

March 31, 2009

Health Information Security and Privacy Collaboration

Harmonizing State Privacy Law Collaborative Final Report

Prepared for

RTI International

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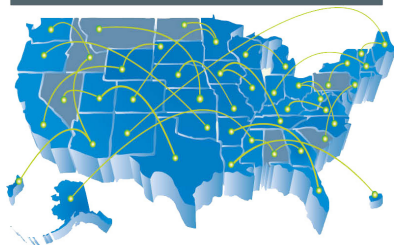
Prepared by

Harmonizing State Privacy Law Collaborative

Florida, Kansas, Kentucky, Michigan, Missouri, New Mexico, Texas

Health Information Security & Privacy

COLLABORATION



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1. PURPOSE AND GOALS OF COLLABORATIVE

The Harmonizing State Privacy Law Collaborative (HSPLC) was formed as part of Phase 3 of the Health Information Security and Privacy Collaboration (HISPC) to support the implementation of both intrastate and interstate electronic health information exchange (HIE) by helping states to identify, analyze, and where needed, reform laws that relate to HIE. Inconsistency in state and federal laws in terms of definitions, organizational structure, and content is often cited as a barrier to participation in and implementation of HIE. As the Office of the National Coordinator for Health Information Technology (ONC) notes,

Over several decades, states have passed laws to protect the privacy of health information. These laws differ from state to state and often narrowly target a particular population, health condition, data collection effort, or specific types of health care organizations. As a result, states have created a patchwork of privacy protections that are not comprehensive or easily understood.¹

As states have enacted new laws regarding the use and disclosure of health information, fragmentation of relevant statutes and regulations has only increased. Some states have adopted legislation to provide greater privacy and security in the exchange of electronic health records (EHRs).² However, definitions and standards for EHRs continue to evolve and, while there is guidance, no clear consensus in these efforts has yet emerged. Statements from stakeholder groups indicate that a greater harmonization of state laws would be beneficial and that reform of state laws, combined with revisions in federal laws, must be considered.

Extensive discussions and activities with stakeholders during the first phase of HISPC (2006–2007) determined that lack of clarity and divergent interpretation of legal standards have created barriers to participation in and implementation of HIE. While some impediments to the exchange of health information are essential to protect privacy interests, unnecessary and unintended barriers resulting from confusion or inconsistency can prevent the timely and appropriate exchange of information essential for medical treatment and population health activities. Whether the movement to transform health care through HIE involves private grassroots efforts, state-specific initiatives, a single federal approach, or any combination thereof, the availability and use of common tools and resources is essential for establishing workable information exchange standards and practices within and among states.

¹ Office of the National Coordinator for Health Information Technology. Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Information. Washington, DC, December 15, 2008.

² Update to October 9, 2007, Report on State Laws Related to Electronic Health Records and Electronic Health Information Exchange, Harmonizing State Privacy Law Collaborative, Health Information Security and Privacy Collaboration, June 30, 2008.

2. COLLABORATIVE PARTICIPANTS

The HSPLC's seven participating states were represented by a diverse group including lawyers with expertise in health and information technology issues, university faculty members, senior state agency staff, health services research and communications experts, and clinicians well versed in health information technology (health IT) issues. Missouri and Texas were new to HISPC, while the other five states had participated in the earlier phases. Several participants were involved in other HISPC Phase 3 collaboratives and other federal initiatives, including the Provider and Consumer Education Collaboratives and the Data Use and Reciprocal Support Agreement (DURSA) work group under the Nationwide Health Information Network (NHIN) Trial Implementations. Detailed information on participating states' experience with HIE and related legal issues is provided in Appendix A.

3. RESEARCH METHODS

The goal of HSPLC's research was to develop a set of analytical tools and a narrative guide to assist states with the identification and adoption of workable standards and practices. The tools were intended to serve as a roadmap that provides flexible guidance and accounts for the wide variation in relevant state law, and the range of states' progress toward the implementation of HIE networks. Its development was based on extensive research to identify best practices for identifying, evaluating, and reforming state laws related to the disclosure of health information.

The HSPLC began this process by collecting and reviewing existing legal analyses from a wide range of sources in both HISPC member and nonmember states. Examples of collected documents include Health Insurance Portability and Accountability Act (HIPAA) preemption analyses, deliverables from HISPC Phases One and Two, and state-initiated reports. The HSPLC supplemented these documents by gathering information from online search tools for primary and secondary legal research sources such as state codes and legal periodicals. In collecting and analyzing this information, the collaborative identified common content and organizational themes among the analyzed documents. Based on this review, the HSPLC developed consensus regarding overarching principles.

The HSPLC determined that the following four principles are critical for a thorough analysis of the state law relationship to HIE:

Laws must be surveyed: A survey of state statutory and regulatory law involving or affecting the exchange of health information (whether paper or electronic) must be conducted.

Laws must be organized logically: Identified laws must be organized into logical subject-matter areas for review and analysis.

Laws must be analyzed in relation to HIE: Each law (or gap in the state's law) must be reviewed and analyzed to determine whether a change in the law would facilitate HIE within the state.

Feasibility of changing the law must be determined: For laws identified as requiring change, a consistent analytical process for determining the feasibility and priority of that change must be applied.

The collaborative then reviewed a 50-state analysis and inventory of state laws, other analyses, and legislative information to identify statutes directly related to the exchange of health information. The product of this research was a June 30, 2008, working document that updated the October 2007 *Report on State Privacy & Security Laws Related to Electronic Health Records and Electronic Health Information Exchange*. In addition, the collaborative submitted a report on progress and lessons learned that reviewed and consolidated the group's work up to that point.

The next phase was the development of an analytical matrix based on models provided by Randy McDonald (New Mexico) and Julie Roth (Kansas). The collaborative developed a set of subject matter categories for the analytical matrix that contains more than 140 topics and includes major subject headings to aid in organizing the material (e.g., health/medical records, provider specific provisions, consent/authorization, definitions). The matrix provides for a side-by-side presentation of state and federal laws with citations and comments.

Each participating state used the matrix to evaluate state laws with regard to such factors as stringency compared with the HIPAA Privacy Rule, interaction with other federal law, and likelihood that the state law would be an impediment to HIE. The analytical matrix was paired with an assessment tool based on a model provided by Kelly Coyle (Michigan), and each state team solicited feedback from its legal working group (LWG). The state LWGs also provided insight on procedural guidance needed to complete and use the analysis and assessment tool.

More information on the LWG process of HSPLC states is provided in each state's narrative, found in Appendix A. The Appendix provides a brief description of each state's experience in using the analytical matrix and assessment tool as it relates to the state's laws. It includes comments and suggestions for improvements in the tools and instructions that were reviewed by the HSPLC and incorporated by mutual agreement.

4. THE ROADMAP

The culminating work of the HSPLC was the development of a comprehensive guide called the Roadmap that states could use as they move toward the implementation of HIE. An important part of the Roadmap's preparation was the distribution of a draft for feedback from entities likely to be engaged in related activities. Attached as Appendix B is a list of the organizations contacted by HSPLC. Specific recommendations were reviewed by the collaborative, and most were incorporated into the final document.

The complete Roadmap provides extensive guidance for other states, including detailed instructions for how to use the Comparative Analytic Matrix (CAM) and the Assessment Tool, as well as recommendations for stakeholder engagement, participatory strategies and resources, and lessons learned from the HSPLC's participating states. The Roadmap contains findings and recommendations from the common experiences of HSPLC states in identifying areas for reform and the feasibility of changes in law. It concludes with a review of the positive features of the analytical tools for furthering interstate cooperation and opportunities if widely implemented.

5. LESSONS LEARNED

The state-specific reports that follow this summary provide informative guidance from the individual states' experiences with the Roadmap tools. A few examples follow:

- The Assessment Tool is not designed for individual self-administration. It requires a carefully designed process involving preparatory meetings or communications to the group, facilitated discussion, and opportunities to follow up regarding specific issues or concerns. Stakeholders using the tool should have the opportunity to discuss their views of key concepts. More than one meeting is likely to be necessary to work through the process.
- Having the Legal Working Group (LWG) meet face to face proved to be a critical part of the process. Without the opportunity for the LWG to interact and discuss the CAM, the process did not quite work.
- To assemble a shared legislative agenda, the leadership group must build communication, relationships, and trust. Members of this group represent various constituencies, each with its own agenda. It takes time for the individuals at the table to recognize that while they may vary on some issues, there will be a set of goals that they can champion collectively.
- An educational process is needed regarding legislation that impacts or creates barriers to the facilitation of the exchange of electronic health information or EHRs. Issues of population health and disease already reported to the Department of Health were discussed, along with their potential impact on the electronic exchange of health information.

The Roadmap identifies the following elements as critical to state-specific legal assessments:

- legal expertise in populating the CAM and reviewing the group's analysis for completeness,
- a facilitator for group considerations of the CAM and Assessment Tool,
- planning for more than one group meeting and follow-up communications to produce consensus,
- developing a state mission and vision,
- striving for consensus rather than unanimity,
- taking small steps initially to build trust,
- maintaining convener neutrality and independence,
- identifying and addressing knowledge gaps,
- reassessing progress periodically,
- including a range of stakeholders whose interests might be affected by legislative changes, and
- including participants experienced in the legislative process.

6. NEXT STEPS

The 2008–2012 Strategic Plan issued in June 2008 by the ONC includes a timeline that points to ongoing HSPLC-related activity through calendar year 2011. The relevant plan elements are

1.1.5: Address apparently inconsistent statutes and regulations for exchange of electronic health information; and

2.1.2: Address apparently inconsistent statutes and regulations for exchange of population health information.³

HSPLC members have worked productively and collegially to achieve a plan for use by other states, but member states' own experiences indicate that extensive guidance, refinement, and benchmarking will be needed if HIE-related laws are to reach true harmonization. HSPLC methodology can also be used to integrate analysis of the new HITECH law's privacy provisions with the knowledge base on the HIPAA Privacy Rule and state law.

Successful response to the Obama Administration's HIE stimulus initiatives will require legally sound and trusted privacy protection, a goal that can be achieved most efficiently and effectively by continued support to states for the work of the HSPLC.

³ Federal Health IT Strategic Plan (ONC): 2008-2012; June 3, 2008.

APPENDIX A: STATE EXPERIENCES: STATE REPORTS AND LESSONS LEARNED

Florida

Governance and Stakeholders

In 2004 the Florida Legislature directed the Agency for Health Care Administration (Agency) to develop a strategy for the adoption and use of EHRs. This section was subsequently amended in 2006 to require the Agency to include in its strategy the development of an electronic health information network to exchange electronic health records among health care facilities, health care providers, and health insurers. The Agency is to report to the Governor and legislature on legislative recommendations to protect the confidentiality of EHRs. Under Section [408.062](#)(5), Florida Statutes, the Agency may develop rules to facilitate the functionality and protect the confidentiality of EHRs.

Initially, the Agency focused on the funding of HIE pilot projects under the leadership of the Governor's Health Information Infrastructure Advisory Board (Advisory Board). The Agency developed the Florida Health Information Network (FHIN) Grants Program, including program requirements and evaluation criteria. The Advisory Board evaluated FHIN Grant Program applications and recommended awards. According to the time limit set in the original Executive Order, the Advisory Board served out its term effective June 30, 2007.

The Legislature broadened the technical assistance responsibilities of the Agency related to health information technology with the passage of House Bill (HB) [7073](#) in 2006. This bill amended Section [408.05](#)(4), Florida Statutes, providing that the Agency shall integrate health care data from state agencies and make the health data available to health care practitioners through a state health information network.

In May 2006, the Agency was awarded a contract by RTI International, Inc., to participate in the nationwide HISPC project. During this first contractual period, the Agency completed an analysis of barriers to the exchange of health information and produced an implementation plan for addressing these issues through an extensive round of meetings by stakeholder groups. The Agency received an extension of the HISPC contract in July 2007 to begin implementing selected objectives identified in the implementation plan including identifying consensus recommendations for statutory changes to facilitate HIE. The project produced a report, *Analysis of Florida Statutes Related to Health Information Exchange*, containing an analysis of Florida law related to HIE and the legislative recommendations of the LWG.

In December 2007, the Agency established the Health Information Exchange Coordinating Committee (HIECC) under the State Consumer Health Information and Policy Advisory Council authorized in Section [408.05](#)(8), Florida Statutes. The HIECC is continuing the work

of the Advisory Board by assisting the Agency in promoting the adoption and sharing of EHRs. The HIECC includes representatives of hospital and medical associations, regional health information organizations, health plans, rural health care providers, economic development organizations, and consumer groups.

Status of HIE

Prior to 2005, there were no Regional Health Information Organizations (RHIOs) and few organized electronic HIE networks operating in the state. The Florida Health Information Network grants program was initiated in FY 2005–2006 with an appropriation of \$1.5 million to spur the creation of pilot projects to demonstrate the feasibility of health information networks serving multiple stakeholders. The first awards were issued in January 2006. The Agency received \$2 million in each subsequent fiscal year to continue the pilot project through FY 2007–2008. A Point of Care Model EHR Grants Program was funded at \$100,000 for FY 2008–2009.

In 2007, several local HIE organizations formed the Florida Association of RHIOs (FAR) to maximize their collective resources and promote increased utilization of electronic HIE across the state. Through leadership and collaboration, the Florida Association of RHIOs offers a unique opportunity to address barriers to effective exchange of protected health care information. As of July 2008, there were eight RHIOs listed as members of the FAR on its website.

The Agency has recently developed Medicaid EHR data sharing requirements and is seeking to partner with other payers who can supply a web portal for health care providers to submit claims, verify eligibility, and view EHRs for their patients, which are derived from multiple payer sources. The Agency is also promoting greater use of electronic personal health record systems as a public safety measure.

Legal Landscape for HIE

Recent Legislation

Probably the most significant legislation related to HIE to be adopted within the last 5 years is legislation related to medical records and records custodians. Other legislation of note includes notification of breach provisions adopted in 2005.

Senate Bill (SB) 1408, which creates and describes the functions of a *records custodian*, was adopted in 2006. Section 456.057, F.S., titled “Ownership and control of patient records; report or copies of records to be furnished,” was amended to recognize a third-party custodian of medical records which include pharmaceutical records. The provisions require the records custodian and any health care practitioner’s employer who is a records owner to be subject to the same statutory confidentiality and disclosure requirements for the records as the licensed or regulated health care practitioner who created the records.

HB 481, which was adopted in 2005, created Section 817.5681, F.S., requiring that any person who conducts business in Florida and maintains computerized data in a system that contains personal information must provide notice of any breach of security of the system. Specifically, the notice would need to be provided in the event that unencrypted personal information was, or was reasonably believed to have been, acquired by an unauthorized person. The legislation also amended Section 817.568, F.S., which describes criminal use of personal identification information and related sanctions. Medical records were included in the prohibitions and sanctions of this section.

Topics Not Addressed in Florida Law

There is no comprehensive EHRs act in Florida statutes. Generally, Florida law addresses creation, maintenance, and use of medical records in separate practitioner and provider statutes with electronic formats treated as an adjunct topic. The *Analysis of Florida Statutes Related to Health Information Exchange* found many differences in how Florida law addresses specific topics. For HIPAA-covered entities, the fact that a topic is not addressed in Florida law may mean that the provisions of HIPAA would govern, which could be the intent. A comprehensive act has the potential to improve the coordination of state and federal law and clarify the relationships.

Some policy areas that could be addressed in a comprehensive EHRs act include

- consumer protections regarding personal health records (PHRs),
- coordination of HIPAA and Florida laws,
- uniform patient authorization standards including authorizations by guardians,
- release of sensitive or other restricted records in an emergency, and
- definitions of EHRs.

In 2007 the Florida LWG recommended the creation of a uniform patient authorization form in law to facilitate HIE. A comprehensive EHR act could create a uniform process for patient authorizations. It might also address specific barriers to participating in health information exchange where there is consensus for change. The LWG has recommended revisions to statutes that would reconcile the health record disclosure language in Chapter 456, F.S., regulating Health Professions and Occupations with Chapter 395, F.S., Hospital Licensing and Regulation, and Chapter 483, F.S., Health Testing Services ("Florida Clinical Laboratory Law").

Personal health records, previously lacking statutory recognition, were formally recognized and defined in the "Health Information Technology for Economic and Clinical Health Act,"⁴ ("HITECH"), signed into law as a part of the American Reinvestment and Recovery Act. Prior

⁴ The HITECH Act was included as a part of the American Reinvestment and Recovery Act, (Public Law 111-005, Title XIII), signed into law February 17, 2009.

to the HITECH Act protection for patients utilizing PHRs was unclear and seemed to be largely dependent on the terms of use established by the various PHR suppliers and vendors. While PHRs maintained by covered entities on behalf of their patients were arguably subject to the protections of HIPAA, the HITECH Act now bridges the gap by extending certain patient protective regulatory requirements to the noncovered entity PHR vendors.

Florida Experience with Analytical Framework

The Agency is the state agency under contract to participate in the Harmonizing State Privacy Law (HSPL) project of the HISPC in Florida. As part of its deliverables, the Agency reconvened the Florida Legal Work Group, originally established in 2006 during Phase I of HISPC, to review the materials assembled by the HSPL, develop priority recommendations for legislation, and provide comment on the proposed legislation. The LWG was asked to use the Ranking Tool⁵ with the Comparative Analysis Matrix developed by the HSPL collaborative as a test of the tool and the clarity of the directions for using the tool.

It should be noted that the LWG met and issued priority consensus recommendations in 2007 through a similar process, but without use of a formal Assessment Tool. Therefore, this exercise was an opportunity for the group to review the information in the CAM, apply the Assessment Tool, and determine whether any additions or modifications to the previous recommendations were suggested as a result.

The **Florida Legal Working Group** consists of 25 members from diverse backgrounds including medical, legal, consumers, information technology, and other stakeholders. Membership includes the Florida Hospital Association, Florida Medical Association, Florida Justice Association, Florida Department of Health, health plans, AARP, and others. The members hold extensive expertise and knowledge in the areas of law, health care, and legislation. The diversity of the group ensures a range of viewpoints in developing recommendations.

Review Process

The HSPL collaborative developed a roadmap for states to use to analyze the legal landscape related to the use of EHRs and to facilitate communication with state policymakers on common issues. The roadmap consists of a narrative guide, analytical documents, and other supporting materials to support these efforts. One of the tools the collaborative designed to address current state health care law is the CAM. The purpose of the CAM is to provide a common framework across the states for analysis of laws related to HIE. The Assessment Tool works with the CAM and is designed to assist policy makers in evaluating the impact of a change in law and the feasibility of making legislative changes.

⁵ The name of the tool was subsequently changed from Ranking Tool to Assessment Tool by the HSPLC after the initial test by state stakeholders.

To test the utility of the CAM and Assessment Tool, members of the Florida Legal Working Group were invited to an open public session held September 23, 2008, where they received a summary and the full version of the completed CAM. They were shown the Assessment Tool document along with an explanation of the instrument. Members were informed that they could issue a disclaimer regarding their organization's position to encourage participation. Members were asked to complete the evaluation from their viewpoint and provide comments to explain their answers.

Subsequently, each member was sent a segment of the CAM and Assessment Tool consisting of 12 areas of law designated for ranking. The 12 areas include health condition and facility-specific statutory provisions that are more stringent in Florida law than in the HIPAA Privacy Rule. Members were also sent the entire CAM and told that they could rank other areas from the CAM at their preference including "gaps"—topical areas not addressed in Florida statutes. Lastly, members received an accompanying document containing definition of terms and directions. The LWG was initially given a week to fill out the sample tool (subsequently extended) and submit their work to the HSPL project office. Comments and suggestions were encouraged to explain responses and any other thoughts on the tool itself.

Response from the Legal Work Group

Responses were received from 14 members of the Legal Work Group. Several follow-up phone calls and e-mails were made to encourage responses. Only one member ranked additional subject matter categories beyond the requested 12 areas. Several members provided comments on both the Assessment Tool and substantive suggestions for priority recommendations.

The responses were tabulated by staff and average scores for the 12 areas of law computed. Two subject matter areas receiving the highest priority ranking for legislative change were "hospitals" (s. 395.3025 FS.) and "testing and clinical labs" (483.181(2) FS) in the facility specific provisions section of the CAM. These results are consistent with the previous recommendations of the LWG and address specific issues related to the ability of treating physicians to exchange health information.

The average scores from the CAM and the Assessment Tool were shared with the LWG at its December 17, 2008, meeting. Members had an opportunity to consider their previous recommendations to determine whether there were any changes to the consensus recommendations as a result of the CAM review or other new information. The previous recommendations include the following:

1. Establish a uniform patient authorization form and process.
2. Address release of health information in an emergency.
3. Conform hospital licensure provisions related to treating physicians.

4. Provide for disclosure of clinical laboratory results to treating physicians.

The comments from LWG provided a frank and helpful assessment of the Assessment Tool and the adequacy of the directions provided. In general, there were several comments that indicated that it was not entirely clear how the Assessment Tool was to be used. There was concern that it was unclear as to what underlying proposal or change was being assessed as well as specific issues related to lack of clarity in scoring some of the criteria. Other comments related to members' views of priority recommendation. These comments reconfirmed previous LWG recommendations, or the commenter offered additional suggestions for legislation changes.

The comments from the LWG members provided insight into how the tool could be improved and the amount of guidance required for successful use.

Lessons Learned

Most of the concerns regarding the use of the CAM and Assessment Tool are probably not a result of the tool itself, but emphasize the importance of adequate orientation and guidance in the use of the tool. The Assessment Tool in its current configuration cannot be effectively self-administered and would require a controlled, facilitated process involving preparatory meetings or communications to the group, facilitated discussion, and opportunities to follow up regarding issues raised. It is essential that the stakeholders using the tool are provided an adequate opportunity to discuss their view of key concepts such as "health information exchange" and "population health." Multiple meetings are probably necessary to work through the process successfully.

The CAM and Assessment Tool have many positive features that a facilitator could use to focus and stimulate discussion. The facilitator might encourage the group to focus on certain subject matter areas or gaps in law. Stakeholders may decide to concentrate initially on facilitating patient care HIE and leave population health information exchange for a later time. Alternatively, the group might divide into subgroups, depending on interest and expertise, and bring their recommendations to the larger group for consideration.

Another key lesson learned was that it is important to provide guidance as to modifications of the tool that may be requested by stakeholders. The benefits of the CAM are greater to the extent states use it without modifying the subject matter categories. This consistency will enable interstate analysis and facilitate stakeholder education and communication across the states.

The Assessment Tool can be modified and adapted to local needs and stakeholder preferences without necessarily having a negative impact on its effective use among multiple states. To encourage participation, stakeholders should have an opportunity to discuss alternative scoring processes, whether scores will be public or private, and the extent to which the group scores will be binding. The group scores could be used to inform

the discussion, but not necessarily determine the final recommendations. The primary value of the tool is to facilitate stakeholder interaction and problem solving.

There were some concerns with the Assessment Tool that suggest specific revisions. The meaning of the ranking criterion “effect on consumer privacy protection” was unclear, and it appeared at least one member scored this section in reverse order from the intent. Some other evaluation criteria and scores seem counterintuitive and it may be possible to improve these. The placement of definitions within the tool and careful review of definitions prior to ranking is essential.

Kansas

Introduction

The potential transformation of health care in terms of quality and cost through the use of health IT and HIE has been, and continues to be, a high priority at both the federal and state level. In recent years, Kansas has supported the adoption of health IT and participation in HIE through a number of public and private sector activities. The purpose of this report is to describe those activities and discuss how Kansas is now uniquely positioned to facilitate the widespread adoption of health IT and participation in HIE within the state.

Background

In its 2008-2012 *Federal Health IT Strategic Plan*, ONC identified the federal activities necessary to achieve the nationwide implementation of a health information technology infrastructure. ONC's activities support two goals: (1) higher quality, more cost-efficient, patient-focused health care through access and use of electronic health information, and (2) the appropriate, authorized, and timely access and use of electronic health information to benefit public health. The specific objectives for each of these goals are built around themes of privacy and security, interoperability, IT adoption, and collaborative governance. While such federal leadership and activities are vitally important, the ONC Strategic Plan recognized that federal initiatives must be evaluated and integrated with existing legal frameworks, policies, and efforts at the state and local levels. "State legislatures and local governments play a critical part of overall leadership in their roles as regulators, safety net providers, and payers."⁶ Without state government leadership, guidance, and standards, stakeholders are faced with confusion about the interplay of federal and state standards, perceived inconsistencies in various legal standards, and fear of liability for unintentionally breaching medical privacy.

The State of Kansas has been working collaboratively with stakeholders to establish the infrastructure necessary to support HIE both within and outside of the state. Governor Kathleen Sebelius, in particular, has played an integral role in this process as a convener and facilitator of the continuing efforts to establish HIE in Kansas. The Governor initiated this process by creating the Kansas Health Care Cost Containment Commission ("H4C"). H4C identified health IT and HIE as key to a long-term strategy for improving quality, safety, and efficiency in the Kansas health care system. Based on H4C recommendations, the Governor's Office continued to lay the groundwork for the adoption and implementation of HIE by establishing an HIE Commission and subsequently the e-Health Advisory Council within the Kansas Health Policy Authority (KHPA).⁷ Kansas has also participated in HISPC, a federally funded grant established by the U.S. Department of Health and Human Services

⁶ Kansas Health Information Exchange Roadmap Briefing Paper, January 10, 2006, p. 10.

⁷ KHPA is responsible for coordinating a statewide health policy agenda that incorporates effective purchasing and administration with health promotion strategies.

that addresses the privacy and security issues related to multistate electronic HIE. Concurrently, through the H4C, the HIE Commission, HISPC, and now the KHPA e-Health Advisory Council, Kansas stakeholders were engaged in multiple efforts related to HIE and the adoption of health IT within the state. Such efforts included the initiation of a variety of public and private projects that use HIE networks and health IT to communicate patient information.

Overall, the urgency of the national agenda for HIE and health IT, combined with the current activities underway in Kansas, have established a strong foundation and momentum for significant progress toward comprehensive HIE and health IT within Kansas.⁸ Kansas is uniquely positioned to continue the process of identification, evaluation, and adoption of policies and laws designed to support the widespread implementation of HIE and health IT across the state. Kansas is also positioned to work collaboratively with neighboring states, such as Missouri, that are also in the process of pursuing HIE and health IT initiatives.

Foundation for HIE in Kansas

Health Care Cost Containment Commission

When Governor Sebelius created the H4C in December 2004, she charged it with making recommendations on solutions to reduce health care administrative processes that increase costs without improving patient care, advising and supporting the Governor and her staff as they developed and implemented strategies for more efficient and effective uses of health-related information, and identifying obstacles to revamping Kansas' health system infrastructure and provide recommendations to remove or minimize those obstacles. H4C identified health IT and HIE as key to a long-term strategy for improving quality, safety, and efficiency in the Kansas health care system. In October 2005, the H4C commissioned the Kansas Statewide Health IT/HIE Policy Initiative to develop recommendations for infrastructure needed to support HIE in Kansas. Specifically, it was recognized that early adoption of a statewide health information infrastructure would improve health care quality, safety, and efficiency in Kansas by

1. ensuring health information was available to health care providers at the point of care for all patients;
2. reducing medical errors and avoiding duplicative procedures;
3. improving coordination of care between hospitals, physicians, and other health professionals; and
4. providing consumers access to quality and cost information as well as to their own health information to encourage greater participation in their health care decisions.

It was also recognized that any health information infrastructure in Kansas must protect the privacy and security of health information.

⁸ Kansas Health Information Exchange Roadmap Briefing Paper, January 10, 2006, p. iii.

The HIE Commission

Following the conclusion of the H4C, Governor Sebelius issued an Executive Order on February 7, 2007, establishing the “HIE Commission” to serve as a leadership and advisory group for HIE in Kansas. The Executive Order required the HIE Commission to

1. promote the public good by ensuring an equitable and ethical approach to HIE for the improvement of health care,
2. encourage collaboration and facilitate a standardized approach to interoperable HIE in Kansas and across state lines,
3. recommend policy that would advance HIE in Kansas while protecting the privacy and security of citizens’ private health information, and
4. leverage existing HIE initiatives in Kansas and proactively seek opportunities to utilize HIE for the betterment of Kansas’ health care system.

The Executive Order required the Commission to meet regularly and to provide regular updates to the Governor, including an annual written report on plans, activities, accomplishments, and recommendations for HIE in Kansas. Just over 2 weeks after issuing the Executive Order creating the HIE Commission, the Governor signed House Bill 2368, which made appropriations for the upcoming fiscal year. Section 120 of the bill required the Kansas Health Policy Authority (KHPA) to use funds appropriated for fiscal year 2008 to support ongoing HIE initiatives including HIE infrastructure planning, privacy and security collaboration, an advanced medical identification card, a community health record, strengthening electronic prescribing processes and electronic medical records (EMRs), development of pilot programs, and enhancing compatibility with the private sector.

On August 31, 2007, the HIE Commission submitted its report and recommendations to Governor Sebelius. The report identified “leadership” and “resource needs” as key aspects necessary for supporting and stimulating HIE on a statewide level. With respect to leadership, the HIE Commission unanimously recommended a hybrid of a private and public model that would involve

1. establishing the Kansas Health Information Exchange Coordinating Entity as a not-for-profit, tax-exempt 501(c)(3) corporation; and
2. appointing a Board of up to 21 members consisting of 6 governmentally appointed members including at least one KHPA representative and up to 15 members from the following stakeholder groups/individuals:
 - a. an executive director,
 - b. consumers,
 - c. nurses,
 - d. health plans,
 - e. labs/medical services,

- f. medical practice managers,
- g. mental health,
- h. employers,
- i. physicians,
- j. hospitals,
- k. public health,
- l. pharmacy,
- m. long-term care,
- n. dental, and
- o. other health care entities (e.g., Quality Improvement Organizations or Health care Foundations).

To address the need for adequate resources for the support of HIE efforts across Kansas and to foster successful HIE at the local level, the HIE Commission recommended that the first priority of the Coordinating Entity should be to establish a mechanism or function for providing financial and nonfinancial resources to HIEs across Kansas. Financially related services provided by the HIE Commission would involve

1. determining priorities for community HIE funding,
2. identifying potential projects to be funded, and
3. developing eligibility requirements and selection criteria for the awarding of funds when funds are available.

The nonfinancial services provided by the HIE Commission would involve

1. education (for consumers and HIEs as appropriate over time),
2. standardization,
3. legal and regulatory assistance (including privacy and security issues),
4. guidelines and tools,
5. contracting,
6. subject-matter expertise,
7. a knowledgeable library, and
8. metrics.

The Governor sunsetted the HIE Commission late February 2008.

HISPC

Since June 2006, Kansas has been participating in HISPC, which is a federally funded effort to identify common solutions to privacy and security issues related to electronic HIE.⁹ HISPC is composed of several “collaboratives,” each responsible for addressing a specific component of HIE.¹⁰ Kansas participates in both HSPLC and the Consumer Education and Engagement Collaborative (CEEC).

The HSPLC was formed to support the facilitation of both intrastate and interstate electronic HIE by assisting states in identifying, analyzing, and reforming their laws as they relate to the participation in HIE.¹¹ Extensive discussions and activities with stakeholders during the first phase of HISPC determined that an overall lack of clarity in legal standards, and interpretation of those standards, has created multiple barriers to HIE. To assist states with the identification and adoption of workable standards and practices, the HSPLC is developing a set of analytical tools and a narrative guide. One HSPLC tool is based in part on work conducted by the Kansas Legal Workgroup in 2007, and involves a means through which state laws pertaining to the exchange of health information can be “gathered” and evaluated. The tool is designed to be used by individual states to facilitate discussion about laws or gaps in law that may present barriers to participation in HIE within the state. The tool is also designed to facilitate discussion about the feasibility of a potential legal change in terms of need, cost, ease of reaching consensus, and impact on privacy. The HSPLC will produce the set of tools and guides by March 2009.

The HISPC CEEC is a federally funded effort to advance multistate efforts in the area of educating consumers and engaging them in the facilitation of HIE.¹² The CEEC states are diverse in their resident populations and health care resource needs, and each state is implementing individualized projects to meet its unique state needs. Such projects target specific resident patient populations and incorporate literacy and language considerations. The CEEC states are also developing educational resource toolkits that may be used as templates for general use by other states and organizations. The Kansas CEEC is targeting residents of rural Kansas, and is currently working toward the following goals:

- Identify rural consumers' HIE and health IT privacy and security education needs and solicit feedback on preferences in regard to dissemination of messages.
- Search for, customize, develop, and refine educational materials for informing consumers in rural Kansas about privacy and security of health IT and HIE.

⁹ Currently, 42 states are participating in HISPC.

¹⁰ HISPC Collaboratives include Consent 1: Data Elements, Consent 2: Policy Options, Harmonizing State Privacy Law, Consumer Education and Engagement, Provider Education, Adoption of Standards and Policies, and Interorganizational Agreements.

¹¹ The HSPLC includes Florida, Kansas, Kentucky, Michigan, Missouri, New Mexico, and Texas.

¹² The CEEC includes Colorado, Georgia, Kansas, Massachusetts, New York, Oregon, Washington, and West Virginia.

- Develop a communication plan to disseminate the targeted messages on HIE and health IT privacy and security to consumers.
- Pilot test select resources from the toolkit developed.
- Develop a plan to evaluate the impact of the health IT and HIE privacy and security education materials on knowledge and attitudes of consumers in rural Kansas, and document lessons learned.
- Make an educational tool kit available to the CEEC and others through a Web portal. Currently, materials are posted on the University of Kansas Center for Health care Informatics website. Once materials are vetted and approved, they also will be available on the ONC website.
- Collaborate with other states to catalog relevant materials and tools, and to develop a glossary on health IT and HIE privacy and security terms. The glossary is currently available through the University of Kansas Center for Health care Informatics Web site.
- Collaborate with other states to advance education of consumers on HIE and health IT privacy and security issues.

E-Health Advisory Council

In February 2008, the KHPA established a Health Information (E-Health) Advisory Council at the Governor's request to build on the recommendations developed by the HIE Commission. The purpose of the Advisory Council is to provide guidance on policy issues related to health information technology and the development of a resource center for stakeholders.

Specifically, the Advisory Council was designed to serve in an advisory role to the Governor and the KHPA to do the following:

1. Explore options and make recommendations to leverage Kansas' purchasing power to promote the use of health IT, including consideration of a statewide community health record.
2. Provide guidance related to the operation and function of the resource center for stakeholders as outlined in the HIE Commission's recommendations, including the implementation of a statewide education plan to coordinate efforts across governmental and private entities to inform key stakeholders (e.g., consumers, providers, employers, payers, and policymakers) about the importance of health IT and HIE in improving health care delivery in Kansas.
3. Provide recommendations on policy issues related to health IT on topics such as
 - review and analysis of state and federal laws pertaining to the exchange of health information in Kansas;
 - identification of health care informatics standards and best practices to improve the exchange of health information;
 - development of model policies, procedures, and guidelines for the exchange of health information;
 - development of policies and models that allow for consumer access to personal health information to promote personal responsibility and self-management of care; and
 - strategies to successfully participate in HIE.

In July 2008, the Governor and KHPA appointed a total of 16 members to the Advisory Council that represent the following stakeholder categories:

- consumers
- physicians
- nurses
- hospitals
- health plans/systems
- legal services
- mental health
- safety net clinics
- public health
- labs/medical services
- pharmacies
- medical practice managers
- dental
- quality improvement organizations
- long-term care
- employers
- academia

The Continued Need and Opportunity for HIE in Kansas

From the creation of the H4C and the HIE Commission to the establishment of the E-Health Advisory Council within KHPA, the state's call for HIE in Kansas has been consistent and continuous since 2004. Kansas Department of Health and Environment (KDHE), Kansas Health Policy Authority (KHPA), and Kansas Association of Local Public Health Departments (KALPHD) have been actively engaged in these efforts. The many individual programs, projects, and initiatives involving HIE within the state reinforce the need to facilitate the continued expansion of health IT and HIE. These organizations have a strong track record in working with public and private organizational partners in assessing barriers to HIE and working to improve systems which support public health functions such as emergency response. However, as is true in many states, the public health infrastructure requires additional funding and resources because there is more work to be done. A recent report suggests that Kansas would benefit from further increased use of HIE and health IT from a public health standpoint. In December 2008, the Robert Wood Johnson Foundation released an "issue report" titled "*Ready or not? Protecting the Public's Health from Diseases, Disasters, and Bioterrorism.*"¹³ The purpose of the report is to describe the progress that has been made in improving the country's ability to respond to public health emergencies by assigning each state a readiness score. The score is based on the presence or absence of certain public health readiness indicators such as availability of emergency vaccines, adequacy of state public health labs, and the legal framework for the services of volunteers and organizations who serve in public health emergencies. Kansas received a score of 6 out of 10 points possible. One element for which Kansas was deducted a point is a lack of a "disease tracking system to collect and monitor data electronically via the Internet."

¹³ The report may be accessed at <http://www.khi.org/resources/Other/1242-bioterror-report-2008.pdf> (last accessed 12/19/2008).

The Need for Statute Modernization to Foster Adoption of Health IT and HIE

Whether the call for HIE is for patient-focused care or public health, or both, and whether that call is answered by state or federal policies, or a combination of both, stakeholders will require guidance as to how new HIE policies fit within the State's existing legal framework and how new policies and laws may permit HIE while protecting patient privacy and data security. To date, the HISPC Kansas Legal Workgroup has identified approximately 180 statutes and regulations involving the collection, use, or disclosure of personally identifiable health information. These laws are scattered across numerous articles of the Kansas statutes, such as those addressing public health, regulation of health professions, insurance regulation, rights of minors, mental health, probate proceedings, domestic relations, civil procedure, and crimes and law enforcement. In general, these statutes and regulations have been enacted/promulgated independent of one another to serve the individual intent and priorities of the statutory or regulatory body involved. Some of the statutory and regulatory provisions contemplate that medical records may be maintained in multiple mediums, including computerized formats. However, no Kansas statute or regulation addresses the electronic format or standardized data elements to be used for an EHR. Further, Kansas statutes and regulations do not comprehensively address other issues specifically related to EHRs or the electronic exchange of health information such as data security, consent for participation in HIE, or maintenance of personal health records.

The process of identifying and evaluating Kansas health information laws during the second phase of HISPC led the Kansas Legal Workgroup to the conclusion that the current confusing lack of harmony in the Kansas statutory and regulatory structure presents a barrier to the broad use of technological advancements for the purpose of promoting the appropriate and secure collection, use, and exchange of health information. The Kansas Legal Workgroup developed a draft resolution for consideration by the Legislature designed to raise awareness among legislators regarding the importance of a comprehensive legal framework promoting and enabling health IT/HIE. The key components of the draft resolution recognize the following:

1. Individuals in Kansas have the primary interest in the confidentiality, security, integrity, and availability of their personal health information.
2. The availability, quality, and efficiency in the delivery of health care depend on the efficient and secure collection, use, maintenance, and exchange of health information.
3. The use of current and emerging technology facilitates the efficient and secure collection, use, maintenance, and exchange of health information.
4. Kansas' antiquated and decentralized statutory and regulatory scheme, and its interaction with federal mandates, creates confusion and is a significant barrier to the efficient and secure collection, use, maintenance, and exchange of health information.

The draft resolution, which the Kansas Legislature is encouraged to pass, resolves that the laws of Kansas should be reviewed, modified as necessary, and construed to protect the interests of individuals in the confidentiality, security, integrity, and availability of their health information; to promote the use of modern technology in the collection, use, maintenance, and exchange of health information; to promote uniformity in policy; and to codify all standards in a cohesive and comprehensive statutory structure.

With respect to HIE, the Kansas Health Information Exchange Roadmap Briefing Paper commissioned by H4C notes, “a wide range of legal issues beyond organization and governance need to be addressed including those related to user and vendor agreements, fraud and abuse, antitrust, liability and malpractice, data uses and rights, and compliance with HIPAA and state privacy laws.”¹⁴ The evaluation of Kansas law using tools currently available and some still under development will enable Kansas to continue to move toward implementation of HIE networks and health IT.

Since studies have shown that consumers are more receptive to the exchange of their information electronically when they are better informed,¹⁵ the tools and resources currently being developed by the Kansas CEEC may assist the continuation of the previously mentioned HIE-related projects which are currently underway in Kansas. Additionally, these resources will also supplement other ongoing efforts to educate consumers about the benefits of participating in HIE. For example, the Kansas Health Information Management Association, through resources provided by the American Health Information Management Association, is training Kansans through train-a-trainer techniques to educate consumers about personal health records. Another example is Kansas Health Online (KHO), a portal that was developed from an initiative seeking to disseminate health information to consumers in Kansas, empowering them to be better decision makers about their health. Through the work of the Kansas CEEC and these other educational efforts within the state, the adoption of HIE can be encouraged and more quickly achieved.

Next Steps

By building on existing initiatives in the state and using the multiple legal and educational resources available, Kansas is uniquely positioned to take significant further steps toward participation in HIE within the state. Potential steps specifically related to consumer and stakeholder outreach include the following:

- Working with KHPA to assist with planning for the design of the section of KHO for health IT/HIE privacy and security materials and developing this section of the KHO website.

¹⁴ Kansas Health Information Exchange Roadmap Briefing Paper, January 10, 2006, p. 11.

¹⁵ eHealth Initiative Foundation

- Working with the e-Health Advisory Council to assess the most effective approaches for relaying the messages, and involving key stakeholders to advise the project and to disseminate messages.
- Working with the e-Health Advisory Council and the Legal Work Group to develop a plan for communicating recommended legislative changes to policymakers.
- Developing a data agreement with KHPA for reviewing reports and survey results from the KHO focus groups for discussions on privacy and security HIE/health IT issues.
- Making findings public through the KHO portal and other materials, and developing an online and paper survey tool for ongoing feedback.
- Identifying new areas of focus to develop messages, and augmenting existing materials to meet Kansas' needs, leveraging HISPC resources provided through the CEEC and the HSPLC.

Potential steps specifically related to statute, policy, and regulation changes to foster participation in HIE include

- adoption of the Draft Resolution,
- establishing and scheduling study sessions for ongoing legal analysis, and
- convene stakeholders to review statutes, policy, and regulations and develop consensus-based recommendations related for changes to foster participation in HIE such as emergency medical services, social services, and transitions in care among hospitals and long term-care facilities.

The HISPC III project work was presented to the Kansas Health Policy Authority in 2008 in conjunction with a review of the work and outcomes accomplished by HISPC Phase I and HISPC Phase II. The information was well received and members agreed that a better understanding of how this work can be leveraged in Kansas was needed. At the most recent eHealth Advisory Council meeting in February of this year, discussion included consideration of submitting the HISPC II Draft Resolution to the state legislature with modification to include the concept of "medical home." Also discussed was the need to further explore use of the CAM at the next eHealth Advisory Council meeting. Planning is underway to accomplish these objectives. In summary, the members of the Kansas HISPC team have been working with leadership of Kansas Health Policy Authority to ensure that Kansas will be positioned to fully leverage the work accomplished through HISPC Phases I, II, and III for future work in modernizing state statute, policies, and regulations to foster the adoption of electronic health information.

Conclusion

Kansas is positioned to take immediate steps toward effective widespread adoption of HIE and health IT programs and initiatives within the state and to leverage funding opportunities provided through American Recovery and Reinvestment Act (ARRA). While the groundwork for HIE and health IT has been laid through the recommendations of appointed leadership

entities and the recommendations made through Kansas HISPC workgroups, Kansas is still in the process of evaluating and implementing those recommendations. This process will likely be time-consuming because it may involve policy, statutory, and regulatory changes, as well as the need for ongoing financial and nonfinancial resources. However, “through dialogue and collaboration among the many diverse stakeholders in Kansas, supported by lessons now being learned in different parts of the country, the region has the opportunity to achieve significant gains in quality, safety, and efficiency through the effective and appropriate use of information technology and connectivity and interoperability across its many health care organizations.”¹⁶

¹⁶ Kansas Health Information Exchange Roadmap Briefing Paper, January 10, 2006, p. 15.

Kentucky

Introduction

This report provides an update on HIE activity in Kentucky. It addresses public and private sector HIE projects, stakeholders active in promoting the initiative, and the activities of the E-Health Network Board that guides policy and planning in this area.

Governance and Stakeholders

In 2005, legislation codified as Ky. Revised Statutes 216.261 established the governance structure for Kentucky's e-health initiatives. The two entities created by the 2005 statute have distinct roles: the Ky. e-Health Network Board (KEHN) is responsible for policy and oversight, while the Ky. Health care Infrastructure Authority carries out research and evaluation, and provides related guidance. The Ky. e-Health Corporation, created by House Bill 185 of the 2007 Regular Session of the Ky. General Assembly, has operational responsibility for facilitating public-private partnerships to develop the state e-health network. The Ky. Cabinet for Health and Family Services provides administrative and technical support for the Kentucky e-Health Network Board.

The KEHN Board is a 22-member appointed body co-chaired by representatives of the University of Kentucky (UK) (Carol Steltenkamp, MD) and the University of Louisville (UL) (Larry Cook, MD). Board committees include Privacy and Security (which also serves as the steering committee for HISPC and HSPL work), Health Information Technology Adoption, Health Information Exchange, and Economic Development. More than 50 volunteers from a range of stakeholder groups participate in these committees.

Stakeholder engagement has also been the focus of two E-Health Summits, in 2006 and 2007, which brought more than 300 participants together for productive interaction. A strategic planning session convened in July 2008 involved more than 100 participants in the revision of the state's e-health enterprise vision and mission.

Technical Assistance Activities

Throughout the implementation of health IT initiatives in Kentucky, the Office of Health Policy has drawn on expertise from internal and external consultants, including members of the e-Health Network Board and its committees, the Ky. Health Infrastructure Authority, and consultative staff.

Kentucky was one of 33 states that participated in HISPC, funded by the ONC and the Agency for Health care Research and Quality. The goal of this collaboration was to assess variations in privacy and security policies and procedures, both formal and informal, and their impact on HIE. Technical input on this project was provided under contract with legal and information technology experts at UK and UL. A final report and implementation plan

were released in April 2007. Based on the recommendations in the implementation plan, Kentucky received additional HISPC funding for the period July–December 2007. During this time, an extensive analysis and recommendations for revision of relevant Kentucky regulations were prepared by expert private practice counsel and UK College of Public Health faculty.

UK and UL faculty conducted and reported on two statewide assessments in 2008: a comprehensive analysis of Kentucky’s medical trading areas and a series of surveys addressing the level of EHR adoption in Kentucky, the primary vendors used in health care settings, and the barriers and needs related to health information technology adoption.

Legal Landscape for HIE

Recent Legislation

House Bill 185, enacted by the 2007 General Assembly, gives the KEHN Board authority to establish a nonprofit organization under its authority to assist with the development and implementation of the statewide network. With this legal authority, the Ky. e-Health Corporation was created and incorporated in September 2007, and met for the first time in December 2007.

House Bill 551, enacted during the 2008 Regular Session of the Kentucky General Assembly, mandates that contracts between carriers and pharmacy benefits administrators requiring electronic submission of claims also require electronic payments to the participating provider or designee for clean claims submitted electronically, and that all electronic claims are to be in compliance with HIPAA regulations on privacy of electronic submissions.

Proposed Bills Related to HIE

House Bill 48 in the 2008 legislative session would have established an application process for receiving data from the electronic system for monitoring controlled substances that prohibited sharing personal identifying data; it was sent to committee early in the session and garnered no further action.

Health Information Exchange Topics Not Addressed in Kentucky Law

Kentucky lacks a comprehensive EHRs act. The analysis of Kentucky regulations prepared in Phase II of the HISPC project found many discrepancies in Kentucky law regarding specific topics such as release of medical records in an emergency or HIPAA preemption.

For HIPAA-covered entities, the fact that a topic is not addressed in Kentucky law may mean that the provisions of HIPAA would govern, and this may be the intent embodied in these omissions. However, a comprehensive act has the potential to improve the coordination of state and federal law and clarify the relationships.

Status of HIE

Kentucky Medicaid and Other State Agency Health Information Exchange

The Centers for Medicare & Medicaid Services awarded Kentucky a \$4.9 million Medicaid Transformation grant, and revised plans for its implementation are scheduled for release in early 2009.

The e-Prescribing Partnerships in Kentucky (ePPIK) Grant Program is offered by the Cabinet for Health and Family Services in partnership with the KEHN Board and the Kentucky Department for Local Government. The ePPIK Program will promote the formation of partnerships between provider offices, hospitals, pharmacies, and other entities to facilitate electronic prescription processing. Some \$635,000 in grants has been awarded to date for implementation of e-prescribing in communities across the state.

Regional Health Information Organizations (RHIOs)

HealthBridge, one of the most successful HIE networks in the United States, includes Kentucky in its three-state service area. Its activity focuses on clinical messaging but additional functionality continues to emerge. LouHIE, a personal health records banking initiative in Louisville, has completed an extensive community engagement process and is in the process of selecting a vendor for core functionality processes. The Northeastern Kentucky RHIO is also being developed under the auspices of St. Claire Medical Center, which has established an HIE with most local medical practices and several other providers.

There is no association of RHIOs in Kentucky.

Rural Outreach

Kentucky has an extensive and well-established telehealth network that is used for many health-related purposes but does not operate as a HIE network. The University of Kentucky is exploring HIE with a range of providers in more rural areas of eastern Kentucky in conjunction with Accenture.

Other Private Sector Initiatives

In addition to the RHIO-related development noted above, several hospitals are encouraging EMR implementation among their medical staff and affiliates through technical assistance and system networking.

Kentucky Experience with Analytical Framework

The Kentucky Cabinet for Health and Family Services (Cabinet) is the agency under contract to participate in the HSPL project of HISPC in Kentucky. As part of its deliverables, the Cabinet reconvened a subcommittee of the Kentucky Legal Work Group (originally established in 2006 during Phase I of HISPC) to review the materials assembled by the HSPL, develop priority recommendations for legislation, and provide comment on the

proposed legislation. The LWG was asked to use the Assessment Tool with the CAM developed by the HSPL collaborative as a test of the tool and the clarity of the directions for using the tool.

The LWG issued priority consensus recommendations in 2007 through a similar process but without use of a formal Assessment Tool. Therefore, this exercise was an opportunity for the group to review the information in the CAM, apply the Assessment Tool, and determine whether any additions or modifications to the previous recommendations were suggested as a result.

The Kentucky LWG membership has changed since it was originally constituted because of a change in gubernatorial administration in 2008. The full workgroup includes 18 members representing medical, legal, consumers, information technology, and other stakeholder groups. The Working Group is co-chaired by Professor Mark Rothstein, a nationally recognized health privacy expert and faculty member at the University of Louisville, and Barbara Baker, ARNP, Senior Policy Advisor in the Cabinet for Health and Family Services. Membership includes the Kentucky Hospital Association, Kentucky Medical Association, Kentucky Department for Public Health, Kentucky HIMSS, health plans, academic specialists, and others. The members hold extensive expertise and knowledge in the areas of law, health care, and legislation. The diversity of the group ensures a range of viewpoints in developing recommendations.

Review Process

One of the tools that the collaborative designed to assess current state health care legislation is the CAM. The purpose of the CAM is to provide a common framework across the states for analysis of laws related to HIE. The Assessment Tool works with the CAM and is designed to assist policy makers in evaluating the impact of a change in law and the feasibility of making legislative changes.

To test the utility of the CAM and Assessment Tool, members of the Kentucky LWG were convened via conference call on October 9, 2008. In advance of the call, they received abridged and full versions of the completed CAM, as well as the Assessment Tool document and a user guide. Members were informed that they could issue a disclaimer regarding their organization's position to encourage participation. Members were asked to complete the evaluation from their viewpoint and provide comments to explain their answers.

After responses were catalogued and entered into the CAM, each member was sent a segment of the CAM and Assessment Tool consisting of seven areas of law designated for ranking. The seven areas include facility-specific and procedural provisions that are more stringent in Kentucky law than the HIPAA Privacy Rule. Members were also sent the entire CAM and told that they could rank other areas from the CAM at their preference including "gaps"—topical areas not addressed in Kentucky law. Members were sent an accompanying

document containing definitions and directions. The LWG was initially given a week to fill out the sample tool (subsequently extended) and submit their work to the project office.

Comments and suggestions were encouraged to explain responses and any others on the tool itself. Responses were received from five members; others commented that they did not feel adequately equipped to work on the ranking part of the exercise.

Participants made several comments and recommendations beyond the scope of the CAM, addressing federal rather than state laws.

Response from LWG

Responses from the initial 10-participant meeting were tabulated by staff and average scores for the 7 target laws computed. The results were consistent with the previous recommendations of the LWG and addressed specific issues related to the ability of facilities and clinicians to exchange health information.

Members will have an opportunity to consider their previous recommendations to determine whether there are any changes to the consensus recommendations as a result of the CAM review or other new information. Draft language prepared as part of the late-2007 phase of HISPC will also be shared for further input.

Lessons Learned

Thorough orientation and guidance are essential to effective use of the Assessment Tool. Stakeholders using the tool should have an opportunity to discuss their view of key concepts such as “health information exchange” and “population health.” A series of meetings could be necessary to work through the process successfully.

The CAM will be more useful to the HSPL collaborative if states use it without modifying the subject matter categories. This consistency will enable interstate analysis and facilitate stakeholder education and communication across the states. However, some modifications to the Assessment Tool in response to local needs and stakeholder preferences would not necessarily undermine its effective use among multiple states. If stakeholders are given an opportunity to discuss alternative scoring processes, whether scores will be public or private, and the extent to which the group scores will be binding, they may be more likely to engage in the ranking process. The group scores could be used to inform the discussion but not necessarily determine the final recommendations. The primary value of the tool is to facilitate stakeholder interaction and problem solving.

Michigan

Introduction

In her 2006 State of the State address and subsequent communications, Governor Jennifer M. Granholm promoted the vision of a statewide health information network that would bring Michigan's health care into the electronic age and boost efforts to lower costs, improve quality, and increase consumer involvement. In partnership with the Michigan Department of Community Health (MDCH) and the Michigan Department of Information technology (MDIT), Michigan State University, and the Michigan Public Health Institute (MPHI) supported the Michigan Health Information Network (MiHIN) Conduit to Care process in the summer of 2006. The resulting report provided a substantial framework for developing full-fledged HIE networks across the state.

Michigan's first step in this process was the creation of the Michigan Health Information Network (MiHIN), which issued a report in December 2006 based on its Conduit to Care planning process. The Michigan Health IT Commission and MDCH created nine distinct regions within the state, known as medical trading areas. These geographic regions were constructed based on the analysis of treatment pattern data. The state awarded grants to five regional groups for planning projects, two regional groups for implementation projects, and to create the MiHIN Resource Center.

The state, the health IT Commission and the MiHIN Resource Center, while supporting the regions local efforts, are also exploring statewide strategies to expedite HIE. Likewise, Blue Cross and Blue Shield of Michigan (BCBSM) has expressed willingness to help the regions while it expands its own administrative data system.

Governance and Stakeholders

For the MiHIN Project, a statewide Steering Committee and six workgroups—clinical, financial, governance, legal, regional, and technical were established to address specific issues, foster statewide involvement and provide recommendations. Health care leaders and experts representing major health care organizations, public health agencies and public and mental health providers, government, providers, health care consumers and payers, information technology, academia, and others contributed their time and expertise to developing this report. Project management and oversight of all the workgroups was provided by a team composed of Michigan Department of Community Health, Michigan Department of Information Technology, Michigan Public Health Institute, Health Network Services Group and eHealth Initiative.

The volunteer workgroups were initiated in May 2006. All workgroup meetings were open to the public. This open and inclusive makeup of workgroup membership provided a channel for all interested individuals and organizations to be represented and heard. There were

approximately 200 people who volunteered their time to participate in the Conduit to Care workgroups.

Technical Assistance Activities

Michigan shares many barriers and challenges with other states, but it also has unique strengths and experiences that can be built on to help ensure success. The state continues to provide vision, leadership, and direction on health IT—telemedicine, vital records, immunization registry, disease surveillance, Medicaid management, pharmaceutical pricing, and others.

Specific to health IT, according to a report commissioned by Blue Cross Blue Shield of Michigan and the Partnership for Michigan’s Health (composed of the Michigan Health & Hospital Association, the Michigan State Medical Society, and the Michigan Osteopathic Association), many of Michigan’s health care providers have had widespread success in implementing electronic medical systems. According to the report, Michigan is also outpacing most states in adopting computerized forms of physician order entry. The report also pinpointed barriers to adopting a statewide system, which include inconsistent coding systems between providers and computer systems that vary between hospitals.

Legal Landscape for HIE—Recent Legislation

All workgroup volunteers articulated and understood the importance of laws and regulations in the health care industry, especially in protecting patients’ rights. Therefore the Conduit to Care specifically reviewed those laws and regulations that impact health information organizations and the sharing of information. The laws discussed below are those which are likely to have the most extensive and pervasive impact on HIE; however, this list is not exhaustive.

Working within a highly regulated industry, health care providers and health-related information are subject to myriad laws at both the state and the federal levels. “Law” includes both statutes passed by Congress or the state legislature, regulations adopted by governmental agencies as promulgated pursuant to statute and court rulings (common law). Laws that impact HIE include the following:

- **Privacy and Confidentiality Laws.** Federal, state, and common law create minimum protections regarding the privacy and confidentiality of identifiable health and personal information in electronic, written, verbal, and any other form. These include the federal privacy regulations under HIPAA, federal Alcohol and Other Drug (AOD) confidentiality regulations, Michigan’s Public Health and Mental Health Codes, and Michigan’s Social Security Number Privacy Act. These laws, and Michigan’s Medical Records Access Act, establish patients’ rights regarding access to their health information. Patients’ rights include the right to inspect and obtain copies of their own health information, to request restrictions on disclosure of health information, seek amendments for inaccuracies, and obtain an accounting of certain disclosures.

- **Security Laws.** Federal security regulations under HIPAA, although technology neutral, require implementation of appropriate security safeguards to protect certain electronic health care information that may be at risk while permitting appropriate access, availability, and integrity and use of that information. Covered entities must conduct an assessment of the potential risks and vulnerabilities to the confidentiality, integrity, and availability of electronic protected health information held by the entity. Also, they must implement sufficient administrative, physical, and technical safeguards (considering their size, funding and ability) to protect information that the covered entity creates, receives, maintains, or transmits. The regulations contain standards for each type of safeguards, and implementation specifications for each standard.

The requirements in the security regulations are designed to be technology neutral to accommodate changes in technology. This flexibility also allows clinical service providers to choose technologies to best meet their specific needs, taking into account size, capabilities, the costs of the specific security measures, and the operational impact. This means that specific security measures adopted by clinical service providers may comply with the security regulations yet impede interoperability and HIE.

Conclusion

There is an expansion of Michigan health IT and HIE initiatives currently in operation or in the planning stages. Michigan is working to ensure that these initiatives are coordinated across the state and do not develop into “islands of information.” The Conduit to Care Report delivers a strategy for future development of HIEs and incorporates the discussions, recommendations, and admonitions of the workgroups and participants. Additionally, the report initiates an incremental approach for building a strong foundation upon which leadership in the State of Michigan can transform health care.

Success can be defined many ways; however it can be summarized as the long-term tangible improvements in health care quality, safety, and costs through focused, collaborative, incremental efforts. Achieving success will be possible with the collaborative contributions and efforts of many Michigan public and private partners, each with a sense of urgency and commitment to advance health information exchange.

Michigan Experience with Analytical Framework

Process

Michigan’s approach was to utilize the LWG that was originally convened to work on both the HISPC project and the MiHIN Conduit to Care project. The LWG participants, through previous meetings, had built trust and a level of comfort in sharing ideas. In 2007, using an issues matrix, the LWG developed a “top 10” list of priorities to be addressed by the state legislature and policymakers for review by the health IT Commission, with the overall goal of facilitating and supporting effective HIE. The LWG ranked the priorities’ matrix subject

areas based on overall impact, need for timely action, and ease of reaching consensus among stakeholders throughout the state.

The LWG was provided with an update on the HISPC project, including a brief overview of areas that the other HISPC Collaboratives were addressing. The MiHIN Resource Center gave an update on HIE activities in Michigan. The Director of Legal Affairs from the Michigan Department of Community Health gave an update on 2007 legislative recommendations, discussing current action related to MDCH updating the state's Stark rule to reflect recent amendments.

The CAM and Assessment Tool were reviewed by the group. The general consensus was to decrease the criteria to be applied, thereby making it easier to complete the matrix. The question was raised as to how to get a "global picture" moving from page to page when ranking all of the state's laws. A suggestion was made to simplify the matrix by utilizing the subject matter headings and then listing the details under the headings.

The LWG then went into discussion regarding the content of the CAM and the specific legislative recommendations made in 2007. Upon review of those recommendations, it was conceded that many were already outdated and unnecessary.

Some of the updates to the recommendations were as follows:

- *Informed Opt Out*: Consistent with last year's recommendation that informed opt out is how Michigan should proceed, for those specially protected types of health care information (HIV/AIDS, substance abuse, mental health, STDs, genetic information, etc.) opt in will be the standard. Again, consumer education in regard to this aspect of HIE participation is the most critical component, and there is a consensus that legislation is not needed, but that instead the state would recommend this policy and draft opt-out language for providers to add to their Notice of Privacy Practice.
- *Promote the use of software that is nonproprietary*: Promote the use of vendor software that permits access to clinical systems even if software license is not specific.
- *Use technology-neutral, interoperable systems and platforms*: The LWG recommended that this "legal" objective be achieved not through legislation or rulemaking, but rather through general guidelines or education. There are, however, federal-level standards (i.e., CCHIT) for deeming systems "interoperable." These standards could help serve as a basis for any Michigan HIE.
- *Require licensure/registration for access to HIE by providers*: Because providers who will have access to HIE will either be licensed with the state or will be employees of licensed facilities, this recommendation from last year stands.
- *Set minimum standards for retention of records for HIE*: This recommendation from last year was viewed as no longer important—at least not for the HIE—and should not place the burden on the HIE to retain the records. The discussion was to encourage the use of existing standards with references to HIPAA as a standard for medical records.

- *Definitions:* Last year, the LWG recommended that definitions for HIE, health IT RHIO, and a few other terms be defined in legislation. There may be generally broad consensus for this legal goal/priority because it is relatively easy to achieve, either by explicitly amending existing law/regulation or adopting other definitions at the federal level.

Lessons Learned

Having already formed the LWG in 2007, Michigan had the advantage of reconvening an established group of experts and stakeholders who were familiar with the HIE landscape in Michigan and developments in both law and technology. The LWG was also familiar with the matrix-style analysis and had previously made recommendations to the health IT Commission. The CAM was introduced to the LWG via e-mail, with detailed instructions. In addition, the matrix and recommendations from 2007 were sent in the same e-mail. However, the size of the CAM proved to be a bit intimidating to the LWG. There was a great deal of additional information contained in the pilot CAM compared with the original matrix that the LWG completed in 2007—which was a barrier for some volunteers. Having the LWG meet face to face proved to be a critical part of the process. Without the opportunity for the LWG to interact and discuss the CAM, the process did not quite work. The LWG was convened for a face-to-face meeting in late 2008 to review the CAM. It was agreed in Michigan, as it was by most states, that having an in-person meeting that included a facilitator and a subject matter expert was necessary to the process.

To keep up with the legal and technological changes, it was determined that the LWG should meet at least annually to review recommendations, recognize new state and federal laws, and determine how the state should address those changes.

Conclusion

Since 2007, the workgroup's list of legal priorities for HIE has shifted. The shift in areas identified by the LWG as "priorities" were disclosed in the face-to-face meeting resulting from the members' increased comfort and familiarity with certain legal issues relevant to HIE. For example, the issue of limiting the liability of providers who participate in the HIE has a higher priority ranking in 2008, while creating exceptions to medical information and record confidentiality (i.e., FOIA exceptions) has become less important in 2008, compared with the 2007 ranking.

As noted above, despite the shift in priorities identified by the LWG, the underlying legal issues are noted for the development of HIE in Michigan. To support further effort by the LWG, as well as legislators and policymakers, it is important to articulate legal arguments in support of assigning priority to these issues, as well as the disadvantages associated with these legal positions.

Missouri

Governance and Stakeholders

On January 17, 2006, Missouri Governor Matt Blunt issued Executive Order 06-03, which recognized the potential of health information technology to improve the state's health care delivery system. The order created the Governor's Health Care Information Technology Task Force to assess the status of health care information technology adoption; identify technical, security, and privacy issues related to the electronic exchange of health care information; and recommend best practices and policies for state government and private entities to promote the adoption of interoperable health care information technology by the Missouri health care delivery system.

In the final report of the Task Force submitted to the Governor in September 2006, the group made recommendations for strategic action. First and foremost was the recommendation that Missouri form a Steering Committee to continue work beyond the life of the Task Force, which expired on December 1, 2006. The group outlined an ambitious agenda for the Steering Committee including creation of a board of directors and a private, not-for-profit organization. These new entities were envisioned to continue promoting collaboration in public and private partnerships for nurturing the adoption of interoperable electronic health information exchange. Unfortunately, the recommended Steering Committee was never established, and subsequent efforts by the legislature to develop an oversight body for health care technology have not been successful.

When the opportunity arose to join the Health Information Security and Privacy Collaboration (HISPC) under the ONC, Missouri saw this as a means to once again assemble a multi-stakeholder leadership group to coordinate activities and advance the agenda of interoperable health information exchange in the state. Governor Blunt named Primaris, a not-for-profit health care consulting firm and the state's Medicare Quality Improvement Organization (QIO), to lead Missouri's efforts. The state team was successful in joining both the Harmonizing State Privacy Law (HSPL) and the Provider Education Toolkit (PET) collaboratives.

As the contracts were executed, the Missouri team recruited an exceptional array of thought-leaders from various stakeholder groups around the state. Our colleagues responded enthusiastically and Missouri's HISPC Steering Committee is now composed of representatives from such engaged sectors as health care providers, patients/clients, payers, state agencies, private health care systems, and special interest groups. In addition to the voices represented on the Steering Committee, the Missouri team has developed relationships with more than 40 organizations and entities around the state with an interest in improving health care through health IT and HIE. Continuing dialogue with all

stakeholders will inform Missouri's ongoing participation in the collaboratives and the umbrella HISPC.

Status of HIE

On March 2, 2007, Governor Matt Blunt issued an Executive Order (EO 07-12) which required each Missouri state agency that administers or sponsors a state or federal health care program to support various measures toward expanding interoperable health information exchange while protecting patient privacy as required by law. All appropriate state agencies provided the Governor with a plan for implementing this order.

MO HealthNet (Medicaid)

In Missouri, Medicaid is administered under the MO HealthNet program within the Department of Social Services. MO HealthNet employs current technology to enhance transparency and access to services. Health care providers can follow a participant's medical history through an EHR and plan of care. MO HealthNet is increasing reimbursement for physician-related services over time to attract and retain "health care home" providers and to improve access. A "Pay for Performance" program links quality of care and evidence-based performance measures with financial incentives beyond reimbursement for services.

A \$25 million Health care Technology Fund, established in 2006 by Governor Blunt and funded by the General Assembly in 2007, finances projects which improve the safety and quality of health care, and which embrace technology to reduce paperwork, increase efficiency, improve transparency, and deter fraud. The Department of Social Services has used the Health care Technology Fund to implement a solid infrastructure for health information exchange within the MO HealthNet program. Projects funded to date include telemonitoring, automated prior authorizations, prospective drug utilization review, MoRX Compare, electronic medical histories, Medicaid management information system modernization, and installation of technology at federally qualified health centers.

A member of Missouri's HISPC Steering Committee helped lead the transformation at MO HealthNet. At the group's meeting in June 2008 the committee member reported on the status of implementation of the EHR system for Medicaid patients and provided statistics on usage. The system was populated with paid claims data and is now processing 80 million claims a year. It was noted that a "big draw" has been the inclusion of an interface between the EHRs and evidence-based practices, providing an "if...then" tool which helps reinforce the provider's treatment plan. The committee member reported that 65% of participants use the tool on a regular basis.

Interagency Coordination for HIE

Building on the successes of HIE activity within MO HealthNet, an effort is underway to link state agencies so that their health information will be interoperable and can be more easily

and appropriately shared. Information technology professionals at Missouri's Department of Social Services, the Department of Health and Senior Services, and the Department of Mental Health are in the early stages of this effort. All three state agencies are represented on Missouri's HISPC Steering Committee so all of our stakeholders can stay informed about these efforts and use the knowledge to help others in the public and private sectors with similar initiatives.

Other Efforts at HIE

At this time, Missouri is home to a limited number of early-stage but promising HIE initiatives. The St. Louis Integrated Health Network (IHN) comprises a partnership of safety net providers serving more than 250,000 uninsured and underinsured residents in St. Louis City and County. In 2006, the St. Louis Regional Health Commission and the St. Louis Integrated Health Network launched the Primary Care Home Initiative. This effort seeks to build health literacy and connect the uninsured and underinsured in St. Louis with a primary care home.

CareEntrust is a not-for-profit, employer-based regional health information organization (RHIO) in the greater Kansas City area, and was the first such network in the country. The CareEntrust Health Record (CHR) "collects and organizes health care visit information including medication and lab data to create a secure repository for much of what a health care provider needs to know in order to effectively treat their patients." An employer-based system, CareEntrust is being offered by employers and organizations as a health benefit. Built on a Cerner platform, the system had some 90,000 participants in the fall of 2008.

Legal Landscape for HIE

HISPC funding allowed Missouri to engage a legal consultant to develop an extensive 230-page matrix of its state laws related to the privacy and security of health information, compare those laws with HIPAA and other legal requirements, and suggest what implications they might have on the participation in HIE. Missouri law is largely silent in regard to health IT, EHRs, and HIE. Proposals before the 2007 and 2008 legislatures to create public/private oversight bodies did not see final action.

Cohesive, ongoing leadership remains a key issue for Missouri. While there are many forces in the state with an interest in health IT and HIE, our state's involvement in HISPC and Missouri's HISPC Steering Committee are the only avenues currently available to work toward consensus among the various stakeholder groups. In November 2008, Missouri's HISPC team approached Governor-elect Jay Nixon's transition team. A meeting with the Governor's staff was held on March 2, 2009, to encourage participation by a representative of the Governor's office in Missouri's HISPC Steering Committee. Continuity in public/private leadership is essential to encouraging the development and growth of HIE networks in the state.

Missouri Experience with Analytical Framework

Working from its own analysis of state law, Missouri's HSPL team participated in the development and refinement of the comparative analysis matrix (CAM) and the Assessment Tool developed by the HSPL collaborative. When the time came to test the CAM and Assessment Tool by populating the matrix and inviting stakeholder feedback on priority issues, it quickly became apparent that Missouri is challenged by the lack of key foundational elements, which are allowing the veteran states in the HSPL collaborative to move confidently forward. These include a staff attorney with expertise in health and privacy law and an engaged, experienced LWG.

Legal Working Group

The structure and process for pursuing these tasks in the veteran HSPL states include reliance on a functioning LWG. These LWGs were formed under HISPC early in the collaboration and have been in operation through Phases I and II. The groups vary in size from state to state, and some have had continuity issues similar to the overall leadership continuity issue described for Missouri. At the same time, however, most of the LWGs have provided available and willing participants, with extensive expertise and knowledge in the areas of law, health care, and legislation, and with a history of working together on projects in support of a better climate for HIE. A similar group had not been established in Missouri.

HISPC funding allowed Missouri to capture and analyze its statutes which relate to the privacy and security of health information and the impact they may have on health information exchange, as described above. Completed in May 2008, the information was updated in August 2008 to capture relevant additions and changes as of that year's legislative session.

Many HSPL states have begun the process of populating the CAM and applying the Assessment Tool by having an attorney staff member prepare a populated CAM. Missouri does not have an attorney on its HISPC staff. Attorney members of the Steering Committee expressed the belief that translating Missouri's laws from our matrix to the CAM should be done by a single individual or a small group, so that the reasoning for placement would be consistent throughout. The possibility of using law students to handle the chore was discussed, but the group concluded that law students do not yet have the degree of familiarity with statutes and case law needed to successfully complete the task.

Missouri's Structure and Process

Missouri used available resources to populate the CAM and work toward applying the Assessment Tool. The HSPL co-chairs and Missouri's RTI liaison agreed that it would be necessary and appropriate to extend the deadline for our state to accomplish this task. One benefit of Missouri's protracted experience is that it may serve as an example of what it will be like for those states which have yet to approach analyzing and harmonizing their statutes

around the privacy and security of information. In that respect, Missouri believes its participation will prove helpful by highlighting the foundational elements necessary for progress. Comments on a number of these resources are being written into HSPL's report on this process.

One member of Missouri's Steering Committee who serves as General Counsel for a major provider organization volunteered his time, and that of his assistant general counsel, to work with Missouri's HISPC legal consultant to translate the state's legal matrix into the CAM. Over a 5-week period in October–November 2008, the group met once in person and twice by extended conference call. As a result, the process of plugging information on Missouri's laws into the HSPL CAM has now been completed.

Our legal consultant then worked to flesh out the remaining columns in the CAM, leading up to the column which helps determine whether the statute (or lack of a statute) is problematic enough that change should be considered. This work was completed by December 1, 2008. The consultant then used administrative staff to insert web links for each of the identified statutes into Missouri's completed CAM.

As for value-ranking legislative issues or gaps in legislation which may artificially or unnecessarily interfere with the exchange of health information, Missouri recruited an additional volunteer to its ad hoc LWG which is scheduled to further develop the Assessment Tool during an extended conference call on March 10, 2009. The results of their work will be taken to Missouri's full HISPC Steering Committee at its meeting on March 18, 2009, to begin building consensus around a shared legislative agenda.

At the September 2008 meeting of the Steering Committee it became clear that leaders from various stakeholder groups are still exploring what the issues are and how the agendas they represent may mesh or conflict with the agendas of others around the table. Airing of a handful of potential legislative concerns in September did result in constructive conversation and likely advanced the perception that there will be some issues on which the various parties can agree.

Progress toward developing Missouri's legislative agenda is now moving hand in hand with the necessity of ensuring continuous leadership for this initiative into the future—an issue which the Steering Committee self-identified as its top priority. We are seeking to involve a representative from Governor Jay Nixon's administration to further strengthen our ongoing public/private leadership body to oversee health IT and HIE development in the state. We anticipate using a facilitated session at the March 18 Steering Committee meeting during which participants will use the Assessment Tool to rank the issues for potential action.

Lessons Learned

States that have not yet approached the tasks of analyzing their laws and harmonizing them to better facilitate HIE may be able to learn a great deal from Missouri's experience. The Missouri team offers the following comments:

- The analysis of state law around privacy and security of health information is a lengthy and involved process. In addition to state law, it must involve state regulations and case law, and applicable, overlapping federal statutes and regulations. The analysis must include not only what exists in state law, but also what may be missing that could impede the exchange of electronic health information. In addition, plans must be made to continually update the analysis with each passing year to keep it current.
- A staff attorney (or two) with expertise in health and privacy law and regulations, case law, and the legislative process may be your best asset for accomplishing the necessary analysis. If your state organization does not have this talent available on staff, be certain you have made adequate plans to "beg, borrow, or steal" this expertise for the process.
- When it comes to teasing out the value judgments which can help assemble a shared legislative agenda, do not underestimate the value of building communication, relationships, and trust among your leadership group (Steering Committee). Because members of this group represent various constituencies, each with its own agenda, time is needed to help the individuals at the table recognize that—while they may vary on some issues—there will be a set of goals that they can champion en masse. Missouri's first exploration of legislative issues came at the second meeting of the Steering Committee which, in retrospect, was too soon for the group to have reached an appropriate level of comfort.
- Time and trust are not the only prerequisites for ranking issues on the legislative agenda. Experiences from our sister states clearly show that the process will benefit from a talented, informed facilitator to help the leaders understand the ranking process and apply the Assessment Tool uniformly.

Missouri looks forward to continuing the process outlined by the HSPL collaborative in working with the Assessment Tool from its populated CAM. Joining the collaborative in Phase III required us to move quickly to form the relationships that can support consensus building in a multi-stakeholder setting. Although it has sometimes felt like we were taking "two steps forward, one step back," Missouri's HISPC team knows that we are making progress toward a better environment for enhancing health care through the interoperable exchange of health information.

New Mexico

Introduction

This report provides a brief overview of the current status of HIE activities in New Mexico and the need for legislation that supports the transmission of electronic health information.

Proposed Legislation

In January 2008 proposed legislation was introduced in the 48th New Mexico Legislature to address identified state law barriers to the electronic exchange of health information. The legislation passed the New Mexico House of Representatives, but did not pass the Senate. Health information exchange legislation was also introduced during the Governor's special legislative session in August 2008. Once again, issues that could not be reconciled such as liability, the assumption of a mandate for providers to acquire an EHR system, and patient privacy were of primary importance and caused the proposed legislation to fail. A redraft of the bill was introduced in the 49th New Mexico Legislature 2009. The legislative session will close the third week in March. The Governor has until early April to sign the passed legislation into law.

New Mexico's Public and Private Sector Health Information Exchange (HIE) Projects

New Mexico, like many other states, has a number of emergent HIE initiatives. The New Mexico Health Information Collaborative (NMHIC) is the primary HIE in the state and the only HIE designed to provide statewide service. NMHIC was created in late 2004 with funding from Agency for Health care Research and Quality (AHRQ) and community organizations within New Mexico. The objective of NMHIC is to create an HIE network for the state that will provide cross-organization data to providers at the point of care and eventually to patients. NMHIC is governed by a 33-member Steering Committee. Patient, provider, and institutional issues of privacy and security have been a concern for NMHIC from the onset. However, until legislation addresses these issues directly, NMHIC will continue to allow data sharing across organizations for purposes of treatment, payment, and operations that are HIPAA compliant and in a manner that complies with New Mexico state law.

HIE and Legislative Assistance Activities

New Mexico Telehealth and Health Information Technology Commission

The Commission was created by Senate Bill 473 during the 2005 legislative session. Its purpose is to encourage a single, coordinated system statewide to advance telehealth and health information technology in New Mexico. Two members of New Mexico's HISPC team are members of the Commission. The Commission has been meeting on a regular basis since 2005 and supports all activities of HIE initiatives in New Mexico.

Legal Landscape for HIE

Recent Legislation

According to the research conducted by the New Mexico HISPC team, New Mexico has numerous privacy laws that were written long before health care information could be stored or communicated electronically. It has been determined that many of these laws are likely to be impediments to an electronic HIE network.

New Mexico laws regarding the protection of health information are fragmented and dated. There are numerous acts and statutory provisions that affect or could be interpreted to impact EHRs and HIE. These laws were enacted, for the most part, prior to the adoption of the HIPAA Privacy Rule and, generally, without consideration of the positive impact that electronic health records and HIE can have on patient care.

Many provisions of New Mexico law are, or can be interpreted as, more stringent than the HIPAA Privacy Rule, and, therefore, are not preempted by the HIPAA Privacy Rule. Unless the application of New Mexico's fragmented and outdated laws to electronic health records and HIE is clarified, an HIE network operating in New Mexico and providers who maintain EHRs in New Mexico will have to comply in all respects with HIPAA and with each statutory provision that is more stringent than HIPAA.

Statutory clarification of the ability to create and maintain health information in electronic form would also be beneficial to health care providers in New Mexico. While legal compliance is a burden that in all cases must be met, the outdated and fragmented nature of current state law and the difficulty in interpreting existing laws in relation to EHRs and HIE makes compliance difficult, if not impossible. This presents a significant barrier to HIE in New Mexico. The nationwide HISPC project has demonstrated that this problem is not unique to New Mexico.

Proposed Bills Related to HIE

In January 2008, proposed legislation was introduced in the 48th New Mexico legislative session that would have (1) clarified the legality of the creation and use of EMRs; (2) generally required patient authorization for the disclosure of medical records in other than certain specified circumstances; (3) specifically authorized disclosures to an HIE; and (4) permitted out-of-state disclosures to the extent that the disclosure would have been permissible with the state.

Significant provisions of the proposed act included the following:

- Definitions of "demographic information," "EMR," "HIE," "medical emergency," and "record locator service."
- Clear authorization for the creation and use of EMRs, and that EMRs satisfy any requirement that records be maintained or written.

- Generally requiring patient authorization for the disclosure of information in a medical record.
- Placing a 1-year time limit on the effectiveness of patient authorizations.
- Allowing disclosure without authorization in the case of a medical emergency.
- Allowing disclosure of demographic information to a record locator service or HIE network, but allowing an individual to elect to not participate in the record locator service.
- Allowing out-of-state disclosures of information in an individual's medical record if the disclosure would have been permissible in-state under the act.

After amendments that eliminated any restrictions on disclosure that exceed the requirements of the HIPAA Privacy Rule, the proposed legislation passed the New Mexico House, but failed to pass on the floor of the New Mexico Senate. The legislation was reintroduced in a fall 2008 special session, and was once again not passed.

The Governor's office decided to reintroduce the bill and a second redraft of the EMR legislation was initiated in December 2008 for the 49th legislative session. The legislation retained the same legislative sponsor that carried the bill during the 2008 special legislative session. Requirements for consent were reinstated. Currently the redraft legislation addresses the following:

- require patient consent for disclosure of information in an EMR (except as allowed by state and federal law);
- require an audit log of individuals obtaining access to an electronic medical record, as well as an audit log of all access for an individual health care consumer;
- provide a mechanism for an individual to "opt out"—to exclude demographic information and the location of their EMRs from the record locator service;
- require that providers or institutions warrant that a request for an individual's EMR has consent of the individual or is otherwise permitted by state or federal law;
- give providers, health care institutions, or HIE networks exclusion from liability for any harm caused by an individual's exclusion of information; and
- provide for both in-state and out-of-state disclosure of information.

Legislation passed initial committees with numerous questions about provider liability and use of the record locator service. Legislation passed in the Senate and was heard before the House Judiciary Committee and then was presented to the House where it received a do pass. The EMR Act is currently waiting for the Governor's signature. Since the bill was a part of the Governor's legislative agenda, we believe it will receive his signature by early April 2009.

HIE Topics Not Addressed in New Mexico Law

Because HB 37 and special session HB 5 failed to pass during the 2008 legislative sessions, no changes have been made that would address the barriers to participation in HIE in New Mexico resulting from outdated and fragmented laws. Despite the failure of the legislation to pass, the introduction of the proposed legislation provided an opportunity to begin the process of educating legislators and the broader community about participation in HIE.

Privacy remains the most significant legal issue facing the HIE in New Mexico. From the standpoint of proponents of the HIE, the most significant problem is that under New Mexico state law disclosure of certain types of medical information (e.g., HIV/AIDS, mental health, and genetic information) requires patient authorization that exceeds the requirements imposed under the HIPAA Regulations. New Mexico HIE proponents, like those in other states, continue to struggle with addressing how to deal with the patchwork of protections afforded certain types of information. At present, it appears that the only practical means of addressing the issue, short of legislative change, is to require patient authorization for all disclosures to be made through the HIE network.

Other privacy issues also surfaced during the attempt to pass HB 37 in New Mexico. Providers and health care organizations clearly opposed any effort to impose requirements that would have exceeded those imposed by the HIPAA Regulations. On the other side of the issue, the ACLU and other privacy advocates argued that the HIPAA Regulations were not strong enough on protection of patient privacy, and sought to use HB 37 as a means of increasing patient privacy protections. During the special session in August 2008, legislators voiced concern about liability issues for providers. The potential benefits of the HIE network were often seen as a secondary issue to these larger concerns, and the legislature, at least during the 2008 sessions, was unable to make a determination of the appropriate response.

Conclusion

New Mexico is fortunate to have the Telehealth and Health Information Technology Commission, which serves as an umbrella coordinating entity for HIE/health IT in New Mexico. Since 2005, the Commission has been pivotal in its support and coordination for NMHIC, UNM Center for Telehealth, the Telehealth Alliance, and HISPC. Without the support of the Commission, the remarkable work of these HIE/health IT organizations, and the federal and state funding for these diverse initiatives, New Mexico would be sorely lacking in its capability and capacity to address health care needs in all areas of the state. New Mexico is fortunate to have made significant HIE progress through these initiatives, the work of the Commission, and the passage of new legislation that addresses the exchange of health information. Through New Mexico's experiences and the initiative of the Harmonizing State Privacy Law collaborative, we hope to create tools and information to help states update their state privacy laws addressing EHRs and the HIE.

New Mexico Experience with Analytical Framework

Lovelace Clinic Foundation (LCF) is a tax-exempt, nonprofit corporation that has contracted with RTI to participate in HSPL collaborative project of HISPC. As part of its deliverables, LCF convened a group of stakeholders to review the materials assembled by HSPL collaborative and to develop priority recommendations for legislation to facilitate HIE in New Mexico. The New Mexico Health Information Collaborative (NMHIC) [New Mexico's statewide HIE project] members were identified as the stakeholder group asked to use the Assessment Tool with the CAM developed by the HSPL collaborative as a test of the tool, to assess the clarity of the directions for using the tool, and to continue efforts to educate stakeholders about the effect of state laws on the exchange of health information.

Prior to the review by the NMHIC stakeholder group, New Mexico's HSPL presented the concepts of the CAM and Assessment Tool to the New Mexico Telehealth and Health Information Technology Commission. The Commission acts as the New Mexico HSPL Steering Committee. The Commission was interested in the analytical function of the CAM and Assessment Tool and indicated an interest in a follow-up once the CAM and Assessment Tool were vetted by the stakeholder group.

NMHIC's stakeholders are made up of 35 statewide organizations with the purpose to advise NMHIC on goals and direction, and to encourage the involvement of state agencies and the Governor's Office to promote and coordinate the exchange of electronic health information programs in the state. NMHIC's members are from diverse backgrounds with extensive expertise in the areas of law, health care, and the legislative process. The comprehensive and knowledgeable makeup of the NMHIC stakeholder group provided perspectives and insights germane to New Mexico.

Review Process

The purpose of the CAM is to provide a common framework across the states for analysis of laws related to the exchange of electronic health information and electronic medical records. The Assessment Tool works with the CAM and is designed to assist policy makers and stakeholders in evaluating the impact of a change in law and the feasibility of making legislative changes.

To convene the stakeholders in New Mexico, members of NMHIC were invited to attend two statutory review meetings on October 27 and 29, 2008. During a NMHIC meeting in mid-October, stakeholders were introduced to the goals of the HSPL meeting and invited to attend. The stakeholders were then sent written invitations explaining the tasks and the need for their expert opinions. Eleven individuals participated in the meeting on the 27th and nine participated on the 29th. Participants who reviewed the identified New Mexico statutes and utilized the Assessment Tool included individuals from the New Mexico Hospital Association, Tricare Reference Laboratory, Presbyterian and Lovelace Health Systems, New

Mexico Health Policy Commission, University of New Mexico Health Science Center, and a health care attorney. During the two meetings, participants received the full version of the completed CAM along with the statutes identified by the New Mexico HSPL as requiring change. The purpose and utilization of the Assessment Tool and the definition documents were once again reviewed. New Mexico's HSPL team walked members through the process and requested that they evaluate not only the statutes, but the usefulness of the CAM and the Assessment Tool.

Response from the Stakeholder Group

New Mexico's HSPL team planned to ask the stakeholder group to review and assess New Mexico statutes in 10 different CAM subject matter areas during the two meetings. The review of the first statute involving the disclosure of information related to sexually transmitted diseases was the most time-consuming, because participants needed considerable time to familiarize themselves with the CAM, the Assessment Tool definitions, and the statute.

For the CAM and Assessment Tool review and assessment process the New Mexico HSPL team chose statutes that it believed had significant impact on the development of HIE networks within the state. These statutes were selected primarily because the requirements of the statutes are more restrictive than HIPAA Privacy Rule. This results in a different higher standard for use and disclosure of certain "sensitive" health information than does the HIPAA-based "treatment, payment, and operations" standard. Several of the statutes dealing with "sensitive" conditions had similar provisions restricting the use and disclosure of information. The need to meet two standards imposes a significant barrier to participating in HIE. Out of the 10 areas that were proposed for review, only 6 were actually reviewed in the time allowed.

Only a few participants had reviewed the statutes and ranked the categories prior to attending the review and assessment meeting. The majority of attendees appeared to prefer guidance in how to use the CAM and the Assessment Tool.

As the group familiarized itself with the statutes and process, participants labored over the Assessment Tool and whether the numbering system was correct in its assumption that the higher the number indicated a greater likelihood for change. This concept was particularly prominent on the last category: Effect on Consumer Privacy Protection. Participants thought that the statement of the scale (1=little, 2=moderate, and 3=significant) was perplexing. Did a score of "1=little effect" register a positive or a negative connotation to consumer privacy? Participants thought the direction and intent of the scoring should be better referenced in the definition section.

The participants also thought that totaling the numbers for each statute did not support their ideas and suggestions of whether the statute should be changed. They saw the totaling

as an ineffective measure. The participants would have preferred no total and a written recommendation as to which statutes should be targeted for legislative change.

Given the participants' expertise and knowledge of statutes and the legislative process, three categories in the Assessment Tool were determined to be unproductive: Cost of Change (fiscal impact), Need for Timely Action, and Immediate Impact (low hanging fruit). For Cost of Change, participants could not determine how this category was different from weighing the economic impact identified in the next column. Participants believed the Need for Timely Action category was ambiguous. They always gave it an average (neutral) score regardless of the statute under consideration. Participants stated they could not determine, given their expertise and the activities of the legislature and state government, how this category could be scored with anything other than a neutral value. Immediate Impact was another category the participants thought added little to the review process and suggested that it could be eliminated from the Assessment Tool.

Out of the five ranked categories (Facilitates HIE, Ease of Reaching Consensus, Positive Impact on Patient Focused Health Care, Positive Impact on Population Health, and Effect on Consumer Privacy), only two had numerical values that varied. Those two categories were Ease of Reaching Consensus and Positive Impact on Population Health. The other three categories consistently scored similar numerical values from all of the participants for each statute under consideration.

The comments from the stakeholders provided insight into how the tool can be improved and the amount of guidance required for successful use. Also, in spite of the limitations, members were successful in using the tool to express their views.

Lessons Learned

Most of the concerns regarding the use of the CAM and Assessment Tool were a result of the ambiguous nature of some of the tool's categories and the numerical ranking process. Even though a few of the participants assessed and used the Assessment Tool prior to the meetings, it was determined by the questions asked that the tool does not lend itself to self-administration.

During the meetings a prominent theme emerged that there is a need for an educational process regarding legislation that impacts or creates barriers to the facilitation of the exchange of electronic health information or EHRs. Issues of population health and what was already reported to the New Mexico Department of Health as a reportable disease was a topic of discussion and how that could possibly positively impact the electronic exchange of health information from one health care entity to another.

Given these issues, clarification of how to use the tool and the need for legislative education, it was determined by New Mexico's HSPL team that use of the Assessment Tool should not be completed on an individual basis. For future use of the CAM and Assessment

Tool, it is essential that stakeholders are provided with adequate guidelines, and an opportunity to discuss their viewpoints for the process to have the greatest success.

It was also clear that the use of the CAM and the Assessment Tool had an unanticipated benefit apart from the creation of a set of legislative priorities. The process itself, by gathering key stakeholders and identifying specific statutory barriers to HIE, provided the opportunity for discussion of the issues among stakeholders, and educated the stakeholders about the specific barriers to HIE caused by certain state laws.

The following are recommendations from those who assessed and used the CAM and Assessment Tool.

1. Create a narrative document of the statutes that need to be assessed and reviewed.
2. Define what “more stringent” means.
3. Determine whether both federal and state statutes are needed in the review process.
4. Delete the following categories in the Assessment Tool: Cost of Change, Need for Timely Action, and Immediate Impact.
5. Be more specific in the numerical scale process. Make sure that “little” and “significant” are defined so that participants understand the actual intent of the numerical order.
6. Disregard the “total” and focus more on the comments and document participants’ concerns.
7. The review and assessment process should take place in groups facilitated by someone with a prior understanding of the CAM and Assessment Tool.

The responses from the CAM and Assessment Tool review and assessment and the lessons learned were shared with the HSPL collaborative the final development of the Analytical Framework of the Roadmap.

Texas

Governance and Stakeholders

Recognizing the need for collaboration to promote the adoption of EMRs and participation in HIE, Texas has brought knowledgeable and interested parties together in several committees.

The 79th Legislature, which met in 2005, created the Health Information Technology Advisory Committee (HITAC) through Senate Bill 45. The purpose of the HITAC was to develop a long-term health IT plan for Texas looking at both the private and public health systems and exploring both EHRs and other technological means of improving care and lowering costs. HITAC's report was released on September 29, 2006,¹⁷ and provided a suggested roadmap to health IT adoption and use in Texas, recommending use of EMRs and the development of a statewide HIE network. HITAC focused on the following nine principles in developing the roadmap:

1. Be patient-centric.
2. Engage stakeholders.
3. Emphasize market-based solutions.
4. Promote regional HIE solutions.
5. Leverage existing health IT initiatives and resources.
6. Recognize IT as an enabler.
7. Proceed via an incremental and evolutionary process.
8. Remain cognizant of federal efforts.
9. Recognize effect of health IT on a culturally diverse population.

HITAC's report helped inform health IT initiatives in Texas and later health IT advisory groups.

The Texas Health Care Policy Council (HCPC) was created by the 79th Legislature through House Bill 916. Among the goals of the HCPC's creation was for it to promote health IT in Texas, and to monitor related initiatives and coordinate its activities with other state entities involved in health IT adoption.

Acknowledging the importance of continuing Texas's examination of health IT, the Governor issued Executive Order RP61 on October 9, 2006, calling for the creation of the Health Care System Integrity Partnership. The Partnership was a committee of stakeholders, whose recommendations built from the HITAC report and the work done at that time by HCPC. The

¹⁷ See http://www.dshs.state.tx.us/chs/shcc/hitac/hitac_default.shtm for links to the executive summary and the full report.

Partnership's goal was to make necessary recommendations to build the financial and governmental structures needed for a statewide private-public health IT collaborative.

In response to the Partnership's work, the 80th Legislature, which met in 2007, passed House Bill 1066, which created the Texas Health Services Authority (THSA). The THSA is a private-public collaborative charged with implementing the HITAC's roadmap and supporting health IT in Texas as a means of improving patient safety and quality of care.

The 81st Legislative Session began in January 2009. Several health IT- and HIE-related bills have been filed, the most significant of which may be House Bill 1218 by Rep. Donna Howard. The bill would direct the creation of a pilot project to allow secure exchange of electronic health information between the Texas Health and Human Services Commission and local or regional HIE networks. Other health IT/HIE bills include Sen. Jane Nelson's Senate Bills 286-289, all of which look at electronic data processing and exchange within the Texas Medicaid and Children's Health Insurance Program. Sen. Dan Patrick's Senate Bill 531 would also address electronic information within the state's Medicaid program. The session ends in late May 2009 and may be a significant one for the state of HIE in Texas.

Legal Landscape for HIE—Recent Legislation

The Texas Legislature has examined health IT and created legislation since its 79th Regular Session in 2005. Continued emphasis on health IT was seen during the 80th Regular Session in 2007.

The most important pieces of legislation from the 79th Session were those that created HITAC and HCPC, because they set the stage for the development of health IT plans in Texas.

The 80th Legislature enacted a number of bills relating to health IT in Texas. As discussed above, the THSA was created by legislation during the 80th Legislature, as part of House Bill 1066. In addition to the bills discussed below, several pieces of legislation were passed regarding Texas's electronic eligibility information systems for health and human services programs.

House Bill 522, another bill passed by the 80th Legislature, required the Texas Department of Insurance to establish a technical advisory committee to identify standards for the use of electronic data exchange by health plans and providers. An identification card pilot program was to be developed as part of the project.

House Bill 921 expanded the HCPC's role in health IT by requiring HCPC to work with the Department of Information Resources to develop standards for exchange of electronic health data among relevant state agencies.

House Bill 1060 authorized hospitals to obtain electronic information from an individual's drivers' license or personal identification card and allowed the hospitals to transfer such

information as needed to business associates, as defined under state and federal privacy law.

Doctors and funeral homes were directed to use electronic means of data exchange with respect to death certificate filings under House Bill 1739; some exceptions apply.

Vendors selling EMR systems to health care providers in Texas were required to include information-sharing capabilities that are compatible with the Texas Immunization Registry under Senate Bill 204. The impact of the bill remains to be seen, however, as it is only enforceable after immunization standards are incorporated into relevant electronic accreditation standards.

Senate Bill 994 authorized the use of e-prescribing for Schedule III, IV, and V drugs by certain health care practitioners.

Senate Bill 10, the 80th Legislature's omnibus Medicaid reform bill, also included health IT/HIE-related provisions. The bill creates definitions, including one for EHRs and health IT, and authorizes the Health and Human Services Commission to implement health IT in the Medicaid program to the extent feasible and allowable by federal law. It also directed the Commission to create a pilot project to provide EHR systems and other health IT to primary care providers who participate in Medicaid.

The 80th Legislature's Regular Session was a large one for health IT in Texas. Texas's 81st Regular Legislative Session began January 13, 2009. At the time of this report, Sen. Jane Nelson, Chair of the Senate Committee on Health & Human Services, has filed four bills related to the use of health information technology in administration of Texas's Medicaid and CHIP services. Two of the bills, SB 287 and SB 288, relate to the use of e-prescribing. Two others, SB 286 and SB 289, support expansion of the use of health IT for the populations served by Medicaid and CHIP.

HIE Topics Not Addressed in Texas Law

One of the weaknesses in Texas's privacy law is that relevant provisions are scattered throughout various codes and various sections. The wide net needed to capture all of Texas's medical privacy related laws is reflected by the Attorney General's Office's HIPAA preemption analysis, and the need of the task force to review almost every state code.

Texas law also does not currently reflect HIPAA preemption law, because proposed bills to do so have failed to pass the previous two sessions. This makes compliance more difficult than necessary for covered entities.

Texas law also lacks specific information about HIE and health IT privacy and ownership of electronic medical records. While Texas has provisions relating to privacy and security of medical records, they are largely focused on paper records and fail to address the different security and privacy needs relating to electronic information. For example, as in many

states, Texas law discussing access to medical records creates a maximum allowed fee, but there is no distinction made for electronic records as opposed to traditional paper records.

Texas privacy law in general and HIE and health IT law specifically would be greatly strengthened by a thorough review of existing law, a full-scale updating project to ensure that the law reflects changing technology, and the creation of a single comprehensive privacy law located in a single area of code.

It is likely that the HCPC, the current HSPLC project, and the THSA will engage in the relevant statutory analysis needed for Texas law to reflect the state's policy priorities regarding health IT and HIE.

APPENDIX B: ORGANIZATIONS CONTACTED FOR FEEDBACK

American Health Informatics Association

Association of State and Territorial Health Officers

Data Use and Reciprocal Support Agreement Work Group (members)

Health Information and Management Systems Society

National Association of County and City Health Officials

National Association for State Health Policy

National Association of State Medicaid Directors

National Conference of Commissioners on Uniform State Law

National Conference of State Legislatures

National Governors' Association