PRIVACY AND PUBLIC HEALTH PRACTICE SERIES

Information Management for State Health Officials

Integrating Child Health Information Systems While Protecting Privacy

A Review of Four State Approaches

ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

INTEGRATING CHILD HEALTH INFORMATION SYSTEMS WHILE PROTECTING PRIVACY: A REVIEW OF FOUR STATE APPROACHES

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The Association of State and Territorial Health Officials is the national non-profit organization representing the state and territorial public health agencies of the United States, the U.S. territories, and the District of Columbia. ASTHO's members, the chief health officials in these jurisdictions, are dedicated to formulating and influencing sound public health policy, and assuring excellence in state-based public health practice.

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ASTHO

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Executive Summary

State public health agencies leading the development of integrated child health information systems in the United States are finding ways to construct integrated child health information systems based on their own needs and resources. Differing approaches used by the Missouri Department of Health and Senior Services, the Oregon Department of Human Services, the Rhode Island Department of Health, and the Utah Department of Health can serve as model systems for other states working to build integrated child health information systems. All of these agencies were funded by the Maternal and Child Health Bureau of the Health Resources and Services Administration (HRSA/MCHB) to build integrated child health information systems. Additionally, the strengths of these varying architectures provide insight on building an Electronic Health Record (EHR) at the national level.

The implementation of the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule and other privacy laws complicated the design of integrated health information systems, but states are discovering solutions to these challenges, allowing them to move forward with their integrated child health information systems. Solutions include building privacy protections into the systems, improving information technology (IT) infrastructure, assessing vulnerabilities in their systems, and educating system users about HIPAA and other privacy issues. While these four states were able to implement information systems that adequately safeguard protected health information, attaining compliance with HIPAA and other privacy laws did not come without spending human and financial resources.

Key Findings

All four state public health agencies reported that strong executive leadership and shared vision within their agencies and state governments guided the successful implementation of integrated child health information systems. While the architecture of each state’s integrated child health information system varied, security and privacy protections included in the systems were common among the states. Additionally, the four states reported similar benefits to key stakeholders. Children receive more coordinated delivery of health care services. Providers spend less time tracking down records and have access to more complete medical histories on their patients. Public health agencies and programs can collect more timely and complete data, which can be used to deliver more targeted interventions.

According to the profiled state public health agencies, the HIPAA Privacy Rule presents a greater barrier to buy-in from users of integrated child health information systems than it does to integration of data sets. Thus far, HIPAA has not prevented integration of a data set into any of the four integrated child health information systems included in this report. However, concerns among HIPAA covered providers, programs, and departments about patient data security in the integrated systems limited initial buy-in among these users. The four state health agencies reviewed in this report addressed this challenge with education on the public health exemption under HIPAA[1] and data security protections within each integrated system, and by sharing data management

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[1] The public health provision [45 CFR 164.512] allows covered entities to disclose protected health information for public health activities and purposes such as preventing or controlling disease, injury, or disability

responsibilities with incorporated programs through Data Sharing Agreements.

Other state and federal laws related to privacy may pose greater barriers to integration of child health data sets. For example, the Family Education Rights and Privacy Act (FERPA), which protects the confidentiality of school records,[2] limits integration of information from school-based health programs, such as early intervention programs. Additionally, state privacy laws that are more stringent than HIPAA preempt the Privacy Rule.[3]

An additional policy concern centers on the lawfulness of sharing data across state lines. Policies regarding privacy and interstate health data sharing vary by state. Sharing data among states can also benefit child health in a similar way, especially given the mobility of the U.S. population. Additionally, as the United States moves forward in developing an EHR, interstate data sharing policies and the potential need for a national level policy must be considered.

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[2] Consistent with [34 CFR 99]
[3] Consistent with [45 CFR 160.203(b)]

About ASTHO

The Association of State and Territorial Health Officials (ASTHO) is the national nonprofit organization representing the state and territorial public health agencies of the United States, the U.S. territories, and the District of Columbia. ASTHO's members, the chief health officials of these jurisdictions, are dedicated to formulating and influencing sound public policy, and to assuring excellence in state-based public health practice. Guided by ASTHO's policy committees, the organization addresses a variety of key public health issues and publishes newsletters, survey results, resource lists, and policy papers that assist states in the development of public policy and in the promotion of public health programs at the state level.

About the HIPAA Task Team

Due to the complexity of the HIPAA rules coupled with the timeframe for implementation, ASTHO formed a group that could identify and share states' needs for HIPAA implementation. The purpose of the HIPAA Task Team (HTT) is to identify issues that impact primarily state health agencies—recognizing many of these same issues will also pertain to local health agencies. The HTT, which has been in place for more than three years, consists of senior leaders in state health agencies, as well as members of the National Association of County and City Health Officials, ASTHO affiliate organizations, and other interested organizations. ASTHO has provided leadership to the HTT by developing forums for states and other interested parties to discuss the HIPAA rules as they pertain to public health.

ASTHO is working with the Centers for Disease Control and Prevention (CDC) Privacy Rule Coordinator, Beverly Dozier, JD, to continue the HTT forums and to write issue reports around pertinent topics.

The topic for the fourth report in the Privacy and the Public Health Series is " Integrating Child Health Information Systems while Protecting Privacy: a Review of Four State Approaches." This issue report includes a review of the Privacy Rule's impact on integrated child health information systems, and provides overviews of integrated child health information systems in Missouri, Oregon, Rhode Island, and Utah. The information in this report is largely based on interviews with the following people: Nancy Hoffman, RN, MSN, Deputy Center Director, Center for Health Information Management and Education (CHIME), Missouri Department of Health and Senior Services; Rhoda Nicholas, MBA, PMP, Chief Information Officer, Utah Department of Health; Sherry Spence, MCH Data Systems Coordinator, Office of Family Health, Oregon Department of Human Services; and Amy Zimmerman, MPH, Chief, Office of Children's Preventive Services, Division of Family Health, Rhode Island Department of Health.

Other reports in this series include:

- Meeting the Challenges Presented by the HIPAA Privacy Rule in Public Health Practice
- The Impact of the HIPAA Privacy Rule on Syndromic Surveillance
- Data Sharing with Covered Entities Under the HIPAA Privacy Rule: A Review of Three State Public Health Approaches

These reports are available on the ASTHO website at www.astho.org.

Introduction

According to the Institute of Medicine, "timely and reliable data are an essential component of public health assessment, policy development and assurance at all levels of government."[4] Integrating child health information across a number of information systems enhances public health knowledge and presents opportunities to develop more effective and targeted interventions. Integrated child health information systems reduce duplication of data collected and improve the coordination of services provided, ensuring that all children receive appropriate preventive care and at-risk children receive appropriate testing, follow-up, and case management.[5,6,7] Integrated child health information systems also provide state public health agencies capacity for accountability, evaluation and decision-making.[5,6,7] However, integrating multiple information systems is challenging, and maintaining HIPAA compliance when integrated programs are a mix of covered,[8] non-covered, and hybrid[9] HIPAA entities is complicated.

The HIPAA Privacy Rule governs the design of integrated child health information systems in two ways, through both the security standards[10] and privacy of individually identifiable health information.[11]

The benefits of integrated child health information systems hinge upon data entry at the provider or clinic level. However, since compliance with the Privacy Rule became mandatory on April 14, 2003, varying interpretations of the Rule have caused confusion regarding data sharing, and many covered entities refrained from sending health data to public health authorities because of these uncertainties. The HIPAA Privacy Rule recognizes the responsibility of public health authorities to monitor health-related data, as is stated: "a public health authority is authorized by law to collect or receive protected health information for the purpose of preventing or controlling disease, injury, or disability."[12]

This paper reviews four of the more advanced integrated child health information systems in hopes of sharing valuable lessons with those working on integrated health information systems and the Electronic Health Record (EHR).

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[4] Institute of Medicine. The Future of Public's Health in the 21st Century. The National Academies Press 2003. Available at http://bob.nap.edu/books/030908704X/html/

[5] Association of State and Territorial Health Officials. Issue Report: Integrating Information Systems to Improve MCH. December 2003. Available at: http://www.astho.org/pubs/IntegrationIssueReport-final.pdf

[6] Public Health Informatics Institute. Integrated Child Health Information Systems: An update on the status and near-term future of information systems that consolidate information about the multiple health care services a child receives. May 2004. Available at: http://www.phii.org/Files/IntegratedCHIS.pdf

[7] Fehrenbach SN, Kelly JCR, and Vu C. Integration of Child Health Information Systems: Current State and Local Health Department Efforts. *Journal of Public Health Management and Practice*. 2004; Nov(suppl):S30-S35.

[8] Covered entity—health plan, healthcare clearinghouse, or healthcare provider as defined by the HIPAA Privacy Rule [45 CFR 160.103]

[9] Hybrid entity—a single legal entity that is a covered entity, whose business activities include both covered and non-covered functions, and that designates healthcare components in accordance with paragraph 164.105(a)(2)(iii)(C) as defined by the HIPAA Privacy Rule [CFR 164.103]

[10] Consistent with [45 CFR 164 subpart C]

[11] Consistent with [45 CFR 164 subpart E]

[12] Consistent with [45 CFR 164.512(b)(1)(i)]

MISSOURI

Overview of the Missouri Health Strategic Architectures and Information Cooperative (MOHSAIC)

The Missouri Department of Health and Senior Services (MDHSS) developed MOHSAIC to be a fully integrated electronic public health medical record. Planning for the integrated information system began in the early 1990s as one of the objectives in the Department's Year 2000 Plan. At the time, Missouri ranked 49th in childhood immunizations. While the Department could report how many vaccines were administered, it could not determine how many of these vaccines were given to children. Nancy Hoffman, Deputy Director of the Center for Health Information Management and Evaluation in MDHSS said, "We were data rich and information poor. And so we decided it was time to do something different."

INTEGRATED DATA SETS
- Registration, demographics, scheduling, and inventory
- Immunizations and tuberculosis skin testing
- Family Planning
- Service Coordination
- Early Periodic Screening and Diagnostic Testing/Healthy Children & Youth (EPSDT/HCY)
- Traumatic Brain Injury eligibility
- Lead
- Family/Care Safety Registry
- Bureau of Narcotics and Dangerous Drugs
- Child Care licensing
- Newborn Hearing and Metabolic Screening

LINKED DATA SETS
- Birth Records
- Medicaid eligibility files
- The Department of Social Service managed care/primary physician
- Private physician records
- Special Supplemental Nutrition Program for Women, Infants, and Children (WIC)
- Laboratories
- The integrated disease surveillance system

Fig 1: Data sets integrated into and linked to MOHSAIC.

MDHSS pulled together all the division directors to design an integrated health information system. Strong support from the state's executive leadership and the involvement of key stakeholders including representatives from the local public health agencies, the Missouri Nurses Association, the Hospital Association, and the Primary Care Association helped the division directors design MOHSAIC. Currently, there are thirteen data sets integrated into the system, meaning that the data reside in the MOHSAIC database (See figure 1). Eight data sets are directly linked to the database. Though the data in these data sets are not stored in MOHSAIC, they are accessible in real-time through a direct link between MOHSAIC and the respective database housing the information. The MOHSAIC database is centralized with one client record per patient. For infants born in Missouri, an initial client record is generated from the birth certificate files. Household records are linked allowing for family management of health services. For example, when a child comes in to receive an immunization and his or her record comes up, the provider may see that the child's sibling is also due for an immunization. If available, the second child can be vaccinated on the same visit, saving both the provider and the family time.

Privacy Protection

To protect clients' private health information, each MOHSAIC user must sign a confidentiality agreement and is given a user identification name and password to the system. Access to MOHSAIC is role-based. Roles are determined by programs as they are integrated into the system with privacy laws and the "need to know" governing who receives access to what data. Within each program, there can be multiple types of roles. Some users can only view data while others may update or add data. There are similar roles for administrators. Access to information is determined at the screen level. This means when a user does not have access to a specific data set, the tab for that set will not appear on the user's screen when he or she requests the client's record. Additionally, users can only add to the record. Information cannot be deleted. The system audits which users access or make additions to specific records and when these changes occur.

State law requires parental consent to share results of the dried blood spot newborn screening with those undertaking the care of the child. The system tracks consent, ensuring that consent has been given before the results are made available.

HIPAA Effect

Thus far, HIPAA has not prevented integration of any data sets into MOHSAIC. Missouri is designated a Hybrid Entity under HIPAA and most of the services provided are mandated under state public health laws. These state laws provide guidance on sharing of data. The Family Education Rights and Privacy Act (FERPA) imposes more restrictions with respect to data sharing between schools and local public health agencies. These agencies must seek parental authorization to receive data from the schools.

Initially, the HIPAA Privacy Rule limited buy-in from Missouri providers. They were concerned about data security and preferred to keep patient information on their own office computers, which they knew to be secure, rather than in a statewide database. However, education efforts detailing data security features of MOHSAIC alleviated this resistance, and providers ultimately joined the system.

The time and resources needed to comply with HIPAA had a financial impact on the development of MOHSAIC. MDHSS invested funds to build the necessary infrastructure and assess vulnerability in order to ensure the security of the database. The state bolstered its administrative policies in response to HIPAA. In addition, regular walk-throughs in state offices identify and correct weaknesses in privacy protection.

Benefits of MOHSAIC

MOHSAIC facilitates coordinated delivery of health services for children. Parents no longer need to keep track of their child's immunization or other public health service records. In MOHSAIC, a client's entire health profile is available in one location. This record can be accessed from any authorized MOHSAIC user in the state. When patients move, their records follow them. Parents are also able to retrieve health information from MOHSAIC through the MDHSS. Currently about 68 percent of Missouri's two-year-olds have immunization records in MOHSAIC.

The integrated system benefits providers by saving them the time and effort of searching for patient immunization records and other screening results. Additionally, the linkage of family members in the system allows physicians to practice family health management.

Using MOHSAIC at the population level allows MDHSS to turn data into useful information, improving their epidemiology and the state's ability to make informed public health decisions. For example, the state can examine vaccination rates among age cohorts, find "pockets of need" for a particular health service within the state's population, or map elevated blood lead levels with geographic information systems (GIS) to determine where lead abatement is necessary.

The Missouri Department of Health and Senior Services also noted that since launching MOHSAIC, they can provide better information to policymakers in less time. Legislators can then use the information to make policy decisions.

Challenges

Missouri faced a few difficulties in implementing its system in addition to limited initial provider buy-in stemming from HIPAA concerns.

The integrated system was difficult to build from a technical standpoint. Each program utilizes the same basic demographic information but has additional unique information and preferences for how the information should be arranged. Managing the needs of and gaining consensus from so many different programs was complex.

Now that MOHSAIC is operational, lack of financing presents a challenge. Many funding opportunities are available for development of integrated health information systems, but little is available for maintenance of them.

Conclusion

Strong executive leadership and directors dedicated to their shared vision for MOHSAIC enabled MDHSS to design an integrated health information system. HIPAA presented a few challenges to the expansion of MOHSAIC, mostly related to provider concerns about the security of data stored in the system. Providers were apprehensive to disclose data to MDHSS. Missouri overcame this by educating providers on security features included in MOHSAIC and the public health exemption under HIPAA. Funding for maintenance and expansion of MOHSAIC continues to be a challenge for MDHSS.

OREGON

Overview of FamilyNet

The Oregon Department of Human Services (ODHS) developed FamilyNet with the goals of creating individual health files with integrated program data, improving data capture and health services administration, and better utilizing information. Currently, the system integrates data collection and use at the point of service from two state programs (see figure 2). Oregon's strategic plan for FamilyNet calls for integration of six additional components.

In FamilyNet, each client has a single record in the central client master. This record contains the client's computer generated ID number and basic demographic elements (name, address, date of birth, etc.). The program modules are linked to each other through the client master system via the client's ID. However, each module remains separate and adaptable to the program's needs.

CURRENT DATA SETS

- WIC Program: The WIC Information System Tracker (TWIST)
- Immunization Program: Immunization Record Information System (IRIS)
- And the Oregon Immunization ALERT Registry

FUTURE ADDITIONS

- School-based health centers
- Women's reproductive health
- Day care
- Nurse consulting
- The Family and Child Module (FCM)
- Group education, monitoring and screening

Fig 2: Data sets currently included in FamilyNet and data sets in ODHS's strategic plan for future addition to FamilyNet.

Privacy Protections

FamilyNet users log on with a user ID and password. User access is role-based. A user's role controls which screens or functions that person can view or update. The role in the system is determined by the "need to know" and the user's relationship with the client. Programs, such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and Immunization, establish Data Sharing Agreements between themselves in accordance with HIPAA and other privacy laws. Without a Data Sharing Agreement, data sharing only occurs within a program module.

When a module serves more than one program, Oregon seeks client or parental consent for sharing of a client's health information among programs or providers. Parents can choose whether or not to share their child's information.

The combination of these two privacy measures creates a "lock and key" model for data security. Parental consent for data sharing, Data Sharing Agreements, and public health laws comprise the "lock" on a client's information. A user's role in the system and their relationship to the client serve as the "key" to unlock only the minimum necessary information in the client's record.

During the design process, Oregon brought in a HIPAA privacy expert to assist with planning. This expert pointed out potential vulnerabilities and areas of concern the public may have, and provided examples of how private organizations dealt with these matters. Using the HIPAA privacy expert's report and the DHS Security Office's assistance, Oregon created a data access policy for FamilyNet.

HIPAA Effect

Integration of data sets has not been prevented by the Privacy Rule, but privacy protections included in FERPA preclude integration of early intervention programs. This has affected the Early Hearing Detection and Intervention (EHDI) program, which will be in the Family and Child Module. Concerns about FERPA delay the agreement of local Early Intervention (EI) offices to participate in EHDI. ODHS is working with the state's Department of Education on a solution to this challenge.

Initially, parents and healthcare professionals were wary of the integrated information system. Effectively communicating how records can be stored securely in a large database with access to information limited by the user's role in specific programs can be challenging. To help Oregonians understand how FamilyNet protects patients' health information, ODHS created a communication strategy. The strategy targets clients, parents, and healthcare providers, educating them on the security measures that safeguard their protected health information (PHI) and how better technology allows this.

ODHS also noted the financial impact of HIPAA. The state invested heavily to build a compliant information system. A partnership with the Health Alert Network (HAN) helps to fund the installation of infrastructure necessary for connectivity in the state.

Benefits of FamilyNet

Since the launch of FamilyNet, client care is more coordinated. Providers are benefiting from fewer duplicative data entries, ease of use, and greater connectivity resulting from infrastructure upgrades necessary for FamilyNet. Sherry Spence, Maternal and Child Health Data Systems Coordinator for the Office of Family Health, reports, “Many providers see returns on their initial investments within one or two years of joining FamilyNet.”

At the population level, FamilyNet allows the Oregon Office of Family Health to better assess needs and evaluate their programs. They receive better data with less duplication. Additionally, because changes in the system are seen instantly, the Office of Family Health can see changes in health trends as they happen rather than simply looking at two points in time. This allows for better surveillance and longitudinal tracking of immunizations, program participation, and outcomes, leading to proactive program planning and outreach efforts.

Challenges

Financing proves challenging for ODHS as it builds the necessary infrastructure to support FamilyNet. ODHS is working to overcome this barrier by collaborating with other national, state, and local government agencies and private sector organizations in the information system development process and to improve connectivity throughout the state of Oregon by upgrading the IT infrastructure.

Financing for expansions and maintenance of the integrated child health information system continues to present challenges for ODHS because limited funding opportunities for expansion and maintenance of integrated health data systems exist.

Conclusion

The obstacles Oregon faced with respect to HIPAA revolved around funding for IT infrastructure, cooperation of healthcare providers, and buy-in from parents. Partnerships helped with financing challenges and acceptance that FamilyNet is indeed HIPAA-compliant. Oregon also anticipated difficulty “selling” parents on the benefits of health data sharing. A communications strategy, which details the security features of FamilyNet and how data access is managed, alleviated most parental concerns. Funding for expansion of FamilyNet continues to challenge Oregon. The state also noted that FERPA and other states’ laws regarding interstate data sharing may limit data integration more than HIPAA.

RHODE ISLAND

Overview of KIDSNET

The Rhode Island Department of Health (RIDOH) created its integrated child health information system, KIDSNET, to ensure that all children receive preventive care that is coordinated and comprehensive while offering better service to families.

Currently, KIDSNET includes data from ten programs (see figure 3). RIDOH plans to expand KIDSNET to include even more programs. Additionally, they plan to share relevant information with the Rhode Island Department of Children, Youth, and Families for children already in foster care.

The momentum to build an integrated information system arose when RIDOH started developing its immunization registry. Around the same time, families in Rhode Island expressed frustration over the various health programs requesting the same information from them. The state decided it would be best to integrate the immunization registry with data from other health information systems to facilitate information sharing.

To steer the development of KIDSNET, RIDOH formed an internal working group. This group determined which programs share data through development of an integrated database. Additionally, an advisory group of both internal and external representatives was convened to help develop policies for data access privileges and address other privacy concerns.

CURRENT PROGRAMS
- Immunizations
- Newborn Developmental Risk
- Vital Records
- Lead Poisoning Prevention
- Early Intervention
- Home Visiting
- WIC
- Newborn Bloodspot
- Newborn Hearing Screening
- Birth Defects

POSSIBLE FUTURE ADDITIONS
- School Hearing Screening
- Foster Care
- Children with Special Health Care Needs

Fig 3: Programs currently contributing data to KIDSNET and programs RIDOH is considering as future additions to KIDSNET.

KIDSNET is a data warehouse. The data sets are stored in a central database but can be accessed by providers and programs throughout the state of Rhode Island via a server. Those programs for which no previous independent data system existed (e.g., immunizations and home visiting) have complete data sets stored in KIDSNET. Those programs with pre-existing data systems (e.g., WIC, early intervention, and newborn screening) have a subset of their data stored in KIDSNET.

Privacy Protections

Access to KIDSNET is role-based and determined at the programmatic level. Individual users and groups have their level of access specified in User Agreements or Data Sharing Agreements. Access is based on the "need to know." Users are allowed to access certain screens based on their privileges. For example, if a user does not have access to WIC information, WIC data screens are not available to that user. User IDs and passwords enable the system to audit who accesses or changes what information and when and where the user makes changes. The system creates daily logs of this information and identifies activity occurring at odd hours.

Rhode Island law allows for sharing of health data among qualified health care professionals or their designees without patient consent for the purpose of coordination of care.[13] Although consent is

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[13] Consistent with Rhode Island General Laws Chapter 5-37.3 Confidentiality of Health Care Communications and Information Act

not required, families can choose to block data sharing in KIDSNET. RIDOH provides information to parents explaining the purposes of KIDSNET and informs parents about their option to block the sharing of their child's information. RIDOH distributes this information shortly after birth and in pediatricians' offices. A new notification brochure will be distributed when prenatal care is sought as well as at birth. RIDOH also maintains a help line to discuss data sharing options with families in the state.

HIPAA Effect

KIDSNET was implemented prior to HIPPA. Initially, providers feared that managed care organizations (MCO) would get access to practice level or individual level information that could be used punitively against them. To resolve this concern, the KIDSNET User Agreement explicitly stated that MCOs would not have access to identifiable KIDSNET data without provider permission. These concerns no longer exist and as such, the provider agreement has been modified.

To date, HIPAA has not prevented integration of any data sets into KIDSNET. Initially, some providers hesitated enrolling in KIDSNET due to HIPAA concerns. The providers' concerns centered on ways to transmit data to KIDSNET, especially in the case of electronic data transmission. RIDOH used its Provider Relations Unit to address these concerns and to educate providers on the public health exemption from HIPAA and the benefits of sharing data. When providers saw the benefits of data sharing among providers, they became more willing to participate. Today, 70 percent of Rhode Island pediatric and family practice providers use KIDSNET.

Benefits of KidsNet

According to Amy Zimmerman, Chief, Office of Preventive Children's Services at RIDOH, KIDSNET helps programs and providers identify children in need of preventive services. Medical providers utilize the system to improve their provision of preventive health services and now have a stronger relationship with RIDOH. Implementation of KIDSNET also assisted in building the IT infrastructure within the department.

The integrated system permits better surveillance of unmet health needs at the state level. It also reduces errors of omissions, meaning the state can see specifically which children have not been screened or immunized. "With comprehensive, cross-program data from KIDSNET, Rhode Island can target outreach efforts and better serve children in the state," according to Amy Zimmerman. The Department also uses data from KIDSNET for Title V performance measures.

Challenges

Adequate staffing was a challenge for RIDOH as they designed and launched KIDSNET. Initially, no new positions were provided, and KIDSNET was staffed using existing personnel. Furthermore, as the project gained momentum, workloads increased, but the number of staff on the project did not. Eventually the need for provider relations and data management staff was recognized and RIDOH obtained additional staff to meet these needs. Appropriate staffing remains a consistent challenge. Retaining staff has often been difficult. The resulting turnover created ongoing training needs in many areas, especially related to privacy policies and HIPAA. Lastly, training existing staff on informatics and privacy issues also needed to occur.

Like other states who have implemented integrated child health information systems, RIDOH now faces financial challenges in maintaining KIDSNET. Once a system is developed, limited funding is available for maintenance or enhancement.

Keeping pace with technology presents another challenge that is further complicated by limited financing. When RIDOH first designed KIDSNET, it designed system access to meet the lowest common denominator among users. By the time KIDSNET went online, the dial-up access system and its technology were obsolete. RIDOH overcame this hurdle by making the system web-enabled.

Conclusion

As in Missouri and Oregon, HIPAA did not hinder integration of any data sets into KIDSNET. However, some Rhode Island providers were reluctant to use KIDSNET due to data security concerns. RIDOH used its Provider Relations Unit to address concerns around data security, the public health exemption, and benefits of data sharing. Funding for maintenance and the expansion of KIDSNET, retention of staff, and training existing staff on informatics and privacy issues continue to challenge RIDOH.

UTAH

Overview of the Child Health Advanced Records Management (CHARM) System

The Utah Department of Health (UDOH) developed CHARM to achieve patient centricity and see data across programs. The UDOH established a core team consisting of managers of those programs which were to be included in the system and a steering committee composed of higher level executives such as division directors and deputy directors.

CHARM links data from birth records, newborn metabolic screening, newborn hearing, early intervention, and immunization records. Future linkages include birth defects, children with special health care needs, lead screening, WIC, neonatal follow-up, Early Periodic Screening, Diagnosis and Treatment (EPSDT) which is Utah's version of Medicaid's Child Health Evaluation and Care (CHEC) federal program, the Children's Health Insurance Plan (CHIP), and foster care.

CHARM follows a shared data set model. Data are not stored in a centralized warehouse but rather remain within the individual programs. A unique CHARM ID links data between programs. Data exchange occurs via a Service Oriented Architecture (SOA), meaning that a program must request a service—in this case, data organized in a pre-determined way—which is then delivered to the requesting program from the program holding that piece of information. The program that holds the data specifies what data and services it can provide.

Privacy Protection

CHARM protects patient information in several ways. Each CHARM user has a login ID and password. Once a user logs in, the system audits his or her activity to determine which data the user requests and when they request it. Two levels of access exist within each program: users and administrators.

Additionally, the federated data architecture of CHARM prevents break-in to a child's entire health record. Information exchange occurs virtually through the CHARM server by way of the child's CHARM ID number. The CHARM ID number is mapped to the child's ID number in each participating program, but as a protective measure, individual program ID numbers are not stored centrally with the CHARM ID and the CHARM ID is transparent to the users.

The SOA nature of CHARM also protects privacy. CHARM programs develop Data Sharing Agreements to determine which other programs have access to what data and for what purposes. These agreements outline SOA rules that then govern access within the CHARM system. When a data request is made, CHARM verifies the user's access privileges and disseminates the appropriate records. The SOA nature of the system prevents data mining, allowing only requests for subscribed services.

Finally, parents may exercise their right to limit sharing of their children's health information by opting out of the CHARM system.

HIPAA Effect

Thus far, CHARM integrated all desired data sets in compliance with HIPAA, but the Privacy Rule did moderately limit buy-in from programs who were concerned about their ability to maintain the security of their data in a shared access system. Education and Data Sharing Agreements alleviated these concerns. FERPA proved to be a difficult obstacle when UDOH decided to link the Early Intervention Program to CHARM. UDOH overcame this barrier by obtaining parental consent for data sharing in CHARM.

Benefits of CHARM

Since UDOH is still implementing CHARM (see figure 4), long-term benefits are unknown. However, during the implementation process, UDOH lowered the threshold of participation for programs by leaving data storage and management under the control of individual programs. Also, by maintaining separate databases, the CHARM system came together with greater ease than it might have in the case of a consolidated database where all data are centrally warehoused.

Implementation Schedule

- March 31, 2005: Vital Records, Newborn Hearing Screening, and Immunizations launches
- May 31, 2005: Newborn Bloodspot Screening will be added
- June 30, 2005: Early Intervention will be added

Fig 4: Schedule for implementation of CHARM components.

Challenges

Early in development, many programs were skeptical that CHARM's shared data set model would work. Programs in UDOH expressed concern about retaining their ability to control data access. Receiving additional information about CHARM's security and privacy features and seeing the first three programs go online eased most of the worry and doubt. Rhoda Nicholas, Chief Information Systems Officer, UDOH, says, "Now programs ask when they will be allowed to join CHARM."

Conclusion

UDOH is still early in the implementation of CHARM. So far, HIPAA has not prevented integration of any data sets into CHARM. Some programs expressed early concerns about HIPAA and privacy, but allowing programs to form their own Data Sharing Agreements and publish their own data services allayed most of these concerns.

Major Themes

Building Systems

State public health agencies in Missouri, Oregon, Rhode Island, and Utah found ways to construct integrated child health information systems based on their own needs and resources. For instance, the MDHSS fully integrated most of their data sets into MOHSAIC. ODHS's FamilyNet and RIDOH's KidsNet are mixes of integrated and linked information systems, and the CHARM system, developed by UDOH, links separate programmatic databases through a unique CHARM ID. These differing approaches can serve as model systems for other states working to build integrated child health databases. Additionally, the strengths of these varying architectures may provide insight on building EHRs at the national level.

Leadership and Vision

Successful development of integrated child health information systems relied upon the involvement and support of executive leadership within the state public health agencies as well as guidance from program directors, and other key stakeholders who created and still maintain a shared vision for their state's integrated information system. Nancy Hoffman, Deputy Center Director, Center for Health Information Management and Education, Missouri Department of Health and Senior Services, says, "In order to be successful, you have to understand what you are trying to accomplish."

Each of the four state health agencies also had some form of steering committee to guide the development of the integrated system. Steering committees usually consisted of program directors within each state health agency. All four states shared the goal of delivering more coordinated care to patients, and the steering committees in each state strategically designed information systems to benefit their states' public health system. However, the customer, or patient, was the ultimate stakeholder and beneficiary.

Privacy

The HIPAA privacy rule complicated design of integrated health information systems, but state public health agencies managed to find solutions to most challenges related to HIPAA, and moved forward with their systems. These solutions include building privacy protections into the information system, improving IT infrastructure in health departments and among users of their systems (e.g., installing firewalls), assessing vulnerabilities in their systems, and educating system users about patient confidentiality and HIPAA.

While state public health agencies were able to implement HIPAA compliant information systems, attaining compliance did not come without spending human and financial resources. Designing compliant systems took time, and the necessary infrastructure development and improvement required financing.

The privacy protections built into each integrated information system are very similar despite variation in the overall design of the information systems. Each of the four systems utilizes usernames and passwords to access the system. A user's role in the system governs his or her access to data. The user's "need to know" and Data Sharing Agreements among programs or departments determine a user's role. Data Sharing Agreements take into account HIPAA and other state and federal privacy laws. Additionally, each of the systems monitors access and generates activity logs indicating who access what data and when they access it.

All four state health agencies reported that HIPAA has not directly prevented integration or linkage of any data set into their respective systems up to this point. However, potential users of the integrated systems expressed early concerns about sharing data with the systems and cited HIPAA as a reason for this concern. In each state, education focusing around data security features of the system as well as the public health exemption to HIPAA lessened these apprehensions.

Other state and federal laws related to privacy pose a greater barrier to integration of health data sets. Restrictions in FERPA have delayed integration of early intervention program data into CHARM in Utah and FamilyNet in Oregon. Missouri and Rhode Island also expressed concern that FERPA may create similar difficulties for their state health agencies as they expand their information systems to include data sets from schools. Additionally, it is not known how various state laws may affect interstate exchange of child health data.

Benefits to Stakeholders

The states profiled here benefit greatly from integrated information systems. Providers, programs, and the state health agencies use their systems as tools. Simply having an integrated information system does little or no good. The data from the systems must be utilized in a meaningful way.

The benefits of integrated child health information systems to delivery of health care are many and can be seen at the micro- and macro-levels.

State health agencies receive more complete and timely data regarding the health of children in their state. Integrated information systems enable states to do population-based research and see data trends much more quickly. This leads to better surveillance, needs assessment, program design, outreach, and program evaluation. States can use the data garnered from integrated child health information systems to provide policymakers with better information by which to enact sound policies.

Integrated child health information systems benefit providers as well. Physicians and nurses spend less of their valuable time tracking down patient health records. Furthermore, providers know their patients' medical histories better and thus can deliver better care to them.

Coordinating care was an overarching goal for integrating child health databases. Patients receive more coordinated health care because of improved service offered by state health agencies, participating programs, and providers.

Looking Forward

In April 2004, President Bush revealed his vision for health IT. Components of this vision include fully interoperable EHRs, which include a patient's full medical history and allow for electronic ordering and electronic health reminders.[14] Under the President's Executive Order, the Office of the National Coordinator for Health Information Technology (ONCHIT) is charged with implementing the President's vision for widespread adoption of interoperable EHRs by 2014.[15]

Integrated child health information systems aim to improve child health by better coordinating patient care and collecting more accurate, timely information at the individual and population levels. The movement behind EHRs focuses on quality improvement, so those developing EHRs need to determine how they can leverage the information learned while building integrated child health information systems, which provide concrete models for the development of EHRs.

Integrated health information systems were designed to reduce duplicative data entries. However, reducing duplicative entries requires greater data sharing. It is important to reach a balance where duplicative entries do not interfere with the benefits of the integrated system and data sharing is restricted to a level with which patients, providers, and programs are comfortable. Finding this balance may be especially important with respect to EHR development because privacy is a chief concern, especially in regards to misuse of data contained in the record. Lessons learned regarding protection of privacy and HIPAA compliance by those who have created integrated child health information systems may be especially valuable for those developing the EHR.

In addition, the lessons learned by those who developed integrated child health information systems related to leadership, vision, system design, and infrastructure may also be important as the U.S. moves forward to develop EHRs.

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[14] Department of Health and Human Services (DHHS), Office of the National Coordinator for Health Information Technology, President's Vision for Health IT. Available at: http://www.os.dhhs.gov/healthit/presvision.html

[15] DHHS, Office of the National Coordinator for Health Information Technology, Mission. Available at: http://www.os.dhhs.gov/healthit/mission.html

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Department of Education, Family Education Rights and Privacy Act (FERPA) www.ed.gov/policy/gen/guid/fpco/ferpa/index.html

Office of the National Coordinator for Health Information Technology www.os.dhhs.gov/healthit/

Online Resources

Federal Government Resources

CDC Privacy Guidelines
www.cdc.gov/privacyrule

CDC Division of Public Health Surveillance and Informatics
www.cdc.gov/epo/dphsi/index.htm

HRSA Maternal and Child Health Bureau
http://mchb.hrsa.gov/

Department of Education, Family Education Rights and Privacy Act (FERPA)
www.ed.gov/policy/gen/guid/fpco/ferpa/index.html

Department of Health and Human Services Office of Civil Rights-HIPAA Guidelines
www.hhs.gov/ocr/hipaa

National Center for Health Statistics
www.cdc.gov/nchs/default.htm

National Committee on Vital and Health Statistics www.ncvhs.hhs.gov

National Institutes of Health
http://privacyruleandresearch.nih.gov/

Office of the National Coordinator for Health Information Technology

www.os.dhhs.gov/healthit/

State Government Resources

Missouri Department of Health and Senior Services www.health.state.mo.us

Oregon Department of Human Services
www.oregon.gov/DHS/index.shtml

Rhode Island Department of Health
www.health.state.ri.us

Utah Department of Health
http://health.utah.gov

Associations, Nonprofit Organizations, and Academic Resources

American Hospital Association-HIPAA
www.hospitalconnect.com/aha/key_issues/hipaa/index.html

American Medical Association www.ama-assn.org/ama/pub/category/4234.html

Association of State and Territorial Health Officials www.astho.org

Georgetown University Health Privacy Project http://healthprivacy.org

Joint Healthcare Information Technology Alliance www.jhita.org

National Association of Health Data Organizations www.nahdo.org

National Association of Insurance Commissioners
www.naic.org/privacy/initiatives/health_privacy.htm

National Governors Association
www.nga.org/center/HIPAA

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