

This document is offered as written testimony to the American Health Information Community (AHIC) Population Health and Clinical Care (PHCCC) sub-committee. It is our understanding that the PHCCC is focusing on the actual experiences integrating child health information systems, the challenges and barriers that these efforts have faced, and strategies to overcome the challenges. (The Public Health Informatics Institute is a program of The Task Force for Child Survival and Development, a non-profit 501(c)3 corporation.)

As one of the few national level groups working with states specifically on the topic of child health information systems integration within public health departments and in linkage with private health care providers, we believe we have a unique perspective to add. Our comments will focus on the national trends we have identified over the past six years of working with members of the *Connections* Community of Practice (Connections CoP).

Background

The *Connections* CoP was established in June 2001 as part of the All Kids Count project, a national initiative funded by Robert Wood Johnson Foundation to promote the development of immunization registries. In 2004, the Genetics Services Branch of the Health Resources and Services Administration/Maternal and Child Health Bureau (HRSA/MCHB) adapted the existing *Connections* group to support grantees that were specifically working to integrate information system essential to improving the health of children. The *Connections* CoP has an overarching goal to *increase the adoption and use of integrated health information systems to improve health outcomes for children*. The collaborating partners are working to improve health outcomes for children in the United States through development of child health profiles that support clinical decision making.

Which systems comprise Maternal and Child Health?

At this time, the most common programs areas whose information systems are being integrated throughout the US are those that focus on screening at the time of birth, and services delivered in the early childhood years. These include:

- Newborn Dried Bloodspot Screening
- Newborn Hearing Screening
- Vital Records
- Immunization
- Lead Screening

Some states are integrating data from additional early childhood programs such as WIC, early intervention programs, and Medicaid. Very few places have integrated information systems for more than two or three program areas. Exceptions include Utah, Michigan, and Rhode Island, all of which have more than three systems integrated.

a. To what extent are these systems integrated with each other?

Most states have one or two systems integrated, or are working to integrate vital records with either Newborn Dried Bloodspot screening or Newborn Hearing screening.

b. Are they integrated with electronic health records?

In a few places throughout the US, results are shared electronically via websites. Most are not specifically integrated with EMR's. As nationally endorsed standards emerge through the AHIC process, we foresee most public health agencies adopting those standards and redesigning legacy systems to make the exchange of data with EHRs a reality.

c. Are they integrated with registries associated with MCH (e.g. lead, asthma, birth, death?)

The most common registry system that is integrated starts with an Immunization Information System (IIS). [IIS have a longer history of development and standardization, and, as such, are further along in integration efforts]. IIS were the public health program that led the way for linkage with the healthcare delivery sector. IIS possess most of the attributes of a clinical information system (e.g., person-centric records capturing a longitudinal history of care delivered to a child and also supporting decisions at the point of care). Consequently, when states begin thinking about a suitable integration platform for public health systems and a platform for linkage to EHRs, they often conclude that the immunization registry is their most robust platform and the most logical point at which to begin extending the data model to include other programmatic data. As of December 2006, 65% of all children <6 years of age in the US are participating in IIS.

d. Are they able to electronically share information with "like-systems" in other jurisdictions? Dept Ag & WIC?

There are instances in which systems are sharing data with "like-systems" including WIC and Medicaid in the same jurisdiction. Few are sharing information across jurisdictional lines. Much remains to be done in this area.

e. How do you electronically identify pregnancy?

We are unable to respond to this question.

2. What changes can be made to make these systems more consumer-based? Some LHDs and SHDs have to access up to 6 systems to serve 1 child or mother.

Many configurations of hardware and software can bring information together to create a consolidated, unified view of data that public health holds on a given child. The Institute promotes a definition of "integration" that is not tied to hardware or software, choosing to emphasize that it is the presentation of information to the user in an integrated fashion that should define the term integration. This definition presumes that:

1. The integrated information systems are capable of producing a consolidated record, i.e. an authorized user can view at a glance, the services the child has received from the public health systems.
2. The exchange of health information is bi-directional. That is, clinical care providers and other authorized users of the integrated system are able to update records electronically.
3. The information needed is available to authorized recipients in "real time", i.e. at the point of service provision versus retrospectively.
4. This functionality of the information systems is "seamless" i.e. the interoperability of systems occurs regardless of the hardware and software of each user.

The Institute has worked with almost half of the state maternal and child health programs on our child health information integration initiatives. From this experience we find that many are focused on managing their programs wisely within the resources allocated, which is understandable. However, a narrow programmatic focus often conflicts with adopting a customer focus. Recently, we have begun urging public health agencies to view themselves as one node on the larger network of NHIN nodes, whereby a properly authorized and authenticated users and authorized medical practitioners should be able to make a single query and receive in return a consolidated record of information on a child in a timely manner. We find that refocusing public health agencies on a different point of view motivates a greater willingness to consider system integration efforts.

a. What are the points of integration across these systems that would result in a solution that better serves the consumer?

Building a master person index (MPI) represents the single biggest step a public health agency can take towards making its information bases more accessible to authorized providers and families. In partnership with our *Connections* CoP members, we published the Unique Records Portfolio, a book detailing the various architectural options available to organizations that seek to integrate person-centric records into an integrated system. The various architectures demonstrate that regardless of an agency's legacy systems it is possible to create a single record of information held by a public health agency and to deliver that record to a requestor on demand.

We find that public health data integration is best understood as integration within 1 of 3 major domains: surveillance, care management/coordination, and policy/regulatory. Each of these domains operates under very similar business processes consistent throughout the domain. By focusing on the business process rather than the data specific to a given disease program, disease management or a regulatory program, it is possible to show that the automation of common task sets creates a logical point of system integration.

We support the general trends towards e-government and a greater attention to customer focused information delivery by public health agencies. As we work with local and state public health agencies across the country, we find universal support for a more customer-focused approach. The single biggest barrier to moving rapidly in this direction is funding. The second biggest obstacle is the lack of a comprehensive information architecture that supports greater bi-directional information flow between public agencies and private health care and other partners. Rigorously conceived information architecture would address the need for an MPI and comprehensively described and documented business processes. We find that state and local programs follow carefully the architectural announcements of NHIN and PHIN but fail to extend these into state-wide or local/region-wide architectures that will be needed by them to bring universal interoperability to a working reality.

3. Do standards exist to guide the development of MCH systems?

The Institute has created several publications that document success factors in creating integrated child health information systems (ICHIS), however there has been little work completed regarding traditional "standards development" for ICHIS. Because of the variation in the ways maternal and child health programs are organized within public health agencies, there remains some confusion over exactly what "MCH systems" includes. For example, an agency that manages immunizations and lead poisoning prevention within a single MCH department may view these as MCH systems, while an agency that places lead poisoning in an environmental unit may not see it as a MCH system. We believe that AHIC should work closely with HRSA/MCHB, relevant CDC programs and the Association of Maternal and Child Health Programs (AMCHP) to define which functions and responsibilities fall within the MCH reference and, based on this definition, which aspects of automation of those functions should be considered targets for integration. Assuming core functions of MCH programs can be identified, it becomes much more likely that system and data standards will be possible to propagate throughout the states. A legacy of categorical funding for disease programs coupled with the block grant for general attention to MCH has led to a highly fragmented information environment that is less informative to care providers and health policy makers than it should or could be. Our experience has been that there is a reservoir of willingness to reconsider systems and the information they generate if funding could be made available to adopt a new approach and new generation of systems.

4. Which systems should be integrated with EHRs or HIEs?

At a minimum- the five core programs of early childhood that have been identified are being considered as the "core" information for creating a consolidated record, which we refer to as a "child health profile", a concept developed and promoted by the Genetic Services Branch of HRSA\MCHB. These include: vital records, immunization, lead screening, newborn hearing and newborn dried bloodspot screening.

a. What information should be sent to the MCH systems?

As mentioned earlier, the goal of creating integrated child health information systems includes the functionality of “bi-directional” communication between public health program service areas and clinical care providers in the community, laboratories, hospitals and other authorized users. This allows the clinical care provider to update an individual child’s (or mother’s) record for demographic information, immunizations administered, results of audiology examinations, confirmation of follow-up for infants requiring further diagnostic testing when identified through newborn dried bloods spot screening as at risk for metabolic or genetic disorders, and lead screening results. For children with special health care needs, such as those identified through newborn screening, there needs to be a radically improved system supporting long-term follow-up and care coordination. MCH programs today cannot, in most locales, fulfill the assurance role of public health – that is, they cannot tell if a child is receiving necessary or even mandated care, they cannot tell if cost-effective preventive services are being delivered. Thus, for children with special health care needs, care coordination information exchanged among the primary care provider, the medical home, specialists and researchers needs to be addressed immediately.

b. What information should be received from the MCH system?

The concept of the *Child Health Profile* is one that was developed by HRSA\MCHB is promoted through the activities of the *Connections* CoP. The profile is the term we utilize to describe the consolidated record that would be available to authorized users. In reality, most health departments still rely on non-electronic means to share health information including phone calls or faxed messages. From a customer perspective, savvy health departments are realizing that in the information age, it’s not realistic to expect customers to contact each individual program area to find out what services an individual child has received from the public health agency. At a minimum, public health agencies should be able to share screening results and immunizations provided by public health services.

c. For HIEs what information should be sharable within an HIE community?

Data, such as immunization status, newborn hearing results or newborn dried bloodspot lab results, need to be made available to healthcare providers. Public health programs also maintain data needed by providers to assure that scheduled or recommended preventive health services are given on schedule. Thus, one could view data surrounding the neonatal period as one category of data sharable within a HIE community and data about the ongoing delivery of preventive health services as another category. For children who should receive legally mandated services, including children in foster care, notification or status of those services and dates of referral or recent service would help providers avoid duplication of effort, assure optimal health/social/educational outcomes, and help providers guide families/care givers to appropriate community resources. Public health programs also could offer better decision support information through insightful use of EHRs. For example, immunization forecasting algorithms need to work in tandem with EHRs and HIEs to help providers administer the next recommended vaccine based upon a child’s current shot history. As the functions of public health emergency preparedness become better defined, we foresee that event response coordination information should also flow through HIEs.

5. What electronic solutions are available for School Health systems?

We do not work directly with school systems. It is our understanding that in locales where a fully functioning immunization registry exists, school nurses have access to records to help with the school admissions process. Many school based clinics have access to EHR systems. We believe that the AHIC process should reach out to organizations such as the National Association of School Nurses and their member state school nurse associations. Getting these organizations involved early in the interoperability dialogue will pay dividends later. It would also be informative for the AHIC Population health subcommittee to schedule hearings on the challenges posed to data exchange by the Family Educational Rights and Privacy Act (FERPA). Our experience has been that FERPA tends to allow schools to access data from providers and public health but presents barriers to schools exchanging information back to public health programs, such as those involved in assuring appropriate care for children with special healthcare needs.

a. Are they utilized at the primary and secondary school levels?

We do not have experience in this area and cannot comment with authoritative information.

b. Are they linked to immunization registries (IM Systems)? Are they linked to other MCH related Registries (e.g. lead, asthma, birth, death)?

In several states school systems have access to information systems in IIS. In some cases the access is read-only. In other areas authorized users may be able to add information within limits posed by FERPA.

c. What are the potential legal barriers to the exchange of MCH data among the various stakeholders? (i.e. FERPA, WIC regulations)

The two major policies guiding the exchange of information for MCH programs are HIPAA and FERPA. These pieces of federal legislation were developed independently, and often pose problems for the exchange of health information between school systems and the public health system. In our experience, we find FERPA is more of a barrier than HIPAA in the exchange of information. In local jurisdictions, data exchange agreements or memorandums of agreement are developed that address some of these issues. There are proponents that suggest a national level agreement be developed that could be adopted by local and state health departments.

6. In your systems integration efforts, what challenges did you encounter?

There are many challenges and barriers to the sharing of health data between public health agencies, hospitals, laboratories, clinical care providers and community Health Information Exchanges. We've categorized these barriers into three broad areas as a summary of our collective observations of impediments to the electronic exchange of health information.

Policy

- Privacy and confidentiality of health data communicated among healthcare providers – There persists a troubling degree of confusion about HIPAA. The most advanced HIEs seem to have crafted acceptable data use agreements that allow data to be exchanged in accordance with HIPAA. It appears to us that those communities that have fostered dialogue and understanding of about the purpose of the HIE and have shown how data are protected and have presented responsible user authentication policies, have been successful at enrolling practitioners in their information exchange. The most successful immunization registries in states like Michigan demonstrate how these barriers can be overcome.
- Data exchanges with schools remains problematic for public health agencies. Schools in many locales have gained access to immunization registries but FERPA presents barriers to public health and healthcare providers gaining access to school-based health records.

Lack of Infrastructure Support

- Categorical funding of public health services – Public health programs need additional flexibilities in using categorical funds to support integrated infrastructure. While no one wants to see the intent of Congress impeded regarding their directives to federal agencies to promote a specific program interest, it is also fair to say that no one wants to see federal funds spent on duplicative systems that cannot interoperate. Formal policy guidance to federal agencies and to states allowing greater use of categorical funds to support common electronic information infrastructure would accelerate public health conversion to interoperable standards-based systems.
- Lack of dedicated funding for integration of data systems – Maternal and child health programs will require additional financial support to convert to a new generation of standards-based systems. Many of the existing systems are antiquated and unable to be modified to reside in an integration environment and cannot be made to interpret standards-based messages.
- No robust business model for HIE – the major associations of public health have joined together to form the Joint Public Health Informatics Taskforce (JPHIT). This taskforce has been established to respond to the changing e-health environment, to adopt in a nationally uniform manner HITSP and CCHIT interoperability standards and to help public health agencies prepare for linkage to HIEs. When HIEs demonstrate a viable business model, a strong signal will have been sent to partners, like MCH programs, that they must transition to a newer systems

environment. Absent a demonstrated viable business model, it will be hard for state and local legislatures to appropriate funds to support conversion to a new generation of systems.

Lack of coordination and planning for information system development.

- The strong categorical emphasis of public health funding leads to data systems devoted to a single health issue, which thereby reduces the potential for defining data elements in a consistent, standard manner and emphasizing a 'enter once, use many' approach. "Recreating the wheel" each time a data system need is identified leads to a proliferation of systems, none of which will be interoperable outside their silo.
- Variation between states in what services are provided – Even in mandated programs like newborn screening, we see wide variation in how the program is defined. For example, some states define the bounds on screening to end with report of a lab result and notification of a provider when an out of range value is seen. Some states consider it their responsibility to follow a child through the diagnostic phase. Very few receive funding or instruction to assure services through long-term follow-up even though the Secretary's Advisory Committee on Heritable Disorders and Genetic Diseases recommends them to do so.

a. How did you overcome those challenges?

The public health sector lags far behind industry and health care in the electronic exchange of information. In general, our experience has been that technology is rarely the limiting factor.. The barriers experienced in public health are often those of resources and policy, however, one of the greatest barriers to the exchange of information may be the proliferation of information systems that are developed in isolation with little or no thought given to potential interoperability. We promote an approach to systems development which relies on collaboration, engages stakeholders early in the planning phases and gets agreement from stakeholders to work collaboratively.

We have found this approach to be useful in creating successful information technology initiatives (including integration of child health information systems). We define it as "Collaborative Requirements Development Methodology". It is an approach in which public health agencies are brought together to:

1. Analyze their business processes by collaboratively thinking through the tasks they perform to meet specific public health objectives
2. Redesign business processes by rethinking the tasks to improve effectiveness and efficiency.
3. Define information system requirements by articulating with the information system must do to support those tasks.

Successful execution of these elements leads to information systems that meet the full range of needs for multiple stakeholders. For example, in 2002, the Institute worked with 16 public health laboratories on a project to develop information system requirements for Laboratory Information Management. Using a Collaborative Requirements Development Methodology, this project enabled public health agencies to find commonality in their work that could be leveraged in developing information systems. The group defined 16 business processes common to all public health laboratories, which led to the development of a Requirements Definition Document that that allowed public health labs throughout the United states to work with vendors to build products for the Public Health LIMS. For more information, the APHL site includes a summary description of the project:

www.aphl.org/informatics/lims-requirements/pages/default.espx.

Adopting a planning approach for the development of information systems which builds on the commonality of business processes across the public health could be highly beneficial for improving the exchange of health information.

- **In your opinion, what could AHIC do to help remove similar challenges?**
Lack of an information architecture that encompasses MCH – Public health work is gradually being defined in terms of business processes. The Public Health Informatics Institute is presently working in collaboration with HRSA/MCHB and its *Connections* CoP partners to define the business processes of newborn screening. This work is only one piece of the information architecture equation for MCH systems. More attention is needed by HRSA, CDC, AHIC, public health CIOs and the MCH community to define all elements of the needed information architecture. AHIC efforts to date have been very helpful and need to continue.
- Many EMR's have not handled pediatric care appropriately. We believe that the CCHIT interoperability requirements for child health will significantly improve this situation. MCH programs need growth and development data, for example, which will be available through future CCHIT certified systems.
- The general issues of parental notification and consent warrant an AHIC subcommittee hearing unto themselves. The immunization registry experience of the past decade offers the best experience available about which approaches work, how parents and providers can be engaged in the dialogue, and how to engage privacy rights advocates in a productive dialogue.

c. Are there other organizations that should be involved in addressing challenges faced when integrating MCH systems?

The Association of Maternal and Child Health Programs (AMCHP), the American Immunization Registry Association (AIRA), the American Academy of Pediatrics, the American Academy of Family Physicians and Birth Defects Research for Children, Inc. are all organizations that should be consulted. Additionally, the National Association of Chronic Disease Directors includes among its members the state directors of public health chronic disease programs, all of whom deal with aspects of child health. All of these organizations represent leaders who must engage in the integration discussion and must help transform the information infrastructure of their public health agencies.

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