating data-sharing becomes more intricate due to varying regulations like FERPA for schools and HIPAA for healthcare. These regulations, while designed to protect privacy, have unique stipulations and scopes. The differences can breed confusion about what data can be shared, with whom, and under what circumstances. Additionally, it's important to note that individual states may impose their regulations regarding school health data-sharing, and in some cases, these state laws may be more stringent than federal guidelines. For more information on FERPA and HIPAA, refer to [Appendix A. Understanding the Legality of Data-Sharing](#).

In essence, the landscape of school health data-sharing is multifaceted and shaped by many factors, ranging from technological infrastructure to regulatory guidelines and stakeholder perceptions. While some districts harness the full potential of data integration to enhance student health and academic success, others face foundational obstacles that inhibit their full potential. Addressing these disparities necessitates a focus on enhancing data maturity, cultivating a data-centric culture, and adeptly navigating regulatory intricacies. As we move toward a more cohesive health data ecosystem, it's crucial to find a balance: protect student privacy while maximizing the benefits of integrated data. Encouraging collaboration and understanding across sectors is key to leveraging these shared data to improve student well-being and success.

Spectrum of Data-Sharing Possibilities

Data-sharing practice, especially in the realm of school health, varies spanning a continuum from informal, ad hoc agreements to more formalized and tightly integrated systems. Throughout the spectrum, the nature of the data can be aggregate/de-identified data and/or data with personally identifiable information (Figure 4).

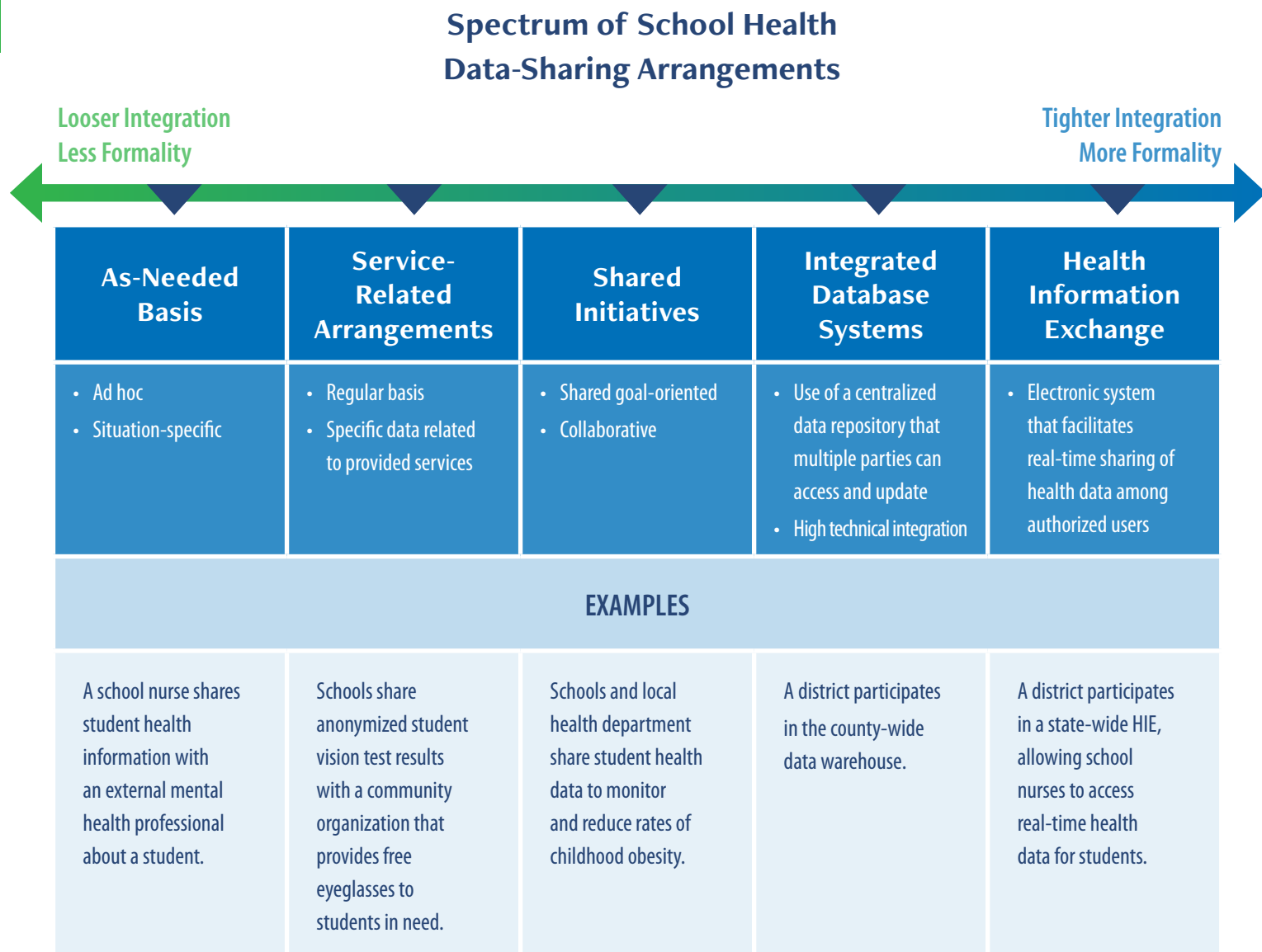


FIGURE 4. SPECTRUM OF SCHOOL HEALTH DATA-SHARING ARRANGEMENTS

Adapted from the [Spectrum of Sharing Arrangements from the Center for Sharing Public Health Services \(2017\)](#)

AS-NEEDED BASIS

Data-sharing on an "as-needed basis" is typically more ad hoc, marked by its informal structure. For instance, a school district may communicate with a local health department to share concerns about a student suspected of having a communicable disease like measles—a disclosure permitted by FERPA—to control potential outbreaks and to protect public health. Similarly, the local health department may proactively share relevant health data or alerts with the school district to inform them of any local health concerns that may impact the student population.

While the term "as needed" might imply infrequency, these exchanges can be more routine based on prevailing conditions. Within this "As-Needed Basis" framework, adhering to standard operating procedures (SOPs) and defined policies is crucial to guarantee data accuracy, privacy, and relevance.



EXAMPLE

A number of students in a school district started showing symptoms of measles. Concerned about the possibility of an outbreak, the school contacted the local health department immediately. Under FERPA's "Health and Safety Exception," the school district shared anonymized information regarding the symptoms, recent school activities, and attendance of affected students. In response, the health department provided the school with up-to-date information about measles cases in the region and suggested containment procedures. Equipped with the timely information, the school district was able to quickly take preventive measures, communicate with parents, and collaborate on a vaccination campaign to ensure the health and safety of the community.

SERVICE-RELATED ARRANGEMENTS

This level of data-sharing involves regularly sharing specific data sets to support the delivery of targeted services. For example, schools may partner with a local mental health agency to provide mental health services to students. The school can share data about attendance patterns, behavioral issues, or academic struggles, which can be early indicators of mental health concerns. In turn, the agency provides regular on-site counseling sessions, workshops, and interventions tailored to the students identified.



EXAMPLE

School-based health centers (SBHCs) are often established within or adjacent to schools to offer comprehensive health services to students. These centers can share data with school districts regarding student health screenings, immunizations, physicals, and other health-related events. In return, the school district can provide SBHCs with data on attendance, academic performance, or physical education assessments, which may be correlated with students' health status. This exchange ensures that both the school and the SBHC can coordinate care more effectively, recognizing and addressing health issues that might impact a student's academic performance.



SHARED INITIATIVES

This often involves multi-stakeholder efforts working toward a specific goal. One example would be a collaborative effort between local health departments and schools in a regional campaign to address childhood obesity. Schools would provide aggregate data on student body mass index, physical activity metrics, and dietary patterns. In response, the health department would analyze this data, offering back analyzed results along with recommendations for potential interventions and policy adjustments. Another collaborative effort can be during flu season; schools can inform both health departments and community health clinics about student absenteeism rates, facilitating a coordinated response to potential outbreaks.

EXAMPLE

The New York City (NYC) Department of Health and Mental Hygiene (DOHMH) has implemented a syndromic surveillance system that utilizes EHR data from school nurse visits. This system tracks conditions such as influenza-like illnesses, allergies, and asthma by analyzing data on school nurse visits. These records are updated and sent daily to DOHMH, enabling real-time monitoring of health trends among schoolchildren. The system's primary goal is to detect potential illness outbreaks or clusters in schools, allowing for timely health interventions and monitoring. Daily analysis of the data provides invaluable insights into student health trends, assisting DOHMH in proactive health management.¹³

¹³ Wilson, E. L., Egger, J. R., Konty, K. J., Paladini, M., Weiss, D., & Nguyen, T. Q. (2014). Description of a School Nurse Visit Syndromic Surveillance System and Comparison to Emergency Department Visits, New York City. *American Journal of Public Health, 104*(1), e50–e56.

INTEGRATED DATABASE SYSTEM/ DATA WAREHOUSE

Further along the spectrum are shared database systems or warehouse data. These platforms involve technical integrations where multiple parties can access and update a central repository of data. An excellent real-world example of a shared database system is a state immunization information system (IIS), also known as immunization registry. IIS serves as centralized, often statewide databases that

maintain immunization records for all residents. Schools, healthcare providers, and public health departments can access IIS to track immunization coverage, identify gaps, and coordinate efforts to improve vaccination rates. This sort of data-sharing allows for a comprehensive view of immunization status of students, enabling proactive prevention measures, and helps both schools and public health systems to control the spread of disease during an outbreak.

EXAMPLE

The [Washington State Department of Health's Immunization Information System \(IIS\) School Module](#) demonstrates the importance of integrated data-sharing systems. The IIS, which serves as a centralized repository, receives documented immunization records from healthcare providers throughout the state. In exchange for access to the repository, schools provide the system with student rosters. Schools can not only access immunization data but also enter data with parental permission.

This two-way exchange of information, which is supported by formal agreements between the Department of Health and school districts, ensures data accuracy and timeliness. Beyond data management, the user-centric design of the IIS School Module provides schools with tools for effective communication about immunization gaps, compliance report generation, and, most importantly, rapid identification of students at risk during disease outbreaks. See [Appendix D. School Health Data-Sharing Exemplars](#) to learn more.

EXAMPLE

The Department of Human Services (DHS) in Allegheny County, Pennsylvania, operates a data warehouse. This system consolidates data from various county departments, including the housing authority, jail, probation office, and health department, among others. Additionally, the warehouse integrates data from local school districts and other non-county entities, aiming to streamline client-level information across these systems. This integration aims to enhance service delivery and outcomes by supporting informed decision-making. In 2009, the Pittsburgh Public School (PPS) district pioneered a data-sharing agreement with DHS. Following this, similar agreements were inked with other local school districts. These agreements, designed to comply with both FERPA and HIPAA regulations, leverage a FERPA exception that permits data usage for "action research." Central to these agreements is the "action research" provision. Under this, DHS can generate analytical reports about students in the district who utilize DHS services. Together, DHS and the school districts create, implement, and evaluate strategies based on these insights. [Learn more.](#)



HEALTH INFORMATION EXCHANGE

At the far end of the spectrum is a **health information exchange (HIE)**,¹⁴ systems for sharing health data among authorized healthcare providers, demanding the highest degree of technical sophistication, data management, and security protocols. Participation in HIEs may help improve coordinated care and enhance health outcomes by facilitating the real-time exchange of health data.

Consider a scenario where a school district is part of a state HIE. The integration allows school nurses to access updated students' health records from various healthcare providers in real-time, enabling the provision of immediate and suitable care. This system can be especially beneficial for managing students with chronic conditions such as asthma or diabetes. Here, real-time updates on recent doctor visits or alterations in medication can profoundly influence the school's ability to effectively manage students' conditions and prevent emergencies.

However, the effectiveness of this system is contingent on the reliability and accuracy of the data exchanged. Discrepancies or inaccuracies in the data can potentially impact the quality of care provided, making it imperative for healthcare providers and school nurses to validate HIE data with other reliable sources and clinical assessments.

Despite the potential limitations, the scalable and integrated nature of HIEs renders them a valuable asset in informing population health efforts and enhancing student health outcomes by providing a comprehensive view of health trends and facilitating coordinated care, so long as the data utilized are approached with discernment and supplemented with other reliable sources as necessary.

¹⁴ www.healthit.gov/topic/health-it-and-health-information-exchange-basics/what-hie

Decision-Making Process and Key Questions to Ask before Deciding to Participate

The Network for Public Health Law has developed a [Checklist of Information Needed to Address Proposed Data Collection, Access and Sharing](#). Adapting from this document, [Data Sharing Guidance for School Nurses, Student Health Collaborative Implementation Guide](#), and other available resources,^{15,16,17} on data-sharing, we have created a list of decision-making processes and key questions to consider before considering a data-sharing arrangement.

Decision-Making Process



1 Define the Purpose

- WHAT IS THE PURPOSE OF DATA-SHARING?
- HOW DOES IT SUPPORT THE DESIRED STUDENT OUTCOMES?

It is essential that all involved parties agree on the purpose of data-sharing before developing any data-sharing agreement. The objective of data-sharing should be centered around enhancing student health outcomes. The rationale behind data-sharing must be transparent from the beginning, as this can influence the legal stipulations surrounding data-sharing and use. For instance, determining if exceptions within FERPA are applicable depends on this stated purpose.

2 Identify the Parties

- WHO ARE THE PARTIES INVOLVED?
- ARE THERE CONFLICTS OF INTERESTS?
- DO ALL PARTIES HAVE THE TECHNOLOGICAL AND POLICY RESOURCES FOR SECURITY AND ACCESS CONTROLS?

Clearly identify the stakeholders involved. These stakeholders are not limited to those who will have direct access to the student data; they also include the key advocates championing the cause of data-sharing. Understanding who these parties are and delineating their relationships fosters a trusting and transparent context for all parties, ensuring that each stakeholder is aligned with the data-sharing partnership's objectives.

¹⁵ University of California, Berkeley. Center for Healthcare Organizational and Innovation Research (CHOIR). (2016). [Accountable Communities for Health: Data-Sharing Toolkit](#).

¹⁶ StriveTogether. (2021). [A Guide to: Data Sharing](#).

¹⁷ National League of Cities. (2014). [Sharing Data for Better Results: A Guide to Building Integrated Data Systems Compatible with Federal Privacy Laws](#).

3 Understand the Data

- WHAT SPECIFIC TYPES OF DATA ELEMENTS ARE INVOLVED?
- DO THEY INVOLVE PERSONALLY IDENTIFIABLE INFORMATION (PII)?

Identify the particular data elements intended for sharing, along with where these data originate from. It's worth noting that the legal constraints surrounding the sharing of de-identified data—data from which personally identifiable information has been removed—are typically less stringent. As such, it may be worthwhile to explore if this type of de-identified data could fulfill the sharing requirements. A careful and clear definition of the data elements to be shared is crucial, as this can help avoid misunderstandings or misuse of information down the line. Data contributors should also provide data dictionaries, descriptions, and related documentation.

4 Research Applicable Laws

- WHICH LAWS APPLY?
- FERPA, HIPAA, STATE-SPECIFIC LAWS?

When schools share student health information, they typically fall under the regulation of FERPA. Some states have passed student privacy laws that may be more restrictive than federal law. The prevailing legal framework should direct the procedures for disclosing, storing, handling, and retaining data.

These laws provide a structure for managing the data, ensuring that all actions align with legal mandates. Understanding these laws is vital when crafting a data-sharing agreement and helps stakeholders anticipate potential legal challenges. By proactively preparing for these issues, stakeholders can reduce legal risks, ensuring a seamless operation and preserving the integrity of the data-sharing process.

5 Weigh Benefits and Assess Risks

- HOW DOES IT BENEFIT STUDENTS?
- HOW DOES IT BENEFIT THE SCHOOLS?
- WHAT POTENTIAL RISKS OR HARM MIGHT OCCUR FROM SHARING DATA?

Evaluating the benefits and potential risks is vital. For schools, data-sharing can inform strategic decision-making, guide resource allocation, determine best practices, and enable effective partnerships with community health organizations. The insights from shared data can lead to better health programs and policies, improved health education, and stronger community relations.

However, alongside these potential benefits, we must also be mindful of the risks. Potential risks may involve data breaches, misuse of information, or unintended violation of privacy regulations. It's crucial to ensure that the benefits decisively outweigh these risks and that robust safeguards are in place to protect student information. In doing so, districts can confidently move forward with data-sharing, knowing that they're acting in the best interest of their students and the larger community.

6 Determine Cost and Resources Needed

- WHAT ARE THE FINANCIAL COSTS TO THE DISTRICT?
- WHAT ARE THE RESOURCES NEEDED?

Assessing the financial implications and the resources necessary for successful data-sharing is a pivotal step in the process. It's not just about calculating the immediate monetary costs; it's about mapping out the broader landscape of resources required to bring the data-sharing partnership to be effectively and sustainably implemented. The implementation work can take months to years to develop.

First, a careful financial analysis will aid in understanding the initial investment required and any ongoing costs associated with the maintenance and security of the data-sharing system. Moreover, non-monetary resources, such as time and technical expertise, must also be considered. The process may require significant staff for training, developing data management policies, and coordinating with external partners. Additionally, data-sharing might require specialized technical resources, from hardware and software to support from IT professionals who understand data integration, analysis, and security.

The question of sustainability also plays a critical role. Districts must consider whether the resources needed for the data-sharing partnerships can be met consistently over time. This involves exploring various funding sources, considering potential impacts on the district's budget, and ensuring sufficient technical and human capacity to sustain the initiative.

7 Determine the Type of Agreement

- WHAT KIND OF AGREEMENT(S) IS NEEDED? (DSA VS MOU)

Establishing a written agreement is a best practice to ensure all stakeholders have a clear understanding of their roles and expectations in the data-sharing process.¹⁸

The primary purpose of both **data-sharing agreements (DSAs)** and **memoranda of understanding (MOUs)** is to document the parties' legal authorities to share data. Each type of agreement has its advantages and limitations, and the choice depends on the specific needs and constraints of the data-sharing arrangement. This helps ensure that all parties are on the same page regarding their roles, responsibilities, and expectations of the data-sharing arrangement.

This section draws heavily from the Actionable Intelligence for Social Policy (AISP)'s [How to Create a Strong Legal Framework for Data Integration](#) and the Network for Public Health Law's [Data Sharing Guidance for School Nurses](#).

¹⁸ https://studentprivacy.ed.gov/sites/default/files/resource_document/file/Vendor%20FAQ.pdf

DATA-SHARING AGREEMENT (DSA)

A DSA is a legally binding contract that formalizes the process of sharing data between different parties. This could include organizations and individuals while maintaining the security and integrity of any pre-existing data rights, such as confidentiality and privacy. Since DSAs carry legal weight, they imply that involved parties are willing to undertake a formal commitment to each other.

DSAs can be designed to cover a single project or specific data exchange, but they can also be structured to manage an extensive, ongoing collaboration, with separate appendices created for individual projects. DSAs are flexible in the sense that they can be arranged between two or multiple parties and can span different jurisdictions.¹⁹



SAMPLE DATA-SHARING AGREEMENTS

- The Network for Public Health Law. (2020). [Data Sharing Guidance for School Nurses, Appendix A.](#)
- Practical Playbook. (n.d.). [Sample Data Agreement: Data Sharing between a Health System and the Data Recipient.](#)
- National Neighborhood Indicators Partnership. (2018). [Collection of Example Data-Sharing Agreements: Education.](#)

MEMORANDUM OF UNDERSTANDING (MOU)

In contrast to a DSA, an MOU is a non-binding agreement. It outlines the terms, scope, and expectations of a data-sharing collaboration and details the roles and responsibilities of the parties involved. An MOU is typically used when parties aim to establish a mutual understanding and alignment of intentions rather than a formal legal obligation to one another.

The MOU guides the partnership and documents an agreement of principles and procedures. When an MOU is deemed sufficient, parties often favor this option because it can bypass extensive contract review processes, which makes the MOU relatively more straightforward and quicker to execute.

The choice between an MOU and a DSA often depends on the particular stage and specific requirements of the data-sharing arrangement.

¹⁹ Actionable Intelligence for Social Policy. University of Pennsylvania. (2022). [Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration.](#)

An MOU is typically the initial agreement establishing a collaboration. It's an overarching agreement that lays the groundwork, including the purpose, principles, and management structures of the data-sharing initiative. For instance, if a local health department and a school system want to collaborate on a project to share aggregate data to improve student health and attendance, they would first establish an MOU.

On the contrary, a DSA is used when there is a need to define precise terms and protocols for data handling. It outlines how data will be transferred, protected, and managed. This is more appropriate when the data-sharing arrangement is well-established and needs to set legally binding terms about data usage. For example, after the health department and the school system have agreed on the overarching terms of their collaboration and need to decide on the exact procedures for sharing, storing, and using specific student health data, a DSA becomes necessary to ensure strict, enforceable rules are in place.²⁰

A DSA can exist independently or be incorporated as a part of an MOU. While an MOU may incorporate a DSA, it's not an obligatory inclusion.

Determining the terms of data use and means to enforce violations is an important step. There should be well-defined consequences for any violation of the agreement terms. This promotes responsibility and accountability among the data users, enhancing the trustworthiness of the data-sharing arrangement. See [Appendix B: Key Components of Successful Data-Sharing Agreements](#).



REFERENCES USED AND RESOURCES FOR FURTHER GUIDANCE

- Actionable Intelligence for Social Policy. University of Pennsylvania. (2022). [Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration](#).
- U.S. Department of Education Privacy Technical Assistance Center (PTAC). (Revised 2015). [Written Agreement Checklist](#).
- Practical Playbook. (n.d.). [How to Draft Successful Memorandums of Understanding and Data-Sharing Agreements](#).
- U.S. Department of Education, Privacy Technical Assistance Center (PTAC). (n.d.). [Data Governance Checklist](#).

²⁰ Actionable Intelligence for Social Policy. University of Pennsylvania. (2022). [Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration](#).

Commonalities of Successful Data-Sharing Partnerships

Successful data-sharing partnerships share several key characteristics that enable them to navigate challenges and optimize outcomes.^{21,22,23,24} These common factors provide a valuable blueprint and framework for shaping and refining data-sharing approaches. As we aim to enhance and modernize school health data-sharing, it's crucial to identify the attributes foundational to successful partnerships. In this section, we'll classify these shared attributes under the core pillars of CDC's Data Modernization Initiative: **Data, People, and Policy**.

Data

CLEAR PURPOSE AND GOALS

Every successful partnership has a distinct purpose, collaboratively understood and agreed upon by all stakeholders. This guiding objective facilitates the development and implementation of data-sharing agreements and ensures sustained commitment.

ACTIONABLE DATA USE

Successful partnerships place a significant emphasis on harnessing shared data for action. These systems don't just collect and share data; they use data as a powerful tool to influence policymaking, guide targeted interventions, optimize operational processes, apply for external funding, and, ultimately, improve student outcomes.

ROBUST DATA SECURITY AND PRIVACY PROTECTIONS

Given the sensitivity of school health data, successful partnerships prioritize data security and privacy. They implement strong technical and procedural measures to protect data at all stages of sharing, from collection and storage to transfer and analysis. This not only ensures compliance with legal requirements but also helps to build trust among the parties and the students and families whose data are being shared. Additionally, setting up clear and comprehensive data-sharing agreements is crucial, as it defines the parameters of use, responsibilities, and obligations, further strengthening the foundation of trust and transparency in the partnership.

²¹ StriveTogether. (2016). [Data Drives School-Community Collaboration: Seven Principles for Effective Data Sharing](#).

²² Data Across Sectors for Health (DASH). (2016). [Four Tips for Navigating Consent to Facilitate Data Sharing](#).

²³ Nemours. (2019). [Data Sharing Across Child-Serving Sectors: Key Lessons and Resources](#).

²⁴ StriveTogether. (2021). [A Guide to: Data Sharing](#).

“ Transparency about data handling procedures, access rights, and benefits of data-sharing can foster a culture of trust.

INNOVATIVE SOLUTIONS AND WORKAROUNDS

Embracing innovation is another common characteristic of successful data-sharing partnerships. They employ innovative solutions and technological tools to simplify the process, improve efficiency, and enhance security. For instance, a secure website that allows districts to view, opt-in, and control their data-sharing can be a powerful tool. The use of technology not only streamlines data-sharing but also puts control in the hands of the data owners, further enhancing confidence in the system.

People

TRUST AND TRANSPARENCY

Establishing trust with not only the data-sharing partners but with the students, parents, and the community is critical for the success of data-sharing partnerships. Transparency about data handling procedures, access rights, and benefits of data-sharing can foster a culture of trust. Creating opportunities for open dialogue and collaboration is equally important, allowing stakeholders to voice their concerns, provide input, and feel invested in the process. One way to achieve trust and transparency is by posting about the partnerships and the data-sharing agreements on their public websites, clearly listing the types of data shared, how the data are used, and the reasons behind the data-sharing partnerships. Indicating that consent was appropriately obtained can also build trust and transparency.

ONGOING COLLABORATION AND COMMUNICATION

Effective data-sharing goes beyond a singular transaction—it’s a continual effort requiring sustained engagement and collaboration. Such systems actively foster a culture of collaboration that includes all parties. Regular updates, meetings, training, or reports can help identify and resolve issues early, share successes and learnings, and keep all parties engaged and committed to the collaboration. It’s also crucial to share updates and findings back to the community members, especially students and their parents, to ensure transparency and trust.

Policy

SYSTEM-LEVEL DATA-SHARING AGREEMENTS

Centralized and standardized data-sharing agreements, whether at the district or state level, can simplify and streamline data-sharing. Standardized agreements can help establish a consistent framework, thereby reducing variability and redundancy.



MORE TIPS ON SUCCESSFUL DATA-SHARING

- StriveTogether. (2016). [Data Drives School-Community Collaboration: Seven Principles for Effective Data Sharing](#).
- Data Across Sectors for Health (DASH). (2016). [Four Tips for Navigating Consent to Facilitate Data Sharing](#).
- Nemours. (2019). [Data Sharing Across Child-Serving Sectors: Key Lessons and Resources](#).
- StriveTogether. (2021). [A Guide to: Data Sharing](#).
- Casey Foundation. (2022). [How Transforming Child Welfare Systems: How can Data Sharing across Child- and Family-Serving Systems be Implemented Effectively?](#).
- Connecticut Office of Policy and Management (OPM). (2020). [Legal Issues in Interagency Data Sharing](#).

Common Barriers and Strategies to Sharing School Health Data

This section presents common barriers faced in establishing school health data-sharing collaborations and potential strategies to navigate them. We've aligned our proposed strategies with CDC Data Modernization Initiative (DMI)'s five priorities:

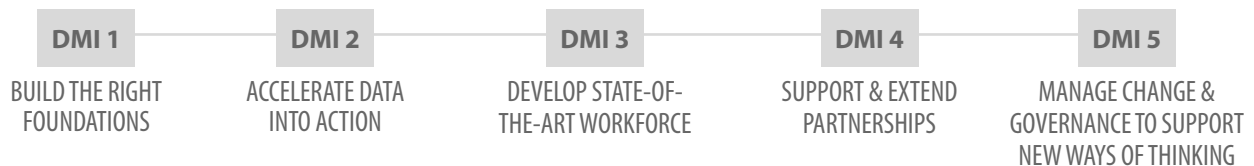
1. Build the Right Foundations
2. Accelerate Data into Action
3. Develop State-of-the-Art Workforce
4. Support and Extend Partnerships
5. Manage Change and Governance to Support New Ways of Thinking

This alignment offers a framework that resonates with the broader public health objectives, ensuring that our strategies are both actionable for school health leaders and in tandem with best practice recommendations promoted nationally. A more detailed description of the barriers and strategies can be found in [Appendix C. Common Barriers and Strategies to Sharing School Health Data](#).

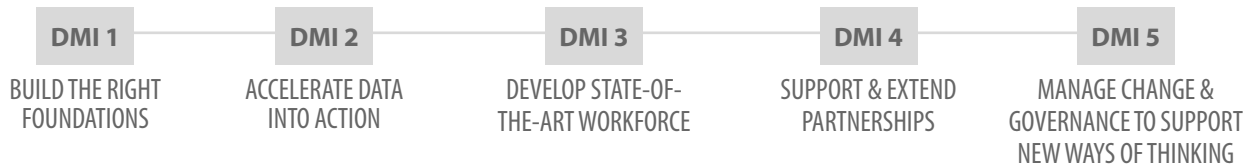
Five Priorities of DMI



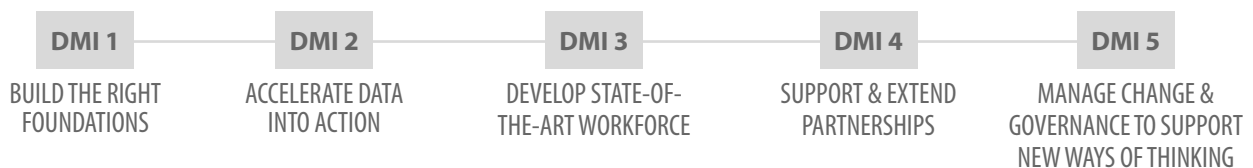
Barriers	Strategies	
Privacy Concerns	Build Trust and Maintain Robust Privacy Protection Measures	DMI 1
<ul style="list-style-type: none"> Schools, parents, and students may be wary of the potential misuse of sensitive health data. This concern is compounded by valid fears of data security breaches. 	<ul style="list-style-type: none"> Implement stringent data security protocols, including encryption and strict access controls. Consider conducting a penetration testing process to evaluate and resolve potential data security concerns. Foster trust through clear communication and mandating confidentiality training for all involved parties. Engage parents and students early in the process in open dialogues about data use and benefits. Publish details of the data-sharing arrangements, such as on the school district’s public-facing website. 	
Data Ownership Concerns	Establish Clear Written Agreements	DMI 4
<ul style="list-style-type: none"> Uncertainties and conflicts over data ownership hinder effective data-sharing. Control, access, and data usage often lead to disagreements among stakeholders. 	<ul style="list-style-type: none"> Utilize formal written agreements to clarify terms of data ownership, access rights, usage, and additional terms. Ensure that agreements provide clear roles and responsibilities for all parties. Regularly update agreements to keep with evolving data-sharing practices and changing regulations. 	
Interoperability Issues	Promote Interoperability through Data Standards	DMI 2
<ul style="list-style-type: none"> Interoperability is the capability of different IT systems to communicate and exchange data effectively. Educational data often maintained in student information systems (SIS) are not interoperable with electronic health records (EHRs) used in healthcare sector. The lack of adherence to common health data standards by school EHRs complicates data-sharing, making it inefficient, error-prone, and sometimes even impossible. 	<ul style="list-style-type: none"> Adopt school EHRs designed with widely recognized healthcare data standards such as LOINC, SNOMED CT, and HL7 FHIR. Encourage districts to prioritize interoperable software and update acquisitions as standards evolve. Use existing tools and platforms for data alignment and sharing if overhauling entire systems is not feasible. 	



Barriers	Strategies	
Lack of Professional Capacity	Leverage Targeted Funding	DMI 5
<ul style="list-style-type: none"> School staff are often overburdened with their primary tasks. Introducing additional data responsibilities can lead to fatigue and apprehensions regarding the sustainability of such partnerships. Furthermore, the technical nature of data handling and sharing requires specialized training and skill development, which can be challenging to implement and maintain due to existing workload pressures. The absence of standardized trainings on best practices for data-sharing leaves school districts largely on their own to navigate this complex landscape. Finding funding for these partnerships is particularly strenuous, as it is required not just for the operational aspects but also for building infrastructure, providing training, and securing legal expertise. The intricate nature of these projects makes them resource-intensive, and the scarcity of funds dedicated to such comprehensive needs often impedes the establishment and sustainability of these partnerships. 	<ul style="list-style-type: none"> Advocate for specific funds to support school health data-sharing initiatives. Explore external grants, partnerships with nonprofits, or shared platforms to minimize costs. 	
	Invest in Training and Upskilling	DMI 3
	<ul style="list-style-type: none"> Enhance the abilities of current staff with data-related responsibilities. Offer workshops and courses on data management, analysis, and sharing. 	
	Adopt User-Friendly Data Systems	DMI 1
	<ul style="list-style-type: none"> Simplify tasks with intuitive data collection and sharing systems. Choose systems that reduce the time and effort required from staff. 	
	Utilize External Expertise	DMI 4
	<ul style="list-style-type: none"> Collaborate with external data specialists or agencies. Benefit from specialized knowledge and best practices to streamline data-sharing processes. 	



Barriers	Strategies	
Limited Legal Understanding	Utilize External Expertise	DMI 4
<ul style="list-style-type: none"> • Many districts lack dedicated resources for understanding data-sharing practices. • Absence of legal expertise leads to potential non-compliance with regulations. • Districts may adopt a more restrictive stance due to complexities in data-sharing laws. • With multiple priorities, data-sharing often isn't a primary focus, leading to overlooked benefits. 	<ul style="list-style-type: none"> • Engage legal consultants specializing in education and health data privacy for tailored district guidance and to navigate data-sharing legalities. • Smaller districts might consider pooling resources, allowing them to share the cost and benefits of expert services. Additionally, states can provide standardized data-sharing agreements. 	
	Develop Standardized Data-Sharing Agreements	DMI 1
	<ul style="list-style-type: none"> • Using standardized or overarching agreement documents can help streamline the data-sharing process and ensure adherence to legal requirements. 	
“We’ve Always Done It This Way” Mindset	Showcase Tangible Benefits and Success Stories	DMI 5
<ul style="list-style-type: none"> • New data-sharing collaborations often face resistance due to established routines and mindsets present in both the education and healthcare sectors. • While the education sector has historically been cautious about data-sharing due to student privacy concerns, the healthcare sector is progressively emphasizing more integrated health data exchange. 	<ul style="list-style-type: none"> • Emphasize how data-sharing partnerships can reduce administrative tasks like data entry and allow professionals like nurses to spend more time on direct care, leading to better outcomes for students. • Share success stories from other school districts that have benefited from data-sharing partnerships, providing a relatable example of its potential advantages. 	



Moving Forward...

As we look to the future, the role of cross-sector data-sharing in enhancing individual, community, and population health outcomes is becoming increasingly significant. Schools, in this context, harbor an untapped wealth of health data. If properly utilized, school health data can be valuable in the broader healthcare ecosystem. Data-sharing collaborations enable schools to gain actionable knowledge and wisdom from already existing school health data. To unlock this potential, school health leaders must recognize the intrinsic value of the data and champion their use.

At the heart of unlocking this potential is the standardization of data as we transition to a more interconnected healthcare landscape. It ensures that data from various sources can be seamlessly integrated, understood, and applied in different sectors, making the data more actionable. **By championing data standardization, we not only facilitate data exchange but also enhance the capacity to identify and address specific health issues.**

For school health leaders, advocacy is important. Common data standards such as Logical Identifiers Names and Codes (LOINC) and Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT) are improving how health data are understood and shared. Their alignment with innovative technologies like HL7 FHIR can lead a paradigm shift in how school health records can be managed and exchanged. It is crucial for school nurses to advocate for EHRs that adhere to these common data standards and exchange capabilities.

Moreover, the burgeoning field of health information exchanges (HIEs) and other data aggregator organizations offers a compelling opportunity for school health services. Active engagement with these exchanges provides schools with coordinated, real-time access to student health data, leading to optimized healthcare service delivery and a more holistic approach to student health.

As a part of the transition toward more integrated data systems, school health leaders need to foster innovation. This extends beyond embracing advanced technology to reshaping our strategies and roles in promoting student health.



By championing data standardization, we not only facilitate data exchange but also enhance the capacity to identify and address specific health issues.

Conclusion

Data-sharing collaborations help schools tap into the powerful potential of school health data. While establishing these partnerships can present challenges, the benefits for schools can be immensely valuable. Data-sharing collaborations empower school districts to make evidence-based decisions, ultimately enhancing student health and academic success. Furthermore, showcasing specific student health needs can help schools to access additional resources and funding. Beyond streamlining school operations, data-sharing bridges community connections and fosters new collaborations.

The link between health and education is clear: healthier students are more likely to succeed academically, and their academic success, in turn, promotes better short- and long-term health outcomes. Viewing schools as vital parts of the healthcare and public health ecosystem aligns with the [National Education Association's \(NEA\) Community Schools Model](#). This model envisions schools as pivotal community centers that prioritize educational excellence while fostering robust partnerships with local stakeholders.

Implementing school health data-sharing collaborations is more than a logistical process. The decision symbolizes the deliberate positioning of schools as central community pillars, steering schools toward innovative frontiers and emphasizing their essential role in the education, healthcare, and public health sectors.

By actively engaging in data-sharing partnerships, schools not only gain valuable insights into student health and success but also contribute to the larger goal of improving community and population health outcomes. This collaborative approach fosters cross-sector synergy, ultimately benefiting the entire community by addressing holistic needs and cultivating an innovative culture.



Additional Resources

All In. (2019). [All In: How and Why Communities Are Using Data to Drive Community Health Improvement](#).

Association of State and Territorial Health Officials (ASTHO). (2012). [Comparison of FERPA and HIPAA Privacy Rule for Accessing Student Health Data: Fact Sheet](#).

Association of State and Territorial Health Officials (ASTHO). (n.d.). [Public Health Partnerships with Education and Medicaid: Improving School Health](#).

Data Across Sectors for Health (DASH). (2016). [Four Tips for Navigating Consent to Facilitate Data Sharing](#).

Healthy Schools Campaign. (2018). [Education Data for Health Systems: Challenges and Opportunities](#).

Healthy Schools Learning Collaborative. (2019). [Legal Guide to School Health Information and Data Sharing in Colorado](#).

Institute of Education Sciences. (2017). [Ask a REL Response: Data Sharing Agreements between K–12 Schools and School-Based Health Centers or Other Health Care Systems](#).

National Center for Youth Law. (2018). [HIPAA or FERPA? A Primer on Sharing School Health Information in California, Second Edition](#).

National Center for Youth Law and School-Based Health Alliance. (2023). [Information Sharing and Confidentiality Protection in School-Based Health Centers: A Resource Guide to HIPAA and FERPA](#).

Public Health Informatics Institute (PHII). (n.d.). [Using Data to Improve Child and Adolescent Mental Health \(CAMH\): The Opening Playbook](#).

StriveTogether. (2017). [Data Drives School-Community Collaboration: Seven Principles for Effective Data Sharing](#).

StriveTogether. (2021). [A Guide to: Data Sharing](#).

U.S. Department of Education. (2016). [Data-Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy](#).

U.S. Department of Education Privacy Technical Assistance Center. (2017). [Integrated Data Systems and Student Privacy](#).

U.S. Department of Education Student Privacy Policy Office. (2023). [Family Educational Rights and Privacy Act: Guidance for School Officials on Student Health Records](#).

U.S. Department of Health and Human Services and U.S. Department of Education. (2019). [Joint Guidance on the Application of the Family Educational Rights and Privacy Act \(FERPA\) And the Health Insurance Portability and Accountability Act of 1996 \(HIPAA\) To Student Health Records](#).

U.S. Department of Housing and Urban Development. (2017). [Data Sharing Road Map: Improving Student Outcomes through Partnerships between Public Housing Agencies and School Districts](#).

References

- 20 U.S.C. § 1232g(a)(4). <https://uscode.house.gov/browse/prelim@title20/chapter31/subchapter3/part4&edition=prelim>.
- 34 C.F.R. § 99.3. <https://www.ecfr.gov/current/title-34/subtitle-A/part-99/subpart-A/section-99.3>.
- 34 C.F.R. § 99.31 (b)(1). <https://www.ecfr.gov/current/title-34/subtitle-A/part-99/subpart-D/section-99.31>.
- 45 C.F.R. § 164.103. <https://www.ecfr.gov/current/title-45/subtitle-A/subchapter-C/part-164>.
- Actionable Intelligence for Social Policy. (2015). Framework for Collaboration: The Memorandum of Understanding between Allegheny County DHS and Pittsburgh Public Schools. <https://aisp.upenn.edu/wp-content/uploads/2015/10/FrameworkforCollaboration.pdf>.
- Actionable Intelligence for Social Policy. (n.d). Legal Agreements & Supporting Documents. <https://aisp.upenn.edu/resources/legal-agreements-and-other-supporting-documents/>.
- Actionable Intelligence for Social Policy. University of Pennsylvania. (2022). Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration. <https://aisp.upenn.edu/wp-content/uploads/2022/06/AISP-Finding-A-Way-Forward-Final-6.16.2022.pdf>.
- Allegheny County Department of Human Services. (2018). Allegheny County Data Warehouse. https://www.alleghenycountyanalytics.us/wp-content/uploads/2018/07/18-ACDHS-20-Data-Warehouse-Doc_v6.pdf.
- ASCD and Centers for Disease Control and Prevention. (2014). The ASCD Whole Child Approach to Education. <https://www.ascd.org/whole-child>.
- Centers for Disease Control and Prevention. (n.d.) Data Modernization Initiative. <https://www.cdc.gov/surveillance/data-modernization/>.
- Data Across Sectors for Health (DASH). (2018). A Legal Approach to Sharing Health & Education Data. <https://static1.squarespace.com/static/6320ea657f0aff58aef9a3ca/t/6362a8cdf9d4864499e77d28/1667410128542/DASH-Bright-Spot-Chicago.pdf>.
- Makel, M. C., Hodges, J., Cook, B. G., & Plucker, J. A. (2021). Both Questionable and Open Research Practices are Prevalent in Education Research. *Educational Researcher*, 50(8), 493–504.
- National League of Cities. (2014). Sharing Data for Better Results: A Guide to Building Integrated Data Systems Compatible with Federal Privacy Laws. <https://ncwwi.org/files/Data-Driven-Decision-Making-CQI-Data-Sharing-for-Better-Results.pdf>.
- StriveTogether. (2021). A Guide to: Data Sharing. https://strivetgether.my.salesforce.com/sfc/p/#4P000000hKdh/a/4P000000LmIY/t8m912cO7ws4Zy3rVKUjiAcf5M0d.7TLmat_lqhGOvl.
- StriveTogether. (2017). The StriveTogether Data Maturity Model: A Compass for Building and Advancing Data Infrastructure across Community Partners. <https://www.strivetgether.org/wp-content/uploads/2017/09/StriveTogether-Data-Maturity-Model-Report-Sept2017.pdf>.
- University of California, Berkeley. Center for Healthcare Organizational and Innovation Research (CHOIR). (2016). Accountable Communities for Health: Data-Sharing Toolkit. <https://static1.squarespace.com/static/632be03c30bc581b81337668/t/639281c4eab4105f1a9ff400/1670545861956/ACH-Data-Sharing-Toolkit-December-2016.pdf>.

Appendix A:

Understanding the Legality of Sharing School Health Data: Is it Legal to Share School Health Data?

This section provides a summary of information adapted from the [Data-Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy](#) from the U.S. Department of Education and the [Data Sharing Guidance for School Nurses](#) from the Network for Public Health Law.

It is important to note that this document does not serve as a replacement for legal advice, and we recommend seeking the guidance of an experienced attorney when creating or reviewing any data-sharing agreement.

FERPA vs. HIPAA

The Family Educational Rights Privacy Act (FERPA) is a federal law that regulates the confidentiality and exchange of information found in student education records within educational institutions.²⁵ FERPA is applicable to all primary and secondary institutions that receive funds from the U.S. Department of Education. On the other hand, the Health Insurance Portability and Accountability Act (HIPAA) oversees data privacy and sharing in the healthcare sector. However, in the context of school health data, FERPA takes precedence because HIPAA explicitly excludes education records protected under FERPA.²⁶

Therefore, FERPA applies to all "education records" of students, including student health information, such as health screening results, school nurse office visits, chronic conditions, and immunization records, gathered and maintained by schools or school nurses. FERPA does not differentiate between health information and other types of personal information in an educational record. In other words, students' health information is handled in the same way as any other student information, such as grades or assessment scores.

The applicability of FERPA to health-related records is determined by the service provider's association with the educational entity. FERPA covers records like medication details made by school nurses, irrespective of their direct employment or contractual status with the school.

It also applies when a school collaborates with public or mental health agencies for student services. Conversely, FERPA doesn't govern records from school-based health centers managed by external health organizations if they operate independently of the school. In such cases, other regulations, like HIPAA, could be relevant.

²⁵ [20 U.S.C. § 1232g\(a\)\(4\); 34 C.F.R. § 99.3](#)

²⁶ [45 C.F.R. § 164.103](#)

It's important to note that both FERPA and HIPAA cannot apply simultaneously to the same set of information, since health information held in educational records is explicitly excluded under HIPAA.

In addition to these federal regulations, various state laws also influence data-sharing and may enforce stricter or more detailed rules for data confidentiality and privacy.

For a comprehensive understanding of FERPA, see:

- [U.S. Department of Education FERPA](#) and guidance for [K–12 school officials](#).

For more information on the application of the two federal laws, see:

- U.S. Department of Health and Human Services and U.S. Department of Education. [Joint Guidance on the Application of the FERPA And the HIPAA To Student Health Records](#).
- Association of State and Territorial Health Officials (ASTHO). [Comparison of FERPA and HIPAA Privacy Rule for Accessing Student Health Data: Fact Sheet](#). [ASTHO Legal Preparedness Series: Public Health & Schools Toolkit](#).

Categories of Legal Data-Sharing

Three primary categories of legally shareable data exist according to the U.S. Department of Education, each with its unique set of rules:

- 1. DE-IDENTIFIED DATA**
- 2. DATA WITH PII SHARED WITH WRITTEN CONSENT FROM THE PARENT OR ELIGIBLE STUDENT**
- 3. DATA SHARED UNDER A FERPA EXCEPTION**

1. DE-IDENTIFIED DATA

Data that have been de-identified or summarized remove any details that could link the data back to individual students, such as names, Social Security numbers, or student identification numbers.²⁷ While there is no legal obligation for schools to secure consent before sharing such de-identified or aggregate student data, it is recommended that schools communicate their plans to parents. This includes sharing details about the intention of data-sharing, the parties involved, and the reasons behind such sharing, as a way to foster openness and trust. Additionally, schools should carefully examine de-identified or aggregate data to make sure they do not unintentionally reveal identifiable details. Techniques like suppression, blurring, and perturbation can aid in this process to ensure the data remain truly de-identified.²⁸

²⁷ [34 C.F.R. § 99.31 \(b\)\(1\)](#)

²⁸ U.S. Department of Education. (2016). [Data-Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy](#).

2. DATA SHARED WITH PARENTAL CONSENT

Sharing personally identifiable information (PII) typically requires written consent from a “parent” for students under age 18. Under FERPA, “a parent means a parent of a student and includes a natural parent, a guardian, or an individual acting as a parent in the absence of a parent or a guardian.” A consent form should be signed and dated clearly specifying 1) the purpose of data-sharing, 2) the type of information being shared, and 3) the parties it’s being shared with. It’s important that the responsibility of obtaining consent is clarified in advance and aligned with privacy policies to ensure effective partnerships.

For further resources on parental consent, see:

- Healthy Schools Campaign. [Legal Guide to School Health Information and Data Sharing in Colorado. Appendix A: Requirements for Release of Information Forms.](#)
- The Network for Public Health Law’s [Data Sharing Guidance for School Nurses. Appendix B: Sample Consent Form for Disclosures by School District to Health Department.](#)

3. DATA SHARED UNDER A FERPA EXCEPTION

FERPA outlines specific instances where schools may disclose personally identifiable information (PII) without needing to secure consent. These exceptions to the usual consent requirement come into play when seeking consent may not be feasible.

- School Official Exception
- Studies Exception
- Audit/Evaluation Exception
- Directory Information Exception
- Health and Safety Exception

FERPA Exceptions²⁹

School Official Exception	<ul style="list-style-type: none"> • Most commonly used for in-school volunteers and contracting. • Conditions for using this exception: <ul style="list-style-type: none"> » Organization performs a service or function that would otherwise be done by school or local educational agency (LEA) employees. » Organization is under the direct control of the school or LEA in terms of using and maintaining the education records. » Organization agrees not to use or disclose the data outside the designated purpose. » Organization meets criteria in school's or LEA's Annual Notification of FERPA Rights as a school official with a legitimate educational interest.
Studies Exception	<ul style="list-style-type: none"> • Allows sharing with an organization conducting studies for or on behalf of a school or LEA. • Conditions for using this exception: <ul style="list-style-type: none"> » School enters into a written agreement with the organization that includes privacy requirements. • Organization is conducting a study in developing, validating, or administering predictive tests; administering student aid programs; or improving instruction.
Audit / Evaluation Exception	<ul style="list-style-type: none"> • Often used for evaluating program effectiveness. • Conditions for using this exception: <ul style="list-style-type: none"> » LEA designates certain organizations to act as its authorized representative in a written agreement. » LEA meets conditions listed in the FERPA regulations. » Shared PII from education records must be used to audit, evaluate, enforce, or comply with legal requirements of an education program.
Directory Information Exception	<ul style="list-style-type: none"> • Allows sharing of directory information that would not generally be considered harmful if disclosed. • Conditions for using this exception: <ul style="list-style-type: none"> » Schools and LEAs must give public notice about items designated as directory information and inform parents/students of their right to opt out. » A reasonable amount of time must be provided for requests of non-disclosure. » Directory information does not include sensitive data such as Social Security numbers, grades, disability, race, or sex.
Health and Safety Exception	<ul style="list-style-type: none"> • Allows sharing PII during health or safety emergencies. • Conditions for using this exception: <ul style="list-style-type: none"> » Disclosures are limited to duration of emergency. » The disclosures must pertain to actual, impending, or imminent emergencies, such as: <ul style="list-style-type: none"> › Natural disasters › Terrorist attacks › Campus shootings › Epidemic disease outbreaks

²⁹ U.S. Department of Education. [FERPA Exceptions—Summary](#).

Further Information on FERPA Exceptions

- Privacy Technical Assistance Center (PTAC). [FERPA Exceptions—Summary](#).
- Privacy Technical Assistance Center (PTAC). [The Family Educational Rights and Privacy Act Guidance for Reasonable Methods and Written Agreements](#).
- Healthy Students Promising Futures. [Appendix C: Exchanging Information and Data between Schools and Health Providers in Colorado: Quick Reference Chart to Confidentiality Laws](#).
- U.S. Department of Education. [Data-Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy](#).

Resources for Further Guidance

- U.S. Department of Education. [Family Educational Rights and Privacy Act: Guidance for School Officials on Student Health Records](#).
- U.S. Department of Education. [FERPA Exceptions—Summary](#).
- U.S. Department of Education. [Data-Sharing Tool Kit for Communities: How to Leverage Community Relationships While Protecting Student Privacy](#).
- U.S. Department of Education. [Written Agreement Checklist](#).
- U.S. Department of Education. [Online Training Modules](#).
- U.S. Department of Education. [Data Security: K–12 and Higher Education](#).
- The Network for Public Health Law. [Data Sharing Guidance for School Nurses](#).
- U.S. Department of Health and Human Services and U.S. Department of Education. [Joint Guidance on the Application of the FERPA And the HIPAA To Student Health Records](#).
- Centers for Disease Control and Prevention (CDC). [Health Information & Privacy: FERPA and HIPAA](#).
- Association of State and Territorial Health Officials (ASTHO). [Comparison of FERPA and HIPAA Privacy Rule for Accessing Student Health Data: Fact Sheet](#).



While these resources provide valuable guidance on federal laws such as FERPA and HIPAA, it's also essential to recognize that states may have their own specific rules and guidelines regarding data-sharing within schools. These rules can often augment or sometimes even supersede federal laws and can have a substantial impact on how school districts handle data-sharing. Therefore, in addition to considering federal guidelines, school districts should consult with their state laws to ensure compliance with all relevant data privacy and sharing laws.

Appendix B: Key Components of Successful Data-Sharing Agreements

Creating robust data-sharing agreements is a vital part of setting up efficient and secure school health data-sharing systems. A well-structured agreement provides a solid foundation for collaboration, outlining clear expectations, delineating roles, and ensuring legal and ethical compliance. The following section, adapted from the [Data Sharing Agreements and Memorandums of Understanding: Considerations for Development](#) by the Regional Educational Laboratory at WestEd, provides a detailed checklist of elements to consider when developing or negotiating DSAs and MOUs. Each component plays a crucial role in ensuring the agreement is comprehensive, transparent, and mutually beneficial. By paying careful attention to these details, schools can ensure they establish effective, secure, and ethical data-sharing practices.

Section	Information to Consider Including	Section	Information to Consider Including
Document type	<ul style="list-style-type: none"> Is this a DSA or an MOU? 	Confidentiality	<ul style="list-style-type: none"> How will confidentiality of the data be ensured?
Purpose	<ul style="list-style-type: none"> Statement of purpose or intent for data-sharing 	Data governance roles and responsibilities of each party	<ul style="list-style-type: none"> Delineate roles and responsibilities by organization: data collection; data storage; data ownership; data management; data analysis; dissemination; accountability
Period of agreement	<ul style="list-style-type: none"> Define the initial time period for the agreement Consider adding provisions to allow flexibility in the timeframe if adjustments are needed 	Resource allocation	<ul style="list-style-type: none"> Fund sharing arrangements and requirements Data infrastructure maintenance Fixed, variable, and recurring costs: fees; personnel (including time, labor, and travel); data infrastructure development
Description of data	<ul style="list-style-type: none"> The nature and scale of information to be gathered, used, or made available 	Amendments	
Legal	<ul style="list-style-type: none"> Ethics, privacy, and confidentiality Security (i.e., technical, and procedural protections/contingencies) Local, state, and federal compliance requirements Other legal requirements 	Date and signature	
Data ownership	<ul style="list-style-type: none"> Who owns the data (e.g., institution, formal partnership, regional consortium, and/or funder)? 		
Data storage	<ul style="list-style-type: none"> Location of data Data storage format and security Data archiving, preservation, and disposal responsibility, schedule, and procedures 		
Data access	<ul style="list-style-type: none"> Who will have access to the data? What are the concerns about student, institution, consortium, and district confidentiality? What are the solutions? Method of access 		

ADDITIONAL RESOURCES:

U.S. Department of Education Privacy Technical Assistance Center (PTAC). (2015). [Written Agreement Checklist](#).

U.S. Department of Education Privacy Technical Assistance Center (PTAC). (2015). [Guidance for Reasonable Methods and Written Agreements](#).

Appendix C:

Common Barriers and Strategies in School Health Data-Sharing

Barriers	Strategies
<p>Privacy Concerns</p>	<p>Build Trust and Maintain Robust Privacy Protection Measures</p>
<p>Privacy concerns are paramount when dealing with student health data. Schools, parents, and students may be concerned about the potential misuse of data, which can create resistance to data-sharing partnerships.</p>	<p>Ensuring the highest data privacy and security standards is vital to alleviate concerns related to sharing school health data. Schools can increase confidence in their data handling by adopting strict data security protocols similar to those in the healthcare sector. This can include measures such as encryption, secure data storage and transmission, strict access controls, advanced anonymization techniques, thorough consent processes, and robust data governance frameworks.</p> <p>However, having technical measures alone is insufficient. Strategic efforts to foster trust among stakeholders should supplement technical measures. This could include clearly explaining the privacy measures in place, working with the district's communication department to ensure these messages are effectively communicated to all stakeholders, and providing confidentiality training to those who handle the data.</p> <p>Furthermore, holding meetings with parents and students to explain the purpose of the data-sharing partnership, demonstrate the security measures in place, and discuss the benefits for student health outcomes can be beneficial. Such open communication can help to alleviate concerns, increase buy-in, and pave the way for a successful data-sharing partnership.</p>

EXAMPLE

The [Washington State Immunization Information System \(IIS\) School Module](#) places a strong emphasis on maintaining privacy standards. As part of this commitment, all non-health professionals who are delegated to input information into the module are required to sign confidentiality agreement forms. This requirement signifies a tangible commitment to safeguarding the privacy of the data handled within the system. [Learn more.](#)

EXAMPLE

Chicago Department of Public Health (CDPH) and Chicago Public Schools (CPS) have a data-sharing collaboration where CPS shares de-identified student health data. To ensure transparency and mutual understanding between the entities, their data-sharing agreement contains specific provisions. Any analysis of the CPS data intended for publication must be approved by both parties. This clause significantly alleviated CPS's concerns about potentially revealing sensitive information, such as school-specific obesity or immunization rates, through the release of de-identified data. [Learn more.](#)

Barriers	Strategies
<p>Data Ownership Concerns</p>	<p>Establish Clear Written Agreements</p>
<p>Uncertainties or conflicts over data ownership can pose a significant barrier to effective data-sharing. Questions often arise concerning the control, access, and usage of the data, leading to potential disagreements among various stakeholders.</p>	<p>Addressing these concerns effectively requires clear communication and consensus regarding data ownership, access rights, and usage. A formal written agreement is an essential tool for laying out these details. It provides a tangible reference point that clarifies the roles and responsibilities of each party, thereby mitigating potential conflicts.</p> <p>In such an agreement, all parties involved should be clear about who owns the data, who has access to the data, how the data can be used, and under what conditions the data can be shared. These stipulations should be transparent to all stakeholders, enhancing accountability and fostering trust in the data-sharing initiative.</p> <p>Regularly revisiting these agreements is also crucial. As data-sharing practices evolve and as regulations and requirements change, these agreements should be regularly updated to reflect the current reality. This helps to ensure that all parties remain on the same page and that the data-sharing practices continue to be effective, responsible, and compliant with all necessary rules.</p>



EXAMPLE

The [Michigan DataHub's](#) online module is a prime example of effectively addressing data management concerns. This platform grants school districts easy access to and control over their data-sharing agreements. Districts can selectively choose the data they share and have the flexibility to toggle data-sharing on or off as circumstances dictate. Such transparent control mechanisms significantly ease apprehensions regarding data ownership and oversight, making data-sharing safer for schools. [Learn more about MiDataHub.](#)

Barriers	Strategies
<p style="text-align: center;">Interoperability Issues</p>	<p style="text-align: center;">Interoperability through Data Standards</p>
<p>Interoperability refers to the ability of different systems to communicate, exchange data, and utilize the information that has been exchanged. One of the main challenges in school health data management is the interoperability issue between student information systems (SIS) and school nurse electronic health records (EHRs), as well as between school nurse EHRs and other health data systems in the broader healthcare and public health sectors. The lack of interoperability leads to significant hurdles in integrating and analyzing data from these diverse sources. For example, schools often use distinct software systems for tracking student attendance, health records, and academic performance. When these systems cannot communicate effectively with each other or with external healthcare systems, it results in a cumbersome and inefficient process for consolidating and utilizing data. The absence of uniform data standards in school EHRs, particularly those that are not aligned with formats used by other healthcare providers like Health Level 7 Fast Healthcare Interoperability Resources (HL7 FHIR), exacerbates these challenges, leading to time-consuming, error-prone, and often manual data exchange processes.</p>	<p>Data interoperability is a cornerstone of effective health data-sharing. To address these interoperability challenges, it is crucial to implement standardized data formats and exchange protocols across both internal school systems (SIS and school nurse EHRs) and external healthcare and public health systems. The adoption of standard terminologies, such as Logical Identifiers Names and Codes (LOINC) and Systematized Nomenclature of Medicine-Clinical Terms (SNOMED CT), and exchange standards such as the HL7 FHIR may provide solutions. These standards facilitate the exchange of health data across various platforms and settings, enhancing data compatibility and streamlining communication.</p> <p>School health leaders can support more uniform, efficient data management by advocating for the adoption and use of school health EHR systems that use common data terminologies and exchange standards. If redesigning entire EHR systems is not feasible, adapting existing platforms for data integration may provide a faster, more feasible solution.</p>



EXAMPLE

An example of a successful implementation of interoperability is the data-sharing agreement between the [New Jersey Immunization Information System \(NJIIS\)](#) and the [Genesis Student Information System \(SIS\)](#). Genesis, predominantly a student information system, also incorporates a nursing module, serving as an electronic health record (EHR) system for school nurses.

In this setup, immunization data from the NJIIS are automatically updated in the Genesis SIS nurse modules. This automated, nightly exchange of data significantly reduces the need for manual entry and ensures that the health records accessed by school nurses are always up to date with the latest immunization information.

This example of interoperability creates a comprehensive and effective platform for managing student health data by bridging two systems that serve distinct yet interconnected functions. The resulting system simplifies the process for school nurses and gives them an accurate and complete overview of student immunization records. This fosters more informed healthcare decisions and interventions, supporting prompt attention to adequately meeting students' health needs.

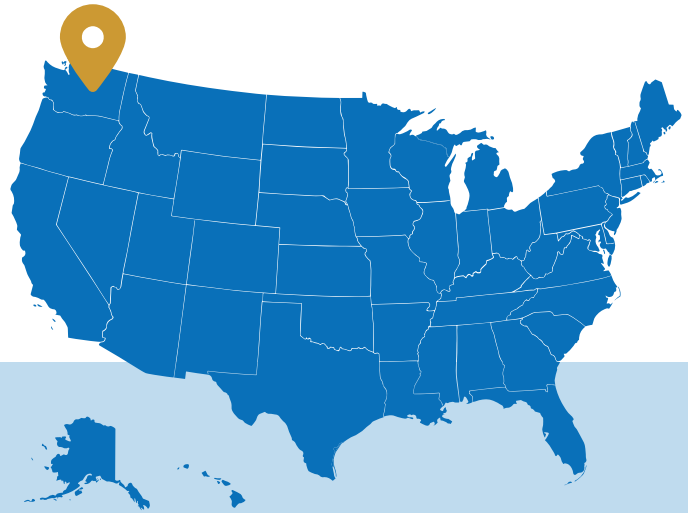
Barriers	Strategies
<p data-bbox="240 310 573 384">Lacking Professional Capacity and Resources</p>	<p data-bbox="927 331 1317 367">Leverage Targeted Funding</p>
<p data-bbox="115 426 686 1094">The educational and healthcare sectors frequently have limited resources, making it difficult to handle the complex data collection, analysis, and dissemination tasks. These industries, which are already dealing with chronic overwork, find it especially taxing when professionals are expected to perform additional data-related tasks in addition to their primary responsibilities. Such increased demands can cause fatigue and raise concerns about the long-term sustainability of these data-sharing collaborations. The technical nature of this work adds to the difficulty. It requires considerable mental effort and diligence, making timely implementation difficult especially when combined with other daily responsibilities.</p>	<p data-bbox="740 426 1393 615">One strategy is to actively seek funding opportunities dedicated to supporting school health data-sharing partnerships. Various federal, state, and local agencies periodically offer grants for projects that align with their objectives.</p>
	<p data-bbox="894 653 1349 688">Invest in Training and Upskilling</p>
	<p data-bbox="740 737 1463 1083">In addition to hiring new employees, schools can invest in training current employees to handle data-related tasks. Offering workshops, courses, or seminars on the fundamentals of data management, analysis, and sharing can empower current employees and create a resilient internal workforce capable of handling data responsibilities without feeling overwhelmed. Continuous training also ensures that professionals stay updated with the evolving demands and methodologies of data management.</p>
	<p data-bbox="878 1119 1365 1155">Adopt User-Friendly Data Systems</p>
<p data-bbox="740 1199 1446 1350">Simplifying the data collection and sharing process by adopting intuitive systems can mitigate the stress on staff. When the systems are easy to use, it can reduce the time and effort required, making the process less burdensome.</p>	
<p data-bbox="943 1388 1300 1423">Utilize External Expertise</p>	
<p data-bbox="740 1472 1474 1854">Schools can also leverage the power of external expertise. Engaging with external specialists or agencies, particularly those proficient in data management and sharing, can offload some of the workload on internal staff. These experts bring specialized knowledge, innovative tools, and best practices that can streamline the data-sharing processes. By outsourcing certain tasks or collaborating with these agencies, schools can ensure that data collection, analysis, and sharing are conducted efficiently and effectively, without overburdening their current staff.</p>	

Barriers	Strategies
<p data-bbox="224 268 521 302">Legal Understanding</p> <p data-bbox="116 346 625 852">Many districts may lack legal expertise or a comprehensive understanding of how to share data in a manner that respects student privacy and complies with pertinent regulations, such as FERPA and HIPAA. The absence of a dedicated legal consultant or an in-depth understanding of data-sharing complexities may lead districts to adopt a more restrictive stance. Moreover, with various competing priorities vying for attention, data-sharing may not be at the top of the list, resulting in its potential benefits being overlooked.</p>	<p data-bbox="911 268 1268 302">Utilize External Expertise</p> <p data-bbox="670 346 1494 972">One approach involves tapping into external expertise. Districts could consider partnering with legal consultants or entities specializing in education and health data privacy. These experts can provide guidance tailored to the district's specific needs and context, helping navigate the complex legal landscape surrounding data-sharing. Smaller districts, especially those with limited resources, could collaborate and share the services of such experts, pooling their resources to share costs. Moreover, states can play a pivotal role by providing standardized agreements, vetted by legal counsel, for all districts to utilize. Such statewide efforts can not only streamline the data-sharing process but also promote a culture of informed data decision-making and sharing at a broader level. Additionally, developing and utilizing a standardized data-sharing agreement can streamline the process and ensure legal compliance. Tools like the Written Agreement Checklist by the U.S. Department of Education can guide districts in crafting such agreements.</p>
<p data-bbox="224 1052 521 1085">Resource Constraints</p> <p data-bbox="116 1136 602 1404">Data collection, storage, and maintenance require significant resources. Schools, particularly those in resource-constrained settings, may find it challenging to adequately fund the necessary technology, staff training, and data management resources.</p>	<p data-bbox="894 1052 1284 1085">Leverage Targeted Funding</p> <p data-bbox="670 1136 1442 1325">To address these constraints, schools can advocate for targeted funding dedicated to data-sharing initiatives. This could involve investigating opportunities for grant funding, cultivating partnerships with non-profit organizations or private sector entities, or leveraging shared platforms and resources.</p> <p data-bbox="670 1356 1468 1587">Consider this not as a barrier but as an investment. The act of implementing effective data-sharing practices can spotlight areas where resources are most needed. For example, if data reveal a significant number of students are grappling with mental health issues, the data provide compelling evidence to advocate for more funding toward mental health resources in schools.</p> <p data-bbox="670 1619 1500 1885">Moreover, shared data can be employed to assess the effectiveness of existing programs and interventions. This ensures that resources are allocated where they will have the greatest impact. It can highlight areas of success and spotlight areas needing improvement. This data-informed approach allows school districts to make strategic decisions, directing resources where they are most needed and where they can make the most significant difference.</p>

Barriers	Strategies
<p data-bbox="233 302 672 373">Overcoming the “We’ve Always Done It This Way” Mindset</p>	<p data-bbox="972 302 1365 373">Showcase Tangible Benefits and Peer Success Stories</p>
<p data-bbox="118 403 719 590">A significant obstacle to innovation in data-sharing is the deeply rooted "we've always done it this way" mentality. This mindset often breeds resistance to change, especially when established routines are perceived as comfortable.</p> <p data-bbox="118 623 764 1171">Traditionally, education and healthcare have operated in separate silos. The interconnectedness of healthcare providers and systems relies on the fluid exchange of data. In contrast, the education sector traditionally approaches data-sharing with more caution, largely driven by the paramount importance of student privacy. This dichotomy creates a wide range of practices among school districts, with some adopting a more health-sector-like approach to data-sharing, while others adhere to stricter data-sharing controls typical of the education sector. The reluctance often stems from concerns about student privacy, lack of understanding of the benefits of data-sharing, or insufficient resources to affect change.</p> <p data-bbox="118 1199 769 1667">Yet, it's crucial to challenge this fixed mentality. The COVID-19 pandemic showcased our collective ability to adapt swiftly to unprecedented challenges. It reminded both the healthcare and education sector of the importance of reevaluating established norms in the face of changing realities. With the increased complexity in the health and social needs of children today, we have a responsibility to continuously reassess and optimize our practices. Given this, it's essential to reevaluate our data-sharing methods to better address modern challenges and ensure we're best serving our students.</p>	<p data-bbox="833 403 1484 869">By highlighting the positive outcomes of data-sharing and providing education and resources, districts can shift toward a more forward-thinking and effective approach to data-sharing. By openly addressing these concerns, providing education and support, and showcasing the benefits of data-sharing, districts can shift toward a more innovative culture and effective approaches to school health data-sharing. This strategic reevaluation can be a rallying point for stakeholders, emphasizing that the "way we've always done it" may not sufficiently address today's unique challenges and opportunities.</p> <p data-bbox="833 900 1490 1446">To overcome this barrier, showcasing the tangible benefits of improved data-sharing practices can be effective. Demonstrating, for example, that less time spent on data entry means more time for nurses to deliver direct care services, could be a compelling argument. Each selling point should address specific problems and present clear, evidence-based benefits that resonate with the target audience. In addition, sharing success stories from other school districts that have successfully adopted data-sharing practices, and the benefits they have achieved on education or health related outcomes, can be a powerful motivator. It provides a relatable, real-world example that such a change is possible and beneficial.</p>

Appendix D: School Health Data-Sharing Exemplars

Washington State Immunization Information System (WAIIS) School Module



Recognizing the vital role that robust immunization compliance plays in preventing disease outbreaks, the Washington State Department of Health launched the [Washington State Immunization Information System \(IIS\) School Module](#). This system acts as a centralized hub for managing detailed student immunization records and student rosters from school districts across the state.

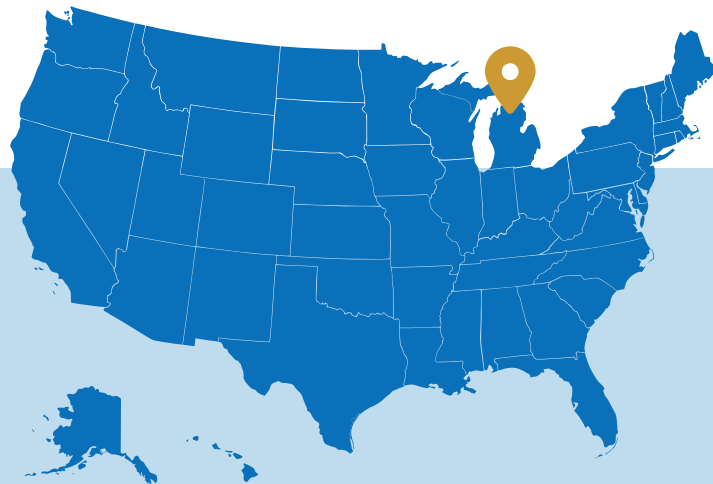
The IIS School Module embodies a vision of a unified, state-wide system designed to streamline immunization management. Its primary purpose is to foster efficient immunization compliance and enable rapid identification of students at risk during disease outbreaks.

The system operates on a principle of reciprocal data exchange. School districts provide the IIS with student rosters, and in return, they receive access to the students' immunization records stored within the system. This mutual data exchange is governed by formal agreements between the Washington State Department of Health and each participating school district.

What distinguishes the IIS School Module is its forward-thinking approach. It offers a user-friendly, web-based tool for managing student and school-level immunization information efficiently. The system serves as a comprehensive tracking and management tool, empowering schools to access verified data, add records, generate compliance reports, communicate with parents about missing immunizations, and importantly, identify vulnerable students during a disease outbreak.

Beyond administrative convenience, the IIS School Module has proven to be an invaluable resource in safeguarding the health of students across the state. It exemplifies the transformative potential of data-sharing systems when implemented effectively, offering benefits not just to school administration, but more importantly, contributing to the overall health and well-being of students.

Michigan Data Hub



The [MiDataHub](#), short of Michigan Data Hub, is a collaborative statewide initiative aimed at simplifying data integrations among numerous educational systems. By providing a unified platform, MiDataHub has streamlined data exchange processes for schools, all while preserving districts' control over data.

MiDataHub was developed out of a recognition of the fragmented nature of educational data systems. It successfully brought together school districts across Michigan to establish a centralized system, merging isolated data silos into a cohesive, usable format.

Within this framework, schools contribute student roster data to an operational data store (ODS), a real-time database collating data from various systems. The ODS serves as the foundation for a multitude of solutions, including generating actionable reports, facilitating a statewide single sign-on, and managing state reporting. Consequently, MiDataHub effectively integrates a wide array of systems, encompassing student information, assessment, special education, food service, library, and transportation services.

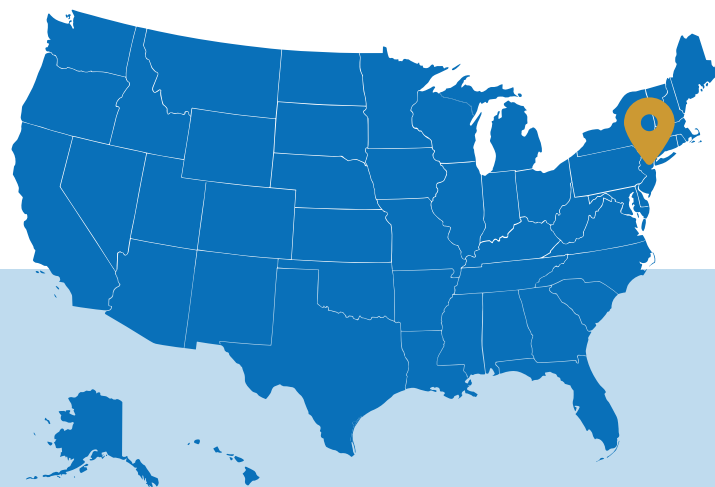
At the heart of MiDataHub is its data hosting agreement, which clarifies the terms of data-sharing and offers districts easy access and control over their agreements.

Housed on the platform's built-in module, this agreement fosters trust and cooperation by promoting transparency and control.

MiDataHub features an opt-in model, which allows districts to choose to participate in certain components of the data-sharing initiative based on their needs and capabilities. This element of customization ensures districts can fully benefit from the initiative without overextending their resources. Furthermore, the system allows for automatic renewals for up to 10 years after the initial year-long term. This extended timeframe emphasizes the initiative's commitment to long-term, sustainable data-sharing practices.

As MiDataHub continues to evolve, it plans to expand its reach beyond school data systems, integrating social emotional learning agencies like BHworks and XSEL Labs. These partnerships not only enrich the spectrum of data shared within the system but also pave the way for incorporating other health data in the future.

New Jersey Immunization Information System (NJiIS) and Genesis Student Information System (SIS)



A unique data-sharing agreement that embodies the integration of health and education sectors is that between the [New Jersey Immunization Information System \(NJiIS\)](#) and the [Genesis Student Information System \(SIS\)](#). Genesis, predominantly a student information system, also incorporates a nursing module, serving as an electronic health record (EHR) system for school nurses.

Originating from a mutual goal to streamline the tracking of immunization records, this agreement was fostered with the central purpose of ensuring that students' vaccination records were up-to-date and easily accessible. This kind of inter-system collaboration enhances the overall health management within schools, directly contributing to the well-being of students.

The data-sharing method is based on an innovative nightly query where Genesis pulls information from the NJiIS, updating newly added vaccination records directly into the school's system. These data are then seamlessly integrated into the school's system, offering daily updates to the records. This automated process streamlines the school nurses' workflow, providing them direct access to accurate, up-to-date immunization records. As a result, it greatly reduces manual data handling and minimizes the potential for human error.

The data elements involved in this sharing are specific to immunization records, critical information in ensuring students' adherence to vaccination schedules and supporting public health initiatives to prevent the spread of communicable diseases.

Despite being a paid service, the agreement has been implemented across numerous districts, testament to the value seen in this collaborative data-sharing model.

In essence, the NJiIS-Genesis data-sharing agreement represents an innovative, efficient, and cost-effective solution to managing students' immunization records. By leveraging technology and cross-sector collaboration, it exemplifies a strategic alliance that can significantly improve student health management.



phaboard.org/initiatives/center-for-school-health-innovation-quality/



C4SHIQ@phaboard.org