Assessing What Child Health Information Systems Should Be Integrated: The Michigan Experience

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This project examined which child health data would be appropriate and useful to integrate with an existing real-time Michigan Department of Community Health (MDCH) application, such as the Michigan Childhood Immunization Registry. A consultant was secured to conduct data gathering analysis activities. An advisory committee of MDCH Administrators convened to guide the project. Interviews were conducted with MDCH administrators, program managers and representatives from the public and private health care provider community. These interviews focused on answering three main questions: (1) What MDCH data resources do you currently use? (2) How do you use and access these data? and (3) What is your vision for expanding, enhancing, and linking these data to meet Michigan's future health goals? Acceptance of the Michigan Childhood Immunization Registry by the pediatric and family practice community demonstrates the utility of providing more information electronically to the medical community in Michigan. The MDCH has completed a stakeholders analysis and is moving forward with requirements gathering sessions in order to create an integrated child health data system. The integrated child health data system will include data from immunizations, newborn screening, newborn hearing, lead, the Women, Infants, and Children program, and Medicaid.

KEY WORDS: child health, integration, public health data

Michigan Childhood Immunization Registry (MCIR) is a Web-based and robust system that currently stores 2.8 million child records and over 35 million immunization encounters. The purpose of MCIR is to protect communities from vaccine preventable diseases and to ensure that all children in Michigan are appropriately immunized with the most efficient use of program resources.

MCIR is an integral component of the data infrastructure of the Michigan Department of Community Health (MDCH) and interoperates with a number of other systems internal and external to the infrastructure. MCIR is populated with the electronic birth certificate (EBC) of every child born in Michigan since January 1, 1994. Demographic data of all new births are extracted from the MDCH birth certificate system for loading into MCIR on a weekly basis. MDCH currently receives EBCs from all Michigan birthing hospitals, capturing 99% of all births within two weeks. MCIR interoperates with the MDCH death certificate system, from which death records are extracted on a monthly basis and matched to registry records.

Seventy-five percent of private providers of childhood immunizations in Michigan regularly use MCIR. MCIR allows immunization providers to assess the immunization status of a patient, generate clinic profile assessment reports, and generate reminder recall notices for their patients. MCIR receives data from 10 billing systems, 15 Health Systems, and over 2,000 provider offices. Additionally, MCIR is linked to the Women, Infants, and Children (WIC) system and the Medicaid Management Information System (MMIS). These linkages allow MDCH to generate coverage level reports for WIC and Medicaid populations in Michigan. In the fall of 2004, Michigan will release a School Immunization Record Keeping System that is integrated with MCIR for all schools and day cares to report school immunization data on new enterers and all sixth graders in the state.

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All Kids Count invited Michigan to participate in the Connections program in July of 2000. Connections was developed by All Kids Count to assist public health practitioners in sharing that knowledge with their peers, accelerating solutions to everyday and extraordinary problems.[1,2] Connections provided a grant to MDCH to assess what health data resources are publicly collected that may be of value to be integrated with or linked to MCIR for access by the MDCH and health care provider community.

● Methods

A consultant was secured to gather and analyze data, and an advisory committee of MDCH administrators was convened to guide the project. Establishment of the integrated MDCH Data Warehouse had already included an inventory of data resources within selected divisions of MDCH. Content from the joint application design document for the MDCH data warehouse was used to help guide interviews with advisory committee members, MDCH front-line program staff, and representatives from the public and private provider communities.

Three data gathering efforts were conducted during the course of this study, each of which employed a well-recognized and commonly used qualitative research technique.

The interviews focused on 3 main questions: (1) What Michigan Department of Community Health data resources do you currently use? (2) How do you use and access these data? and (3) What is your vision for expanding, enhancing, and linking these data to meet Michigan's future health goals?

First, semistructured in-depth interviews were conducted with health care administrators (eg, bureau and division chiefs) within MDCH regarding their respective responsibilities, data resources, and perspectives on using data and improving data within their areas of responsibility. Copies of the interview instrument that was used for most of these interviews are available from the authors. Two other administrators were interviewed using more personalized sets of questions due to their unique administrative responsibilities. A total of 8 administrators were interviewed during the spring of 2002.

A second set of in-depth interviews was conducted with program managers or front-line operatives of programs that specifically deal with early childhood and juvenile health issues. Of 10 program managers and front-line operatives identified as potential interviewees, 6 participated in interviews; 1 refused. These interviews were more traditional, structured interviews that focused on many of the same issues discussed

with the program administrators. Finally, a number of program managers in the field were interviewed to discuss how data resources are used in the field and what could be done to enhance field operations through the use of data resources. These data were gathered through a group interview process. Two group interviews were conducted on May 15, 2002. Approximately two dozen healthcare providers and field managers for programs that relate to children's health were provided with some background materials regarding the project and were invited to participate in one of the two scheduled group interview sessions. Unfortunately, only 5 individuals chose to participate in these group interview sessions. Those who chose to participate included representatives of 2 managed care organizations, 1 representative of a federally qualified health clinic, and 2 local public health officials.

● Results

Health care administrators

A concise set of themes emerged from these interviews for which there is a relatively high level of consensus. Among the most important are needs for:

- data-driven health care decisions and operations, especially with regard to special-needs children
- consolidation and coordination among (eg, linkages between) diverse and disparate data resources
- elimination of duplicated efforts and expenditures

Interviews with health care administrators in MDCH about their visions for the use of data elicited two types of responses: (1) focusing on the data warehouse as a strategic resource, mainly to link diverse datasets to facilitate policy decisions, create greater efficiencies, and to prevent waste, fraud, and abuse in state programs and (2) focusing on improving the data collected, improving the process of data collection, and improving data usage in order to more directly address the health of Michigan's residents. Respondents identified the following desired enhancements:

- more and better data
- easier data collection (including easier and greater ability to input data)
- greater availability of data to those who need them
- more extensive use of data to drive evidence-based policy decisions within the public health environment

Underlying these suggestions is recognition of an evolving focus in public health toward an evidence-based focus on the health of populations. One health

care administrator described a bias in public health toward programmatic intervention, registries, and surveillance without systematic evaluation of the programs, their outcomes, or the use of data to drive decisions. Another administrator put it more simply, "We could do better if we used our data more effectively." Other interviewees concurred with this observation and provided several examples of what is meant by "using data more effectively." Examples included:

- Research outcomes of Medicaid mothers to evaluate the impact of various programs on the health of their children.
- Track the health problems of the indigent.
- Examine the relationship between child and adolescent morbidity and behavioral risk data for children.
- Link data about communicable diseases with data resources from other state agencies and elsewhere, including socioeconomic data and environmental data.
- Look at the relationship between the incidence of pediatric asthma and the physician population density within the same geographic area.
- Track the cyclical incidence of hepatitis and other temporal patterns of communicable diseases.
- Collect data that go beyond traditional health indicators, including air and water pollution, chemical spills, land use policies, and so on.

Program managers and operational staff

The most enthusiastic supporters of consolidating health information resources and using those resources more effectively to address the health needs of the very young were the professional workers who deal most directly with these issues.

Among the front-line managers and program staff who contributed their perceptions and opinions to this study, the vision for data use in fulfilling the mission of the Michigan Department of Community Health is overwhelmingly practical. One informant stated, "We need to have data analyzed in a timely manner and sent to programs that could use the data." Another informant said, "We serve the people of Michigan ... Data are needed to fulfill our stated role." Front-line managers identified two ideas that would allow a quantum leap in their ability to identify the health needs

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of Michigan residents—especially children—and deal with these needs much more effectively. Specifically, participants indicated a need for substantive data about program participants' characteristics and needs, and data linkages or integration among data sources.

Substantive data

Most of the programs that were explored in this study include a registry or participant identification component as well as an outreach or service delivery component. For programs that focus on service delivery, the vision is to move beyond the current focus on financial and insurance data and move towards data that track the use of resources by various patient populations. This can help determine the impact the children who receive these services will have on services and programs later in life, including educational and social services. More utilization data also allow greater coordination of services among these children, ultimately leading to more efficient provision of services for clients. More data about the specific characteristics of the client or patient at a given time would allow addressing health issues earlier and more fully, thus resulting in fewer negative outcomes at a later time. For example, greater information about the personal, social, and geographic characteristics of WIC clients and their use of specific prenatal services may result in fewer birth defects, and fewer children with birth defects mean fewer special needs children with fewer special health, education, and welfare issues later in life.

Care coordination also depends on more data than are often available; It requires information on the types of services provided within a population, to whom they are provided, who provides them, and so on. This information allows fact-based discussion among local public health officials, program administrators, and front-line personnel of what services are actually needed and where they are needed. In northern Lower Michigan, according to one informant, common wisdom holds that there is little need for Children's Special Health Care Services (CSHCS). More substantive data on the patterns of birth defects and other conditions occurring to residents of that region, as well as the services provided to these residents, would go a long way in determining what health care services (including respite care for caregivers and transportation) and special equipment are truly needed. More substantive data were also cited as being necessary for developing outcome and performance indicators that could help to determine if existing services are effective and if the outcomes of various programs are commensurate with the funds expended.

Finally, more substantive data are needed to identify underlying physical, social, and environmental

factors that may be associated with specific diseases or syndromes.

Data linkages

Front-line program managers and operatives expressed their greatest enthusiasm for the potential benefits of linking diverse data sets and sharing data with other programs. When asked what Michigan could do with data to improve the health and well being of the citizens of Michigan, comments included:

> What is really important is integrating the data or providing a means to cross-reference the data to get at related issues.

> We need to integrate or cross-reference data. We don't need to know all of the information about individuals, but we need to know basic information in order to make services available to families in need. We need to link databases. . .This would facilitate case finding and linking families with services.

> Several programs focus on the same targets (children with special needs) and do their "own thing" without coordination or linkages with other programs. This is very frustrating.

Specific suggestions included:

- linking the Birth Defects Registry with the state Department of Education's Early On program for infants and toddlers
- establishing linkages that will allow automatic referrals for WIC clients to other programs, including Medicaid, CSHCS, and Early On
- compiling community-level reports in order to generate greater community awareness or greater community support for and greater physician willingness to refer patients to various local public health programs
- making the data that are collected more compatible in terms of data definitions and fields included so that they may be linked and used more easily
- creating a repository of basic data (eg, demographics, history, nutrition and immunization data) that would be available online to a number of programs if, and when, a client applies to participate in those programs.

Health care providers

Immunization providers (and their representatives) see an opportunity to link all of the data for newborns and infants that are collected through various screening and testing programs. The providers' vision includes: real-time access to child immunization, lead screening, metabolic screening, TB screening, and hearing screening data by any child's public health clinic or primary care provider. Beyond these programs, there is a desire to link childhood health information with WIC data, both in terms of eligibility as well as prenatal information about both mother and child. It would be of great value if providers had comparative information for individual communities, counties, or regions within Michigan, as well as for different population groups. This would provide the analytical information that would allow them to go beyond dealing with individual cases and attempt to understand and address some of the social and behavioral factors that might be contributing to children's health needs.

● Discussion

The broadest conclusion that may be reached from this study is that MCIR is widely recognized as a prototype for what MDCH must do to achieve its public health objectives. According to those interviewed, Michigan needs a comprehensive and integrated electronic surveillance system to track the health of Michigan residents by collecting data on both chronic and acute diseases, behavioral risk, vital records, and so on. Moreover, this system must be available to MDCH administrators, program managers and field staff, local public health officials, and, in some cases, health care providers. These resources must be easily accessible through a mechanism, such as the "Single Sign On" system, it must be flexible to accommodate diverse queries, it must be timely through the incorporation of real-time or frequently updated data, and it must protect the confidentiality of the data from unauthorized use. (Single Sign On is a security portal that allows users to have one ID and password to access multiple Web applications.) In practical terms, this dynamic approach to health care data must serve 3 distinct responsibilities within MDCH:

1. *Client services*—Effective and efficient provision of services requires information on who receives services, where they are located, what services they receive, and information on participation in other programs including non–MDCH.
2. *Health surveillance*—Epidemiological information and research on acute outbreaks of communicable diseases, the chronically ill, vital statistics, registries of all sorts, and outcomes of interventions are important data-dependent aspects of maintaining and improving the health of Michigan. The ability to link data resources among data and service-related programs is a critical component.
3. *Administration*—As has been demonstrated through the use of the data warehouse to administer Michigan's Medicaid program, large and complex

data systems are required to manage federal funds that are used to pay for the provision of services and the processing of payments. The means to identify potential patients, get them into the appropriate programs, prevent fraud and abuse, and then report back to the funding agencies, legislature, and public at large requires very sophisticated systems in Michigan.

● Data Linkages

The overwhelming consensus of those who participated in this study is that real-time data, like the MCIR itself, should be linked to other real-time childhood screening data. Specific data resources identified included the following:

1. Registry data

   - Birth Defect Registry
   - Tuberculosis Registry
   - Cancer Registry
   - Michigan Childhood Immunization Registry

2. Screening data

   - Lead screening
   - Hearing screening (EHDI)
   - Newborn (metabolic) screening
   - Vision screening

3. Programmatic and other data bases

   - WIC—Women, Infants, and Children's Program
   - CSHCS—Children's Special Health Care Services
   - Medicaid
   - EarlyOn (Michigan Department of Education)
   - Pregnancy Risk Assessment Monitoring System
   - MIHAS—Maternal and Child Health Advocacy Service
   - Fetal and Infant Death Review Program
   - Behavioral risk data
   - Environmental data
   - Vital Records Information

The consensus across each of the 3 groups of informants who participated in this study is that MDCH does not need to initiate any significant new data collection activities in order to meet its public health obligations. In some specific cases, however, respondents recommended that current data activities be expanded or that linkages be initiated with data resources available outside of the department. Front-line program managers feel that more "utilization" data should be extracted from the data that are collected. For some programs, the focus has been mainly on enrollment and financial data. Managers need more specifics: services used, procedures performed, and outcomes demonstrated. Some of these data elements may be found within the billing or other data resources used to administer several MDCH programs. For Children's Special Health Care Services, respondents called for tracking utilization data for various patient populations so that some determination may be made of the types and amounts of service CSHCS enrollees will need later in life. Some informants suggested a "dashboard concept." (The Dashboard Concept is a child health profile Web screen that allows users immediate access to other databases.) Providers already have access to the MCIR at the point of service, the day-to-day operations of health care. With a "dashboard" of real-time data resources available to the practitioner, the focus of practitioner care and MDCH outreach can become more efficient and effective. For example, the provider would log in and immediately see that Johnny Smith is due for a lead testing or that his newborn metabolic screening came back positive and he needs a follow-up.

● Access and Confidentiality

There is broad recognition of and extensive sensitivity to confidentiality among all of those interviewed regarding MCIR as a prototype for access to data in Michigan. While little or no explicit mention was made of HIPAA guidelines concerning patient confidentiality and data security, virtually all respondents recognized the varying levels of sensitivity of the various data resources discussed, and they almost always made reference to patient confidentiality as an important issue. Most respondents recognized that health care providers needed more data to provide services effectively, but none proposed any broad expansion of direct provider access to primary data resources. Instead, there was call for indirect access by allowing providers and other non–MDCH personnel access to the results of screenings or other indicators rather than to the primary data themselves. For example, no one proposed allowing providers direct access to all metabolic screening data, but it would be very helpful for primary care providers to be able to access the results on their own patients at the point of service, for instance, at the time of the first follow-up visit after hospital discharge.

● Conclusion and Future Direction

The Michigan Department of Community Health completed the stakeholder analysis and is moving forward with the requirements gathering process. The programs involved are listed in Box 1.

The barrier to Michigan linking databases with MCIR is that MCIR legislation requires that only

BOX 1 ● Michigan Department of Community Health programs involved in planning the integrated system

- Immunization
- Lead
- Newborn Screening
- Newborn Hearing (EHDI)
- Vital Records
- Michigan Disease Surveillance System
- Women, Infants, and Children (WIC)
- State Laboratory
- Medicaid

immunization data will be stored in the registry. To move forward linking databases with MCIR, legislation must be amended to allow entry of other medical information into the registry. Letters of support from the health plans, health systems, and coalitions have been sent to the governor and legislators demonstrating the need to open up the registry to other health data.

Integrated Child Health Data Committees have been organized. The executive committee includes participation from division directors who will have oversight and work on funding for the project. The steering committee participants are department managers and will provide oversight. The project lead team includes the program managers who will work with the design team and perform quality review and testing for the system.

MDCH will continue to upgrade the newborn screening, newborn hearing, and vital records database in preparation for linkages. The acceptance of MCIR by the pediatric and family practice community demonstrates the utility of providing more information electronically to the medical community in Michigan. The Michigan Department of Community Health looks forward to creating a useful tool that will provide timely, accurate, and electronic medical information for health care providers.

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