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On the Road to RHIO: What State CIOs Need to Know

We've all been there. Every American healthcare consumer can likely relate to sitting in a physician's office waiting room with a clipboard of countless forms that have been filled out numerous times before; carrying paper folders of medical records from a primary care physician to a specialist's office in order to ensure fully informed care; being concerned that pre-existing medical conditions for oneself or a loved one are known at the time of emergency care; or possibly undergoing unnecessary duplicative procedures simply because prior results are not available to a current care provider.

Eliminating paperwork, cutting down on duplicate tests and reducing healthcare costs are all drivers behind the health information technology movement that has reached fever pitch proportions. Fixing the admittedly broken healthcare system, and using technology to do so, has become an issue that has captured national attention through exploring the use of electronic medical records and making those records available to healthcare providers across organizational boundaries. ***Considered to be the building blocks for an eventual National Health Information Network (NHIN), regional health information organizations (RHIOs) bring physician offices, hospitals and branches of government together for a common goal of providing better care by sharing critical patient information.*** These organizations have a shared interest in improving health care quality and have agreed to work together to promote information sharing and data exchange.

Often referred to as Health Information Exchanges (HIEs), RHIOs are self-defining in nature and imitate the environment in which a consumer will naturally seek out healthcare. As consumer healthcare needs expand, they tend to seek providers located within a reasonable driving distance from their home. Regional efforts have evolved as area providers seek to exchange critical patient data with one another since they may often share patients within the same geographic area. ***RHIOs are a way to develop health information exchange systems where most people will seek care – locally.***

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It is essential that state CIOs obtain a seat at the table early in state RHIO efforts, because CIO involvement will become inevitable as these efforts expand and mature.

Why Should a State CIO Be Involved?

Through state Medicaid programs, employee and retirement benefit plans, and often directly through public health or public hospital/medical provider services, state governments are one of the largest health care purchaser/providers within their own boundaries. A great deal of money and resources are at stake, as is the health care for hundreds of thousands of citizens. Moreover, there are substantial technology decisions in play – technology decisions that would benefit from enterprise-level expertise and may ultimately affect state programs.

Because of the nature of RHIOs, it is often not feasible for a state CIO to act as a convener of stakeholders, or as the office responsible for spearheading these efforts.[1] However, state CIOs can play a key role in championing health IT efforts as a participant in RHIO initiatives in their state and by communicating the benefits of health IT initiatives in their state. It is essential that state CIOs establish strong business partnerships with state and community health departments from the outset in order to build relationships, increase influence and develop support for health information exchange initiatives.

By being involved in RHIO efforts from the ground up, a state CIO can help craft and drive policies relating to health information exchange rather than being thrust into an already-developed data exchange structure in the future. It is essential that state CIOs obtain a seat at the table early in state RHIO efforts, because CIO involvement will become inevitable as these efforts expand and mature.

While a few small states, or states with smaller populations, have RHIOs that are statewide, many states have multiple regional intrastate efforts in place. ***In larger states where there may be multiple RHIO efforts, state CIOs will play a pivotal role in joining these RHIOs together to form a statewide health information exchange system.*** Integrating these regional efforts will become a critical aspect of state CIO responsibility.

There are over one hundred HIEs currently in progress, though there are only a handful that are fully operational.[2] Faced with the unprecedented task of health information exchange on a broad scale, RHIOs face enormous challenges as they attempt to navigate this uncharted territory.

RHIOs are formed through a coalition of willing providers that come together on their own, or are brought together in response to legislative or gubernatorial direction to develop a health information exchange pilot program. They also can be formed in response to the receipt of a federal or state grant or, as in some instances; RHIOs are already in the beginning stages prior to legislative action and will lobby state legislatures in order to fund their existing initiative. ***It is important to note that every state and every RHIO will likely follow a different formula in its creation, development, financial viability, implementation and sustenance.***

There is currently no universally recognized definition of a RHIO. While there are common themes between all RHIOs, each state or region will introduce unique features by virtue of differences in local healthcare markets, market players, state policies, and technology environments. Therefore, there are few absolute truths regarding RHIOs. Despite the vast differences between them, there are four key areas that every RHIO must address:

- Funding
- Governance
- Technology
- Privacy & Security

Funding a RHIO

RHIOs are generally funded through federal and state grants. They can also be funded by private organizations that may or may not be RHIO participants. Continuous funding is a major issue for RHIOs across the nation. Since RHIOs are often created through and operate from a grant, they are frequently working against a ticking

clock. The sunset dates on these grants are typically only two to three years and, given the enormity of the task at hand, this is often not enough time for a RHIO to become financially sustainable on its own. This is a key obstacle in achieving health information exchange today.

RHIOs must often continue to rely on government funding or receive grants from other stakeholders in order to ensure continuity. For example, the California Regional Health Information Organization (CalRHIO) received a $1 million grant from Sutter Health, a non-profit health care system, in June of 2007 in order to continue its work toward the formation of a statewide health information exchange.[3] ***Funding and sustainability issues are the main reasons why RHIO efforts will fold, not technology-based problems.*** While it is unlikely that a state CIO will be actively involved in the funding facet of a RHIO, it is important to understand the main challenges that RHIOs face on the road to sustainability. It is essential that from the outset of a RHIO initiative that there is concerted thought given to sustainable operating funding models.

RHIO Governance

With most collaborative efforts, there is typically one organization that takes on a leadership role.[4] In a RHIO, this is often not the case. ***Since all entities taking part in forming the RHIO are dependent on one another for success, leadership usually comes from a board or other advisory group comprised of representatives of all stakeholders.*** In essence, the RHIO itself becomes the governing entity after its formation. For this reason, it is sometimes not immediately clear at the outset what the RHIOs governance structure will be.

Though a governance model does not always have to be firmly established at the outset of a RHIO formation, determining a clear governance structure will help in ensuring sustainability.[5] As with any collaboration of this magnitude, efforts can quickly go awry if no entity is certain who is leading the initiative. Membership on these boards or advisory groups can be determined in enabling legislation, incorporation, or executive order establishing the RHIO.

In some instances, state CIOs will sit on these boards or advisory groups automatically due to legislative or executive mandate. In others, state CIOs must seek out opportunities to become involved, or they may be contacted by RHIO stakeholders seeking their input. By serving in an advisory role in a health information exchange, state CIOs can act as a voice representing the technical interests of a state's varied health programs.

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RHIOs and Technology

While a major component of health data exchange, technology is not the main challenge facing RHIO development and sustainability. The technology is here. It is how to utilize the existing technology that encumbers many health information technology initiatives from moving forward in a definitive way. Sound policies on both the state and federal level are needed to guide organizations and their use of available technology.

Coordinating the different levels of each participant's technological capability, as well as the varied expertise of the individuals in these organizations, are among the chief technical challenges RHIOs face. Formulating a way for multiple information systems to exchange data, especially complex data that is included in medical records, is no small task.

Health IT advocates frequently cite ATM's as an example of a universally recognized data exchange that can be recognized anywhere in the world at the swipe of a card and the push of a button. Using your ATM card at your home bank or in another country will produce money from your same account, regardless of where you use your card. Why, then, can it not be so easy to transmit health information across organizational boundaries?

This question has been asked repeatedly, but the answer is always the same: *because an individual's medical information is much more complex, therefore more difficult to transmit than bank account information.* While ATM's read and interpret numbers, symbols and codes; a medical record may contain pages upon pages of detailed descriptions of an individual's every illness. ATM transactions are far too simplistic a comparison to medical record data exchange for every individual that is accessible anywhere in the world on demand.

The universally established standards that guide ATM transactions are lacking in the health IT arena. Since there are no federal architecture standards currently in place, state CIOs can advocate for the discipline and process of enterprise architecture as a way to rationalize the complexity of standards. Enterprise architecture can be a path to interoperable health records and state CIOs can bring knowledge and expertise in this discipline to the forefront of RHIO discussions.

Debate is ongoing between those who agree that HIPAA standards are sufficient and privacy advocates who are pushing for more stringent standards.

With no single set of architecture standards to guide them, and very complex and evolving health data exchange standards, RHIOs are inevitably creating some "de facto" local standard variants – increasing the cost of eventual interoperability between RHIOs. Since RHIOs are expected to eventually come together to form a national health information network, the complexity of standards poses a major problem that is widely seen as needing strong federal direction. Standards establishing patient privacy in data exchange are needed before any significant progress can be made. ***State CIOs can advocate on behalf of their state to influence and expedite the standards decision-making process.*** Current federal action toward establishing standards and addressing other aspects of health information exchange are detailed later in this brief.

RHIOs and Privacy & Security Challenges

The privacy and security issues that all RHIOs must address are similar although the approaches vary widely. ***The unique characteristics of each RHIO will determine its privacy and security needs.*** Since national standards are not yet established, there are two ways that RHIOs will typically address privacy and security issues.

The first is by referencing the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Even though most RHIOs are not directly subject to HIPAA's requirements, it can serve as a starting framework for addressing privacy issues; therefore most RHIOs will adopt privacy policies that are a combination of their interpretation of HIPAA along with their existing applicable state laws.[6] However, the HIPAA federal privacy rule's ability to adequately cover the privacy needs of electronic health information exchange is hazy at best. Debate is ongoing between those who agree that HIPAA standards are sufficient and privacy advocates who are pushing for more stringent standards.[7]

A second way that RHIOs will develop their own privacy and security standards is by drawing upon existing standards that are already established by one of the stakeholder organizations. For example, they will adopt the standards already in place by a hospital or other healthcare organization that initiated or is a participant in the RHIO. Neither approach is universally recognized as correct, but both are commonly used. The current challenge is the disparity between state policy practices in each state and the lack of harmonization between them. The push for more stringent federally mandated privacy and security measures in electronic medical record use and data exchange is ongoing.

State CIOs must closely monitor developments in state and federal privacy laws and regulations as they pertain to health

information exchange and the transmission of sensitive data across state, private and non-profit boundaries.

State Benefits of Health IT & RHIO Initiatives

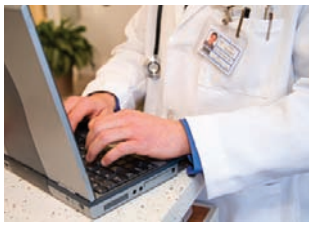
States can play a major role in initiating, motivating and developing health information technology initiative due to the enormous power the state wields as a payer, employer, provider, policy maker, regulator and licensing entity for healthcare providers.[8] In states such as Vermont, where the state is the single largest insurance provider, this illustrates the significant impact that the state would have if it began requiring physicians and hospitals to implement health IT initiatives and require them to be interoperable.

It is no secret that healthcare costs are increasing rapidly. Shrinking state budgets and mounting Medicaid costs have led to a fiscal predicament that has states scrambling for options to counter this trend. To help offset this budget crunch, the first round of federal Health and Human Services Department (HHS) "transformation grants," which are offered by HHS to encourage health IT adoption in Medicaid, were awarded on January 25, 2007 to twenty-six states and the District of Columbia to fund thirty-two initiatives, appropriating more than $103 million for FY 2007 and FY 2008.[9] A second round of HHS "transformation grants" is scheduled to be announced no later than September 30, 2007.

States influence health care at every level – from licensure standards for physicians and other health care professionals, to setting policy and regulations for health care facilities and funding public hospitals. For these reasons, states have a vested interest and influence in any efforts aimed at cost-reduction and also improving health care quality. Health IT is widely considered a means to achieving both of these objectives. ***The purchasing power of the state can greatly influence health IT adoption and help influence national decisions regarding data standards and privacy provisions.*** As state officials, state CIOs have a stake in helping utilize the state's purchasing power to drive health IT adoption.

Federal Action on Health IT and RHIO Efforts

When President Bush issued his 2004 Executive Order calling for most Americans to have electronic health records by 2014, he established the position of the National Coordinator for Health Information Technology within the Office of the Secretary of Health and Human Services (HHS). The Office of the National Coordinator (ONC) is charged with the development and nationwide implementation of an interoperable health information technology infrastructure and provides management for the American Health Information Community (AHIC). AHIC was formed in 2005 to provide HHS with recommendations regarding the advancement of standards for interoperability; the first round of recommendations was made to Secretary Mike Leavitt in May of 2006.[10]



Charged with examining health IT standards development, the Health Information Technology Standards Panel (HITSP) is a multi-stakeholder initiative under a contract with ANSI, in cooperation with strategic partners HIMSS, Booz Allen Hamilton, and Advanced Technology Institute. HITSP is responsible for harmonizing the standards used to exchange health data in the United States and for providing recommendations to AHIC.[11] These nationally-focused organizations all play a role in determining the direction and operation of RHIOs by working to establish universal privacy, security and interoperability standards. ***These efforts are ongoing and are driven by consumer demand and legislative action.***

Members of Congress continue to introduce legislation related to health IT. While

few bills have made substantial progress, their presence garners debate and dialogue regarding health IT initiatives, including RHIOs. Prior Congressional bills have been gridlocked in conference primarily over disputes regarding patient privacy provisions; by relying on existing HIPAA privacy standards, they largely avoided issue of privacy. Critics were highly skeptical of the coverage these existing standards provided to electronic health records in health information exchange, and as a result, significant legislative directives have not occurred.

State Action on Health IT and RHIO Efforts

On the state level, as of June 2007, 168 bills focusing on health IT have been introduced in 41 states and 13 health IT-related bills have been signed into law in 11 states in 2007. In addition, a total of twenty gubernatorial executive orders calling for health IT and health information exchange initiatives to improve health and healthcare have been issued in fifteen states, with seven executive orders occurring thus far in 2007.[12]

Other state efforts currently underway include the National Governors Association's State Alliance for eHealth formed in 2006 in order to provide a forum for stakeholders to work together to explore health information technology policies and best practices. There are three Task Forces dedicated to Health Information Communication and Data Exchange, Health Care Practice, and Health Information Protection. ***There are currently two state CIOs that serve as members of two Task Forces of this Alliance.***[13]

The NGA is also involved in the Health Information Security and Privacy Collaboration (HISPC). Formed in 2005 by the U.S. Department of Health and Human Services, RTI International was awarded a contract to work with the Office of the National Coordinator for Health Information Technology (ONC) and the Agency for Healthcare Research and Quality (AHRQ) to bring together stakeholders and experts in the field in order to address privacy and security issues in the creation of an interoperable health information exchange network.[14]

In 2006, the National Conference of State Legislatures (NCSL) created a health information technology partnership called Health Information Technology Champions (Project HITCh). Comprised of several state legislators and state legislative staff, Project HITCh serves state legislators by providing information and technical assistance on issues surrounding health IT and health information exchange initiatives.[15]

How State CIOs Are Already Involved in RHIOs

During NASCIO's Midyear Conference in May 2007, the audience was polled and asked the question "In your opinion, how involved should the state CIO be with a state's RHIO?"

- 48% answered that a state CIO should be very involved
- 47% answered that a state CIO should have some involvement, but not as a decision-maker
- 5% answered with little involvement

No one answered "no involvement." An audience of state CIOs, their staff and corporate attendees overwhelmingly agreed that state CIOs need to at least have a seat at the table in RHIO developments in their state. State CIOs are involved in many levels of health information technology initiatives, including RHIOs.[16]

- **State CIO Takes RHIO Leadership Role in Vermont**

Tom Murray, CIO for the state Vermont, has been involved in the Vermont Information Technology Leaders (VITL) since his appointment as CIO in March of 2006. Through a mandate from the Vermont Legislature, the state CIO position was

instituted as a standing member of the VITL board of directors when VITL was established in 2005. This assignment was based on the realization that e-health has dramatic impacts on information technology decisions across the disparate state agencies. In 2007, VITL's funding was shifted to the CIO's budget as a further recognition of the critical role that a state CIO can have in this area. Vermont's relatively small size presents an opportunity to pilot statewide models that larger states can then emulate.

Murray has been very involved with several e-health initiatives within Vermont since his appointment by Governor Jim Douglas, who is also considered a leader in e-health initiatives and currently co-chairs the National Governors Association State Alliance for e-Health. Murray estimates that he spends approximately 10% of his time working on e-health issues, but cautions that while that may seem excessive, it is important to remember that healthcare consumes over 50% of the state budget and has a rate of growth that may well empty the state's coffers in the years to come. Murray also points out that while CIOs are pulled into dozens of areas and projects, few of these competing projects can generate the potential savings that e-health can bring to the states.

"As public servants, I think we all seek to contribute and to be able to look back and say that you made a difference in addressing a broad public policy issue," says Murray. "I think our efforts will put Vermont on the right track in terms of containing the rate of growth in healthcare costs and transforming to a proactive healthcare system where the patient is an active participant in their healthcare management."

▪ State CIO lends technical expertise to RHIO in Utah

Steve Fletcher, state CIO of Utah, has been involved in Utah's health information exchange, the Utah Health Information Network (UHIN) since he began as state CIO in 2005. The state CIO's position has a designated place on the Board of UHIN, along with members representing providers, payers and other state government officials.

UHIN, in operation since 1993, currently serves all the hospitals, ambulatory surgery centers, national laboratories and approximately 90% of the medical providers in Utah. Fletcher brings a variety of technical skills to the table through his placement on the UHIN Board and spends time reviewing proposals, financial statements and operational procedures. He is involved in all of the planning activities of UHIN and shares his knowledge regarding IT operations and new technologies that can be beneficial to UHIN.

▪ Former state CIO heads Wyoming RHIO

Larry Biggio, former state CIO for the state of Wyoming (2003-2007), had his first involvement with Health IT in 2004 when the Wyoming legislature funded an HIT/HIE study in Wyoming and the formation of a statewide RHIO was one of the recommendations that came from that study. The Wyoming Health Information Organization (WyHIO) was formed in 2005 by a group of stakeholders and incorporated the organization. Biggio stayed involved during the formative stages of the organizations and the attempts at obtaining state funding by functioning as the unofficial state IT liaison to the WyHIO and served as the primary WyHIO contact with the Legislature.

While WyHIO sought both state funding and a legislation designation as the statewide RHIO, there was not enough support for either of those legislative actions. However, Biggio felt that he was a valued voice in WyHIO efforts in his capacity as state CIO. He found that he played a key role in helping WyHIO to navigate the operations of state government and the budgeting process. Biggio was able to use his contacts in state agencies, helped to prepare budget requests, and also testified before the legislative committees.

"As public servants, I think we all seek to contribute and to be able to look back and say that you made a difference in addressing a broad public policy issue," says Murray

Biggio states that one primary concept of HIE is the ability to match the benefits of HIE to the costs of HIE. Generally, the benefits of HIT accrue to the payers – insurers and major employers. As a major payer, states can use HIE to help reduce costs and increase quality of care. States also hold large amounts of information on both Medicaid clients and state employees. States generally hold that data in a central MMIS or other program based application, and can be a major supplier of information to a statewide or regional exchange. Procedural standards are required for efficient exchanges. State systems, if they are to exchange data, must meet those standards. State CIOs can play a major role in the development and implementation of those standards.

"Wyoming is a sparsely populated, rural state. Much of our healthcare goes out of state. State CIOs, with their strong network through NASCIO, can help bridge those geographic boundaries and facilitate exchanges among states," says Biggio.

Call to Action for State CIOs: Get Involved!

Establish Partnerships

- Develop strong partnerships with public and private healthcare stakeholders in your state by seeking out involvement with their health IT efforts and getting a seat at the table in RHIO development and implementation;
- Encourage executive buy-in and support for RHIO efforts by becoming a champion for healthcare cost reduction for your state and communicating the benefits of introducing information technology in healthcare practices;

Recognize RHIO Opportunities and Challenges

- Understand how RHIOs develop and operate by recognizing the funding, governance, technical and privacy and security aspects of RHIO formation and maintenance;
- Be aware of the current technological capabilities and challenges facing RHIOs;

Promote Technology

- Encourage enterprise architecture as a path to rationalize the lack of universally recognized standards in RHIO efforts;
- Influence the adoption of health IT in the areas of Medicaid and state health plans.

No matter what role a state CIO may play in the development of health IT policy and RHIO efforts, it is important to remember that we all have an important stake in these efforts as healthcare consumers. State CIOs can play a critical role in advancing health information technology efforts, including RHIOs, by getting a seat at the table at the onset of these initiatives. ***Since RHIOs are still in their early stages of development and sustainability, the time for state CIOs to establish their position as a key component of health information exchange is now.***

Appendix A: Additional Resources

NASCIO Resources

Profiles of Progress: State Health IT Initiatives, November, 2006: http://www.nascio.org/publications/documents/NASCIO-ProfilesOfProgress.pdf

The (IT) Doctor Is In: The Role of the State CIO in Health IT, February, 2006: http://www.nascio.org/publications/documents/NASCIO-RoleoftheStateCIOinHIT060222.pdf

Other Resources

eHealth Initiative, *"Health Information Exchange: From Start Up To Sustainability,"* May, 2007: http://toolkits.ehealthinitiative.org/

American Health Information Management Association (AHIMA) and the Foundation of Research and Education of AHIMA, under contract with the Office of the National Coordinator (ONC) released "*Final Report: Development of State Level Health Information Exchange Initiatives*," September, 2006: http://www.staterhio.org/documents/Final_Report_HHSP23320064105EC_090106_000.pdf

California Healthcare Foundation, "*Privacy, Security and the Regional Health Information Organization*," June, 2007: http://www.chcf.org/documents/chronicdisease/RHIOPrivacySecurity.pdf

United States Government Accountability Office, Testimony before the Subcommittee on Information Policy, Consensus and National Archives Committee on Oversight and Government Reform, U.S. House of Representatives, "*Health Information Technology: Efforts Continue but Comprehensive Privacy Approach Needed for National Strategy,*" Statement of Linda Koontz, Director, Information Management Issues and Valerie C. Melvin, Director, Human Capital and Management Information Systems, June, 2007: http://www.gao.gov/new.items/d07988t.pdf

Healthcare Information Management Systems Society: http://www.himss.org/ASP/index.asp

Appendix B: Endnotes

[1] For more information regarding the role of the state CIO in health IT, please visit: "*The (IT) Doctor is In: The Role of the State CIO in Health IT*" <http://www.nascio.org/publications>

[2] HIT Dashboard. Healthcare Information Management Systems Society. <http://www.hitdashboard.com/mapPage.aspx>

[3] For more information on CalRHIO, please visit <www.calrhio.org>.

[4] For more information regarding cross-boundary collaboration, please refer to NASCIO brief "*Getting Started in Cross-Boundary Collaboration: What State CIOs Need to Know,*" May, 2007. <http://www.nascio.org/publications/documents/NASCIO-CrossBoundaryCollaboration.pdf>

[5] "*Final Report on Development of State-Level HIE Initiatives*," Foundation of Research and Education of American Health Information Management Association (AHIMA), September, 2006. <http://staterhio.org/documents/Final_Report_HHSP23320064105EC_090106_000.pdf>

[6] "*Privacy, Security, and the Regional Health Information Organization*," prepared for the California Healthcare Foundation by Avalere Health LLC, June 2007. <http://www.chcf.org/documents/chronicdisease/RHIOPrivacySecurity.pdf>

[7] For more information on HIPAA, please visit: <http://www.hhs.gov/ocr/hipaa>

[8] "*Development of State Level Health Information Exchange Initiatives*," Foundation of Research and Education, American Health Information Management Association, September 1, 2006. <http://staterhio.org/documents/Final_Report_HHSP23320064105EC_090106_000.pdf>

[9] Centers for Medicare and Medicaid Services, Medicaid Transformation Grants, January 25, 2007, <http://www.cms.hhs.gov/MedicaidTransGrants/02_012507awards.asp>

[10] For more information on the Office of the National Coordinator and their ongoing efforts, please visit <http://www.hhs.gov/healthit/onc/mission/>. For more information on AHIC, please visit <http://www.hhs.gov/healthit/community/background/>

[11] For more information regarding HITSP, please visit <http://www.ansi.org/standards_activities>

[12] Janet Marchibroda, eHealth Initiative, presentation at Input's State & Local Marketview Conference, June 12, 2007, with information gathered from eHI Legislative Tracker, <http://ccbh.ehealthinitiative.org/communities>

[13] For more information regarding NGA's State Alliance for eHealth, please visit: <http://www.nga.org/portal/site/nga/>

[14] For the most current information regarding HISPC, please visit: <http://www.rti.org/>

[15] For more information regarding Project HITCh, please visit: <http://www.hitchampions.org>

[16] For more information regarding state CIOs role in health IT, please refer to NASCIO's "*Profiles of Progress: State Health IT Initiatives,*" November, 2006. <http://www.nascio.org/publications/documents/NASCIO-ProfilesOfProgress.pdf>