

## BUILDING A SUSTAINABLE MODEL FOR HEALTH INFORMATION EXCHANGE IN PENNSYLVANIA



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# BUILDING A SUSTAINABLE MODEL FOR HEALTH INFORMATION EXCHANGE IN PENNSYLVANIA

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Reform

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# TABLE OF CONTENTS

	Page Number
Executive Summary	4
Introduction	7
The National Agenda	9
The Pennsylvania Landscape	11
Building a Sustainable Model	
Vision	14
Commitment	17
Adoption & Utilization	18
Technology & Infrastructure	20
Financial Support & Viability	23
Collaboration & Leadership	26
Business Practices & Rules	28
Recommendations & Future Considerations	30
References	33
Glossary	34
Acknowledgements & Contributors	37
PAeHI Board of Directors	38
About the Editor	39

## EXECUTIVE SUMMARY

Establishing long-term sustainability for local, regional or statewide health information exchanges (HIEs) requires implementing a funding model, which is supported by the healthcare community it serves, and a business model that demonstrates the benefits and return on investment.

The trend statewide in Pennsylvania is to create an interconnected, electronic healthcare system that is driven by enhancing healthcare quality and effectiveness and reducing the cost of healthcare. Today, state leaders are recognizing that health information technology (HIT) and HIE can help address many healthcare challenges. However, the development of HIE has been for the most part, driven by local and grassroots efforts since healthcare services and patient healthcare experiences are primarily local. Health Information Exchanges are alive and doing well in Pennsylvania, and the momentum is growing, but until there is a critical mass of adoption as well as adequate funding to promote utilization, the ability to sustain the progress that has been made is tenuous.

Despite evidence that HIT and HIE, which together bring the assurance of interoperability, promises to transform the current healthcare system by ensuring that consumers have access to the highest quality, most efficient and safest care, giving healthcare providers access to the right information at the right time and reducing the overall costs of health care delivery, our nation's health care industry lags behind other industry sectors in IT investments. Establishing a successful HIE requires achieving sustainable vision, commitment, technology and infrastructure, adoption, financial support, collaboration and leadership.

A starting point for all HIEs in Pennsylvania is to establish and keep their purpose and mission at the forefront. High success comes with a strategy to implement the vision and plan in smaller incremental phases, rather than tackling the whole all at once. The best way to drive sustainable change is through smaller incremental steps.

State funding is crucial in the short term to sustain initial development and start up of key operational initiatives. Adequate funding must be provided from additional sources for development, deployment and ongoing operations. In the long term there must be a re-alignment of incentives.

Establishing and implementing a business model that creates incentives for use, and recognizes the need for funding from those stakeholders that derive value and benefits using technology to share health information among key healthcare providers is critical. Adding value to the healthcare system through improving efficiency of care delivery, reducing administrative burdens such as public health reporting requirements, ensuring affordability and access of healthcare and providing the right information to healthcare providers at the right time for more informed decision-making is an end-result of HIE sustainability.

Empowerment of a neutral organization with statewide collaborative capability to bring the diverse array of potential providers and consumers of HIE services to the table to establish common standards for HIE-related value-added services is a necessary initial step toward sustainability. Sustainability is dependent on staying the course, even when encountering

competing priorities. Given the complexity of the healthcare delivery system there will always be challenges in keeping resources from moving to other areas that need attention within their organizations.

Serious consideration and effort in establishing policies and principles around business transactions related to the sharing of information must be an area of focus. Some of the key questions to address in the establishment of the policies are: who has access to what, under what circumstances, and with what protections? Who shares what and who bears the liability? And how can you control access to your Information? Resolving areas of concern like patient consent, authorization, authentication, privacy and security early in the development of HIE will alleviate potential barriers down the road.

Developing a mechanism that reduces the administrative burdens of the current paper-based system and replaces redundant and time-consuming processes for reporting must be achieved. Solutions such as establishing a single standard consolidated data set that would satisfy all provider-related state data reporting requirements; and the ability to submit required reports to one state agency and distributed by that agency to other departments or agencies as appropriate create added-value and promote sustainability.

The state's approach to promoting and establishing widespread use of HIE for the purpose of improving the lives of Pennsylvanians is consistent with the guiding principles laid out in PAeHI's *'Connecting Pennsylvanians for Better Health'*.<sup>2</sup>

**Guiding Principle 1: Patients come first.**

Healthcare must be re-designed to better serve individual patients and entire populations first and foremost.

**Guiding Principle 2: Consumer Privacy, security and confidentiality are paramount.**

Without consumer trust and acceptance of the process, no matter how well the system or network is designed and executed, it will fail. While there is public support for health information exchange, it is also recognized that Pennsylvania citizens have a strong concern for privacy and security of their medical health records.

**Guiding Principle 3: Multi-stakeholder collaboration is needed to implement achievable and measurable initiatives in order to show early progress and value.**

Cooperation and collaboration on the implementation of Health Information Exchange will drive innovation and change within local HIE efforts as well as across the various stakeholders in the state. It is on this front in a local healthcare market where the average citizen will see the greatest administrative relief and impact. Multi-stakeholder involvement is needed to ensure the patient's health information is robust and to foster the sustainability and financial solvency of local HIE efforts.

Despite the significant promise of HIEs to improve the overall quality and efficiency of health care, there are no organizational entities at the federal, state, or local levels, or in the public or private sectors obligated to implement or sustain HIEs. The trend across Pennsylvania is for healthcare providers and provider groups to create an interconnected, electronic healthcare system that is driven by enhancing healthcare quality and effectiveness and reducing the cost of healthcare. Today, state leaders are recognizing that HIT and HIE can help address many healthcare challenges.

Experience indicates that without ongoing contributions from other constituents who could benefit from the HIE it is unlikely provider led efforts will achieve long-term financial self-sufficiency. To address this situation we recommend:

1. A mechanism for payers to support HIEs through a per transaction/usage fee model should be collaboratively designed with payer organizations and the state. We believe that this work is also tightly coupled with the subsequent development of high-value services in more mature phases of HIE development, as described below.

2. Empowerment of a neutral organization with statewide collaborative capability to bring the diverse array of potential providers and consumers of HIE services to the table to establish common standards for HIE-related value-added services (constituents include; state & local health departments, healthcare providers, pharmacies and pharmaceutical concerns, research and academic institutions, insurers, payers, employers, and consumers). In return for the provision of these services, constituent groups would commit to providing financial support to HIEs that can address the following needs:

- **Public health** – immunizations, other preventive services, pandemic and bioterrorism preparedness, reportable diseases, etc.
- **Quality and chronic care** – comprehensive reporting on quality, adverse events, medication reconciliation, disease registries, and chronic care management (supportive of the state’s initiative for providers to implement the Chronic Care Model).
- **Cost effectiveness** – comparative effectiveness analysis (typically not sponsored by the pharmaceutical or medical device industries) to identify which treatments work best and are most cost-effective in order to guide future payment and coverage provisions.
- **Biomedical research** – medical device and pharmaceutical research.
- **Research related to redesign of the delivery system** – efficiently assessing the impact of new regulations, contracting, HIT, or provider payment mechanisms, etc. on delivery system performance.

3. Research should be commissioned to assess the feasibility of public utility or public authority models to help finance HIEs that meet minimum ‘core’ and/or value-added service standards.

4. In order to improve quality, provider payments must be realigned over the long run to appropriately reward and encourage use of HIE data to avoid complications of chronic illness, and eliminate unnecessary, ineffective, or redundant care.

5. Establish ‘core’ standards related to HIE implementation using the same collaborative mechanism as described in #2 above for value-added services. For example, a significant burden could be removed for HIEs if the state were to approve a standard form for use by citizens to authorize use of their healthcare data in HIEs.

6. Accelerate access to pharmacy-related data sources by HIEs to promote accurate medication reconciliation.

7. Develop a mechanism by which a single standard consolidated data set would satisfy all provider-related State data reporting requirements.

# INTRODUCTION

## Pennsylvania Prescribes High Quality Health Care

Pennsylvania, as the Keystone State, is forging ahead as a leader and taking a central role in accelerating the adoption of health information technology (HIT) and health information exchange (HIE). Electronically connecting physicians, hospitals, labs, pharmacies, and other healthcare institutions as well as consumers to give healthcare providers a complete view of a patient's medical information is a massive undertaking, but one Pennsylvanians are committed to implementing.

Joined in their commitment to ensuring that healthcare in Pennsylvania is being delivered in a safe, effective, efficient and timely, patient-centric manner, stakeholders are collaborating in substantial and innovative ways to secure the benefits of HIEs to support enhanced communication, foster clinical best practices, empower consumers to manage their healthcare decisions and support physicians in the delivery of high-quality care.

This paper will describe the health information collaborations and projects occurring in regions across the state and their accomplishments to date. The paper will conclude with key recommendations on how this work might be built upon and effectively advanced, with special attention to areas not being addressed such as integrating community resource organizations and services that augment medical services into the health information architecture.

## Surveying the Landscape of Health Information Exchanges in Pennsylvania

While most agree the introduction of technology in the clinical setting enables numerous possibilities for driving the use of patient-specific data, improving quality through best practices, reducing errors and adverse events and improving efficiency, the rate of adoption and widespread use has not reached a critical mass. The ability to use this information in aggregate form allows for the advancement of evidence-based medical practice, disease management and population health management efforts. Nationwide, there is a flurry of activity around creating a future where critical patient-specific medical information flows seamlessly and securely to the right place at the right time. Note of caution, based on a recent Harvard study despite the widespread interest in regional health information exchanges in recent years, survival is highly dependent and must have a clear and strategic roadmap to becoming financially sustainable.

Recent surveys of 130 health information exchanges report a growing sense of maturity in these efforts. The 2007 response rate increased during 2006, with 46 out of 50 states as well as Puerto Rico reporting results and status of their individual HIE efforts. For the most part, health information exchange initiatives have migrated to a model whereby multiple, diverse stakeholders are participating in the effort. Those organizations that are participating in the governance of health information exchange efforts include hospitals (67 percent), primary care physicians (49 percent), health plans (43 percent), community health clinics (40 percent), local public health departments (28 percent), patient or consumer groups (30 percent), specialty care physicians (27 percent), employers (21 percent) and quality improvement organizations (21 percent).<sup>1</sup>

The trend across Pennsylvania is for healthcare providers and provider groups to create interconnected, electronic healthcare systems that are driven by the desire to enhance healthcare quality and effectiveness and reduce the cost of healthcare. Today, state leaders are recognizing that HIT and HIE can help address many healthcare challenges. However, the development of HIE has been for the most part, driven by local and grassroots efforts since healthcare services and patient healthcare experiences are primarily local.<sup>2</sup>

Despite evidence that HIT and HIE, which together bring the assurance of interoperability, promises to transform the current health care system by ensuring that consumers have access to the highest quality, most efficient and safest care, giving health care providers access to the right information at the right time and reducing the overall costs of health care delivery, our nation's health care industry lags behind other industry sectors in IT investments. Establishing a successful HIE requires achieving sustainable vision, commitment, technology and infrastructure, adoption, financial support, collaboration and leadership.

## THE NATIONAL AGENDA

With medical errors now the fifth leading cause of death as estimated by the Institute of Medicine (IOM) report “*To Err is Human*”, no longer can we hesitate to move aggressively toward solutions that solve this problem. The lack of readily available, comprehensive, individual-centered health information delivered electronically between all key stakeholders in delivering and receiving services, negatively impacts healthcare accessibility and delivery at every level. Not only is the human toll excessive, the impact on healthcare costs is prohibitive. The Centers for Medicare and Medicaid Services states that domestic healthcare spending in 2006 reached a total of \$2.1 trillion, or \$7,026 per person, up from \$6,649 per person in 2005, and will continue to escalate faster than the economy.<sup>3</sup>

Leading authorities such as the IOM, some of the nation’s largest employers, provider and physician groups and payers across the country, Congress and nearly every federal government healthcare agency along with state level governments have called for increased investment in electronic health information systems development, deployment and execution.

Increasing medical malpractice insurance premiums added to the challenges of an already overly complex healthcare system are causing many clinicians to leave practice (or certain specialty focus). Along with an already growing shortage of nurses and pharmacists concerns about medical errors is prevalent.

The opportunity to improve care with the use of clinical guidelines, best practices and decision support has been sub-optimal due to lack of the right resources to deliver these tools at the point-of-care. HIT will close the gap with its ability to access and deliver clinical knowledge and information about the right patient to the right provider at the right time.

The healthcare system in the United States is highly fragmented and compartmentalized with each healthcare entity gathering and storing its own information most often in paper format. Why is it only a fraction of healthcare data is electronically (digitally) transferred when we live in what has been coined “the electronic information age?” More than 90 percent of the estimated 30 billion healthcare transactions in the United States are still delivered by phone; fax or mail.<sup>4</sup> The same research shows that physicians spend an estimated 20 to 30 percent of their time searching and organizing information, time that could better be spent in direct patient care. Because physicians do not readily find what they are looking for in a patient’s paper-based record at the time of visit, a significant number of duplicate or repetitive labs, x-ray and other costly procedures are ordered to ensure appropriate treatments and care have been delivered.

Some real challenges nationally that are keeping mainstream healthcare on the HIE sidelines:

- The variability in current exchange services making all inter-exchange transfers one-off efforts. Each solution has its own proprietary standards. As long as this continues, the NHIN will continue to difficult to achieve.
- Lack of incentives and motivation for health care organizations to participate.
- Uncertainty of legal liability for data that is transferred.
- Lack of EHR / EMR adoption continues to be a big issue nationally, and is clearly a limiting factor for HIE.
- Too much variability in understanding and implementation of HIPAA Privacy and Security, and for data participants who are not at a senior management level.

National healthcare leaders in both the public and private sectors are taking on a number of cited barriers to HIT adoption. These barriers include the lack of consensus on standards required to create interoperable systems; the organizational and clinical process change required in provider institutions and practices (behavior change); and the limited financial resources available or incentives provided to ensure HIT development, deployment and sustainability.

While federal leadership and support is important, it must be integrated with efforts at the state, regional and local levels. State legislatures and local governments play a critical role in working together in partnership with the public and private sectors to address challenges and to collaborate on actionable and viable solutions that are sustainable over time.

## THE PENNSYLVANIA LANDSCAPE

Pennsylvania is in a unique position to encourage HIE, or the electronic transfer of healthcare information across organizations. Pennsylvania is undertaking a multifaceted approach to improve both healthcare quality and safety. Led by the Governors Office of Health Care Reform, the departments of Health, Public Welfare, and Insurance and an independent Patient Safety Authority (PSA), State officials are working to align health information technology initiatives.<sup>2</sup>

PAeHI in its role as a neutral public-private convener can be leveraged to build support for collaboration among the many stakeholders that are needed to create, operate and sustain HIE networks. State leaders should encourage HIE by providing funding sources and driving collaboration.

Health information technology (HIT) is the use of computer software and hardware to process healthcare information electronically, thereby allowing for storage, retrieval, sharing and use of the information, data and knowledge for communication and decision making related to healthcare delivery. The main function of HIT resides within physician offices, laboratories, hospitals, mental health centers, large hospital systems and payor organizations.

Health information exchange (HIE) is an infrastructure to enable movement of healthcare information electronically across organizations within a region or community. It must also have agreed-upon business relationships and processes to facilitate information sharing across organizational boundaries. HIE provides the capability to electronically move clinical information between disparate healthcare information systems while maintaining the meaning and integrity of the information being exchanged.

The difference between HIT and HIE is that HIT relates to the tools and infrastructure that allows information to move seamlessly and securely across a network supporting the movement of information which results in HIE. Another key characteristic relating the two is that the incremental investments in HIT (in support of HIE) are typically borne by the individual healthcare provider organizations or facilities, while much of the benefits of HIE accrue to those outside the individual organization.

It's worth discussing briefly the definition of Regional Health Information Organization (RHIO), which is often used interchangeably with HIE and Local Health Information Exchange (LHIE). RHIOs have been described as a multi-stakeholder organization created for the purpose of electronic data exchange and is focused on improving the quality, safety and efficiency of healthcare delivery. No two definitions of RHIO are the same, however, there are key similar attributes. The Minnesota eHealth efforts define RHIO as is a multi-stakeholder organization that seeks to enable the exchange and use of health information, in a secure manner, for the purpose of promoting the improvement of health quality, safety and efficiency. A RHIO is not a technical service organization but a business organization that is formed to service a defined geographic community. The need for RHIOs derives principally from the fact that most health care services are provided on a regional basis. The business case will result from payers, providers and other stakeholders in a given community agreeing to a common business framework as a means of improving health quality while at the same time strengthening their individual business goals.

According to the findings of a fall 2006 American Hospital Association Health Information Technology Survey, Pennsylvania's hospitals and health systems are outpacing hospitals nationally in their adoption and use of clinical HIT systems.

In 2004, Pennsylvania became the first state to require thorough Health Information Reporting of near misses, in addition to actual medication errors. Pennsylvania hospitals and other healthcare facilities must report "serious events" and "incidents" (i.e., near misses) to Patient Safety Authority as they occur, on a monthly basis, using a confidential Web-based data collection system.

Although there are no hardened quantified estimates that encompass a complete broad-scope picture and use of HIEs in Pennsylvania, there are important data sources that estimate and provide describable benefits to identify potential sustainable sources of revenue through shared savings as well as testimony that exists.

Freestanding and hospital-based ambulatory care services all use external laboratories in some way in Pennsylvania. A HIE would facilitate the reduction of redundant tests and would reduce the delay, associated costs with paper-based ordering and results.<sup>5</sup> These savings can be seen to provide significant dollars to Pennsylvania. In addition, laboratory connectivity would give clinicians better access to patients longitudinal test results, reduce errors associated with reporting orally, optimize ordering processes, thus making tests more convenient to patients.

For example, the Central Pennsylvania Alliance Laboratory (CPAL), located in York, Pa., is a reference laboratory owned by six health care systems in south central Pennsylvania, which includes Summit Health, Pinnacle Health, Reading Hospital, York Hospital, Lancaster General, and Ephrata Community Hospital. For more than a decade providers at these institutions have dedicated themselves to working cooperatively to provide the highest quality and most effective laboratory services that benefit patients, providers, health care institutions, laboratories and communities. The connectivity capability of CPAL reference lab helps hospitals receive test results faster than if they were to send specimens out of state. CPAL performs approximately one million tests per year.

Imaging procedures in physician practices, and those ordered by those in Pennsylvania hospital-based ambulatory practices are sometimes performed by external radiology centers. Connectivity between these organizations would reduce redundant testing and would save time and associated costs. Connectivity also plays a significant role in improving ordering by giving radiologists access to relevant clinical information, thus enabling the clinician to provide the most optimal testing, improve patient safety by the ability for both the attending physician and the radiologist to test for contraindications, facilitate coordination of care and help prevent errors of omission by enabling automated reminders when follow-up studies are indicated.

**Pennsylvania-based Quantum Imaging**, and other Pennsylvania firms, provides e-Radiology capabilities that offer real-time 24/7 Radiology services to compete against non-Pennsylvania-licensed radiology groups in located in Australia, Asia and Europe. Yet, Pennsylvania will outsource more radiology studies (x-rays CT Scans, MRIs) than any other state. HIE in Pennsylvania, would provide for more effective competition by leveling the playing field, especially when our radiologists are paying Pennsylvania medical liability insurances while companies in Australia, Europe and Asia are not. If Pennsylvania radiology studies can be outsourced to Australia, or other overseas countries over the Internet, then why not send these

## A CASE STUDY

*Dr. Jack Devine, Internal Medicine, Lewisburg, PA. and his staff solved their clinical charting needs. His practice serves over 2400 patients. Providers in his practice have their visit and treatment notes complete at the point of care, plus they are always legible as well as accessible anywhere there is internet access. Dr. Devine found that it was time to rid the practice of the old paper charts. His main motivation was to become connected and paperless. Dr. Devine used an imaging module which included a HIE fax component for taking his office entirely paperless. As a result, Dr. Devine was able to scan all letters, consult reports and outside records that are sent to his office on a daily basis. He was also able to tear down his old patient medical charts, and reference those records for future retrieval. Within 30 days all 2400 paper charts were scanned and linked to the patient's electronic medical record. Dr. Devine is now saving more than \$45,000 per year through the use of his software and connectivity to scan instead of paper charts. Even more importantly all his records are right where he needs them to be, accessible at all times night and day.<sup>7</sup>*

radiology studies to Pennsylvania radiologists instead. HIE is one component that make it competitively fair.

The connectivity between providers would help make reporting for vital statistics, disease surveillance and chronic care management more efficient and complete. For example, **Pennsylvania's National Electronic Disease Surveillance System (PA-NEDSS)** has made a positive impact on the Department of Health (DOH,) institutional and private disease reporters in the PA-NEDSS user community and, ultimately the residents and visitors of Pennsylvania. Current trends indicate that it will continue to do so for many years to come. PA-NEDSS establishes a near real-time, secure communication link between laboratories, hospitals, individual medical practices, and the PA DOH. PA-NEDSS enables greater efficiency and effectiveness in reporting, investigating and tracking reportable diseases. Based on reported data, public health staffs have the ability to act quickly and provide appropriate interventions, thereby reducing morbidity and costly health care treatments. In addition, improved access to same-disease and cross-disease analytics provide opportunities to promote public health awareness in targeted communities. Each of these changes serves to improve public health of Pennsylvania.

The implementation of PA-NEDSS resulted in four key benefits; each of these benefits was integral in improving the efficiency and effectiveness of the DOH.

- Consistent and up-to-date data sharing between health jurisdictions.
- Improved communication in the public health community.
- Improved public health of Pennsylvania.
- Enhance disease tracking and analysis.

Provider connectivity would also impact time associated with handling paper charts, referrals and chart reconciliation, resulting in more efficient processes. To broadly examine the potential health and financial benefits of (HIT) it is estimated that the potential savings and costs of widespread adoption of electronic medical record (EMR) systems, in addition to HIE health and safety benefit, we could eventually save more than \$81 billion annually.<sup>6</sup>

*"The future belongs to those who see possibilities before they become obvious."*

## Sustainability of Vision

Today, state leaders are recognizing HIT and HIE can help to address many healthcare challenges. However, the development of HIE has been, for the most part, driven by local and grassroots efforts since healthcare services and patient healthcare experiences are primarily local.

Physicians, clinical service providers and patients live with the realities of highly fragmented, inaccessible and expensive patient-specific clinical information delivery and retrieval every day. Early application of information services focused on the administrative side of healthcare delivery, however, to impact quality, safety and improved clinical outcomes. It is imperative we put attention and resources to outpatient clinical solutions, where our citizens seek care locally.

Pennsylvania shares many barriers and challenges with other states:

- Fragmented healthcare delivery and financing environment
- Historic economic pressures and restructuring serve as challenges and drivers
- Geographic, service scope and diversity call for coordinated local solutions

Pennsylvania also has unique strengths and experiences that can be built upon to help ensure success:

- Vision, leadership, landmark policy and program alignment
- Critical mass of stakeholders

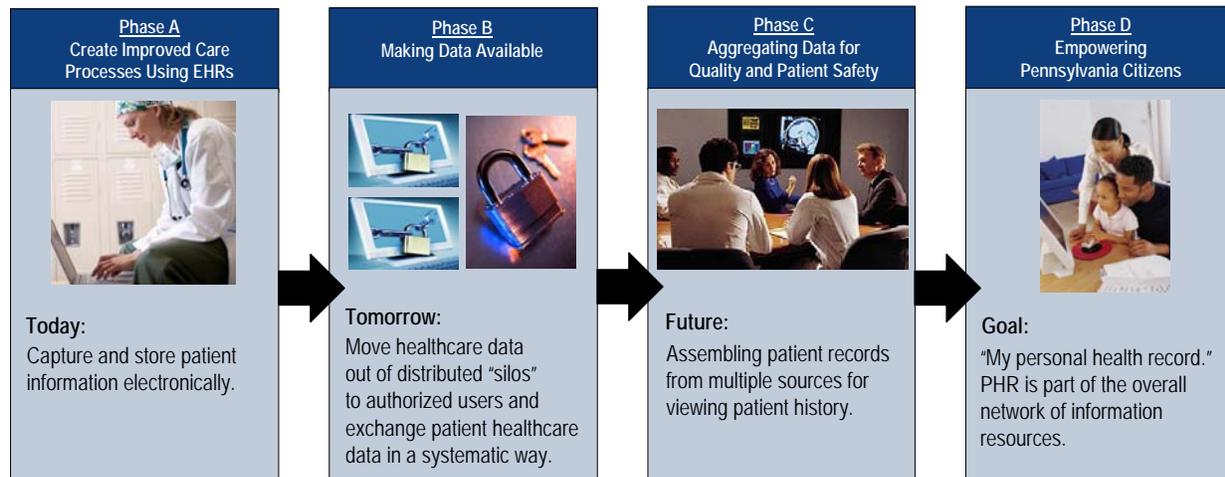
A starting point for a HIE throughout Pennsylvania begins with identifying the key process, understanding what data must be exchanged, identifying where the data exists, aggregating data for quality and patient safety needs and empowering physicians, patients and all stakeholders with a vision to transform our current paper-based, fragmented, error-prone, high-cost healthcare delivery system to one that is electronic, streamlined, focused on patient safety, low-cost, and improves the health status of all Pennsylvanians.

With an agreement on key objectives by all stakeholders on an individual level, the next step is to define the overarching community vision. This vision can be as broad as Agency for Healthcare Research and Quality (AHRQ) RHIO Implementation Grant Project of Central Pennsylvania whose mission is to *"exchange health information for common patients across three hospitals"*, and the Keystone Health Information Exchange (KeyHIE) mission, which is to serve as a *"health information exchange facilitator"* or a more specific goal like Central Pennsylvania Alliance Laboratory (CPAL) a regional reference laboratory located in York whose mission is *"committed to working cooperatively to provide the highest quality and most effective laboratory services to the benefit of patients, providers, health care institutions, laboratories and communities"* and Pittsburgh Health Information Network whose mission is to be a *"central repository for electronic data on diabetic and depressed patients."*

High performing HIEs keep their purpose and mission at the forefront which serves as a mechanism to better keep operational milestones in focus, keeping their end-goal in sight. Another attribute for success is to implement the vision and plan in smaller incremental phases, rather than tackling the whole all at once. The best way to drive sustainable change is through smaller incremental steps. This approach will help to minimize risk and allows the HIE to identify early successes as well as develop corrective action plans when challenges or obstacles arise. The ability to identify and establish quantifiable indicators of quality and to monitor these measures as the HIE phases are implemented can lead to the distillation of “best practices” that when used help facilitate ongoing HIE activity.

The Pennsylvania eHealth Initiative has outlined 4 phases to exchange information electronically focused on use of EHRs, however, this model for exchange will accommodate all data interchanges that lead to a successful HIE. Best-practice HIEs use EHRs, e-prescribing and, to a lesser extent, Personal Health Records (PHRs), to build a solid foundation for sharing data, to increase outreach and adoption rates, and to obtain tangible return on investment in a short period of time.<sup>8</sup>

### EVOLUTION OF THE ELECTRONIC AGGREGATE HEALTH RECORDS IN HIE



**Phase A** is the first step in moving from paper medical records and other critical care information to finding best practices in how to capture, codify, store and retrieve patient-specific clinical information from the right place at the right time. Healthcare providers should be encouraged to move toward implementing, adopting and using standard based medical records and electronic prescribing systems as a first step in this health information technology migration path. [Refer to PAeHI white paper on “Establishing Widespread Adoption of Electronic Health Records and Electronic prescribing in Pennsylvania”]

**Phase B** involves enabling patient-specific clinical and other health information to be accurately identified and associated with the right patient, locating the various disparate locations data for that patient exists, and creating a secure, robust, scalable, interoperable electronic delivery infrastructure/network for sharing that data across multiple entities.

**Phase C** leverages the health information amassed to be integrated into decision support tools for real-time informed decision-making and establishing of best practices in clinical care.

**Phase D** provides information to be accessible by patients via EHRs or PHR systems, where patients can now take an active role in managing and improving their healthcare. Having access to this information and providing additional input will enhance the physician-patient relationship, focusing on real issues and patient needs ultimately improving how care is delivered in this country.

In order to move through these phases successfully, several key issues must be addressed and resolved including:

- Privacy and Security
- Data accuracy and integrity
- Business rules and policies
- Legal and Regulatory
- Accurate Patient Identification
- Interoperability
- Individual participation & control
- Financial support and ongoing funding mechanisms

*“Stay committed to your decisions, but stay flexible in your approach.”*

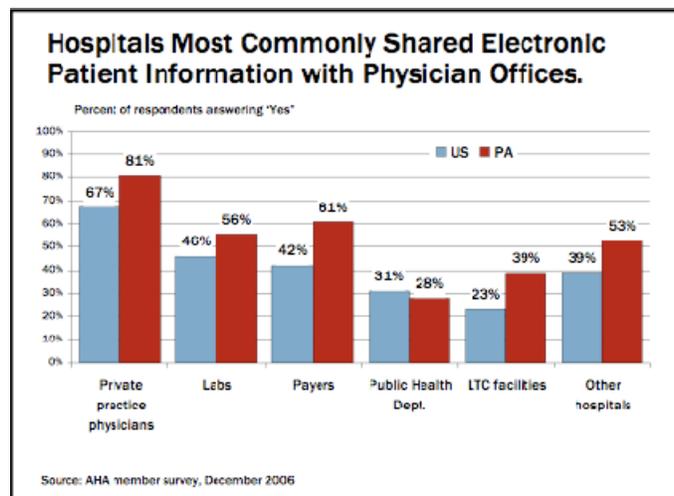
## Sustainability of Commitment

The State of Pennsylvania is resolute in its commitment to move forward through these four phases. Much work has already been achieved on the inpatient (acute care setting) and in that effort Pennsylvania is being recognized as an industry leader. Significant support and encouragement is coming from the state leadership as illustrated by Gov. Rendell’s “Prescription for Pennsylvania”, encouraging hospitals to adopt and implement system wide quality management and error reduction systems and interoperable electronic medical records. The Prescription for PA articulates several key issues that support the adoption of e-health solutions.

- The healthcare system in the United States has been slow to adopt system-wide approaches to preventing errors in the care and treatment of patients.
- Computerized physician order entry systems (CPOE) and medication bar coding are proven ways to eliminate medication errors, yet fewer than 10 percent of Pennsylvania’s hospitals have adopted such systems.<sup>9</sup>
- Electronic health records (EHRs) are known to reduce errors by making patient information more complete and available to healthcare providers in a timelier manner, so more informed decisions be made at the point-of-care.

About one half of Pennsylvania hospitals are participating in a local/regional arrangement to share electronic patient-specific healthcare information, on par with the percentage nationwide.<sup>10</sup> The use of CPOE is growing, and Pennsylvania is ahead of the national average in the percentage of physicians who routinely ordered medications electronically. These information exchanges take place in a variety of formats such as the following:

- Web portals that give physicians access to hospital information systems.
- Sharing of electronic data with other hospitals or facilities with a health system.
- Sharing of data with a laboratory.
- Planned or nascent projects to share information through a regional health information network.
- Hospitals most commonly share electronic patient information with physician offices; reported by 81% of respondents.<sup>10</sup>



*“There's no such thing as sustainability. There are just levels of it. It's a process, not a real goal. All you can do is work toward it.”*

## Sustainability of Adoption

**The Philadelphia Health Information Exchange (PHIE)** is a leading example showcasing successful adoption of HIE, as it is the nation's first diagnostic imaging exchange. This network links healthcare providers in one of the largest and most demanding U.S. healthcare markets encompassing some 4 million patients, 55 hospitals and 30 competing health systems. The exchange has been built to accommodate the most demanding of healthcare environments—multiple competing facilities multiple vendors, both legacy and new technology systems and scalability to securely exchange millions of radiology images. Current participants include the Hospital of the University of Pennsylvania, Thomas Jefferson University Hospital, the Philadelphia Department of Public Health and Community Radiology.

Another example of adoption through collaboration is the **Keystone Health Information Exchange™ (KeyHIE)** organization, established in 2005 to enable the delivery of high quality, convenient, efficient healthcare in central and northeastern Pennsylvania. The Exchange's mission is to create an environment to facilitate secure and timely access to comprehensive healthcare information.

Seven organizations have signed a Memorandum of Understanding (MOU) to move forward to create a regional health information exchange in central and northeastern Pennsylvania and include Bloomsburg Hospital, Evangelical Community Hospital, Family Practice Centers, P.C., Geisinger Health System, Jersey Shore Hospital, Moses Taylor Hospital and Shamokin Area Community Hospital.

The initial focus of the exchange is to provide timely, accurate and secure access to patient information at the point of care in emergency departments. This is often the place where the least information is available about a patient, and where having the right information on the right patient at the right time can be a matter of life and death. The plan was focused on rolling out access in emergency departments in the summer of 2007 and creating connections to three additional KeyHIE organizations by December 2007. The end goal was to have information on more than 3 million patients that could be accessed by clinicians in six regional emergency departments.

A national leader in HIE initiatives is **Geisinger Health System**, which has successfully accelerated the widespread use of an electronic health record with its 670 physicians working in 42 clinics in more than 31 counties with 100 percent adoption. Physicians report improved care processes, enhanced patient-physician communication and patient satisfaction rate of 99 percent. The current system does not have an eprescribing component built in, but the current plan is underway to introduce this functionality in 2008. Anticipated benefits with this new capability include increases in patient convenience and satisfaction, feedback on patient adherence to treatment regimens and overall improvements in quality tracking.

Located in central Pennsylvania north of the capital, Harrisburg, **Susquehanna Health System** treats some 14,000 inpatients each year with a staff of 3,000 employees, including 210 active physicians, nine of those being radiologists. The organization saw the need to improve access to medical images and information for physicians who were geographically dispersed, while enhancing the overall responsiveness, productivity, efficiency, and quality of care of these radiologists. A Picture Archival and Communication System (PACS) was deployed to provide

access to images from multiple remote locations in less time, enabling faster diagnosis and better treatment.

At the **University of Pittsburgh Medical Center (UPMC)**, adoption and utilization of electronic medical records is a reality. The integrated computer system, called electronic health record, or eRecord, allows healthcare professionals throughout western Pennsylvania access to accurate up-to-date, real-time information such as: vital signs, test results and medication history. At the same time, they're also increasing quality and patient safety, while leading the way in what's been called a national healthcare priority. An automatic prescription-writing feature allows physicians to prescribe medications online and print out a typewritten prescription for patients, reducing the chances of handwritten prescriptions being incorrectly interpreted. By listing both brand and generic names, the application helps physicians communicate clearly about sound-alike drugs. The eRecord solution also provides the right drug choices and check-off boxes for specific dose levels, so physicians can be confident they're prescribing the correct drug and the correct dosage

The **Northeast Pennsylvania (NEPA) Regional Health Information Organization (RHIO)** dissolved in June 2007. The primary reason for the dissolution was that it had become evident to the board (and to others involved in NEPA RHIO committees) that the formal organizational structure was an impediment to collaboration rather than an asset. The NEPA RHIO collaborators are evaluating how to integrate a new collaborative framework into the current corporate structure.

NEPA RHIO noted that a major drawback for the organization was that it was a separate entity. The conclusion that has been reached is that the best path towards integration between participating entities is to provide a mechanism ("framework") for each to build the RHIO concept from within their own organizations (at a cost and time agreeable to their own institution) outward to each other and the community. Through collaboration, without the restraints of a formal structure, it is hoped that the next phase of this RHIO initiative will build partnerships through pilot projects among ready and interested entities without an impractical "one-size-fits-all" mindset.

The **Washington Health Information Network (WHIN)** is an initiative connecting the Washington Hospital and more than 200 primary care and specialist physicians from more than 90 practices not under common ownership in Washington and Greene counties. WHIN utilizes a data repository that receives real time diagnostic test results and other patient record documents from the hospital. Information can be accessed by physicians through a secure Web portal. Physician practices can have an interface from WHIN to their respective EHRs so that information can flow directly into the patient's record. This model does not require that physicians use the same EHR, providing the practice with the freedom to choose the EHR solution that is best for the specialty and unique practice business arrangements. This project is jointly funded and coordinated by the hospital and physicians through the Washington Physician Hospital Organization. Future plans are to explore bidirectional interfaces to pull data from physician EHRs to the repository. This project affords opportunities to introduce workflow enhancements at the physician practice level. Quality of care is ultimately enhanced by improving the timeliness and completeness of information available to providers at the point of care.

*"Sustainable development is...development that meets the needs of the present without compromising the ability of further generations to meet their own needs."*

## Sustainability of Technology & Infrastructure

Identifying a technology and network infrastructure that will create the desired integration, define standards for data sharing that protect data and business practices to ensure patient protection is critical to sustainability and success. From a technology standpoint there are several configurations that enable the movement of data to and from disparate information sources. Depending on the approach utilized, the advantages and disadvantages must be considered prior to implementation.

### Centralized

In this configuration, all providers send their data to a central repository on a periodic basis, daily at a minimum to keep the information up-to-date for more informed and accurate decision-making. There may be several community-based centralized repositories in this model as opposed to a single national repository.

#### Advantages

- The data is accessible in a uniform data format; facilitating great ease for interoperability, delivery of care and ongoing management of chronic disease.
- The centralized, "whole" system approach makes it easier to access, maintain and control who is using the information and for what purposes.
- A central repository for all information will enable research, population studies and public health prevention and surveillance efforts.

#### Disadvantages

- Data that is pooled into a central repository may create political challenges around medical data ownership and control such as who owns what data, and questions regarding authentication and authorization for data use, thus creating uncertainty around cost sharing implications.
- A centralized approach is typically associated with more complex implementations and impacts scalability as the number of participants grows.
- Privacy and security issues

### Federated (Record Locator Service)

In this architectural configuration, the data stays at the point of service, and the HIE has and manages a pointer to that information necessitating the need for patient and provider identification capabilities via a record locator service. Each data provider maintains its own health information database and has an interface with every other provider that is participating in the exchange. They share data privately and securely and no one provider has a complete medical record of the patient. They access the data they need when they need it.

#### Advantages

- This model provides the easiest and most efficient way to achieve a model that requires little to no interface work and associated costs to achieve data exchange.
- Because the data remains at the source where it is generated there are fewer conflicts over data ownership.

## Disadvantages

- Policies and procedures need to be implemented and agreed upon in regards to ensuring the authorized and legitimate access to information that is housed in a third-party system.
- Data control and availability of the data is not guaranteed, and issues remain around the accuracy of that information, and who has last updated information.
- Standards and profiles still being defined.

## Hybrid

The best of both worlds, using centralized and federated models based on each HIE arrangement, socio-economic, political and geographic environments, size and so forth. This third approach is most likely what is expected to happen as more regional communities get connected.

## Health Record Data Bank

This is the newest architectural model to emerge, where patients deposit health information (paying a fee themselves or through their health insurer) into health record data banks. This model is similar to the centralized model except here patients control what information is to be made available as opposed to provider-submitted data. With the consent of the patient, providers may also add to and access the information in the data bank.

Experience thus far has demonstrated there is no single model that is appropriate as a technical architecture for organizing and facilitating the electronic exchange of information. There may be multiple technical solutions specific to the stakeholder's needs. It is also possible that new technical models will emerge with technological advances, matured capabilities and experience that yield best practices.

## Solving the connectivity challenges

Locally, **PennTAP** supports technology-based economic development by helping Pennsylvania companies improve competitiveness by providing a limited amount of free technology assistance to help resolve specific technical needs.

**ConnectTheDocs**, a Pennsylvania Medical Society project funded by the Commonwealth of Pennsylvania through a Broadband Outreach and Aggregation Fund (BOAF) grant from the Department of Community & Economic Development is also focused on providing the means for physicians and other healthcare professionals to interact with one another and share information across a network securely, efficiently and effectively. The project will expand broadband network technologies to physician practices in which broadband is not currently used or available and improve healthcare in Pennsylvania, especially in rural areas. For physicians who already use broadband in their practice, this project could potentially offer higher quality broadband access or lower rates. □ The project will create quality-of-care benefits to thousands of patients and enhance the world-class healthcare Pennsylvania physicians deliver to their patients every day. This initiative will yield a more rapid adoption of broadband services by Pennsylvania's physicians.

A 2006 survey by the Pennsylvania Medical Society showed that 9 percent of Pennsylvania physicians have no Internet access or dial-up access in their practices. Another 28 percent have

expensive T-1 lines that have insufficient bandwidth for functions such as telemedicine and transferring digital images. In short, at least 37 percent of Pennsylvania's physicians—about 11,000—lack high-speed Internet access in their offices. Even in practices that have broadband, access is often limited to a single PC that may not be accessible in areas where direct patient treatment occurs. With the \$300,000 provided through Broadband Outreach and Aggregation Fund the medical society began leading a statewide project advocating the use of broadband network technologies to improve healthcare in Pennsylvania, especially in rural and underserved areas. Pennsylvania's estimated 30,000 actively practicing physicians.

## Sustainability of Financial Support & Viability

High performing and successful HIEs have a clear plan for sustainability. HIEs must plan for both the initial seed funding for planning and building the infrastructure for the HIE and then building a sustainable business model to keep the HIE operational long term. The industry has identified several business models in use today for HIE including:

**Not-for-Profit** model where HIEs are driven by their mission to help the patients and the community in which they provide services. Their tax-exempt status can help to reduce funding challenges and provide special tax credits/incentives.

**Public Utility** model where HIEs are developed, deployed and maintained with the assistance of federal/state funds. In return for funding, direction for ongoing operations are provided by the federal/state government.

**Physician and Payer Collaborative** where specific physicians and payers in a given geographical region partner to create and operate the HIE. In this type of model, the collaborative can be either for-profit or not-for-profit organizations; however, the key to sustainability of this type of collaboration is ongoing agreement and achievement of mutual benefits for participating payers and physicians.

**For-profit** HIEs are established with private funding and have specific ROI targets. These organizations look to reap financial benefits from their transactions and have solid start-up funding.

Nationwide experience with development and ongoing operational efforts have illustrated there is no single solution to achieving long term financial stability and sustainability and how provided Pennsylvania efforts with numerous approaches to consider, including:

- 501(c) (6) membership associations
- Subscription/transaction fee approaches
- Pay-for-Performance mechanisms
- Federal loans or grants
- Reduction in medical liability premiums
- Various funding opportunities
- Provide tax credits
- Bonus payments through payers for use of HIT & HIE

An early 2007 survey of regional health information organizations identified that for those HIEs that were functioning without substantial grant funding achieved success through the difficult work of building community support, developing key stakeholders' interest in clinical data exchange, and demonstrating the benefits.<sup>11</sup> The authors suggest that the advantage of grants is the ability to pursue implementation without establishing a self-sustaining revenue model up front. While the disadvantage is that although it enables rapid development of an infrastructure it may prevent the critical buy-in and championing from key stakeholders necessary for long-term success.

The Pennsylvania Senate Appropriations Committee passed a bill that would fund the adoption of electronic health record systems in hospitals illustrates the commitment to accelerate physician utilization. The legislation, which is sponsored by state Senator Rob Wonderling (R), provides grants of up to \$1 million in matching funds to hospitals that have appropriated money for EHR systems. The money can be used to purchase systems, set them up or train employees to use them enabling:

- Providers to send medical test results to patients online;
- Patients to electronically renew their prescriptions; and
- Physicians to send patients medical information via the Internet.

Pennsylvania Congressman Tim Murphy (R), Co-chair of the Congressional 21<sup>st</sup> Century Caucus, believes the absence of information technology in health care significantly contributes to inappropriate or inadequate treatment. These mistakes cost money and they cost lives. According to the Pennsylvania Health Care Cost Containment Council, unnecessary hospitalizations cost \$2.8 billion in unnecessary treatment in Pennsylvania alone. He supports rapid adoption of HIT and HIE, to address the critical need to provide physicians, nurses, and all healthcare professionals with timely, accurate and patient-specific information that results in reduction of medical errors, misdiagnosis and needless test duplications; reduced costs; and improvement in the overall quality of healthcare.

MedPAC, the Medicare Payment Advisory Commission has recommended that functions of IT systems that are linked to quality improvements be included as measures in pay-for-performance initiatives in all sectors beginning with physician offices. Due to the financial realities of the healthcare sector and the cost associated with the adoption of healthcare information technology, the commission favors the use of pay-for-performance as a financial incentive to the adoption of healthcare IT rather than direct loans or grants. It also looks at the need to stimulate community efforts to exchange health information and the impact this could have on public health.

Governor Rendell's "Prescription for Pennsylvania" reform proposals seek to increase use of nationally proven models or "best practices" for treating chronic disease through pay-for-performance and other incentives to providers.

Pay for Performance is widely implemented throughout Pennsylvania as a means to incentivize physicians in adoption of HIT and HIE as well as implementing best practices. Doylestown Hospital in Bucks County, Pa., implemented a pay-for-performance program with Aetna in which the hospital will receive bonuses for using best-practice recommendations from groups like CMS and the National Quality Forum.

**Midwest Medical Insurance Company (MMIC)** announced in September 2007 that it will offer a premium credit to any solo physician or physician group policyholder who implements and uses electronic medical records software, with credit to begin Jan. 1, 2008. To receive premium credits of 2 percent to 5 percent, a physician group must meet the following requirements:

- The EMR system must be certified by the Certification Commission for Healthcare Information Technology (CCHIT), the recognized certification authority for EMR systems.
- The physician group must have implemented or plan to implement the latest vendor updates for their system. (No old school EMR systems, please.)

- At least 75 percent of the physicians in the group must be using the EMR or EHR.
- The group must have been using the EMR or EHR for at least a year.
- The group must be using at least two of the six EMR's functions listed on the application.

The type of financial support may be dependent on the HIE's business model operation such as; not-for-profit, public utility, physician-payer collaborative, hospital system collaborative or for-profit entity.

The current debate is whether HIEs represent small businesses that need viable business models, which require the ability to generate profits as well as value for participants or public goods that require public financing is an important unresolved issue.<sup>11</sup>

## Sustainability of Collaboration & Leadership

Successful HIEs all have one thing in common—starting at the top with clearly articulated goals and mission as well as strong leadership to ensure the achievement of these goals. Healthcare providers recognize the value and benefits of an information exchange, and yet those HIEs that continue to evolve and sustain their vision and mission must serve the needs of all parties involved. Strong leadership must design and build a blueprint for the HIE project by first defining the community and outlining the benefits for each shareholder; considering all of the following parties as constituents: patients, employers, physicians, physician practices, hospitals, home health agencies, community health clinics, local departments of health, and payers (health plans and state/federal).

The establishment of common goals puts the community on a path to success, yet, sustainability is dependent on ongoing communication between stakeholders as well as the ability to mitigate differences in expectations and balance the inherent competitive nature of the various stakeholders. To ensure continuous open dialogue, a formal, participative leadership model is critical to ensure that organizations that are otherwise competing for patients as well as resources remain at the table, even during project challenges. If the issue of competition is not openly addressed and resolved, it may inhibit the sharing of data and information about business practices.

Sustainability is dependent on staying the course, even when encountering competing priorities. Given the complexity of the health care delivery system, there will always be challenges in keeping resources from moving to other areas that need attention within their organizations.

Another attribute of strong leadership is the ability to engage the community, which will require a formal education and outreach program designed and executed to inform all parties of the individual improvements they can see, as well as their role in the larger initiative.

An example of collaboration in the development, deployment and utilization of medical records is being demonstrated by Northrop Grumman Corporation, **Conemaugh Health System** and the Department of Defense. They will develop an electronic medical records program that will allow military, Veterans Affairs and civilian health providers to share information while protecting confidentiality. The system will keep track of wounded veterans after they leave the military hospitals and are discharged from service.

An overriding theme related to the critical factor in achieving successful HIEs is strong leadership and funding. But committed leadership and ample funds cannot alone sustain a regional effort. Long-term success can be achieved only if broad coalitions within communities work together, put aside competitive differences, share a common vision and make these efforts a priority.

Another unique example of private and public collaboration is illustrated in the following case study.

## York County--Common Intake Data System ( CID)

Started in 2001, Info-Matrix designed, constructed and implemented information management systems for health and human services. One of our most unique projects is the York County Common Intake and Data System (CID). The CID system is an example of private and public organizations working together to solve challenges faced by every human service related agency. York's Countywide Web-based application was made possible through a grant from the County Commissioners Association of Pennsylvania (CCAP).

York County, like many other county health and human service agencies, knew they were interacting with many of the same individuals through different agencies. However, agency administrators and staff lacked an information resource that could link the client's needs to the services available. Human service providers knew for years that they frequently provide services to the same individuals and often wished to share information common to their clients and client's families. The York County CID system project was primarily developed in recognition of a lack of shared information and duplicate data entry by county agencies. The CID system collects two types of data: Individual and Household.

Individual is person specific and includes the following categories:

- Demographics
- Social Issues
- Employment
- Training & Education
- Medical
- Transportation

### **LESSONS LEARNED** – (from Robin Rohrbaugh - Project Lead)

That project was entirely supported by Info-Matrix, outside technical consultants. Because there was no internal support, when York County project team encountered technical issues, it was clear how critical technical resources were to the success of the project.

The project focused primarily on the design and development of the system. The committee that worked on this initiative had representation from all of the agencies that supply information to the database, in addition to others. Throughout development the York County team stressed the importance of communication and keeping end users informed each step of the way in regards to what the project entailed, how it would impact them, to solicit their feedback, but fell short of follow-up to ensure those conversations were taking place. As a result many of the end users had no idea what CIDS was until they walked into the room for training, or came in with totally erroneous assumptions about what the system would do. This resulted in spending a tremendous amount of time correcting misinformation - instead of training.

The purpose of our initiative was to give people the tools they needed to improve service delivery to clients and coordination between agencies. It requires users to change the way they think about their jobs and their roles. We seriously underestimated the amount of support and encouragement they would need after training. In retrospect, we should have been more hands on with users throughout the development phase to prepare them for this shift. When we rolled out the system, we should have had people on site at each of the agencies to help them with software problems and to coach them on how the system can help them do their job better. We have people who don't understand the software, but the bigger issue is getting them to believe they should do their jobs differently.

One area we needed to prepare for in advance was to identify users who didn't know how to or were uncomfortable working with a computer. Comprehensive training and ensuring a level of proficiency prior to a "go live" date as well as having IT staff on site the day of system launch would have gone a long way to achieving success.

Buy in or lack thereof became a significant barrier to sustainability. We had community partners who stuck with this planning and development for years, but when it came time to launch and encourage individuals to adopt and utilize the system their commitment waned. As a project lead, I was sensitive to the fact that these agencies didn't have a lot of money and to alleviate that obstacle grants were obtained for virtually the entire cost of the project.

My advice would be to encourage community partners to commit and champion the initiative at every level of the organization. I guess a lesson that I learned is that giving staff time to attend meetings isn't sufficient, that they need to actively participate and own the project, clearly understanding the value and benefits it will bring to the entire organization.

*“To think strategically about cross-sector collaborations, you must have a framework that enables you to envision strategic options”*

## Sustainability through Business Practices & Rules

Successful HIE efforts have policies and principles around business transactions in the sharing of information. Some of the key questions to address in the establishment of the policies are: who has access to what, under what circumstances, and with what protections? Who shares what and who bears the liability? And how can you control access to your Information?

Agreement of all constituencies participating in the HIE must agree to the following key topics:

- Notification and consent
- Uses and disclosures of health information
- Matching patients with their records
- Authentication
- Patient access to their own information
- Audit
- Breaches of confidential information

Agreement can be fostered by developing and deploying “data sharing agreements” or “data distribution Agreements”, which stipulate the conditions for sharing data and the purpose of data use. These agreements should be formal legal and binding partnership agreements and should include provisions for all considerations regarding data sharing including penalties and remedies for violations.

One of the significant barriers to overcome as experienced by many HIEs has to do with patient authorization. For example, the KeyHIE is providing access to the entire health record and may include information that is specifically protected under state law (i.e. drug/alcohol treatment, HIV, mental health notes, etc). This would require getting patient consent to share their information in whole or in part which then requires considerable technical requirements in regards to permissions, opt-in and opt-out provisions and executing some type of record locator service. Some provision at the state level to gather and maintain a database of patients that permit the exchange of their information would reduce the number of authorizations required and alleviate the administrative burden associated with this effort.

## Privacy and Security of HIEs

It would not be appropriate to discuss HIE sustainability without addressing privacy and security. The success of Pennsylvania’s effort in the sum of state and local HIE efforts depends upon the provider and patient confidence in the privacy and security of transmitted care data. In applying the practical application of information exchange, there must be transparent and unambiguous practices in place for privacy and security. Otherwise, health information exchange will not be successful.

At a granular level privacy and security challenges that face Pennsylvania are not unique and the uniqueness of the HIE efforts adds complexity to the privacy and security issues. Some of the issues surrounding HIEs include but are not inclusive of:

- Diversity of hardware and software for EHRs
- Challenge on multi-purpose Administrative and Clinical HIE use

- A diversity in data standards
- Different communication models and mediums
- Policies and procedures difference for patient consent for HIE
- Multiple business practices of HIEs

There exists great diversity in opinions and difference regarding privacy and confidentiality. As HIE networks come on board, the privacy and security issues cannot be vague and must embrace the resolve to move beyond the deadlock that create logjams.

In 2005, AHRQ awarded a contract to RTI International in a national effort to address privacy and security policy questions with HIEs. Under the contract, RTI subcontracted with 33 States and Puerto Rico to assist them with doing the following:

- Identifying variations in organization-level business privacy and security policies and practice that affect electronic HIE.
- For those practices that States consider desirable, documenting and incorporating them into proposed solutions; and for those with a negative impact, identifying the source(s) of the policy or practice and proposing alternatives to meet the same need.
- Incorporating State and community interests, and promoting stakeholder identification of practical solutions and implementation strategies through an open and transparent consensus building process.
- Leaving behind in States and communities a knowledge base about privacy and security issues in electronic HIE that endures to inform future HIE activities

## Conclusion

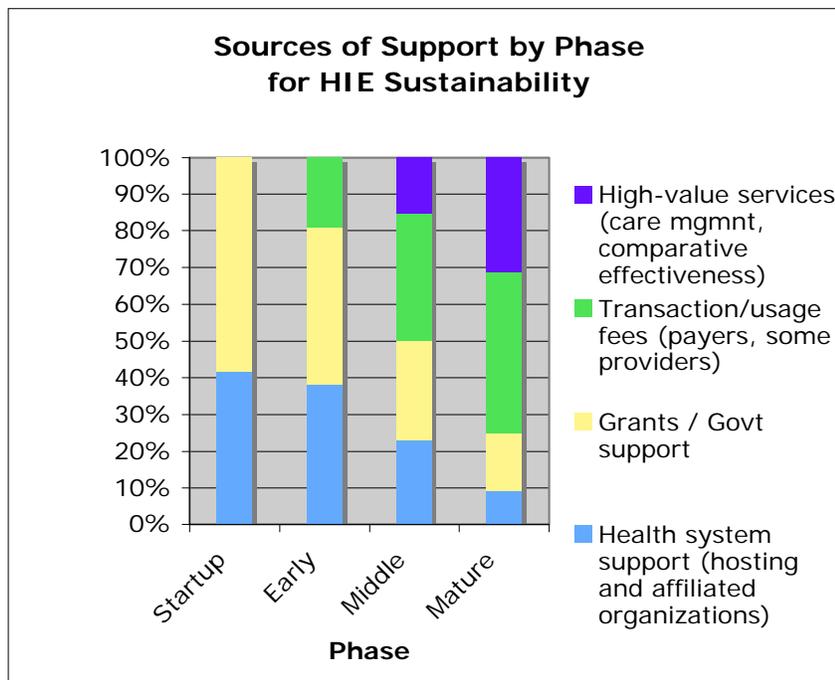
Establishing a successful HIE requires achieving sustainable vision, commitment, technology and infrastructure, adoption, financial support, collaboration and leadership. A connected system of healthcare information in the State of Pennsylvania will be a major shift—but it must come about through incremental change. These changes need to be more than automated or more efficient versions of what we already do. This is the opportunity to look for new ways to support and delivery healthcare; replacement and enhancements for existing processes, procedures, policies and work habits that will ultimately improve outcomes making evidence-based medicine a critical component of the practice of medicine.

## RECOMMENDATIONS & FUTURE CONSIDERATIONS

Establishing long-term sustainability for local, regional or statewide HIEs requires implementing a funding model, which is supported by the healthcare community it serves, and a business model that demonstrates the benefits and return on investment.

Despite the significant promise of HIEs to improve the overall quality and efficiency of health care, there are no organizational entities at the federal, state, or local levels, or in the public or private sectors obligated to implement or sustain HIEs. The trend statewide in Pennsylvania is to create an interconnected, electronic healthcare system that is driven by enhancing healthcare quality and effectiveness and reducing the cost of healthcare. Today, state leaders are recognizing that HIT and HIE can help address many healthcare challenges. However, the development of HIE has been for the most part, driven by local and grassroots efforts since healthcare services and patient healthcare experiences are primarily local. HIEs are alive and doing well in Pennsylvania, and the momentum is growing, but until there is a critical mass of adoption as well as adequate funding to promote utilization, the ability to sustain the progress that has been made is tenuous.

Experience indicates that without ongoing contributions from multiple constituents who benefit from the HIE it is unlikely such provider led efforts will achieve long-term financial self-sufficiency. The most robust models will be those capable of harnessing multiple funding supports and migrating toward a higher value proposition over time. A rough conceptual model of how varied sources might support an HIE at different stages of maturation is given below.



To help ensure that long-term sustainability for local, regional or statewide HIEs occurs successfully we recommend:

**1. A mechanism for payers to support HIEs through a per transaction / usage fee model should be collaboratively designed with payer organizations and the state.** This work should ideally involve all payers and take special account of the Medicaid population, which stands to benefit greatly from HIE capabilities. The collaborative design should allow for payers to help guide and remain involved in the development of data collection and use over time to support their organizations' business needs. Providers who are more often consumers of HIE information rather than suppliers may also be appropriate financial contributors. We believe that this work is also tightly coupled with the subsequent development of high-value services in more mature phases of HIE development, as described below.

**2. Empowerment of a neutral organization with statewide collaborative capability to bring the diverse array of potential providers and consumers of HIE services to the table to establish common standards for HIE-related value-added services** (constituents include: state & local health departments, healthcare providers, pharmacies and pharmaceutical concerns, research and academic institutions, insurers, payers, employers, and consumers). In return for the provision of these services, constituent groups would commit to providing financial support to HIEs. This could create a robust and resilient means to ensure both the financial sustainability of HIEs and their continued relevance and value to stakeholders. Examples of the value-added services that could be conceptualized and further developed include, but are not limited to, improved data capture, transmission and/or real-time analyses for:

- **Public health** – immunizations, other preventive services, pandemic and bioterrorism preparedness, reportable diseases, etc.
- **Quality and chronic care** – comprehensive reporting on quality, adverse events, medication reconciliation, disease registries, and chronic care management (supportive of the state's initiative for providers to implement the Chronic Care Model).
- **Cost effectiveness** – comparative effectiveness analysis (typically not sponsored by the pharmaceutical or medical device industries) to identify which treatments work best and are most cost-effective in order to guide future payment and coverage provisions.
- **Biomedical research** – medical device and pharmaceutical research.
- **Research related to redesign of the delivery system** – efficiently assessing the impact of new regulations, contracting, HIT, or provider payment mechanisms, etc. on delivery system performance.

**3. Research be commissioned to assess the feasibility of public utility or public authority models to help finance HIEs which meet minimum 'core' and/or value-added service standards.** Such a financing mechanism could be used to augment or implement broad constituent financing in exchange for value-added services. Preliminary research done now could inform policy and legislative action as HIE-related privacy, operability, and service standards mature. This could help establish a virtuous self-reinforcing cycle by which assurance of stable funding promotes more systems to launch or expand HIEs meeting established standards.

**4. In order to improve quality, provider payments must be realigned over the long run to appropriately reward and encourage use of HIE data to avoid complications of chronic illness, and eliminate unnecessary, ineffective, or redundant care.** At present, improving

the health of populations through more effective preventive services may result in the net loss of revenues to providers by reducing the number of services paid on a per unit basis. To overcome this misalignment, payment methods for providers will need to be changed for the full potential of an HIE supported care system to be realized.

**5. Establish 'core' standards related to HIE implementation using the same collaborative mechanism as described in #2 above for value-added services.** In addition to the above mentioned value-added service standards, other essential standards related to patient identification, privacy, authorization for information sharing, and interoperability necessary for willing consumer participation and effective linkages across HIEs would be greatly furthered by policy, regulation, or legislation at the state level. For example, a significant burden could be removed for HIEs if the state were to approve a standard form for use by citizens to authorize use of their healthcare data in a HIE. In addition, mechanisms whereby the state might assist in capturing such authorizations (for example at issuance / renewal of a driver's license) could lower the cost of operations for HIEs and improve the percentage of the public able to benefit from such participation. Many of these types of essential or 'core' standards for HIEs are maturing at the federal level and through other national initiatives and we recommend that these be looked to as important reference points.

**6. Accelerate access to pharmacy-related data sources by HIEs to promote accurate medication reconciliation.** The widespread harm and poor quality resulting from medication errors could be greatly reduced by targeting this area. This could immediately help support the business case for HIEs at the local provider organization level.

**7. Develop a mechanism by which a single standard consolidated data set would satisfy all provider-related State data reporting requirements be submitted to one State agency and distributed by that agency to other departments or agencies as appropriate.** This could immediately help support the business case for HIEs at the local provider organization level.

**8. We further recommend that the State's approach to these and other areas of policy be consistent with the guiding principles laid out in PAeHI's 'Connecting Pennsylvanians for Better Health', namely that:**

- Patients come first.
- Consumer privacy, security and confidentiality are paramount.
- Multi-stakeholder collaboration is essential.

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# GLOSSARY

## **Adverse Events**

An undesirable response associated with the use of a drug that compromises therapeutic efficacy, enhances toxicity or both.

## **Agency for Healthcare Research and Quality (AHRQ)**

The Agency for Healthcare Research and Quality was established in 1989. AHRQ's mission is to support research designed to improve the outcomes of quality of health care, reduce its costs, address patient safety issues and medical errors and broaden access to services and provides information that enables individuals to make better decisions about their health care.

## **Ambulatory Care**

All types of health services that are performed on an outpatient basis, in contrast to services provided in the home or in hospital settings.

## **Authorization**

Permission associated with accessing functions or subsets of data. Generally, an administrator will define the users who are authorized to access application functions or data.

## **Authentication**

"Authentication" is a way to ensure users are who they say they are—that the user who attempts to perform functions in a system is in fact the user who is authorized to do so.

## **Broadband**

A medium that can carry multiple signals, or channels of information at the same time without interference. Broadband Internet connections enable high-resolution videoconferencing and other applications that require rapid, synchronous exchange of data.

## **Centers for Medicare and Medicaid Services (CMS)**

The government agency within the Department of Health and Human Services that directs the Medicare and Medicaid programs (Titles XVIII and XIX of the Social Security Act), and conducts research in support of these programs.

## **Centralized architecture**

In a centralized architecture, all data resides in one locale, generally a central server. This approach offers security and system management benefits, although disadvantages with this approach include concerns about "data ownership" and space requirements to support this architecture.

## **Certification Commission for Healthcare Information Technology (CCHIT)**

The Certification Commission for Healthcare Information Technology or CCHIT is a recognized certification body (RCB) for electronic health records and their networks, and an independent, voluntary, private-sector initiative. It is our mission is to accelerate the adoption of health information technology by creating an efficient, credible and sustainable certification program. See [www.cchit.org](http://www.cchit.org)

## **Chronic care**

Care and treatment rendered to individuals whose health problems are of a long-term and continuing nature.

## **Computerized Physician Order Entry (CPOE)**

Refers to computer-based systems that automate and standardize the clinical ordering process in order to eliminate illegible, incomplete and confusing orders. CPOE systems typically require physicians to enter information into predefined fields by typing or making selections from on-screen menus. CPOE systems often incorporate, or integrate with, decision support systems.

## **Confidentiality**

The property the data or information is not made available or disclosed to unauthorized persons or purposes.

## **Consumer**

A person who purchases or received goods or services for personal needs and not for resale.

**Data repository**

Data repository is a database acting as an information storage facility. Although often used synonymously with data warehouse, a repository does not have the analysis or querying capabilities of a warehouse.

**Database**

An aggregation of records or other data that is updateable. Databases are used to manage and archive large amounts of information. Also see relational database.

**Decision Support**

A computer program that analyzes data and presents the information so that clinicians can make medical decisions more easily. Typical tasks of a decision support system include data storage, data analysis, predictive modeling, and risk-adjusted comparison of actual outcomes with predicted outcomes.

**Disease Management**

The process of identifying and delivering within selected patient populations (e.g., patients with diabetes, hypertension, asthma) the most efficient, effective combination of resources, interventions, or pharmaceuticals for the treatment or prevention of a disease. Typically includes team-based approach to delivering care.

**Electronic Health Record (EHR)**

Electronically stored information about an individual's health history, treatments, and other related information held by a health care provider.

**Electronic Medical Record (EMR)**

A computer-based patient medical record. An EMR facilitates access of patient data by clinical staff at any given location; accurate and complete claims processing by insurance companies; building automated checks for drug and allergy interactions; clinical notes; prescriptions; scheduling; sending to and viewing by labs

**Electronic Prescribing (eprescribing)**

A practice in which drug prescriptions are entered into an automated data entry system (handheld, PC, or other), rather than handwriting them on paper. The prescriptions can then be printed for the patient or sent to a pharmacy via the Internet or other network.

**Evidence-based medicine**

Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of an individual. This approach should be balanced with the best external evidence along with the desires of the patient and the clinical expertise of the health care professional.

**Federated architecture**

A network of individual enterprises that are connected to share data. The information resides and is maintained locally within individual entities, but is linked together and can be accessed globally across the network. This is also referred to as a decentralized architecture.

**Health Information Exchange (HIE)**

An infrastructure to enable movement of healthcare information electronically across organizations within a region or community. It must also have agreed-upon business relationships and processes to facilitate information sharing across organizational boundaries

**Health Information Technology (HIT)**

The use of computer software and hardware to process healthcare information electronically, thereby allowing for storage, retrieval, sharing and use of the information.

**Health Insurance Portability and Accountability Act (HIPAA)**

Enacted in 1986 the focus of this act is to provide for:

- Standardization of electronic patient health, administrative and financial data
- Unique health identifiers for individuals, employers, health plans and health care providers
- Security standards protecting the confidentiality and integrity of "individually identifiable health information," past, present or future.

**Information system (IS)**

An interconnected set of information resources under the same direct management control that shares common functionality. A system normally includes hardware, software, information, data, applications, communications, and people.

**Institute of Medicine (IOM)**

The Institute of Medicine serves as adviser to the nation to improve health. Established in 1970 under the charter of the National Academy of Sciences, the Institute of Medicine provides independent, objective, evidence-based advice to policymakers, health professionals, the private sector, and the public. The mission of the Institute of Medicine embraces the health of people everywhere.

**Interoperability**

HIMSS' definition of interoperability is "ability of health information systems to work together within and across organizational boundaries in order to advance the effective delivery of healthcare for individuals and communities."

**Local Health Information Exchange (LHIE)**

Characterized by network of local health information exchanges, each facilitating exchange of health information in a given community.

**National Health Information Network (NHIN)**

A National Health Information Network would link disparate health care information systems together to allow patients, physicians, hospitals, public health agencies, and other authorized users across the nation to share clinical information in real-time under strict security, privacy, and other protections

**Pennsylvania Technical Assistance Program (PennTAP)**

PennTAP supports technology-based economic development by helping Pennsylvania companies improve competitiveness by providing a limited amount of free technology assistance to help resolve specific technical needs.

**Personal Health Record (PHR)**

Electronically stored information similar to electronic health records but often maintained by an individual and limited to information on the individual's health conditions and treatment history.

**Population Health**

Population health is an approach to health that aims to improve the health of an entire population.

**Privacy**

The right of an individual to live free of intrusive monitoring of their personal affairs by third parties not of their choosing and to provide consent for access to that information.

**Regional Health Information Organization (RHIO)**

A neutral organization that adheres to a defined governance structure and like an HIE, facilitates collaboration and coordinates activities to provide the privacy, security, and public trust required to support the exchange of individuals' health information.

**Security**

The ability to ensure that information is neither modified nor disclosed except in accordance to the security policy.

**Telehealth:** The use of telecommunications and information technology to deliver health services and transmit health information over distance. Sometimes called telemedicine.

**Transactions**

Communication, or movement carried out between separate entities or objects, involving the exchange of information.

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