

**Health Information Security and
Privacy Collaboration (HISPC) Phase III**



A Multi-State

Harmonizing State Privacy Law Collaborative:

Kansas State Project

State of the State Report

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March 16, 2009

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Health Information Technology/Health Information Exchange

Kansas State-of-the-State Brief

I. Purpose of Report

The potential transformation of health care in terms of quality and cost through the use of health information technology (HIT) and health information exchange (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 HIT and 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 HIT and HIE within the state.

II. Introduction and Background

In its 2008-2012 *Federal Health IT Strategic Plan*, the Office of the National Coordinator for Health Information Technology (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 level. "State legislatures and local governments play a critical part of overall leadership in their roles as regulators, safety net providers, and payers."¹ 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 HIT 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 a HIE Commission and subsequently the e-Health Advisory Council within the Kansas Health Policy Authority (KHPA).² Kansas has also participated in the Health Information Privacy and Security Collaboration (HISPC), a federally funded grant established by the U.S. Department of Health and Human Services that addresses the privacy and security issues related to multi-state 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 the adoption of HIE and HIT

¹ Kansas Health Information Exchange Roadmap Briefing Paper January 10, 2006, p. 10

² KHPA is responsible for coordinating a statewide health policy agenda that incorporates effective purchasing and administration with health promotion strategies.

within the state. Such efforts included the initiation of a variety of public and private projects that use HIE and HIT to communicate patient information.

Overall, the urgency of the national agenda for HIE and HIT, combined with the current activities underway in Kansas, have established a strong foundation and momentum for significant progress towards comprehensive HIE and HIT within Kansas.³ 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 HIT 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 HIT initiatives.

III. Foundation for HIE in Kansas

A. Health Care Cost Containment Commission

When Governor Sebelius created the H4C, in December of 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 HIT and HIE as key to a long-term strategy for improving quality, safety, and efficiency in the Kansas health care system. In October of 2005, the H4C commissioned the Kansas Statewide HIT/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.

B. 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;

³ Kansas Health Information Exchange Roadmap Briefing Paper January 10, 2006, p. iii.

- 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 two 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: health information exchange infrastructure planning, privacy and security collaboration, an advanced medical identification card, a community health record, strengthening electronic prescribing processes and electronic medical records, development of pilot programs to enhance compatibility with the private sector and establishing a two-phase initiative to collect and make available health and health care quality information developed by the Data Consortium for use by purchasers and consumers.

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 state-wide level. With respect to leadership, the HIE Commission 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	j) Hospitals
b) Consumers	k) Public Health
c) Nurses	l) Pharmacy
d) Health plans	m) Long Term Care
e) Laboratories/Medical Services	n) Dental
f) Medical Practice Managers	o) Other healthcare entities (e.g. Quality Improvement Organizations or Healthcare Foundations)
g) Mental Health	
h) Employers	
i) Physicians	

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 non-financial 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

- 3) Developing eligibility requirements and selection criteria for the awarding of funds when funds are available.

The non-financial 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
- 8) Metrics

After receiving the recommendations from the HIE Commission, the Governor sunsetted HIE Commission late February of 2008.

C. HISPC

Since June of 2006, Kansas has been participating in Health Information Security and Privacy Collaboration (HISPC), which is a federally funded effort to identify common solutions to privacy and security issues related to electronic HIE.⁴ HISPC is composed of several “collaboratives,” each responsible for addressing a specific component of HIE.⁵ Kansas participates in both the Harmonizing State Privacy Law Collaborative (HSPLC) and the Consumer Education and Engagement Collaborative (CEEC).

The HSPLC was formed to support the implementation of both intrastate and interstate electronic HIE by assisting states in identifying, analyzing and reforming their laws as they relate to the adoption of HIE.⁶ 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 the adoption of 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 by 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 the adoption of 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 the first federally funded effort to advance multi-state efforts in the area of educating consumers and engaging them in the implementation of HIE.⁷ The CEEC states are

⁴ Currently, 42 states are participating in HISPC.

⁵ 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.

⁶ The HSPLC includes Kansas, Missouri, Texas, New Mexico, Michigan, Florida, and Kentucky.

⁷ The CEEC includes Kansas, Colorado, Georgia, Massachusetts, New York, Oregon, Washington and West Virginia.

diverse in their resident populations and healthcare 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 towards the following goals:

- Identify rural consumers' HIE and HIT privacy and security education needs and solicit feedback on preferences in regards to dissemination of messages.
- Search for, customize, develop, and refine educational materials for informing consumers in rural Kansas about privacy and security of HIT and HIE.
- Develop a communication plan to disseminate the targeted messages on HIE and HIT privacy and security to consumers.
- Pilot test select resources from the toolkit developed.
- Develop a plan to evaluate the impact of the HIT 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 Healthcare Informatics Web site. Once materials are vetted and approved, they also will be available on the ONC Web portal.
- Collaborate with other states to catalog relevant materials and tools, and to develop a glossary on HIT and HIE privacy and security terms. The glossary is currently available through the University of Kansas Center for Healthcare Informatics Web site.
- Collaborate with other states to advance education of consumers on HIE and HIT privacy and security issues.

D. Kansas Health Policy Authority and the E-Health Advisory Council

The Kansas Health Policy Authority was established in 2005 with passage of S.B. 272 in the Kansas legislature. That bill established KHPA as a state agency within the executive branch of state government (K.S.A. 75-7401, et seq.). The general charge is to improve the health of Kansans and to develop and maintain a coordinated health policy agenda that combines effective purchasing and administration of health care with health promotion oriented public health strategies. KHPA administers the medical portions of Medicaid, the State Children's Health Insurance Program (SCHIP), HealthWave, the State Employee Health Plan and the State Self-Insurance Fund (SSIF), which provides workers compensation coverage for state employees. KHPA is also responsible for the development of a statewide health policy agenda including health care and health promotion components, as well as the development of health indicators to include baseline and trend data on health costs.

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. The Legislature did not fund any of the agency's enhancement requests as recommended by the Governor. This included both the KHPA's request to expand the Community Health Record and

request for funding to advance a statewide system of health information infrastructure, which included a resource center for health care providers who want to leverage information technology in their practices.

The E-Health Advisory Council was designed to serve in an advisory role to the Governor and the KHPA to:

- 1) Explore options and make recommendations to leverage Kansas' purchasing power to promote the use of health information technology, including consideration of a state-wide 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 state-wide 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 HIT and HIE in improving health care delivery in Kansas.
- 3) Provide recommendations on policy issues related to health information technology 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 in order to promote personal responsibility and self-management of care; and
 - Strategies to successfully implement HIE

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

- Consumers
- Physicians
- Nurse
- Hospitals
- Health Plans/Systems
- Legal Services
- Mental Health
- Safety Net Clinics
- Public Health
- Laboratories/Medical Services
- Pharmacies
- Medical Practice Managers
- Dental
- Long Term Care
- Employers
- Academia
- Quality Improvement Organizations

IV. Kansas Health Information Exchange

An environmental scan conducted at the beginning of the Kansas Health Information Technology State Policy Initiative provided a summary of the then current HIT/HIE activities in Kansas. The activities listed below were described in the “Kansas Health Information Exchange Roadmap,” a briefing paper written in partnership with the eHealth Initiative Foundation.⁸

- **Central Plains Regional Health Care Foundation – Clinics Patient Index.** The Clinics Patient Index is a shared repository of patient information that links six community clinics in Sedgwick County via a computerized patient enrollment and tracking system (a master patient index) through a secure Web site.
- **Community Health Center (Health Choice) Project.** Health Choice Network is an organization created by Community Health Centers for the purpose of delegating essential business services that can be more efficiently or effectively operated jointly. The result is that the Centers can serve more patients, offer more services, and enhance the level of care they provide to improve health outcomes. In 2007, Kansas benefited from a \$750,000 Electronic Health Record (EHR) Implementation Initiative Grant from Health Resources and Services Administration. It will help four health centers adopt and implement electronic health records: Flint Hills Community Health Center, Emporia; GraceMed Clinic, Inc., Wichita; PrairieStar Community Health Center, Hutchinson; and We Care Project, Great Bend. This is the first installment of a three year grant to Health Choice Network.⁹
- **Jayhawk Point of Care (POC).** The Jayhawk POC is an integrated solution that ties together all of the Pratt Regional Medical Center's key departments in a single database to improve the availability and communication of vital patient information. The Jayhawk POC will be expanded to reach all referral counties, providing a seamless point of entry for patients regardless of where they enter the system - the clinic level, the emergency level, the regional hospital level or the tertiary hospital level.
- **CareEntrust.** Several leading employers and health care organizations in the Kansas City metropolitan area subscribe to this employer base electronic health record. The CareEntrust business plan involves a Regional Health Information Exchange that would govern and manage a Community Health Record for the bi-state metro-Kansas city area. This Community Health Record (CHR) system consists of a central data repository that stores comprehensive, person-centric health data by aggregating information from health plans, pharmacy benefit managers, laboratories, and immunization registry data. Cerner Corporation, headquartered in the Kansas City area, is a key participant in this effort.
- **Northwest Kansas Health Alliance.** The Northwest Kansas Health Alliance is the largest formal Critical Access Hospital network in the United States. The Alliance has linked members through telemedicine services and expanded them beyond the traditional boundaries of teleradiology. This

⁸ *Kansas Health Information Exchange Roadmap Briefing Paper*, eHealth Initiative, January 2006 (Last accessed June 30, 2008 at <http://www.governor.ks.gov/ltgov/healthcare/items/KansasHITBrief.pdf>)

⁹ KAMU Primary Connection, Fall 2007 (Last accessed June 30, 2007, at: <http://www.kscca.org/pdfs/Primary%20Connection%20Fall%202007.pdf>)

program is supported by Hays Medical Center and is one of the largest programs of its kind in the country.

- ***The Kansas City Quality Improvement Consortium (KCQIC)***. KCQIC was formed in Missouri by the United Auto Workers – Ford Community Health Care Initiative and community stakeholders to address health care quality in the greater Kansas City area. In February 2007, the Robert Wood Johnson Foundation’s “*Aligning Forces for Quality, the Regional Market*” project awarded KCQIC a Community-Based Initiative grant designed to help improve the quality of health care provided to people with chronic illnesses. Many Kansans in the metropolitan area who receive medical care on both sides of the state line are benefiting from this Missouri initiative.
- ***Sedgwick County CHR***. A Community Health Record (CHR) pilot project was implemented in 2006 for the Medicaid managed care population in Sedgwick County to improve quality, safety and cost-effectiveness of care. The project was initiated in partnership with Cerner Corporation and the State’s Medicaid managed care organization (MCO), and had many elements in common with an earlier partnership between Cerner and the State of Tennessee. The CHR allows authorized providers online access to aggregated claims data and health transactions regarding a person’s office visits, hospitalizations, medications, immunizations, diagnoses, and procedures. Positive feedback from the provider community based on a third-party evaluation has led to proposed expansion to double the number of sites.
- ***KAN-ED***. This statewide initiative was established by the Kansas state legislature in 2001. Its objective is to bring broadband capabilities to hospitals and other member institutions within the state. Due to the recent award from the FCC expansion and increased utilization plans are being explored.¹⁰
- ***Kansas Health On-line Consumer Health Online Tool***: The Kansas Health Online Consumer Transparency Portal (www.kansashealthonline.org) was launched in January 2008. It is dedicated to informing health consumers by empowering them with resources to stay healthy, manage their medical conditions, navigate the health system, improve their health literacy, purchase health care, compare provider quality and understand health policy. The website will also include health care cost and quality information as it is developed in collaboration with the Data Consortium.
- ***Rural Outreach*** – In November 2007, Kansas received 3.7 million dollars through a Federal Communications Commission (FCC) rural broadband access grant program.¹¹ Kansas was one of several states that was awarded a FCC grant to expand broad band network capacity. The FCC will pay for up to eighty-five percent (85%) of the costs of the design, engineering and construction of the networks in forty-two states and three U.S. territories. Most of this network will be used for telehealth programs that allow rural areas to share medical expertise and other resources and access the expertise in big medical centers. Some of the projects include e-health

¹⁰ *FCC Rural Health Care Pilot Project*, TeleNews for KU Center for Telemedicine and Telehealth, April, 2008 (Last accessed June 30, 2008 at <http://www2.kumc.edu/telemedicine/2008TeleNews/Archives/2008-04.htm>).

¹¹ *Rural Health care Pilot program, Kansas University Medical Center* ((Last accessed June 30, 2008 at: www.fcc.gov/cgb/rural/rhcp_applications.html)).

records, and others are for specialized purposes such as emergency care, care of stroke patients or those with chronic diseases. Besides facilitating health care delivery in rural areas, the network will facilitate responses to public health emergencies.¹²

- ***KC Carelink*** – KC Carelink is a non-profit collaborative that uses information technology and the secure exchange of health information to ensure that providers across health care safety net organizations can better coordinate and deliver health care to patients who they jointly serve. Currently, twenty-three safety net providers from throughout the Kansas City, Kansas and Kansas City, Missouri metropolitan region use KC CareLink.¹³
- ***Kansas City Bi-State Health Information Exchange (KC-BHIE)*** The mission of KC-BHIE is to enhance access, quality, safety and the efficiency of healthcare in metropolitan Kansas City through the implementation of a secure, integrated, interoperable health information exchange that supports the data needs of authorized users across organizational boundaries including; health care providers, health systems/hospitals, patients, employers, health plans and other regional constituents. Existing health information exchanges in the region including CareEntrust, KCQIC, and KC CareLink supports this nascent effort that is facilitated by the Mid-America Regional Council.
- ***Medicaid Information Technology Architecture (MITA)*** - The State of Kansas has been working collaboratively with other State Medicaid agencies to support the development of MITA since 2004. MITA is a Centers for Medicare and Medicaid Services (CMS) initiative designed to establish a national framework for enabling technologies and processes to support improved program administration for the Medicaid enterprise. The MITA Project was created under the Financial Management Work Group within the HL7 organization in January 2008. Kansas has been involved in the MITA Governance initiative since January 2008. MITA is aligned with the National Health Information Infrastructure (NHII; now known as the Nationwide Health Information Network, or NHIN), and is intended to foster integrated business and information technology transformation to the administration of Medicaid agencies. MITA promotes secure data exchange, the adoption of data and industry standards, reusable components through standard interfaces and modularity, and efficient and effective data sharing through the use of a service-oriented architecture.
- ***MITA supports interoperability and integration*** - State agencies, public and private purchasers, providers, and other stakeholders address the real and perceived barriers for data sharing between these organizations. CMS, through MITA, provides guidance for states to maximize the interoperability of their information systems within the framework of Federal Medicaid/MMIS requirements. One of the unique potential opportunities presented by MITA includes CMS support for infrastructure development which enables Medicaid to interact with Health Information Technology and Exchange (HIT/HIE) efforts such as regional health information organizations (RHIO) in order to share claims, eligibility, and clinical data. State participants, such as Kansas, are in a unique position to be leaders in Medicaid IT transformation. Early adopters, participating through the various MITA workgroups, are poised not only to accelerate the adoption of HIT/HIE initiatives within their own States, they are also on the leading edge of implementing standards that will be eventually followed by all States.

¹² *FCC OK's \$417 Million in Grants for Rural Health Networks*, FCW.COM, November 20, 2007 (Last accessed June 30, 2008 at <http://www.fcw.com/online/news/150853-1.html>).

¹³ See KC Carelink Web site <http://www.kccarelink.org/about/history.php> (Last accessed December 16, 2008)

- ***University of Kansas Center for Telehealth and Telemedicine (KUCTT)*** – The University of Kansas Center for Telehealth and Telemedicine began in 1991 with a single connection to a community in western Kansas. Today, the Kansas telehealth network has grown to more than 100 sites across the state. KUCTT has conducted literally thousands of clinical consultations on behalf of the people of Kansas as well as countless educational events for professionals, teachers, students and the public. The KUCTT currently is one of the most active telemedicine programs in the world. Teleconferencing technology allows for patients in medically underserved areas of Kansas access to more than 300 specialties at the KU Medical Center. A KUCTT exemplar is the TeleKidcare® program. In 2003, this program was honored with the Best Practice Initiative by the Office of Public Health and Science. The Best Practice Initiative is designed to showcase the "best practices in public health from around the country to foster an environment of peer learning and collaboration".
- ***University of Kansas Center for Health Informatics (KU-CHI)*** - The University of Kansas Center for Health Informatics (KU-CHI) is an interdisciplinary center of excellence designed to advance health informatics through knowledge, integration, research and empowerment of faculty and students in the expanding field of biomedical science and information technology. Specific components of the Center include integrating health informatics in the curriculum across academic health professional schools and expanding the current Master's of Science program to include interdisciplinary graduate studies for the MS/certificate option; supporting the use of technology in the clinical arena to address challenges of medical error; inefficiencies, labor shortages and increasing cost; creating new partnerships with business and institutions for the advancement of health informatics; providing a laboratory for research and development of new and innovative technologies; and providing professional development and research support services for practicing health professionals. The KU-CHI is an active participant in the TIGER initiative, the Health Information Technology Scholars (HITS) program and the AMIA 10 X 10 program. For additional information go to <http://www2.kumc.edu/healthinformatics/>.

V. Public Health Informatics

This report highlights the essential role of public health informatics in enabling state and local public health organizations to safeguard health. The Kansas Department of Health and Environment (KDHE) has a long history of leading public health informatics initiatives. In 1994, KDHE led the Health Data Governing Board (HGDB). The mission of the HDGB was to promote the availability of and access to health care data, to provide leadership in health care information management and analysis, and to provide guidance in use of the data for policy-makers, program managers and citizens to make informed health care¹⁴ decisions. Utilizing the information technology and capabilities available to Kansas, KDHE has also undertaken important initiatives which address many of the most costly issues in public health. One such initiative is the annual report on health disparities. Health disparities that result from social determinants of health was identified as one of three cross cutting issues that heavily influence our state's overall health status.¹⁵

Another key KDHE initiative supports access to care in rural and frontier counties. Kansas has many rural and frontier counties and health information technology has played an essential role in facilitating and supporting health care services in these areas. Kansas Rural Health Works (KRHW) has provided information to support local decisionmakers in rural communities to become proactive and intricately involved in planning and supporting their local health systems. The ultimate objective has been to maintain local health care services, including critical access hospitals, to result in healthier rural communities and economies. Health information technology is essential in this continuing effort.¹⁶

Across Kansas there are many health information systems and health information exchanges which support public health functions and goals. One such example is the Track and Trend project lead by the Kansas Association of Public Health Departments in which a web-based dashboard and scorecard system have demonstrated how a performance management system can be used to monitor and improve public health activities such as maternal child health care services, immunization coverage rates, and improved emergency response capabilities. Additional examples, further described below include the following systems deployed by the Kansas Department of Health and Environment: Kansas Health Alert Network (KS-HAN), Kansas Public Health eXchange (PHIX), Kansas Immunization Registry (KS WebIZ), Kansas Cancer Registry (KCR), Kansas Diabetes Quality of Care (KDQOC)/Chronic Disease Electronic Management System (CDEMS). Taken together, the continued development of these systems illustrates the robust and extensive health information exchange activities across Kansas.

The Kansas Health Alert Network (KS-HAN) is a secure, web-based electronic communication system that enables local and state emergency health and safety entities to share public and environmental health and general emergency preparedness information rapidly. Participants in the KS-HAN include local health departments, hospitals, emergency medical services agencies, animal health. The system allows users to send, receive and discuss information in a secure environment. It also allows for the rapid notification of any and all users in the event of an emergency, when the timely distribution of recommendations on investigation, prevention and treatment is critical¹⁷. Kansas Public Health eXchange

¹⁴ <http://www.accesskansas.org/hcdgb/khcdabout.html>.

¹⁵ Kansas Department of Health and Environment, working together for a healthier Kansas: *A Status Report on the Social Determinants of Health in Kansa, 2008*, <http://www.healthdisparitiesks.org/download/DisparitiesReport.pdf>

¹⁶ <http://www.krhw.net/index.html>

¹⁷ <https://kshealth.kdhe.state.ks.us/HealthAlertNetwork/>

(PHIX) is a Kansas public health initiative that provides a secure web-based communication system designed for the rapid exchange of public health information between providers.

Another essential system which supports emergency response is the EMResource. All Kansas community hospitals participate in this initiative designed to provide up-to-the-minute information on available resources for patients. EMResource (a product from EMSsystems) is a Web-based program providing real-time information on hospital emergency department status, hospital patient capacity, availability of staffed beds and available specialized treatment capabilities. EMResource is used to coordinate “routine” and emergency medical operations, like mass casualty incidents throughout the state. EMResource is used to communicate important information, such as public health alerts or notification of potential bioterrorism or other terrorist events, simultaneously and consistently to all users. In Kansas, the service is provided through the Kansas Hospital Education and Research Foundation, an organization associated with the Kansas Hospital Association, and is funded by a grant from Kan-Ed and coordinates with the Kansas Department of Health and Environment’s Hospital Preparedness initiatives. EMResource is open and running on a computer in each hub of participants operations, i.e., in the emergency department of hospitals or in the dispatch centers of transporting EMS agencies. The system is updated twice daily by hospitals, more in a disaster or mass casualty situation.¹⁸

Immunization registries and disease registries have proven to be very effective in improving health care services and health care outcomes. The Kansas Immunization Registry (KS WebIZ), operated and maintained by KDHE, has enrolled more than 1.3 million patients, tracking more than 9 million immunizations across 205 provider offices statewide and continues to expand. Systems such as this have proven their value in increasing vaccination coverage rates, especially among children, and in allowing state officials to better assess health services, target resources to areas most in need, and improve management of disease outbreaks. The Kansas Department of Health and Environment is also developing systems to access immunization data directly through schools and WIC clinics to further ensure immunization coverage.¹⁹

KDHE also supports two state disease registries, The Kansas Cancer Registry (KCR), and the Kansas Diabetes Quality of Care (KDQOC)/Chronic Disease Electronic Management System (CDEMS). The Kansas Cancer Registry (KCR) is the only population-based source of information on cancer incidence in the State of Kansas. Since 1968, the Kansas Cancer Registry has collected nearly 350,000 cancer records. Cancer Registries exist or are being developed in nearly all fifty states. The Kansas Cancer Registry operated through the KU Med Center Research Institute under a contract with KDHE has received the gold standard certification award from the North American Association of Central Cancer Registries, provides information on the occurrence of cancer, stage at diagnosis and survival, and sub-populations affected by different types of cancer. Per Kansas Statute 65-1, 168-174 and Kansas Administrative Regulation 28-70-1 through 28-70-3, cancer is a reportable disease in Kansas. Personal identifiers are protected by K.S.A. 65-102b and may not be disclosed except as provided in the Statute. Registry information can be used by researchers to evaluate the effectiveness of new treatments and by public health professionals to implement and monitor prevention efforts (e.g. early detection). Kansas residents who are diagnosed or treated with cancer in other states such as Missouri, Nebraska, Colorado, Oklahoma, Texas and Washington state are also registered in the KCR database through data exchange.

¹⁸ <http://corp2.emssystem.com/info/emresource.html>

¹⁹ KDHE News, June 2006:
http://www.kdheks.gov/kdhe_news/2008/feb/download/Kansas_reaches_1_million_patients_in_registry.pdf
(last accessed 12/19/08)

Kansas Diabetes Quality of Care (KDQOC)/Chronic Disease Electronic Management System (CDEMS) Project pilot was launched in 2004 by KDHE's Diabetes Prevention and Control Program in more than 90 diverse healthcare clinic sites across the state and is currently collecting quality of care diabetes data to guide improving care for Kansans with diabetes. CDEMS, a public domain software program, is utilized at each site to collect patient and clinic level data thereby improving the health of people with chronic illness (in this case, diabetes), thereby transforming a system that is essentially reactive (responding mainly when a person is sick) to one that is proactive (focused on keeping a person as healthy as possible). There are currently about 9,000 diabetes patients in the CDEMS registry. De-identified patient aggregate data is transferred from each KDQOC Project clinic to a central repository providing the capability to query aggregated data from an individual clinic, group of clinics, clinics by county and all clinics statewide. Quality of care indicator improvement for diabetes patients improved by more than 50% from 2005 to 2008. Queries can also be run for selected indicators such as HbA1c levels, lipid levels, and blood pressure and so on. The success of the pilot project positions the program for systematic replication statewide representing every county as well as expanding the program to include indicators for other chronic diseases. The open source nature of the data collection system makes it conducive for adding a record locator service that has great potential to contribute to a medical home model for the state of Kansas.

Due to the leadership efforts of many organizations in Kansas, much needed public health systems and capabilities have been deployed. However, state and local public health organizations have traditionally been under- resourced and health information technology and health information exchange requirements are substantial. Consequently, there is still more work to be done. Currently, public health informatics systems require: further development of important components in the system, improved coordination and integration across different public health informatics systems, and improved coordination and integration between public health and clinical information systems. With interoperable public health information systems and supportive information exchange laws, public health officials have ready access to reports, data, and links to laboratory, countermeasure, and response administration information, facilitating better support and protection to communities which are at increased risk in the event of a crisis. Additionally, efforts to prevent disease and reduce health care costs are significantly enhanced with the capability to electronically exchange information in public health systems. Public health informatics systems support communities' access to programs that facilitate disease prevention, chronic disease management, and reduction of costs to treat disease.

This state of the state report has described the strong track record and ongoing efforts which Kansas Department of Health and Environment has undertaken in working with public and private organizational partners in assessing barriers in health information exchange and working to improve systems which support public health functions such as emergency response, cancer and chronic disease surveillance and utilizing health information technology to improve health care of patients. As is true in many states, Kansas would benefit from further development of public health systems, interoperable exchange of health data, and supportive legislation to foster adoption of health information technology.

VI. The Continued Need and Opportunity for HIE in Kansas

From the establishment of the Health Data Governing Board, the H4C, and the HIE Commission to the creation of the E-Health Advisory Council within KHPA, the State's call for HIE in Kansas has been consistent and continuous. 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 and coordinate the continued expansion of HIT and HIE. These organizations have a strong track record in working with public and private organizational partners in assessing barriers in health information exchange 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 as there is more work to be done. A recent report suggests that Kansas would benefit from further increased use of HIE and HIT from a public health standpoint. In December, 2008, the Robert Wood Johnson Foundation released an "issue report" entitled, *"Ready or not? Protecting the Public's Health from Diseases, Disasters, and Bioterrorism."*²⁰ 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 six out of ten 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." In addition to substantial funding requirements, health information exchange operations, and new data sharing relationships require new laws to ensure patient privacy, data security, and support innovative business practices. The Electronic Disease Surveillance System is currently under development and is in the testing phase of deployment.

VII. The Need for Statute Modernization to foster Adoption of HIT 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 electronic health record. Further, Kansas statutes and regulations do not comprehensively address other issues specifically related electronic health records or the electronic exchange of health information such as data security, consent for participation in HIE's, or maintenance of personal health records.

²⁰ The report may be accessed at <http://www.khi.org/resources/Other/1242-bioterror-report-2008.pdf> (last accessed 12/19/2008)

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 HIT/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 upon 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; and
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."²¹ 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 and HIT.

Since studies have shown that consumers are more receptive to the exchange of their information electronically when they were better informed,²² 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 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 by the Kansas Health Policy Authority 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.

²¹ Kansas Health Information Exchange Roadmap Briefing Paper January 10, 2006, p. 11

²² eHealth Initiative Foundation

VIII. Next Steps

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

- Working with KHPA to assist with planning for the design of the section of KHO for HIT/HIE privacy and security materials and developing this section of the KHO website
- 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/HIT 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 adoption of electronic health information exchange include:

- Adoption of the Draft Resolution
- Establish and schedule study sessions for ongoing legal analysis
- Convene stakeholders to review statutes, policy and regulations and develop consensus-based recommendations related for changes to foster adoption of electronic health information exchange such as emergency medical services, social services, and transitions in care among hospitals and long term care facilities.

IX. Conclusion

Kansas is positioned to take immediate steps toward effective widespread adoption of HIE and HIT programs and initiatives within the state and to leverage funding opportunities provided through American Recovery and Reinvestment Act (ARRA) the Health Information Technology Stimulus program. The provision of the stimulus bill that includes about \$19 billion to fund HIT and HIE projects is the Health Information Technology for Economic and Clinical Health, or HITECH. The Lieutenant Governor has asked members of the Cabinet and other state leaders to strategize about how Kansas can compete for these federal funds. HIT and HIE have been a consistent focus of the Kansas Health Policy Authority's long-term strategy for health reform in Kansas. There will be an even greater focus as the agency begins to collaborate with Cabinet Secretaries and stakeholders on ways to utilize these additional funds. KHPA is working with HISPC, the E-Health Advisory Council, the Medical Home Working Group, the Telemedicine/Telehealth Working Group and other interested parties to convene an all-stakeholders meeting to discuss potential HITECH projects for the state. The first all-stakeholders meeting is expected to be held in March. The goal of the steering committee will be to develop ways to use the HITECH dollars to advance health care coordination in the state and improve health outcomes.²³

²³ www.khpa.ks.gov/legislative/download/2009Testimony/03022009_KS_HITECH_Plan.pdf

While the groundwork for HIE and HIT 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 non-financial 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 healthcare organizations.”²⁴

Acknowledgement

We wish to recognize and thank the many group leaders that provided input into this document. This detailed report would not be possible without their help.

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²⁴ Kansas Health Information Exchange Roadmap Briefing Paper January 10, 2006, p. 15