

Inventory of Electronic Health Information Exchange in Wisconsin, 2006

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ABSTRACT

Context: The Governor's Board for eHealth Care Quality and Patient Safety plans for universal adoption of electronic health records and information exchange.

Objectives: The inventory sought to describe characteristics, challenges, and policy recommendations of health information exchange (HIE) projects and create a directory and baseline for periodic reassessment.

Design, Setting, Subjects: A cross-sectional Internet survey of any project where electronic patient information was transmitted by multiple organizations in Wisconsin in 2006.

Main Outcome Measures: A description of operational and planned HIE projects, including stage of development, information users, organizational home, funding, governance, geographic scope, data standardization, drivers, internal and external challenges, and recommendations for statewide action.

Results: Twenty-one organizations sponsor 16 operational and 11 planned HIE projects. Most are surveillance programs, but a growing proportion serves clinicians and patients. Under half use data standards for interoperability. Leading internal challenges relate to funding, organizational and staff issues, governance, and technology. Leading external challenges are marketing, enlisting participants, regulatory issues, and sustainability.

Conclusion: Wisconsin enjoys rich experience with HIE, but data remains largely in separate silos. Statewide collaboration, coordination and resource sharing can enhance the future of exchange efforts.

INTRODUCTION

Government and health care leaders have called for adoption of electronic health records to improve the quality, safety and cost-efficacy of patient care and public health.^{1,2} In addition to electronic record systems inside individual organizations, a comprehensive, up-to-date health record requires near-real-time electronic health information exchange (HIE) between the many organizations that participate in each patient's care. Without HIE, each organization typically has incomplete information on each patient, leading to care delays, redundant procedures, costs and errors from manual re-entry of information, and missed opportunities for care improvement.³⁻⁶ In addition to improving care at the point of service, data from HIE can improve the timeliness, completeness, and efficiency of public health programs and initiatives to improve health care quality and safety.⁷⁻⁹

In November 2005, Governor Jim Doyle established the Board for eHealth Care Quality and Patient Safety to guide action toward universal adoption of electronic health records and electronic data exchange between payers, health care professionals, patients, researchers, and government agencies.¹⁰ The Board's ongoing work, including its December, 2006 Wisconsin eHealth Action Plan for 2007-2011, is available at <http://ehealthboard.dhfs.wisconsin.gov>.¹¹

The Board's charge includes annual assessment of the use of electronic information and decision support systems, and assessment of progress toward the interoperable electronic health information systems in Wisconsin. This paper reports an inventory of Wisconsin HIE projects (operational and planned), their characteristics, challenges, and recommendations for action at the state level.

It is intended to be the first of annual inventories to track the prevalence and coverage of HIE in Wisconsin over time, to assess the impact of policy changes to increase health information technology and exchange, to encourage learning between HIE projects, and to help people and organizations locate exchanges relevant to their interests.

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METHODS

The inventory seeks organizational, functional, and technical information, challenges, and recommendations for action from the sponsor of each HIE project. Some items were adapted from other national and state HIE surveys; however, due to differences in inclusion criteria and data collection the comparability of survey results is unknown.^{12,13} The inventory data collection tool may be accessed at <http://ehealthboard.dhfs.wisconsin.gov>.

For this inventory, HIE was defined as “organizations or projects in which multiple independent organizations routinely send or receive electronic clinical information about patients for purposes other than billing or claims payment.” This definition includes information transmitted for public health surveillance as well as for clinical purposes. Projects submitting information that did not meet this definition of HIE are not analyzed, although their information will be added to the inventory directory. HIE projects that were actively exchanging data as of December 2006 were labeled “operational.” Those not yet functional were labeled “planned.”

The eHealth Board, staff, and consultants, members of Board workgroups, and inventory respondents nominated possible candidate organizations for the inventory.

Data collection was performed with SurveyMonkey.com. Those who did not respond to e-mail solicitation were contacted by telephone. Information was collected on organizations, not individuals (except to establish a contact for each project). Respondents were informed that their responses would be public (with redaction of e-mail addresses if desired).

Preliminary inventory results were reported in the Wisconsin eHealth Action Plan for 2007-2011.¹¹ This paper includes additional respondents and analyses since that initial report.

RESULTS

Thirty organizations were contacted and 27 (90%) responded. Six (20%) had no projects meeting the HIE definition (e.g., did not exchange patient-specific information). The remaining 21 respondents identified 16 operational exchange projects and 11 planned exchange projects. One provided only partial information and is included in numerators and denominators only when data was provided. Detailed information on each project can be viewed at <http://ehealthboard.dhfs.wisconsin.gov/>.

Stage of Development

Sponsoring organizations rated their most advanced HIE project on a scale used in the eHealth Initiative survey.¹² These are presented in Table 1. A majority had achieved the implementation stage.

Table 1. Number (Percent) of HIE-Sponsoring Organizations Rating Their Most Advanced Project by Stage of Development*

Stage 1	Recognition of the need for health information exchange	1 (5%)
Stage 2	Getting organized	1 (5%)
Stage 3	Transferring vision, goals and objectives to tactics and business plan	2 (10%)
Stage 4	Implementation—technical, financial and legal	8 (38%)
Stage 5	Fully operational health information exchange	8 (38%)
Stage 6	Expansion	1 (5%)

* N=21 responding organizations sponsoring HIE projects; percentages do not add to 100 due to rounding.

Table 2. Drivers of Operational and Planned Health Information Exchange Projects*

Drivers	Operational Exchange	Planned Exchange
An existing organization with existing technology that others desired to share	1	2
An association, federation or plan whose members identified common needs	2	0
A compelling problem that brought together independent organizations in a new way for the first time	3	5
A community leader or leaders who 'sold' participants on the project	1	3
A vendor or consultant who 'sold' participants on the project	0	0
A source of funding that motivated participants to plan a project together	2	0
Other Reasons[†]		
Legislation	1	0
No response	1	0

* N=21 organizations sponsoring HIE projects

[†] Provided by respondents

Information Users

Of 16 operational projects specifying data users, 7 (44%) deliver information only to centralized registries for public health or quality surveillance, 1 (6%) only delivers information to clinical care providers, and 8 (50%) serve both purposes (exclusive categories). Only 2 (13%) also deliver information to patients.

In contrast, all of the 11 planned HIE projects intend to provide information both to clinicians and centralized registries, and 4 (36%) also plan information delivery to patients.

Organizational Home, Funding, Governance

Of 16 operational exchanges, 10 (62.5%) are based in

Table 3. Leading Internal (Organizational) Challenges for Organizations Sponsoring Health Information Exchange Projects*

Funding and Resources = 15
<ul style="list-style-type: none"> • Funding • Time • Insufficient public health dollars allocated to HIE
Organization and Staffing = 12
<ul style="list-style-type: none"> • Lack of adequate staffing fully dedicated to this project • Assignment of responsibility for project when new hires are not possible • Forming new division to meet need for larger scale • Restructure informatics department to support new goals • Inadequate IT staff for troubleshooting • Involving administrators, directors and end users from multiple facilities in vendor selection and business planning • Building the business infrastructure and recruiting leadership • Buy-in from the Administration and partnering with other programs • Collaboration between the organizational divisions
Agreement on Organization, Priorities and Data = 9
<ul style="list-style-type: none"> • Identifying information to be publicly reported • Determining measures that satisfy health plans, providers and purchasers simultaneously • Agreement between data users and data providers • Developing common agreement on the scope of the organization • Trust and autonomy issues for multiple organizations selecting a common system • Getting all stakeholders and user groups to agree on 1 solution • Getting attention of busy CIOs with their own internal issues to address • Buy-in of public health staff on need for clinical - public health exchange
Technical = 8
<ul style="list-style-type: none"> • Lack of data infrastructure • Conflicts with internal software • Need for common client index for multiple systems in public health. • Lack of common data standards used in multiple systems data sharing
Engaging Participants, Marketing = 4
<ul style="list-style-type: none"> • Engaging all participants • Lack of penalties for non-reporting • Knowledge—understanding our partner organizations • To get people to understand they will have to change the way they work and accept that
Legal = 2
<ul style="list-style-type: none"> • Framing shared legal environment including assurance of information quality; policy creation and enforcement, secure connectivity; confidentiality; data use and ownership; use authentication and federated provisioning; exit structure for entities wishing to leave the HIE with their data in hand, system support; implementation support, fees; and amending the legal structure • Development of agreements to meet HIPAA requirements
Other
<ul style="list-style-type: none"> • "Politics, politics, politics"

* Respondents could offer up to 3 challenges each as free text. Categorized by author followed by edited text responses removing duplications.

government organizations, 2 (12.5%) each are in health care professional organizations, academic institutions, and other nonprofit entities (exclusive categories). A higher proportion (5 [45%]), of the 11 planned projects will be based in nonprofit organizations, with 5 (45%) based in government and 1 (9%) in academia.

Of the operational HIE projects, 73% began exclusively with public funds, 20% exclusively with private funds (including donations, fees, and subscriptions), and 7% using both, compared to 66%, 18%, and 18%, respectively, for planned HIE projects. For continuing operations, 57% of operational exchanges rely entirely on government funds, 21% on private sources, and 21% on a combination of public and private funds. In contrast, only 30% of planned initiatives anticipate operating exclusively on government funding, with 20% planning only private revenues, and 50% a mixture of public and private funding.

Regardless of sponsoring organization, the governance of most HIE projects include multiple stakeholder types, including government (75% of projects); data users (68%); data providers (64%); health care professional organizations (43%); clinicians (39%); health plans, payers and employers, and ancillary service providers (each 25%); patients or patient advocates (21%); and funders (18%).

Geographic Scope

Twenty-six HIE projects described their geographic coverage, of which 14 are statewide, 7 serve southeast Wisconsin, and 2 each serve southern, central, northern, and western Wisconsin. (Some serve more than region.) One project plans to link users of a particular electronic medical record vendor and not a geographic area.

Standards

Less than half of responding HIE projects (n=26) specify the use of vocabulary (46%) or data transmission (46%) standards. The remainder could not identify standards, were undecided, or will not use standards. Planned projects were less likely to name vocabulary or transmission standards (45% and 36%, respectively) than operational projects (47% and 53%, respectively).

Drivers

Responding organizations selected the single most important driver for initiating HIE from a list. Results are displayed in Table 2. The projects were motivated by a wide range of drivers. Operational projects more often cited legislative mandates, pre-existing funding, or association goals, while a majority of planned projects were driven by a compelling need to unite organizations in a new way.

Internal and External Challenges

Respondents described the 3 leading internal and external challenges to implementing HIE. Edited responses, categorized by the author, are listed in Tables 3 and 4.

Recommendations for Statewide Action

Respondents could list 3 ways in which a statewide governmental or public-private initiative could aid information exchange. Edited responses, categorized by the author, are listed in Table 5.

DISCUSSION

This is the first inventory of electronic HIE initiatives in Wisconsin. It is a baseline for periodic assessments, and provides insight into a sizable community of experience and interest. Sixteen projects already exchange information routinely and provide a rich experience base to build on. Existing projects serve every part of the state, and many regional projects are planned.

Public health surveillance projects are the largest set of operational HIE projects. Thus a majority of inventoried projects are government-sponsored and report data to surveillance registries, although many also provide information to clinicians. Even projects dedicated exclusively to surveillance represent streams and pools of electronic health data that might serve other purposes (e.g., point-of-service information for clinicians) if data use, data quality, privacy and confidentiality issues can be resolved. Several public health projects have created products for clinical use (for example the Wisconsin Immunization Registry). Surveillance programs have amassed considerable experience with secure electronic exchange of clinical data.

Planned HIE projects differ from existing (operational) projects in several ways. They more often plan to deliver data to clinicians and to patients. They are more likely to seek operating revenue from fees or subscriptions, while a majority of operational projects rely exclusively on government funding. Planned projects are more often problem-driven, bringing together new partners for the first time, while operational projects were more often driven by existing funding, mandates, or needs identified by an established association. These may indicate shifting trends in HIE, but we cannot know for sure without knowing which and how many planned projects actually succeed.

Of concern is the small proportion of both operational and planned projects that use standardized data vocabulary or transmission. This means their data cannot readily be exchanged or used by other applications, and that considerable effort may be needed to turn

Table 4. Leading External (Inter-Organizational) Challenges for Organizations Sponsoring Health Information Exchange Projects*

Engaging Participation and Marketing = 10
<ul style="list-style-type: none"> • Engaging consumers in information use • Building awareness of initiative among purchasers, providers and payors • Funding for laboratories to participate • Time allocation—partner IT staff are over-committed • Adoption of the health information tool • Unwillingness of health care systems to spend IT dollars on public health interoperability and functions • Clinical buy-in for public health information exchange • Buy-in from public and private health care providers and the public
Government, Regulation and Legal = 8
<ul style="list-style-type: none"> • Getting State involvement • Federal expectations of active surveillance as gold standard • Wisconsin's use of passive surveillance • Regulatory compliance and Certifying Commission for HIT certification • HIPAA • Wisconsin state laws • Wish for state government partnership conflicts with timely completion
Technology = 8
<ul style="list-style-type: none"> • Multiple systems purchased from multiple vendors • Lack of common data standards • Accommodating changes in standards • Lack of high bandwidth connectivity in Central, Northern and Western Wisconsin • Vendor selection • Vendor support • Building 'bridges' from existing data providers systems to internet-served repository
Funding and Resources = 5
<ul style="list-style-type: none"> • Lack of adequate funding • Cost and low return on investment for low volume facilities • Limited external funding for health information exchange
Agreement on Organization, Priorities and Data = 3
<ul style="list-style-type: none"> • Collaboration between projects under different governance • Data access and sharing agreements
Competition = 2
<ul style="list-style-type: none"> • Competing initiatives • Competition for funding
Other
<ul style="list-style-type: none"> • Politics

* Respondents could offer up to 3 challenges each. Categorized by author, followed by edited text responses removing duplications.

Table 5. Recommendations for Action by Statewide Government or Public-Private Partnership*

Coordination or Collaboration = 10

- Support existing reporting instead of creating additional initiatives
- Bring all parties, both public and private, to the table in equal partnership
- Share knowledge about what data is available
- Do not hinder progress already made
- Establish standards for HIE
- Continue coordinating interest in a [data] repository in DHFS and work with Department of Regulation and Licensing and Office of the Commissioner of Insurance (separate agencies)
- Top-level buy-in for 2006 initiatives since front-end deployment is time consuming
- Ensure strong public health voice on permanent eHealth board
- Extend information linkages to include medical records, death certificates, etc.
- Develop collaborative data sharing efforts between database projects

Funding and Resources = 9

- Fund public health HIT/HIE at \$10 million (minimum) annually
- State funding for permanent staff for public health surveillance systems
- Long-term funding
- Funding for face-to-face recruitment, training and support of users
- Support small health care facilities in HIT and HIE implementation through matching grants and loans
- Support acquisition and development of software for merging datasets and analysis, visualization, and reporting

Provide or Mandate Electronic Information = 7

- A Child Health Profile for private and public practitioner information access and use
- Access to administrative databases such as hospital discharge and emergency department visit data
- Fund or mandate electronic medical record sharing
- Require reporting and penalties for non-reporting of public health surveillance information
- Require public health - clinical care information exchange in all state HIE/HIT projects

Legal and Regulatory = 4

- Remove requirement for 'written permission from parents' for collection of child health records.
- Wisconsin state law should match HIPAA
- Remove or address privacy hurdles/barriers
- Create an understandable HIPAA standard for exchange

Standards = 2

- Standardize geocoding of patient addresses across administrative databases
- Fund or mandate use of LOINC, SNOMED

Other

- No government mandate to provide EHR/PMS within an HIE is possible.
- Collaborate on a formal study of the value of an established Wisconsin exchange system
- Research HIT implementation strategies that work in small hospital and practices
- Promote project goals to potential health care participants.

* Respondents could offer up to 3 recommendations each. Categorized by author followed by edited text responses removing duplications.

today's information silos into interoperable systems. The lack of planned standardization even among newly emerging HIE projects highlights the importance of the recommendation made by several respondents for statewide data exchange standards.

Many non-standardized exchange projects belong to public health surveillance programs. Their lack of interoperability may contribute to the finding in a recent survey in which stakeholders gave a largely negative response to the question: "Does Wisconsin's public health system have an integrated electronic information system that provides meaningful information about the health priorities outlined in *Healthiest Wisconsin 2010?*"¹⁴ Some inventory respondents called on state government to address interoperability among its own systems, such as establishing a master index at the Department of Health and Family Services (DHFS) to allow reuse and linking of data across various data systems. Because legislation restricts some state registries regarding data reuse, statute amendments may be needed. Were DHFS to tackle such tasks, it could potentially catalyze considerable progress toward the interoperability of both clinical and public health data systems statewide.¹⁵

Respondents listed internal challenges with organization and staffing, and developing agreement among stakeholders almost as often as they cited funding or technical problems. Leading external challenges included marketing exchange programs and enlisting participants, and dealing with government, regulatory, and legal issues, which ranked higher than technical and funding issues. This implies that organizational capability, governance, marketing, and government policies may be as important as new funding and technologies in spurring evolution of an effective HIE network in the state.

The most common category of recommendations for statewide action related to increased coordination and collaboration. This included sustaining support for existing initiatives rather than just funding new ones, fostering knowledge- and technology-sharing between exchange projects, and extending the reach of existing exchanges and their information capabilities. These were followed in order by recommendations for increased and sustained funding, improving the information supply, addressing regulatory concerns, establishing common standards, performing research, and addressing the needs of smaller health care organizations. Such recommendations can form part of the agenda for the ongoing work of the Governor's Board for eHealth Care Quality and Patient Safety.

CONCLUSION

In summary, there is a rich collection of HIE projects in Wisconsin. However, much data remains in separate, redundant silos with little attention paid to date to standardizing, indexing, and sharing it for reuse. A new generation of initiatives under development promise to deliver more information to clinicians and patients. While additional resources are needed, there is also need for coordinated planning, action, and learning. This inventory seeks to enable communication and coordination among HIE projects toward these ends.

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