

EMERGING TRENDS AND ISSUES IN HEALTH INFORMATION EXCHANGE



*Selected findings from eHealth Initiative Foundation's
Second Annual Survey of State, Regional and Community-Based
Health Information Exchange Initiatives and Organizations*

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2005

Supported by a Cooperative Agreement with the Health Resources
and Services Administration, Office of the Advancement of Telehealth,
Department of Health and Human Services

Letter from the CEO



Dear Reader,

All over the world, bank customers can step up to an ATM and access their up-to-the-minute account information. Instant accessibility to life-and-death patient information should also be the norm for our nation's healthcare providers, and more than 100 local and regional health information exchange initiatives are moving at a fast pace to help make that a reality.

This report analyzes the results of our 2005 Annual Survey of State, Regional and Community-Based Health Information Exchange Initiatives and Organizations—a representation of more than 100 efforts across the country who are actively pursuing the goal of connectivity to support patient care. To put the results in context, it's important to note the results of last year's survey, which showed that communities had not yet implemented their technical approaches and were focused on developing organizational structures and implementation plans to operationalize their initiatives. Organizations were just getting started and struggling with "should we do this?" and "how can we do this?"

Results from this year's survey demonstrate that communities are no longer talking about doing it—they *are* doing it. While last year's results focused on plans for implementation, this year's results demonstrate major achievements in organization and functionality. Sixty-five organizations, or 60 percent of all respondents, identified themselves as "advanced" or well underway with implementation, and in many cases, fully operational. While many of the early stage initiatives are still getting started, it is clear that they are learning from their more advanced counterparts and demonstrating knowledge of emerging common principles related to the organizational, legal, financial and technical aspects of health information exchange.

First among the findings is that technical challenges are fading and the number of health information exchange efforts now actively exchanging data has tripled over the past year. While the number one challenge remains funding, there are many examples of health information exchange efforts developing sustainable models which deliver value to hospitals, physician practices, health plans and purchasers. And in 2005, the use of multi-stakeholder, inclusive governance structures is increasingly becoming the norm.

The findings point to several clear recommendations for the actions that are needed to accelerate interoperability through health information exchange in the United States. It is now clear that implementation of health information exchange to support patient care is complex, requiring the collaboration of diverse stakeholder groups, the creation of new organizational models which enable common agreement on both the technical aspects and policies for information sharing, and the alignment of both the costs and benefits of developing and maintaining a health information infrastructure.

Based on the findings of the survey and our experiences working with hundreds of leaders involved in state, regional and community-based health information exchange efforts in the nation, we believe that without (1) broad adoption of standards, (2) the creation of innovative capital funding sources to support start-up costs, and (3) the alignment of incentives to support the mobilization of information through health information exchange to support patient care, U.S. efforts to expand interoperability on the ground—where healthcare is delivered—will continue to move at a slow pace.

It is important to note that it is not our goal to exhaustively illustrate all of the survey findings through this report, but rather to offer you a snapshot of what health information exchange initiatives are currently doing, and our thoughts for advancing these efforts. Over the coming months, the eHealth Initiative Foundation will release a series of reports to extend this analysis and highlight additional findings emerging from the survey.

We are also continuing to convene national experts, multiple and diverse stakeholders, and “on-the-ground” implementers to develop common principles, policies, and standards to help stakeholders navigate the organizational, legal, financial, and technical complexities of health information exchange. Insights gained from this survey, as well as ongoing research and working group activities, help build an emerging set of guides and tools for health information exchange that will be released over the coming months to support the field.

eHI intends to conduct this survey annually to assist policy-makers, healthcare leaders and health information exchange initiatives to measure progress in the field and continue to identify and clear barriers to interoperability and the mobilization of health information to support patient care.

A report of this breadth would not be possible without the contributions of many individuals. Enormous thanks go to Jennifer Covich Bordenick, eHealth Initiative Foundation vice president, who played a considerable role in developing and fielding the survey and writing the report. Our sincere thanks also go to our experts Francois de Brantes of General Electric; Mark Frisse, MD, MBA of Vanderbilt Center for Better Health; John Glaser, PhD of Partners HealthCare System; and J. Marc Overhage, MD, PhD of Indiana Health Information Exchange, who loaned their expertise and critical insights into the development of the report’s findings; as well as Katherine Capps of Health2Resources and Elisa Garafano of eHealth Initiative Foundation, who provided a great deal of support in preparing the final report. Finally, special thanks also go to the Health Resources and Services Administration Office of the Advancement of Telehealth, which provided the financial support for this work.

Sincerely,



Janet M. Marchibroda
Chief Executive Officer
eHealth Initiative and Foundation

INTRODUCTION

A number of states, regions and communities across the U.S. are mobilizing healthcare information across organizations to improve health and healthcare through multi-stakeholder collaborative efforts. These initiatives involve a broad range of participants, including hospitals and other healthcare providers, physician practices, health plans, employers and other healthcare purchasers, laboratories, pharmacies, public health agencies, state and local governmental agencies, and most importantly, patients.

About the eHealth Initiative and its Foundation

The eHealth Initiative and its Foundation are independent, non-profit affiliated organizations whose missions are the same: to drive improvement in the quality, safety and efficiency of healthcare through information and information technology. Both convene multiple stakeholders, including clinicians, consumer and patient groups, employers and purchasers, HIE organizations, health plans, hospitals and other providers, laboratories, pharmaceutical and medical device manufacturers, pharmacies, public health agencies and representatives of the public sector to reach agreement on and stimulate the adoption of common principles and strategies for accelerating the use of information to support health and healthcare. For more information, go to <http://www.ehealthinitiative.org>.

In May 2005, the eHealth Initiative Foundation (eHI) launched its Second Annual Survey of State, Regional and Community-based Health Information Exchange Initiatives and Organizations. Responses from 109 health information exchange (HIE) efforts are included in our analysis of survey results. The survey includes questions about goals, objectives and functionality; organizational and governance models; financing and sustainability; policies for information-sharing; legal issues; and technical strategies.

Self-reported information from the 109 initiatives across 45 states and the District of Columbia is a significant representation of the collective voice of the health information exchange community. This report documents the emerging trends, issues and challenges facing this community across the U.S.

Why Is This Report Important?

eHI's Second Annual Survey of State, Regional and Community-Based Health Information Exchange Initiatives and Organizations is the first detailed assessment of the current state of HIE efforts across the nation. Conducted by eHI with support provided under a cooperative agreement with the Health Resources and Services Administration's Office of the Advancement for Telehealth within the Department of Health and Human Services, this survey will serve as a yearly "report card" on the current state of activities related to interoperability and HIE across the U.S., highlighting for both policy-makers and on-the-ground implementers the barriers and strategies currently being utilized by collaborative efforts in almost every state in the nation.

With increasing interest in HIT and interoperability by the Administration, Congress, and the private sector, this year's report could not be more timely in supporting emerging policy efforts that will accelerate the secure, standards-based exchange of information across healthcare organizations to support patient care.

Survey results indicate a dramatic increase in the level of interest in and activity related to mobilizing information electronically across markets to support health and healthcare. Results show that a number of new HIE initiatives have emerged over the last year, and in general, such efforts have matured considerably with respect to engagement of key stakeholders, organization and governance, the range of functionality provided, and the technical aspects of HIE.

Survey results also confirm that a number of challenges still remain and represent barriers for states, regions and communities who wish to facilitate interoperability across our fragmented healthcare system to support healthcare goals.

- First, implementation of HIE requires the significant engagement of and collaboration among diverse stakeholder groups and the creation of new organizational and governance models to facilitate common agreement on the technical aspects and policies for information sharing. These goals are difficult to achieve given multiple competing priorities, the competitive nature of markets, and prevailing reimbursement methods that reward volume of services as opposed to the use of information that resides across many organizations to support improvements in patient care.
- Getting to an interoperable, health information network is complex and costly, given the current paper-based, fragmented state of our healthcare system. Securing funding for these efforts continues to be a challenge.
- Finally, achieving sustainability for these efforts is hampered by the misalignment of both the costs and the benefits related to information sharing across organizations to support quality care.

The survey findings, in addition to our experiences working with hundreds of leaders involved in these efforts across the country, tell us that without (1) broad adoption of national standards, (2) the creation of innovative capital funding sources to support start-up costs, and (3) the alignment of incentives to support the mobilization of information through HIE to support patient care, U.S. efforts to expand interoperability on the ground—where healthcare is delivered—will continue to move at a slow pace.

Findings from this year's survey will help policy-makers and national and local leaders understand the current state of HIE initiatives, identify key barriers and develop policies designed to clear barriers to continued forward movement on interoperability and HIE.

We also hope that this year's survey will help to inform and support efforts within the public sector, such as;

- The American Health Information Community chaired by Department of Health and Human Services Secretary Michael Leavitt;
- Standards and interoperability efforts led by the Office of the National Coordinator for Health Information Technology;
- HIT initiatives of the Agency for Healthcare Research and Quality and the National Resource Center for Health Information Technology;
- Collaborative informatics efforts led by the Centers for Disease Control and Prevention;
- The numerous programs designed to support quality, efficiency and accountability within the Centers for Medicare and Medicaid Services;
- Telemedicine projects supported by the Health Resources and Services Administration; and
- Significant HIT-related initiatives within the Department of Defense, the Office of Personnel Management, the National Institutes of Health, and the Veterans Administration.

Stakeholders involved in state, regional and community-based HIE initiatives will use this survey to gauge their progress in relation to their peers. The detailed results of the survey will offer a significant opportunity for such initiatives to benchmark their efforts, identify initiatives that are experiencing similar challenges, and seek out the advice of colleagues who have successfully navigated through challenges they are currently experiencing.

eHI will utilize detailed results of the survey along with other work performed to inform its evolving set of common principles, policies, standards and assessment tools that are designed to support states, regions and communities across the U.S. to navigate organizational, legal, financial and technical challenges.

Details Related to the Compilation of Survey Results

The Second Annual Survey of State, Regional, and Community-based Health Information Exchange Initiatives and Organizations was launched and opened for participation on May 17, 2005. Announcement of the survey was communicated through email, listservs, and the distribution of surveys at conferences and meetings to a wide range of audiences to elicit responses from as many HIE initiatives as possible.

Of the 241 recorded accesses to our electronic survey, only 109 resulted in responses that were included in the final report, each of which was carefully reviewed. Incomplete and duplicate responses, as well as responses from organizations outside of the U.S. were excluded. It should be noted that responses to the survey were self-reported. While responses were reviewed for reasonableness, they were not verified or certified.

Given the time and effort required to fill out the survey, and the fact that we may not have reached out to all potential respondents in the U.S., we believe that there are likely many more HIE initiatives that did not complete the survey.

It should be noted that the survey is not designed to be scientific but rather one of many mechanisms designed to provide a snapshot of what many HIE initiatives are doing, and the actions that can be taken to further advance their efforts.

eHI intends to conduct this survey annually to continue to gauge progress and offer insight into the policies needed to clear the barriers to an interoperable healthcare system facilitated by HIE at the state, regional, and local levels.

The results presented in this report focus on an initial set of eight key findings based upon our early analysis of our 2005 Annual Survey of State, Regional and Community-Based Health Information Exchange Initiatives and Organizations. Over the coming months, eHI will release a series of reports to extend this analysis and highlight additional findings emerging from the survey.

- **Health information exchange activity is on the rise.** Among the 109 Health Information exchange (HIE) efforts identified by our 2005 survey, there is clear evidence of rapid maturation and movement along six distinct developmental stages, with 40 respondents in the implementation phase and 25 fully operational. The reported number of HIE efforts considered "fully operational" has increased from nine in 2004 to 25 in 2005.
- **The key driver moving states, regions and communities toward health information exchange is perceived provider inefficiencies with rising healthcare costs also seen as an important driver.** Seventy-seven percent of all respondents cited "provider inefficiencies due to lack of data to support patient care" as a significant driver for their HIEs, with 99 percent of all respondents citing this as a significant or moderate driver for their efforts. Additionally, rising healthcare costs was a significant drivers for both early stage and advanced stage HIEs, with 60 percent of respondents citing this as a significant driver.
- **Health information exchange efforts recognize the importance of privacy and security.** Fifty-nine percent of advanced stage respondents reported that their policies regarding privacy go beyond HIPAA requirements. Eighty-three percent of advanced stage respondents have contractual agreements among health information exchange participants, 92 percent of which cover authorization of users, 89 percent of which cover privacy and security procedures, and 87 percent of which cover terms for information use.
- **Health information exchange efforts are maturing: organization and governance structures are shifting towards multi-stakeholder models with the involvement of providers, purchasers and payers.**
 - Increasingly, health information exchange initiatives are formalizing their efforts – 60 percent of advanced stage efforts are incorporated, and among them 70 percent are non-profit models.
 - There has been a clear shift towards the involvement of a broader set of stakeholders within governance. While providers continue to be involved in a majority of these efforts, with hospitals (61 percent), primary care physicians (48 percent), specialty care physicians (37 percent), and community health clinics (35 percent) playing a key role, expansion is underway to include other non-provider stakeholders within governance structures. An analysis of survey results from all respondents reveals that health plans (37 percent), local health departments (33 percent), employers and purchasers (27 percent), patient or consumer groups (26 percent), state public health agencies (21 percent), quality improvement organizations (16 percent), and healthcare IT suppliers (12 percent) are now increasingly playing a role in the governance of HIE efforts.
 - Results also show a clear shift towards leadership by a neutral, multi-stakeholder entity. Fifty-five percent of all respondents indicate that their initiatives are led by a multi-stakeholder organization.

- **Advancements in functionality to support improvements in quality and safety are evident.** In addition to the traditional uses of HIE to support the use of information through standard care delivery processes (e.g. reminders, alerts, and results delivery), a number of HIE efforts are now expanding their functionalities to support efforts focused on population health, including chronic care management, quality and performance improvement efforts, and public health functions. Thirty-two percent of advanced stage initiatives are currently providing disease or chronic care management services while an additional 21 percent are expected to provide such services within the next six months. Twenty-seven percent are currently supporting quality performance reporting efforts while an additional 18 percent are expected to provide such services within the next six months.
- **HIE efforts are delivering more information and increasingly using standards for data delivery.** A majority of advanced stage HIE efforts are exchanging (or expecting to exchange within six months) data related to outpatient and inpatient episodes, laboratory results, emergency department episodes, pathology results, and enrollment and eligibility information. A majority of such efforts are employing the use of standards to exchange data electronically. Three out of four (76 percent) of advanced stage initiatives reported using HL7 for messages and 41 percent reported using LOINC for laboratory reporting.
- **Securing funding to support start-up costs and ongoing operations is still recognized as the greatest challenge for all HIE efforts.** Ninety-one percent of all respondents cited "securing upfront funding" as either a very difficult or moderately difficult challenge, while 84 percent of all respondents cited "developing a sustainable business model" as a very difficult or moderately difficult challenge. In addition to funding challenges, 80 percent of respondents indicated that accurately linking patient data was a very or moderately difficult challenge, and 74 percent of all respondents perceived the engagement of health plans as a very difficult or moderately difficult challenge.
- **Funding sources for both upfront and ongoing operational costs still rely heavily upon government funds but alternative funding sources for ongoing sustainability are beginning to emerge.** Forty-six percent of all respondents cited federal government grants and contracts as a current revenue source for upfront funding, while 48 percent of advanced stage initiatives cited this as a revenue source for ongoing operations. Increasingly, HIE efforts are looking towards alternative funding sources for sustainability, with advanced stage initiatives relying upon advance payments from hospitals (38 percent), physician practices (33 percent), public health (19 percent), laboratories (15 percent), payers (15 percent), and purchasers (9 percent) to support ongoing operations.

OVERVIEW

What is Health Information Exchange?

Health information exchange (HIE) is defined as the mobilization of healthcare information electronically across organizations and disparate information systems within a region or community. Currently, the U.S. healthcare system is highly fragmented and paper-based, and information about the patient is stored in a variety of locations and formats. As a result, clinicians often don't have comprehensive information about the patient when and where it is needed most—at the point of care. Those responsible for improving population health don't have the information they need to measure progress and facilitate improvement. Health information exchange initiatives are designed to support interoperability and facilitate access to and retrieval of clinical data, privately and securely, to provide safer, more timely, efficient, effective, equitable, patient-centered care.

eHI works with hundreds of stakeholders across every sector of healthcare, including clinicians, employers and healthcare purchasers, health plans, hospitals and other providers, laboratories, patient and consumer groups, pharmacies, public health agencies, and federal and state agencies, to develop policies and strategies to support the mobilization of health information to support patient care. Through a cooperative agreement with the Health Resources and Services Administration Office of the Advancement of Telehealth (HRSA/OAT) within the Department of Health and Human Services (DHHS), eHI provides seed funding support and develops tools and resources to help state, regional and community-based HIE initiatives and the organizations that support them address the challenges of mobilizing data to support health and healthcare goals.

As awareness of the need for HIE and interoperability continues to grow, many recognize the need to formalize these efforts through the creation of organizations, referred to as "Regional Health Information Organizations" or "RHIOs" by the Office of the National Coordinator for Health Information Technology (ONCHIT) in its July 2004 Framework for Strategic Action² and in several public sector reports which have followed.

Currently there are no formal definitions, standards or policies for such organizations. eHI is convening national experts, multiple and diverse stakeholders, and "on-the-ground" implementers to develop common principles, policies, and standards to help stakeholders navigate the organizational, legal, financial, and technical complexities related to using HIE to support improvements in health and healthcare. Insights gained from this survey as well as other research and working group activities are providing input into an emerging set of guides and tools for HIE that will be released to support the field in the third quarter of 2005.

Health information exchange is defined as the mobilization of health information electronically across organizations within a region or community. HIE provides the capability to electronically move clinical information between disparate healthcare information systems while maintaining the meaning of the information being exchanged. The goal of HIE is to facilitate access to and retrieval of clinical data to provide safer, more timely, efficient, effective, equitable, patient-centered care.

Formal organizations are now emerging to provide both form and function for HIE efforts. These organizations (often called "Regional Health Information Organizations," or "RHIOs") are ordinarily geographically-defined entities which develop and manage a set of contractual conventions and terms, arrange for the means for electronic exchange of information, and develop and maintain HIE standards.

Although HIE initiatives differ in many ways, survey results and eHI's experiences with states, regions and communities across the U.S. indicate that those who are experiencing the most success with HIE share the following characteristics. They:

- Are governed by a diverse and broad set of stakeholders within the region or community;
- Develop and assure adherence to a common set of principles and standards for the technical and policy aspects of information sharing, addressing the needs of every stakeholder;
- Develop and implement a technical infrastructure based on national standards to facilitate interoperability;
- Develop and maintain a model for sustainability that aligns the costs with the benefits related to HIE; and
- Use metrics to measure performance from the perspective of: patient care, public health, provider value, and economic value.

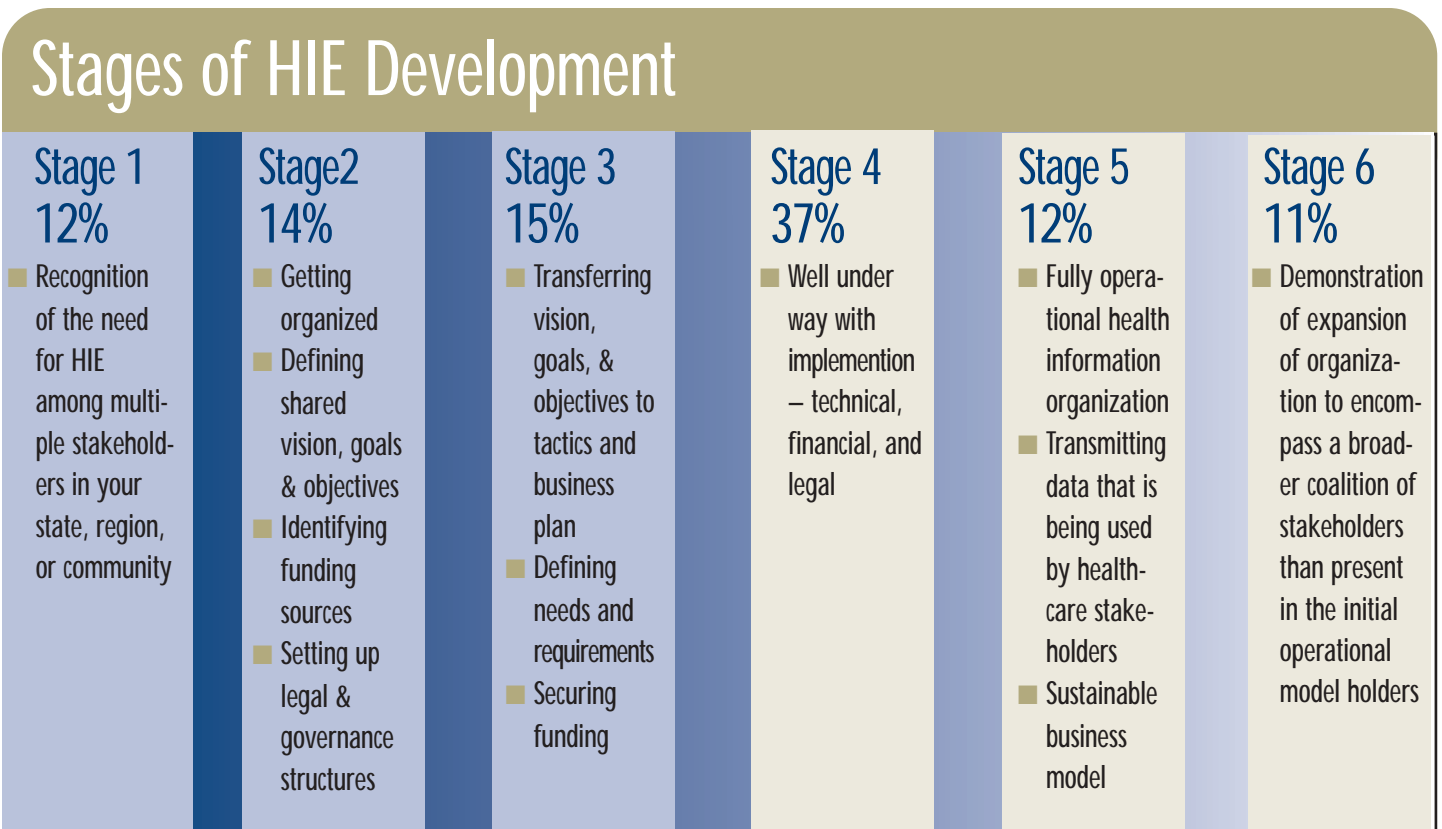
Source: eHealth Initiative, August, 2005

HEALTH INFORMATION EXCHANGE ACTIVITY IS ON THE RISE

This year’s survey reveals that at least 109 initiatives and organizations are currently involved in HIE in the U.S. today. The goal of these initiatives is to develop and implement structures that will enable the mobilization of information across the healthcare system to improve the quality, safety, and efficiency of healthcare in their markets. Survey results indicate a dramatic increase in the level of interest in and activity related to HIE in regions across the country. A number of new HIE efforts have emerged over the last year and survey results show that such efforts have matured considerably with respect to engagement of key stakeholders, organization and governance, functions and services offered, and the development and execution of technical infrastructure to support their efforts.

Tracking the Development of Health Information Exchange Efforts

It is widely recognized that efforts focused on HIE will continue to develop and that most will move through predictable stages of development, but at a varying pace. To track the current state of these initiatives, eHI has developed a framework for assessing the stages of development for HIE. Through our experience working with hundreds of stakeholders involved in HIE, we have identified six distinct stages of development, ranging from “recognition of the need for HIE among multiple stakeholders” (stage one) to “fully operational and sustainable, and demonstrating expansion beyond the current operational model” (stage six). The framework for HIE, along with the results of our survey, is outlined below.



Respondents were asked to specify at what stage of development their HIE effort would be within six months. Forty-four respondents identified themselves as being within the early stages of development (between stages 1 and 3). Sixty-five identified themselves as being in the advanced stage of development, with 40 in the process of implementation (stage 4) and 25 completely operational (between stages 5 and 6).

Since eHI began tracking HIE progress in 2004, there has been a significant increase in the number of initiatives and organizations that are fully operational. An analysis of the last year's survey results determined there were only nine operational HIE organizations³ (those in stages 5 or 6). In 2005, 25 initiatives –or 23 percent–reported that they were fully operational—representing a nearly three-fold increase over 2004 results.

Throughout this report, survey results were analyzed to assess whether early stage organizations experienced different challenges or developed different strategies in comparison to their more experienced counterparts. For purposes of this assessment, initiatives and organizations who reported that they were in stages 1 through 3 are identified as “early stage” while those who reported that they were in stages 4 through 6 are identified as “advanced stage” efforts.

Finding #1:

Health information exchange activity is on the rise.

Among the 109 health information exchange initiatives identified by our 2005 survey, there is clear evidence of rapid maturation and movement along six distinct developmental stages with 40 respondents in the implementation phase and 25 fully operational. The reported number of HIE efforts considered “fully operational” has increased from 9 in 2004 to 25 in 2005.

Control and Prevention, the Centers for Medicare and Medicaid Services, the Department of Defense, the Health Resources and Services Administration, the National Institutes of Health, and the Veterans Administration.

Congress is also playing a significant leadership role in promoting interoperability and HIE. Bipartisan support has accelerated with the introduction of several pieces of legislation. In June and July 2005, five bills were introduced in the House and Senate that included components related to HIT. A number of the bills introduced in 2005 call for the funding and implementation of regional health information networks to support the national implementation of widespread interoperability.

OUR THIRD FINDING

HEALTH INFORMATION EXCHANGE EFFORTS RECOGNIZE THE IMPORTANCE OF PRIVACY AND SECURITY

Stakeholders involved in HIE efforts appear to be well aware of the potential perceived risks related to unauthorized data access which are associated with HIT and are actively developing policies for information sharing and implementing technical architectures designed to help mitigate concerns about privacy and confidentiality. Many recognize that concerns about privacy and security could lead patients to withhold important information that may be critical to their care, therefore reducing the positive impact that HIE can bring to improving the quality and safety of healthcare.

The survey results reveal that many HIE efforts are taking action to assure the private and secure exchange of health information. Fifty-nine percent of advanced stage respondents report that their policies regarding privacy go beyond HIPAA requirements. Eighty-three percent of advanced stage respondents have contractual agreements among HIE participants, 92 percent of which cover authorization of users, 89 percent of which cover privacy and security procedures, and 87 percent of which cover terms for information use.

Finding #3:

Health information exchange efforts recognize the importance of privacy and security.

Fifty-nine percent of advanced stage respondents report that their policies regarding privacy go beyond HIPAA requirements. Eighty-three percent of advanced stage respondents have contractual agreements among HIE participants, 92 percent of which cover authorization of users, 89 percent of which cover privacy and security procedures, and 87 percent of which cover terms for information use.

OUR FOURTH FINDING

HEALTH INFORMATION EXCHANGE EFFORTS ARE MATURING: ORGANIZATION AND GOVERNANCE STRUCTURES ARE SHIFTING TOWARDS MULTI-STAKEHOLDER MODELS WITH THE INVOLVEMENT OF PROVIDERS, PURCHASERS AND PAYERS

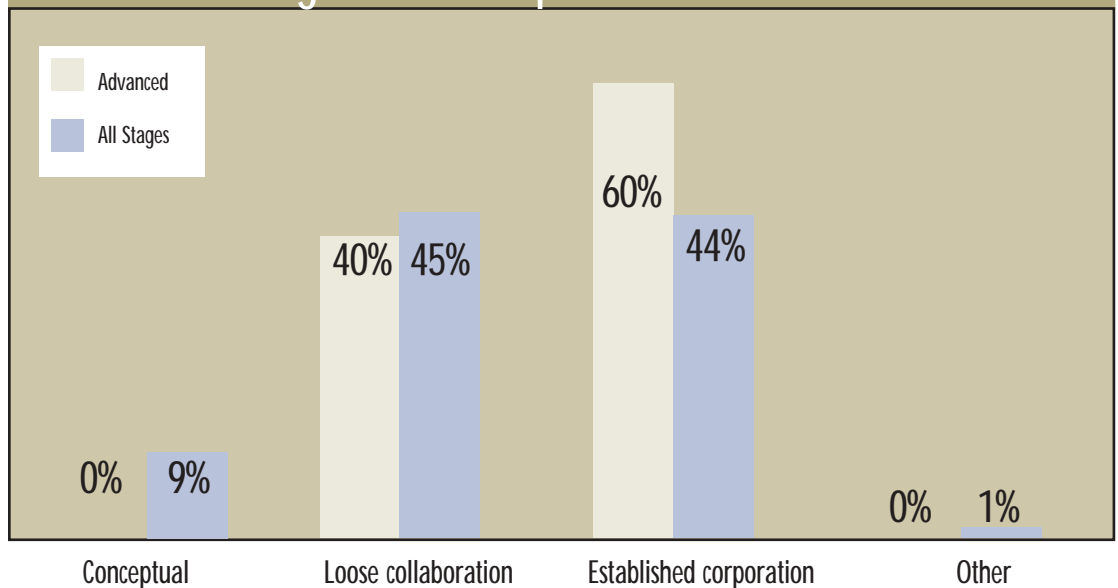
Background

This year’s survey results indicate that there is a clear move towards establishing the commitment and participation of a broad set of diverse stakeholders to support HIE. Because the information needed to support high quality and more efficient care delivery resides in a number of places (e.g., hospitals, laboratories, pharmacies, health plans, etc.), the involvement and active engagement of multiple stakeholders is necessary to facilitate the transmission of data to the point of care.

Health Information Exchange Efforts Beginning to Formalize Their Legal Structures

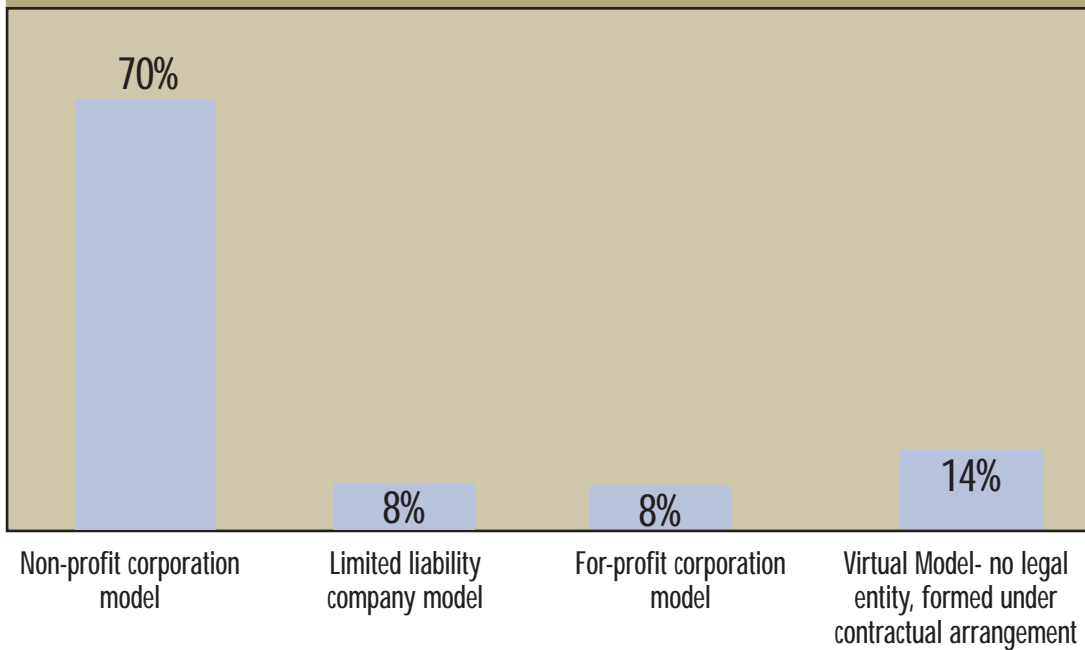
According to this year’s survey results, 44 percent of all respondents are utilizing a corporation to support their HIE efforts while 60 percent of advanced stage organizations are using a corporate model. This compares to 29 percent of respondents in 2004 who reported that they had created a formal legal structure. Forty-five percent of all respondents and 40 percent of advanced stage respondents describe the nature of their HIE initiative as a “loose group of collaborators” while 9 percent of all respondents and 0 percent of advanced stage respondents characterize their efforts as “conceptual.”

Nature of Health Information Exchange Initiatives: Advanced Stage vs. All Respondents



For those initiatives that have created a formal legal organization structure for their efforts, 70 percent of respondents have chosen a non-profit corporation model, 8 percent have chosen a for-profit corporation model, and 8 percent have chosen a limited liability corporation model. Fourteen percent of respondents are utilizing a virtual model which has no legal entity, but which is formed under contractual arrangements.

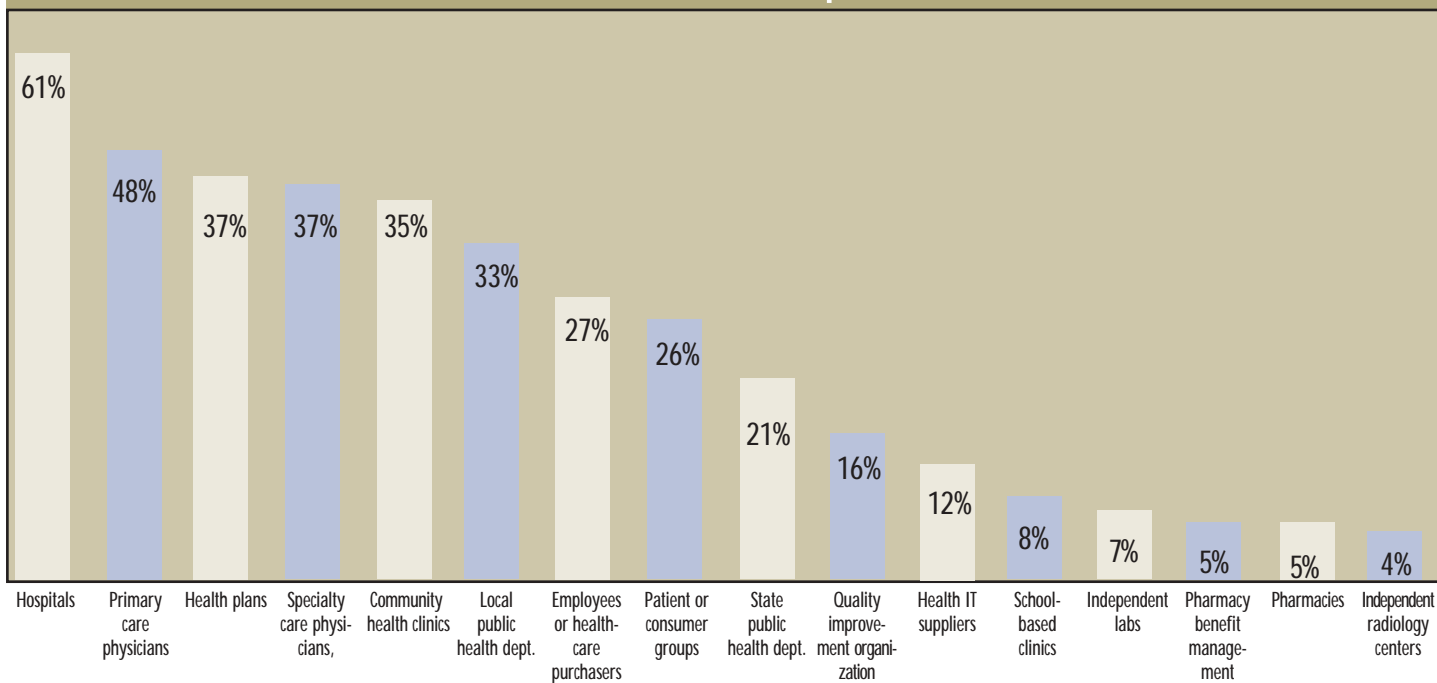
Nature of Health Information Exchange Initiatives



Providers Currently Playing a Key Role in Governance, Involvement of Other Stakeholders Is on the Rise

Of all constituencies, providers are playing the most visible role in the governance of HIE initiatives and organizations. An analysis of survey results from all respondents reveals that 61 percent of those surveyed have engaged hospitals in their governance as well as primary care physicians (48 percent), specialty care physicians (37 percent), and community health clinics (35 percent).

Role of Stakeholders in Governance: All Respondents



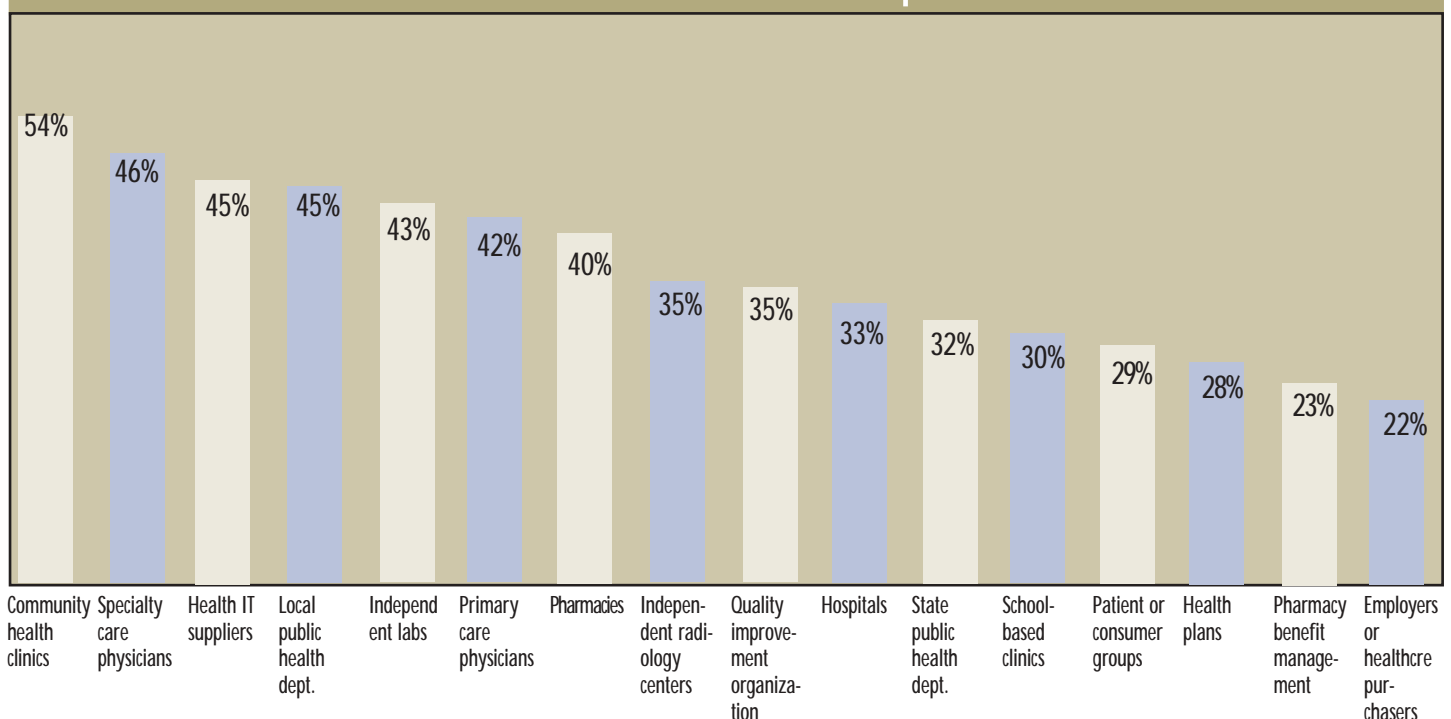
The survey data also shows a trend towards including other key groups in the governance of HIE efforts. An analysis of survey results from all respondents reveals that health plans (37 percent), local health departments (33 percent), employers and purchasers (27 percent), patient or consumer groups (26 percent), state public health departments (21 percent), quality improvement organizations (16 percent), and healthcare IT suppliers (12 percent) are also increasingly playing a role in the governance of HIE efforts. Currently, laboratories, pharmacies and radiology centers are not playing a significant role in the governance of HIE initiatives with survey results indicating levels of involvement at 7 percent, 5 percent and 4 percent respectively.

The direct involvement of physicians in governance structures appears to be increasing as organizations and initiatives mature. The role of the physician is much more pronounced in the more advanced organizations (stages 4 through 6) with 56 percent of such organizations engaging primary care physicians and 42 percent engaging specialty care physicians within the governance of their organizations. This contrasts to less participation within early stage organizations, in which 34 percent involve primary care physicians and 27 percent of which involve specialty care physicians within their governance structures.

Health Information Exchange Efforts Increasingly Engaging Other Stakeholders

Increasingly, HIE efforts in general are engaging the multiple and diverse stakeholders involved in healthcare. Results of this year's survey show a wide range of stakeholder involvement. As noted below, those engaged include community health clinics (54 percent), specialty care physicians (46 percent), local public health departments (45 percent), health IT suppliers (45 percent), independent labs (43 percent), primary care physicians (42 percent), pharmacies (40 percent), quality improvement organizations (35 percent), independent radiology centers (35 percent), hospitals (33 percent), state public health departments (32 percent), school based clinics (30 percent), patient and consumer groups (29 percent), health plans (28 percent), pharmacy benefit management (23 percent), and employers and purchasers (22 percent).

Stakeholder Involvements in HIE Efforts: All Respondents

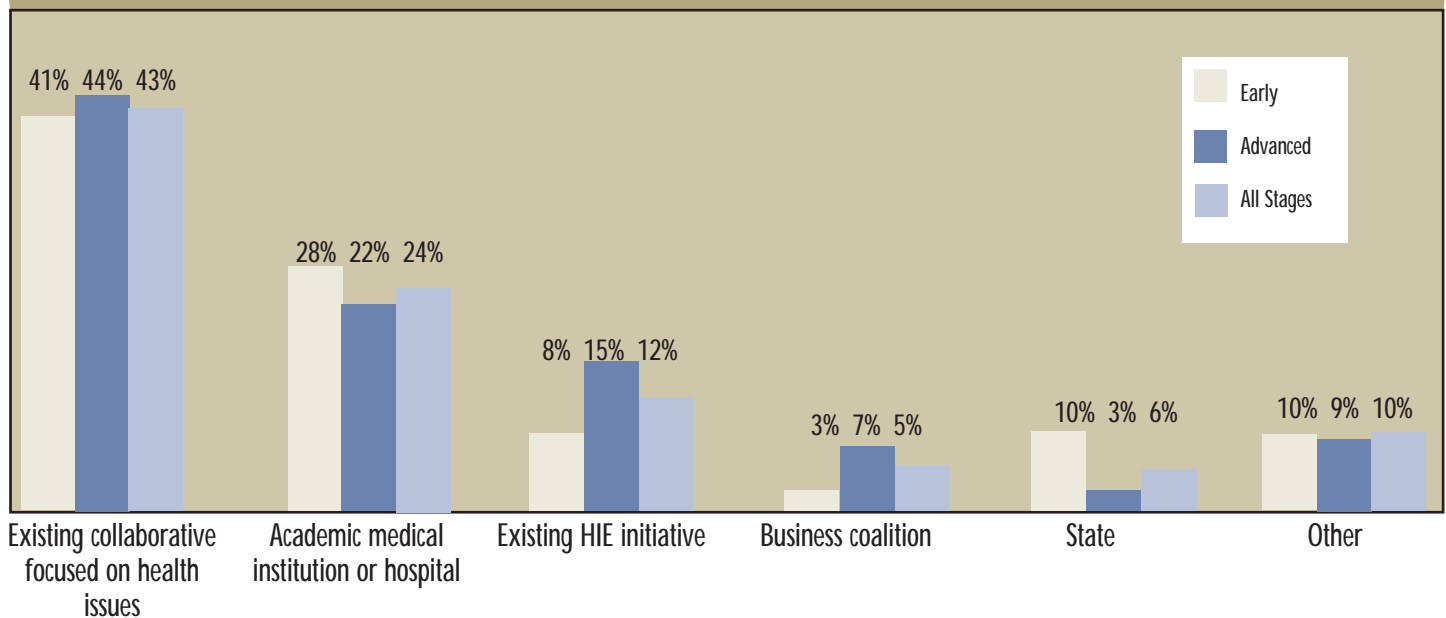


Who's in Charge? Lead Organizations for Health Information Exchange

This year's survey results reveal that the identified "lead" organizations for HIE efforts are migrating towards those involving many stakeholders, such as existing HIE initiatives or existing collaboratives focused on health issues. Fifty-five percent of all respondents indicate that their initiatives are led by multi-stakeholder collaborative organizations—43 percent are existing collaborative organizations focused on health issues and 12 percent are existing HIEs. This compares to the 9 percent of 2004 respondents who reported that their initiatives were led by existing HIE organizations. Twenty-four percent of 2005 respondents reported that they are led by academic medical institutions or hospitals as compared to 49 percent of 2004 respondents who reported that they were led by either a hospital (23 percent), academic health center (10 percent) or provider organization (16 percent).

Not surprisingly, an advanced stage initiative appears more likely to have a multi-stakeholder collaborative organization at its helm with 59 percent of such respondents indicating that a collaborative organization was serving as the lead for their initiative (44 percent cited an existing collaborative focused on health issues and 15 percent cited an existing HIE initiative). This compares to survey results for early stage respondents which indicate that 49 percent of such efforts are led by a collaborative organization (41 percent citing an existing collaborative focused on health issues and 8 percent cited an existing HIE initiative).

"Lead" Organization for Health Information Exchange Early, Advanced, All Stages



State Involvement in HIT and Health Information Exchange Efforts

State and local government entities are critical to the success of HIE efforts. States play a number of roles in healthcare: purchaser, payer, and regulator. The state can play a visible leadership role by raising awareness of the need for HIT and HIE to address healthcare challenges and by creating legislation to remove unnecessary barriers to their progress. As healthcare purchasers and Medicaid administrators, state governments can yield considerable purchasing power and influence by providing incentives that reward the use of HIE to support patient care and performance improvement. State legislatures and governments can also provide a critical source of funding for the crucial resources needed to finance HIT initiatives through the creation of grant and loan programs to support those in need. Finally, state laws and regulations can play a pivotal role in either promoting or impeding initiatives' progress.

According to this year's survey, 53 percent of all respondents have states participating in their efforts. Thirty-five percent of all respondents cite state involvement through their Medicaid program, while 20 percent cite state involvement as purchaser. Public health agencies have traditionally been involved in state and regional data efforts, and the results of this year's survey confirm this still to be true, with 49 percent of respondents reporting state public health department involvement in their HIE efforts.

Spotlight on New York

One state in particular is making considerable progress in the march towards improving health-care quality and safety through HIT and HIE. Public and private sector stakeholders alike are working together in New York to devise a coordinated, incremental strategy for utilizing information technology to support health and healthcare in the state.

Stakeholders Coming Together to Define Principles and Priorities

In October 2004, the United Hospital Fund (the Fund) engaged a broad range of healthcare leaders across the state to determine what steps could be taken to improve healthcare in New York through broader adoption of HIT and HIE. This work, facilitated by the eHealth Initiative Foundation (eHI) with the support of the Health Policy and Strategy Group at Manatt, Phelps and Phillips LLC, helped stakeholders identify barriers to progress and define a set of principles and priorities for moving this work forward within the state.

Having established some broad areas of agreement through the first phase of the summit initiative, eHI and the Fund identified several concrete steps that will further define and advance the HIT policy agenda in New York.

- eHI is developing a draft HIT policy framework which defines how priorities to improve health and healthcare in New York will be addressed through broad HIT adoption.
- The Fund is conducting additional research and consulting with the summit participants regarding options for establishing an ongoing statewide HIT leadership organization.
- eHI is developing a prototype for an HIT policy website that could serve as a vehicle to support ongoing communication and coordination across communities in New York.
- eHI is supporting the identification of specific strategies to estimate HIT value and business models to sustain HIT adoption and use, building on the New York State analysis conducted by the Center for Information Technology Leadership with support from the Fund, which indicates that the net benefit associated with "level four" interoperability within New York over ten years is \$12.4 billion.

The State Is Playing a Key Role

The New York State Department of Health (NYSDOH) is also focusing on opportunities for HIT policy coordination. The NYS HIT Working Group has been established as a vehicle to communicate and coordinate across a wide variety of state agency components – Medicaid, public health, professional licensure, technology procurement, and capital financing, to name a few. And several funding opportunities that directly or indirectly relate to HIT are in process:

- HEAL-NY funds were approved in the state's 2005 budget, and additional federal waiver funds may soon be available as well.
- A request for proposal for disease management demonstration projects has been published, and the budget also established a new "pay for performance" demonstration program.

- Additional funds were appropriated to support physician HIT adoption.

NYSDOH is developing a coordinated approach to guide both the general purposes and specific criteria relating to these funds. It is also exploring opportunities to promote broad adoption of electronic prescribing as a means to improve quality and safety, while also maintaining the state's stringent regulatory provisions relating to controlled substances.

Regional HIT Collaborations Are Spreading Across New York

The Greater New York Hospital Association (GNYHA) recently published a report which profiles 10 regional HIE projects, covering almost every region of the state – from New York City to Buffalo. A number of initiatives were highlighted, including the Taconic Health Information Network and Community which is focusing on physician electronic medical record adoption and the transmission of prescribing and performance measurement information through a web-based data exchange portal; the New York Clinical Information Exchange or NYCLIX, which is being organized by GNYHA to facilitate access to patient information at the point of care in emergency rooms; the Queens Health Connection Card Program; and the Upstate New York Professional Healthcare Information and Education Demonstration Project (UNYPHIED).

Source: United Hospital Fund, Qual-IT Newsletter, August, 2005

Finding #4:

Health information exchange efforts are maturing: organization and governance structures are shifting towards multi-stakeholder models with the involvement of providers, purchasers and payers. Increasingly, HIE initiatives are formalizing their efforts. Sixty percent of advanced stage efforts are incorporated, and among them 70 percent are non-profit models.

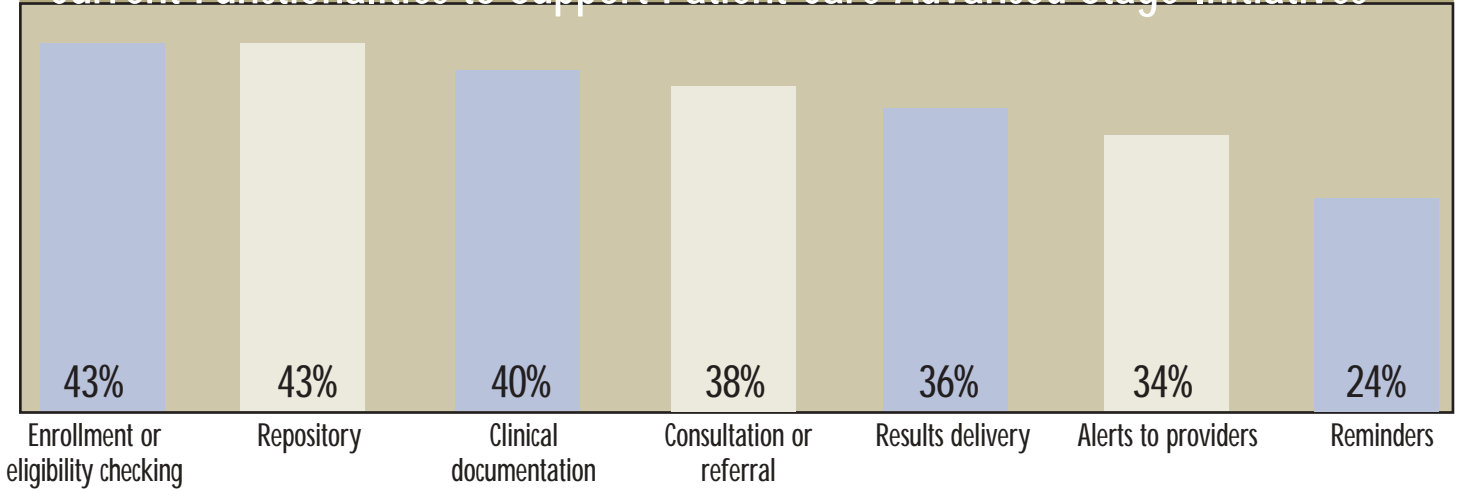
- There has been a clear shift towards the involvement of a broader set of stakeholders within governance. While providers continue to be involved in a majority of these efforts, with hospitals (61 percent), primary care physicians (48 percent), specialty care physicians (37 percent), and community health clinics (35 percent) playing a key role, expansion is underway to include other non-provider stakeholders within governance structures. An analysis of survey results from all respondents reveals that health plans (37 percent), local health departments (33 percent), employers and purchasers (27 percent), patient or consumer groups (26 percent), state public health agencies (21 percent), quality improvement organizations (16 percent), and healthcare IT suppliers (12 percent) are now increasingly playing a role in the governance of HIE efforts.
- Results also show a clear shift towards leadership by a neutral, multi-stakeholder party. Fifty-five percent of all respondents indicate that their initiatives are led by a multi-stakeholder organization.

OUR FIFTH FINDING

ADVANCEMENTS IN FUNCTIONALITY TO SUPPORT QUALITY AND SAFETY ARE EVIDENT

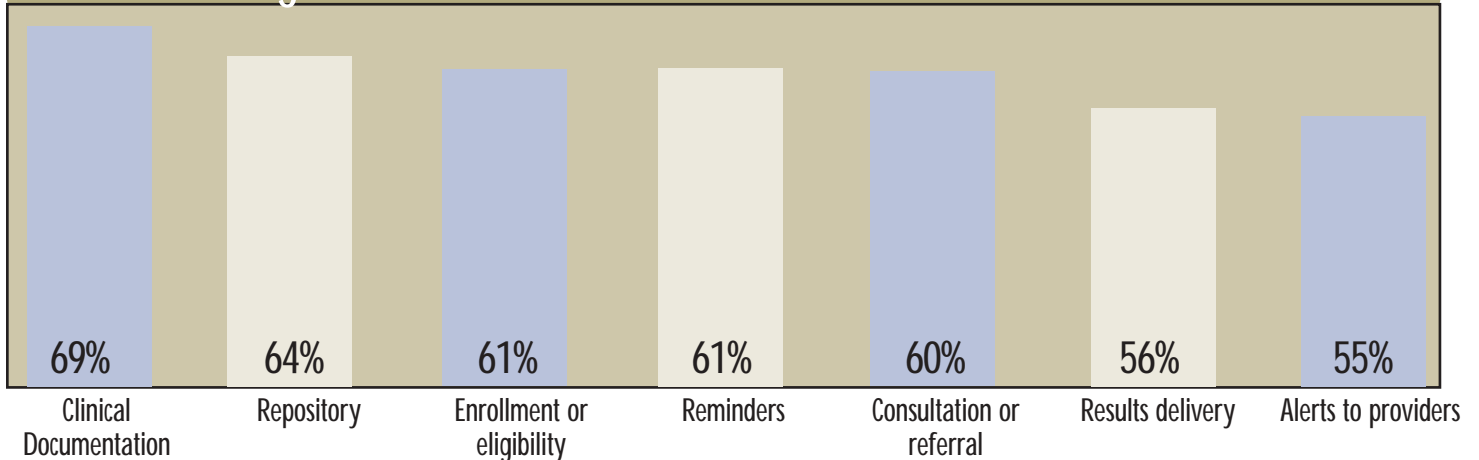
HIE initiatives are expanding the range and depth of functionality and services provided to support improvements in health and healthcare. As in prior years, a majority of the focus of HIE efforts is on supporting standard care delivery processes. As outlined below, more than one-third of advanced stage initiatives are currently focused on providing services such as enrollment or eligibility checking (43 percent), repository (43 percent), clinical documentation (40 percent), consultation/referral (38 percent), results delivery (36 percent), alerts to providers (34 percent), and reminders (24 percent).

Current Functionalities to Support Patient Care Advanced Stage Initiatives



If one combines what advanced stage organizations are both currently providing and expecting to provide within the next six months, the numbers go up considerably. As noted below, 69 percent of advanced stage initiatives are either currently or expect to provide within six months clinical documentation services. Other functionalities expected to be in place within six months include repository (64 percent), enrollment or eligibility checking (61 percent), reminders (61 percent), consultations/referrals (60 percent), results delivery (56 percent), and alerts to providers (55 percent).

Functionalities to Support Patient Care – Current and Within Next Six Months: Advanced Stage Initiatives



Definitions for Functionalities to Support Patient Care

Clinical Documentation is the ability to record, and make available to others, documentation from a clinician about a clinical encounter, either through direct entry by the health-care provider or through transcription from dictation or other means by a third party.

Repository is the capacity to maintain information on a patient that may come from multiple sources so that it may be accessed by other information systems when needed. The information in a repository may or may not be standardized, but is probably centrally secured, backed up, and made available 24/7 to authorized requestors.

Enrollment or Eligibility Checking is the ability to contact the payer before the patient is seen and get a response that indicates whether or not the services to be rendered will be covered by the payer.

Reminders are the ability to remind clinicians to consider certain actions at a particular point in time, such as prompts to ask the patient appropriate preventive medicine questions, notifications that ordered tests have not produced results when expected, and suggestions for certain therapeutic actions, such as giving a tetanus shot if one has not been given for 10 years.

Consultation or Referral is the ability to generate and/or receive summaries of relevant clinical information on a patient that are typically transferred between healthcare providers when a patient is referred to a specialist or admitted or discharged from a hospital.

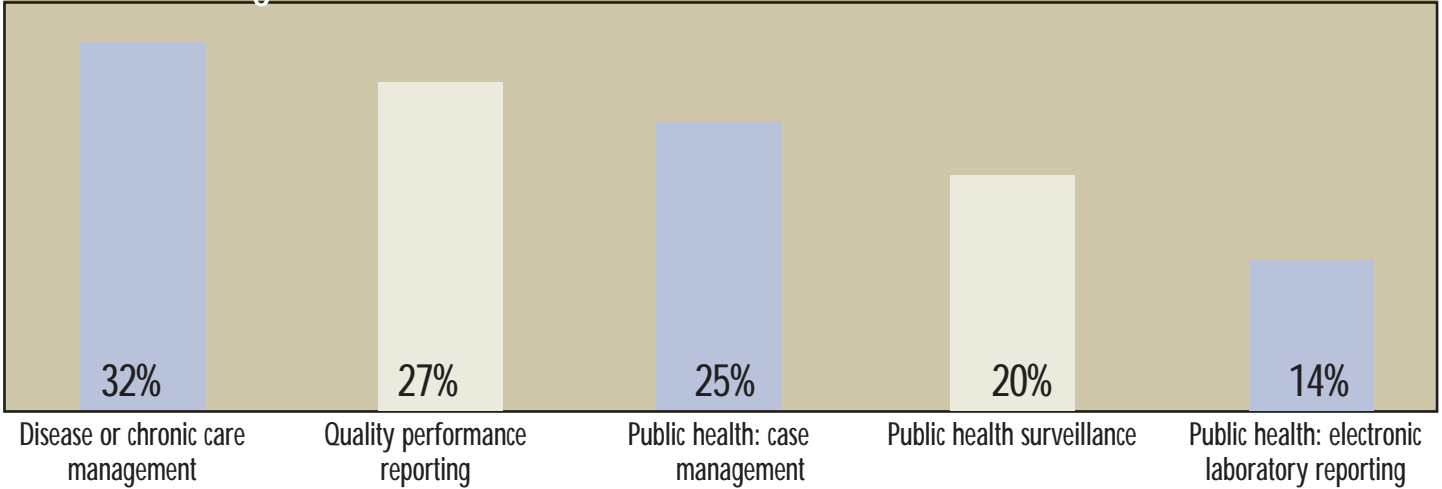
Results Delivery is the ability to accept messages from other data sources, such as clinical laboratories, radiology sources, pathology reports, etc., and integrate the data for presentation to a clinician.

Alerts to Providers is the ability to interpret the clinical data that is entered about a patient using a set of rules or algorithms which will generate warnings or alerts at various levels of severity to a clinician. These are intended to make the clinician aware of potentially harmful events, such as drug interactions, patient allergies, and abnormal results, that may affect how a patient is treated, with the intention of speeding the clinical decision process while reducing medical errors.

Source: eHealth Initiative, August, 2005

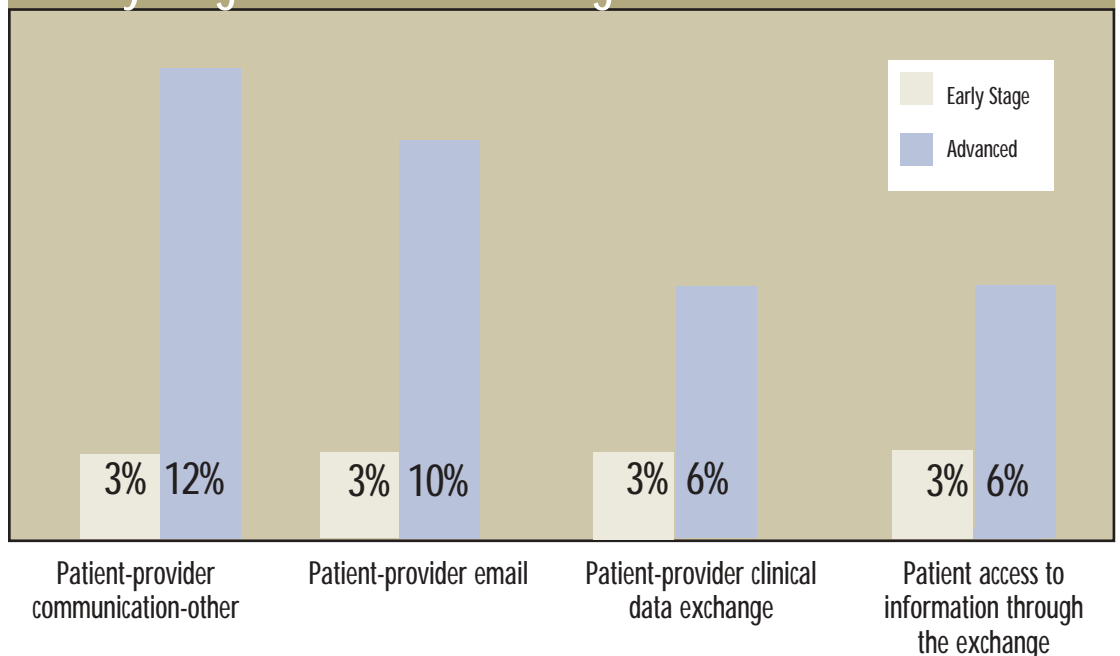
In addition to traditional uses of HIE within standard care delivery processes, a number of HIE efforts are now expanding their functionalities to support efforts focused on population health, including chronic care management, quality improvement and performance reporting efforts, and public health functions. Thirty-two percent of advanced stage initiatives are providing disease or chronic care management services with an additional 21 percent expected to provide such services within six months. Twenty-seven percent are currently supporting quality performance reporting efforts while an additional 18 percent are expected to support such efforts within the next six months. In addition, efforts are underway to support the needs of public health, with 25 percent of advanced stage respondents providing public health-related case management services, 20 percent providing public health surveillance services, and 14 percent providing electronic laboratory reporting services for public health.

Functionality to Support Efforts to Improve Population Health and Patient Safety: Advanced Stage



While efforts to support care delivery and population health are growing considerably, functionalities and services to support patient-physician communication are not widely in place in either advanced stage or early stage efforts. As noted below, only 3 percent of early stage efforts and 6 to 12 percent of advanced stage initiatives are currently engaged in any type of patient-provider communication. The review of responses from advanced stage initiatives which are currently providing or expect to provide patient-provider communication within the next six months presents a more optimistic picture. Twenty-five percent of advanced stage initiatives intend to provide patient access to information through HIE within the next six months and patient-provider email is expected to be occurring among 22 percent of advanced stage respondents within the next six months. Clearly more research and education is needed to enable patients to benefit from emerging HIE initiatives.

Functionality to Support Patient-Physician Communication: Early Stages vs. Advanced Stages



Patient and Provider eConnect

A plan to enhance provider-patient communication is already reaping rewards in Whatcom County, WA, by allowing individuals to collaborate with their families, healthcare professionals and others involved in their care through an online personal health record.

My Shared Care Plan (SCP) facilitates communication between patients and healthcare professionals to support long-term planned care for patients with chronic disease. Funded through a Pursuing Perfection grant from the Robert Wood Johnson Foundation in 2002, SCP began as a paper-based record which patients “invited” into the program could use to fill in information about their care team, diagnoses, medications, history, reactions and even advanced directives. Patients and their health professionals can access the records online, as well as individuals who are designated as important to each patient’s care, such as relatives or neighbors.

After some tweaking and consultation with participants, SCP was rolled out as an online personal health record that encourages patient self-management. Although SCP is not openly advertised, some 650 patients are now using the electronic version. A sample patient record is available at www.sharedcareplan.org.

The program is operated under the Whatcom Health Information Network, LLC (HInet). HInet began in 1991 as a community-wide commitment to collaboration to achieve seamless care in Whatcom County. In 1995, the county’s only hospital, St. Joseph’s, and about 80 physicians went live with a comprehensive electronic medical records system. HInet now provides the infrastructure for electronic HIE for St. Joseph’s and about 2,000 other provider users.

“The Shared Care Plan was developed by patients through the grant process, and we’ve been modifying the application based on patient feedback and modifying support materials before we throw the doors wide open to everyone,” said Lori Nichols, HInet and Pursuing Perfection program director. Any patient in Whatcom County is eligible to use SCP, and Nichols said there are plans to make it more broadly available in the future.

In a recent survey of SCP participants, 80 percent reported that having an SCP helps them organize and keep track of their healthcare information. More than 77 percent reported that having an SCP helps them take a more active role in their own healthcare. More than 72 percent reported that having an SCP helps them communicate with healthcare professionals. Three out of five said they bring a printed copy of their SCP with them when they visit their healthcare providers.

“SCP is directly relevant to provider/patient communication,” Nichols said. “When patients have chronic conditions, it’s important that they have an effective mechanism to communicate with providers. SCP helps patients be more engaged in their care.”

Finding #5:

Advancements in functionality to support improvements in quality and safety are evident. In addition to traditional uses of HIE to support the use of information through standard care delivery processes (e.g. reminders, alerts, and results delivery), a number of HIE efforts are now expanding their functionalities to support efforts focused on population health, including chronic care management, quality and performance improvement efforts, and public health functions. Thirty-two percent of advanced stage initiatives are currently providing disease or chronic care management services while an additional 21 percent are expected to provide such services within the next six months. Twenty-seven percent are currently supporting quality performance reporting efforts while an additional 18 percent are expected to provide such services within the next six months.

Wisconsin HIE Provides Support Functions

As HIEs progress from early to advanced stages, many discover that implementation of an infrastructure for connectivity does not guarantee adoption by local practitioners. "It's a common mistake to believe that if you build it, they will come," said Seth Foldy, MD, principal investigator for the Wisconsin Health Information Exchange and member of the eHealth Initiative Board of Directors. Widespread use of new systems require that HIEs provide support functions as well. Clinicians at the point of care need information that is accessible, understandable, and highly useful.

"Accessibility means that physicians are getting information using the same pathways they're used to using," Foldy said. "For example, in Wisconsin, our pilot project isn't to exchange newly available information, but to allow people to log onto multiple networks simultaneously and to use those networks with a single log on." Accessibility includes ensuring that information flow is immediate. "As a primary care physician, I often have just 10 minutes to see many patients. So I probably won't use a system that takes 10 or even 15 minutes to give me an answer to a question. Turnaround time in HIE is part of the holy grail," he said.

Understandable systems require immediate help desk functions as well. "If very busy clinicians are going to use new stuff, they're going to need to have their questions answered in a hurry. You also need to have a very intuitive interface so physicians can adopt new practices without large amounts of training." Foldy said his group adopted the AZYXXI interface because of its reputation for ease of use among clinicians.

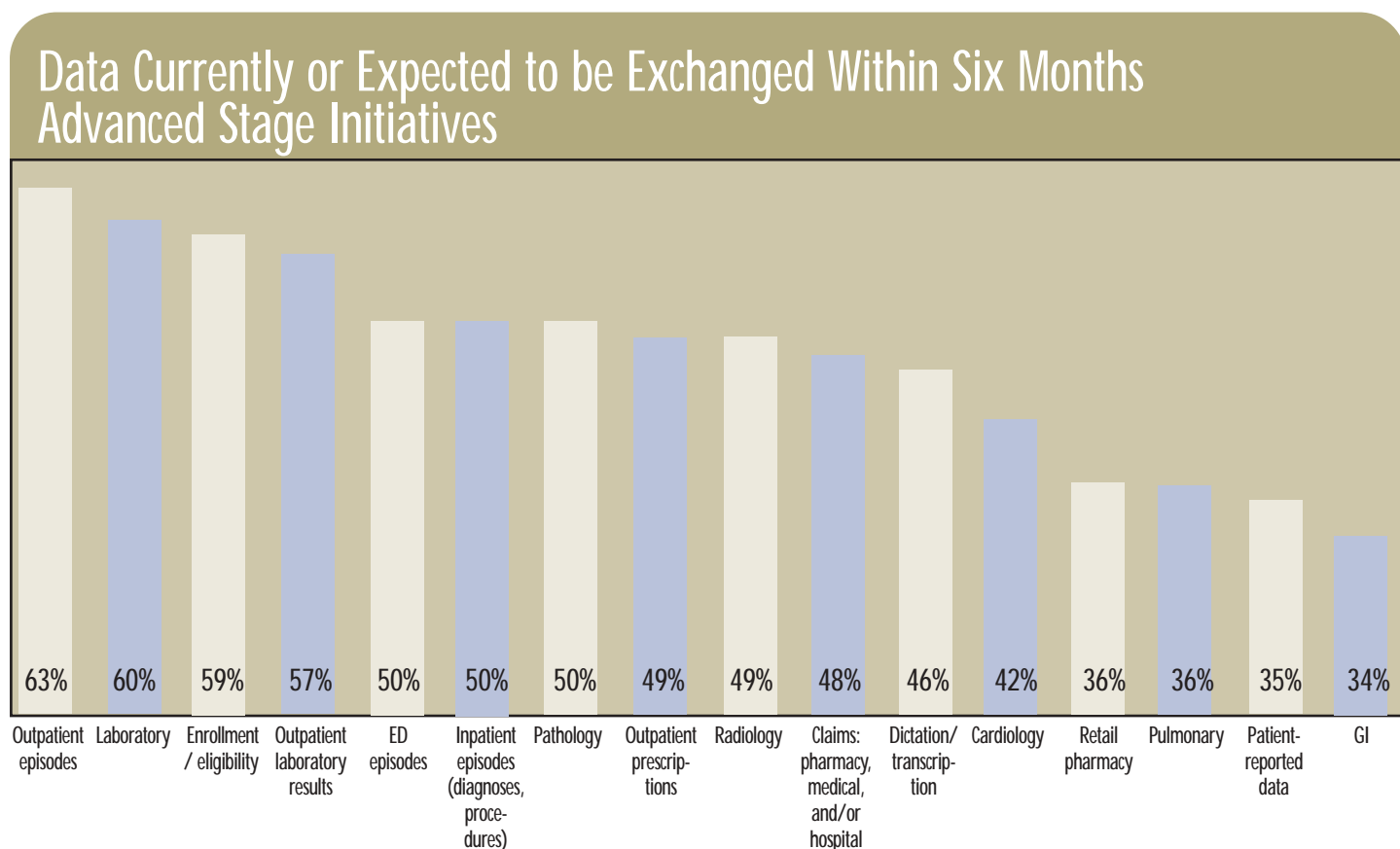
Creating a system that is perceived as highly useful is perhaps the most difficult component to achieve. "Clinicians aren't going to take much time to seek incomplete information--we learned that with immunization registries. Clinicians weren't sure it was worth their while to download partial information." Foldy said it will be a challenge for HIEs to provide sufficient volume and completeness of information to make using the system worth the clinician's time.

Support functions play a role in improving patient safety and healthcare quality both at the point of care and over time through analysis of statistical profiles to determine best practices and workflow patterns. "It all has to fit into the workflow of the fast-paced medical care operation for maximum effect," Foldy said.

HEALTH INFORMATION EXCHANGE EFFORTS ARE DELIVERING MORE INFORMATION AND INCREASINGLY USING STANDARDS FOR DATA DELIVERY

The amount and number of types of data being exchanged within HIE efforts is on the rise. More than half of the 63 advanced stage HIEs are either exchanging or will exchange various types of data over the next six months which will provide for the delivery of a wide range of services and data to support quality, safety and efficiency goals. Either half or more of such efforts are exchanging data related to outpatient and inpatient episodes, emergency department episodes, laboratory data, enrollment and eligibility, and pathology results. And a majority of such efforts are employing the use of standards to exchange data electronically.

The types of data currently being exchanged or expected to be exchanged over the next six months are noted in the chart below.



Use of National Data Standards

The majority of HIE efforts are employing the use of standards to exchange data electronically. Three out of four (76 percent) of advanced stage initiatives reported they are using HL7 for messages and 41 percent reported using LOINC for lab reporting.

Adoption of HL7 Standard Demonstrates Advancement

Use of common standards is a milestone on the road to widespread interoperability and HIE. Survey results indicating that 76 percent of advanced stage initiatives are using HL7 for their messaging standard demonstrates advancement. Standards may be grouped into three categories according to their application:

- **Messaging standards** define the formats for how clinical information is sent so users can tell who is sending the information, to whom the information is being sent, and the patient to which the information is related.
- **Vocabulary standards** define the words and codes that users and electronic systems will use to transfer information; for example, LOINC codes name test results in unambiguous terms that both data sources and recipients can understand.
- **Networking, security and authentication standards** ensure that patient data is securely transmitted over available network systems with senders and receivers clearly identified.

HL7 is the messaging standard that most clinical systems use today. HL7 is a message standard that works in much the same way as the common format for a business letter. For instance, a business letter is expected to be constructed with standard elements: a return address, date, recipient's address, possibly a line stating what the letter is regarding, a greeting, the body and a closing. It is evident who sent the letter by looking at the contents of the closing line and return address. Likewise, the recipient is clearly identified through the address and greeting.

HL7 is an example of a clinical data message format. It includes sections that identify who is sending information and to whom they are sending it, which patient the message is referring to and the clinical result itself. Each of these parts has several components. For example, the information describing a patient has an identifier that the sender uses for the patient, the patient's name, address, phone number and other demographic information. All of this is in a specified sequence.

Without adopting common standards, information exchange can't be accomplished effectively. The use of HL7 by so many HIE efforts in the survey is a positive indicator for future interoperability and standardization of data for HIE.

Finding #6:

Health information exchange efforts are delivering more information and increasingly using standards for data delivery.

A majority of advanced HIE efforts are exchanging or expecting to be exchanging within six months data related to outpatient and inpatient episodes, laboratory results, emergency department episodes, pathology results, and enrollment and eligibility information. A majority of such efforts are employing the use of standards to exchange data electronically. Three out of four (76 percent) of advanced stage initiatives reported using HL7 for messages and 41 percent reported using LOINC for laboratory reporting.

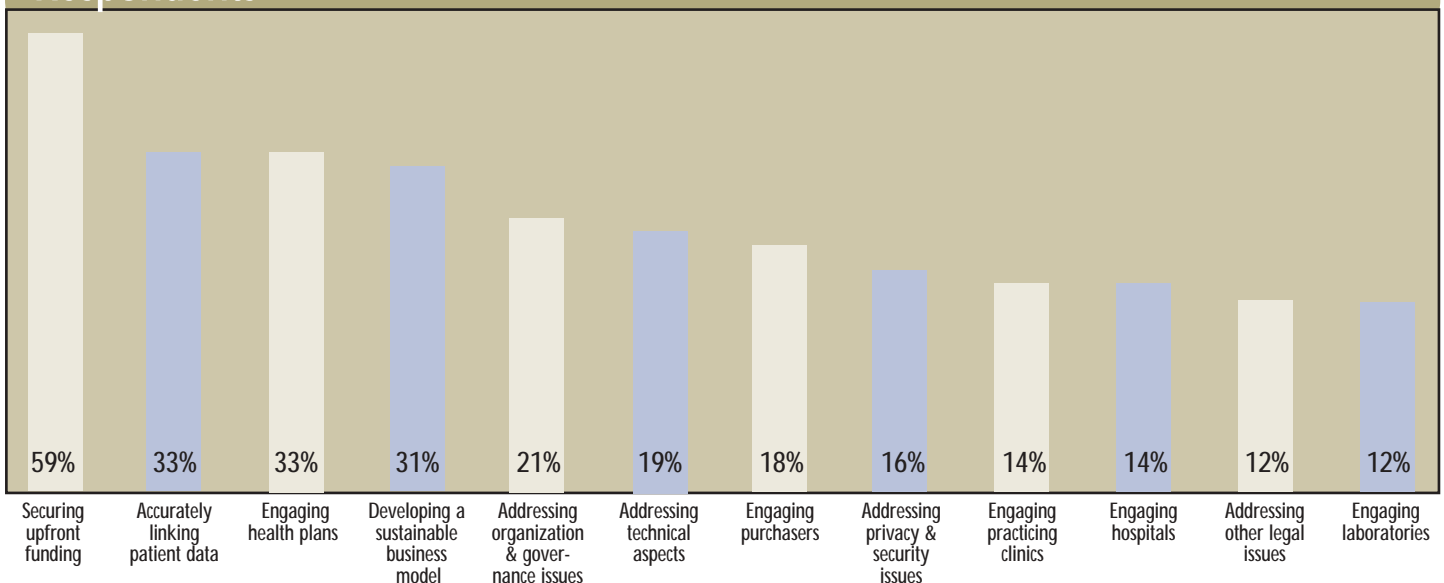
OUR SEVENTH FINDING

SECURING FUNDING TO SUPPORT START-UP COSTS AND ONGOING OPERATIONS IS STILL RECOGNIZED AS THE GREATEST CHALLENGE FOR ALL HEALTH INFORMATION EXCHANGE EFFORTS

Funding a Key Challenge

Securing upfront funding for initial development costs is still recognized as the most significant challenge for all HIE initiatives. Fifty-nine percent of all respondents cited “securing upfront funding” as a very difficult challenge, while 91 percent cited this barrier as either a very difficult or moderately difficult challenge. Achieving ongoing sustainability was also cited as a significant challenge, with 31 percent of all respondents citing “developing a sustainable business model” as a very difficult challenge and 84 percent citing this barrier as either a very difficult or moderately difficult challenge. These findings are similar to the 2004 results.

Very Difficult Challenges for Health Information Exchange: All Respondents



eHI's Parallel Pathways Framework Aligns Incentives with Quality and IT

The difficulties faced in securing funding for upfront development costs and achieving sustainability for ongoing operational costs for HIE stem in part from fundamental problems with our nation's prevailing reimbursement methods which reward the volume of services delivered instead of either the outcomes or processes that would result in higher quality, safer, more efficient, or more effective healthcare. Progress is being made in this area through leadership demonstrated by several members of Congress, the Centers for Medicare and Medicaid Services, and private sector initiatives such as Bridges to Excellence. These efforts acknowledge the misalignment of incentives, or the economic imbalance that exists between those who purchase HIT and those who benefit from its use.

eHI has developed a set of principles and framework for alignment of incentives with both quality and efficiency goals as well as HIT capabilities within the physician practice and HIE capabilities across markets. This Framework, entitled "Parallel Pathways for Quality Healthcare," offers significant guidance to states, regions and communities who are exploring HIE as a foundation to address quality, safety and efficiency challenges. As policies and practices that align payment systems with quality and efficiency become more prevalent, HIEs will have an easier time securing the funding required to support their start-up and sustainability. Policies which call for governmental grant and loan programs, such as those outlined in recently introduced legislation, will also play a significant role in seeding these organizations as new payment methods take hold.

Other Significant Challenges

Other significant challenges indicated by the survey results include accurately linking patient data, engaging health plans, and addressing organization and governance issues. Thirty-three percent of all respondents indicated that accurately linking patient data was a very difficult challenge while 80 percent indicated that it was a very or moderately difficult challenge. Both advanced stage and early stage initiatives and organizations perceived this technical aspect of HIE to be a challenge with 73 percent and 90 percent respectively citing accurately linking patient data as either a very difficult or moderately difficult challenge.

Engaging health plans was also cited as a significant challenge by both advanced and early stage HIE initiatives and organizations, with 30 percent of early stage respondents and 35 percent of advanced stage respondents reporting this as a very difficult challenge. Seventy-four percent of all respondents perceived the engagement of health plans as a very difficult or moderately difficult challenge. While health plan engagement continues to be a challenge, significant progress has been made since 2004 when very few HIE efforts engaged health plans in their organization or governance. Currently 28 percent of all HIE efforts have health plan participation, and 37 percent engage plans in their governance.

Finally, over the last year, while advanced stage HIE efforts have made significant progress in their organizational and governance structures, early stage efforts are still experiencing difficulties. Twenty-nine percent of such initiatives cited "addressing organizational and governance issues" as a very difficult challenge and 82 percent cited this area as a very or moderately difficult challenge. The experiences of advanced stage organizations and the principles that emerge from eHI's work will help these earlier stage initiatives as they progress through their organizational development.

Vermont and Tennessee Tackle Health Information Exchange Challenges

In just one year, the Vermont Information Technology Leaders (“VITL”) organization has already advanced to the cusp of implementation. With strong endorsement and seed funding from the state legislature in place, VITL is facing other challenges common to early-to-mid-stage HIE initiatives and organizations.

Funding was noted as a challenge by nearly three out of four early-stage coalitions responding to the survey. “We are looking for funding sources, both for start-up and for building a sustainable model,” said Greg Farnum, chief information officer of Vermont Association of Hospitals and Health Systems and president of VITL. The organization is actively pursuing private and public grants, and is examining sustainability models, such as a subscriber funding approach.

VITL includes representation from physician groups, employers, payers (including Medicaid), state and regional quality organizations, patients/consumers, and state organizations such as public health and regulatory bodies. “We’re meeting face-to-face and working out the details in a spirit of open communication and collaboration, and we’re problem-solving,” Farnum said. The next challenge for VITL is to refine an implementation strategy and collaboratively choose a technology solution.

Other common challenges have also cropped up, such as building patient trust and data ownership issues. “One of the biggest challenges is trying to balance the different stakeholders’ agendas and needs to achieve the ultimate quality objectives,” said John Evans, VITL board chairman. “It’s not the technology or even necessarily the funding that are the toughest challenge.”

That sentiment is echoed in Southwestern Tennessee, where technology hurdles seem small and start-up funding is in hand. The three-county HIE organization, the MidSouth eHealth Alliance, gained a \$10 million financial commitment from Gov. Phil Bredesen through his Volunteer eHealth Initiative and received an additional \$5 million as one of five AHRQ regional demonstration programs a year ago. While the HIE initiative is not yet mature, it is beginning implementation with some live data test feeds.

An early challenge was forming a sustainable guiding coalition, according to Mark Frisse, MD, director of regional health initiatives for the Vanderbilt Center for Better Health and program director for the MidSouth eHealth Alliance.

“Our healthcare delivery system is not designed to work in collaboration,” Frisse said. “The fact that leaders work so hard with no substantive remuneration is pretty exciting.” Given Gov. Bredesen’s personal interest in the project, Frisse said the group also enjoys strong participation from the state’s senior leadership and from regional political leaders.

A second challenge is to calm fears about security. “The American public’s health information privacy is already imperiled in a paper world, and many believe a digital world will make a bad situation even worse. We disagree.” Frisse said the HIE effort is working with both the eHealth Initiative and the Markle Foundation’s Connecting for Health to overcome the challenge. “This is something we as a nation have to work on together,” he said.

Alternative Funding Sources for Health Information Exchange

HIE initiatives searching for sustainable funding sources can take a cue from one of the nation's oldest such entity: bundle available grant resources to start with pre-payment for services from an operational system.

The Indianapolis HIE ("IHIE") began more than a decade ago as the Indianapolis Network for Patient Care, a project of the Regenstrief Institute, a private, not-for-profit research leader in medical informatics and health services research. Some of the start-up funding came from Biocrossroads, a market/economic development organization, and recently start-up funds for a new project came from the Fairbanks Foundation.

Over the years, Regenstrief received grant support for particular projects from a number of private sources, including the National Library of Medicine, the Agency for Healthcare Research and Quality, and the National Cancer Institute, but IHIE has never looked to the federal government for financial support. The lion's share of ongoing support comes from payment for services from data sources, who benefit from using electronic transfer of information over costlier paper-based models.

"Our current operational funding model is based on clinical messaging," said Marc Overhage, MD, PhD, research scientist for the Regenstrief Institute, Inc. and the chief executive of IHIE. "We receive data from data sources electronically and deliver it to data consumers such as healthcare providers. Data sources currently deliver these messages in a variety of ways, but through shifting to electronic methods and economies of scale, IHIE can deliver them more cost effectively." (cont.)

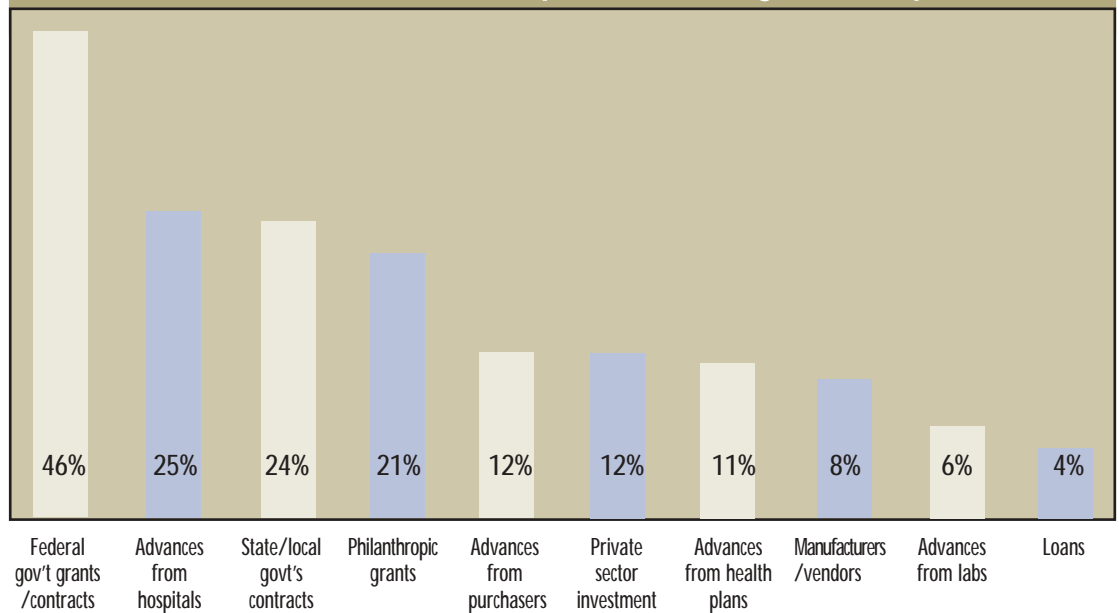
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Legal and organizational concerns are also still a challenge, Frisse said. "When information is shared across institutions, a formidable list of legal issues has to be overcome. Our major solution is to work with national groups as well as local champions to sift through the various agreements and to achieve some consensus view." Frisse said the planning process alone has brought traditional competitors together "in a very promising way."

Frisse identified new cautions on the horizon: the challenges of a maturing organization with diverse stakeholders.

"As a growing number of organizations and individuals see value in specific aspects of HIT, a fairly predictable competition over solutions is emerging," he said. "You might see competition to carve out specific applications with the greatest return for certain groups at the expense of more community-wide applications. And if enough is carved out, there will be no resources left to address public health and other needs."

Current Revenue Sources for Upfront Funding: All Respondents



OUR EIGHTH FINDING

FUNDING SOURCES FOR BOTH UPFRONT AND ONGOING OPERATIONAL COSTS STILL RELY HEAVILY UPON GOVERNMENTAL FUNDS BUT ALTERNATIVE FUNDING SOURCES FOR ONGOING SUSTAINABILITY ARE BEGINNING TO EMERGE

Survey results suggest that revenue sources to cover upfront and ongoing costs still rely heavily upon federal, state and local government grants and contracts. Forty-six percent of all respondents look toward the federal government to support upfront development costs, with 59 percent of advanced stage and 23 percent of early stage initiatives and organizations relying upon such funding sources. Twenty-four percent of all respondents are utilizing state and local government grants and contracts to support upfront development costs, with 29 percent of advanced stage and 17 percent of early stage efforts relying upon such funding sources. Clearly, advanced stage initiatives rely more on governmental funding sources than early stage efforts.

Federal, state and local government grants and contracts, however, do not represent the only source of upfront funding for these initiatives. As noted above, one fourth of all respondents cited advance payments from hospitals and 12 percent cited advance payments from purchasers as a revenue source for upfront development costs. Twenty-one percent cited philanthropic grants as a source for such costs. A review of the responses from both advanced stage and early stage initiatives and organizations did not reveal significant differences.

Sources of Funding for Ongoing Operational Costs

Survey results indicate that HIE efforts are also utilizing federal government grants and contracts to support the costs of ongoing operations. Forty-eight percent of advanced stage initiatives and organizations cited the federal government as a funding source for ongoing operations. Advance payments from hospitals (38 percent), physician practices (33 percent), public

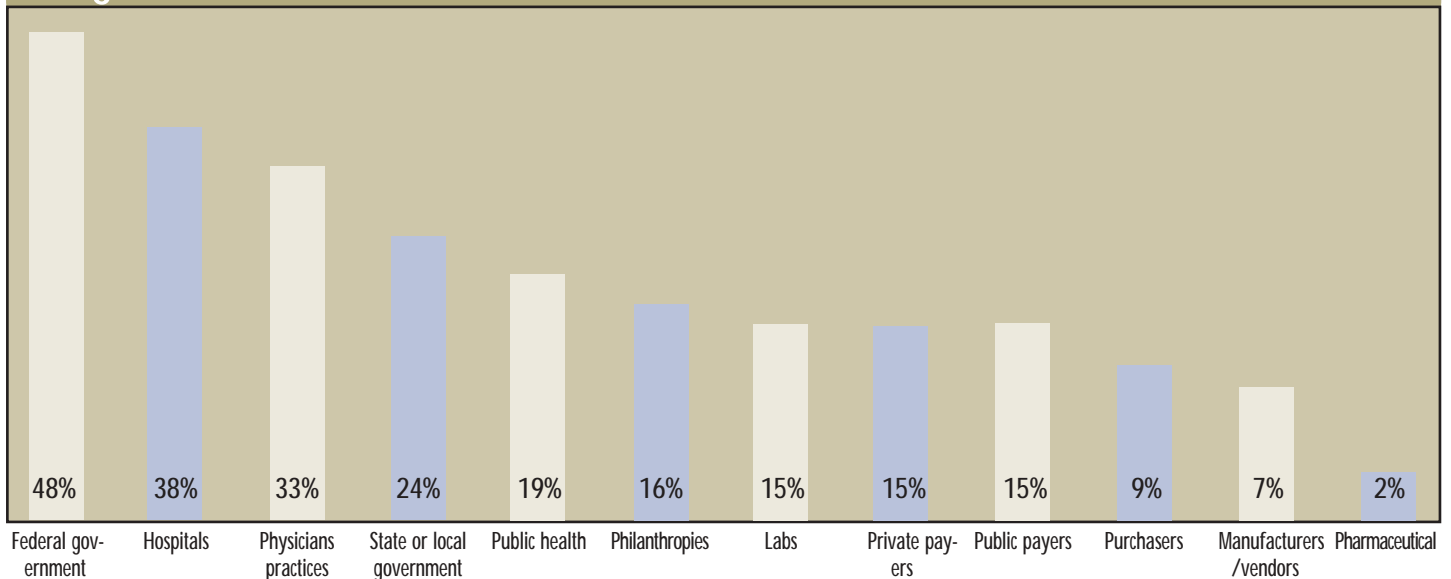
For instance, IHIE analyzed data in Indianapolis and discovered it costs about 80 cents per clinical result for a hospital to deliver it to a doctor's office using paper-based methods. The electronic system delivers the information from data source to physician office at a lower cost, representing a savings of hundreds of thousands of dollars each year for each data source.

As the HIE continues to grow and expand, new funding sources must be found to sustain the growth. Overhage said funding considerations do play a role in determining which new projects a group should take on.

"You have to go after things that will pay the bills to be sustainable," he said. "In order to grow, you have to find ways to fund it as you go along as a not-for-profit. That's challenging."

Within the next six months, IHIE plans to launch two new services that will provide additional revenue streams and additional value, but leverage the existing infrastructure. "We are just beginning to capitalize on the infrastructure we have been creating and the opportunities that HIE creates," Overhage said.

Current Revenue Sources for Ongoing Operational Costs Advanced Stage Initiatives



health (19 percent), laboratories (15 percent), private or public sector payers (15 percent), and purchasers (9 percent) were also cited as revenue sources for such costs. In addition, 24 percent of advanced stage respondents cited state or local government contracts as a funding source for ongoing operations while 16 percent identified philanthropies a source for such costs.

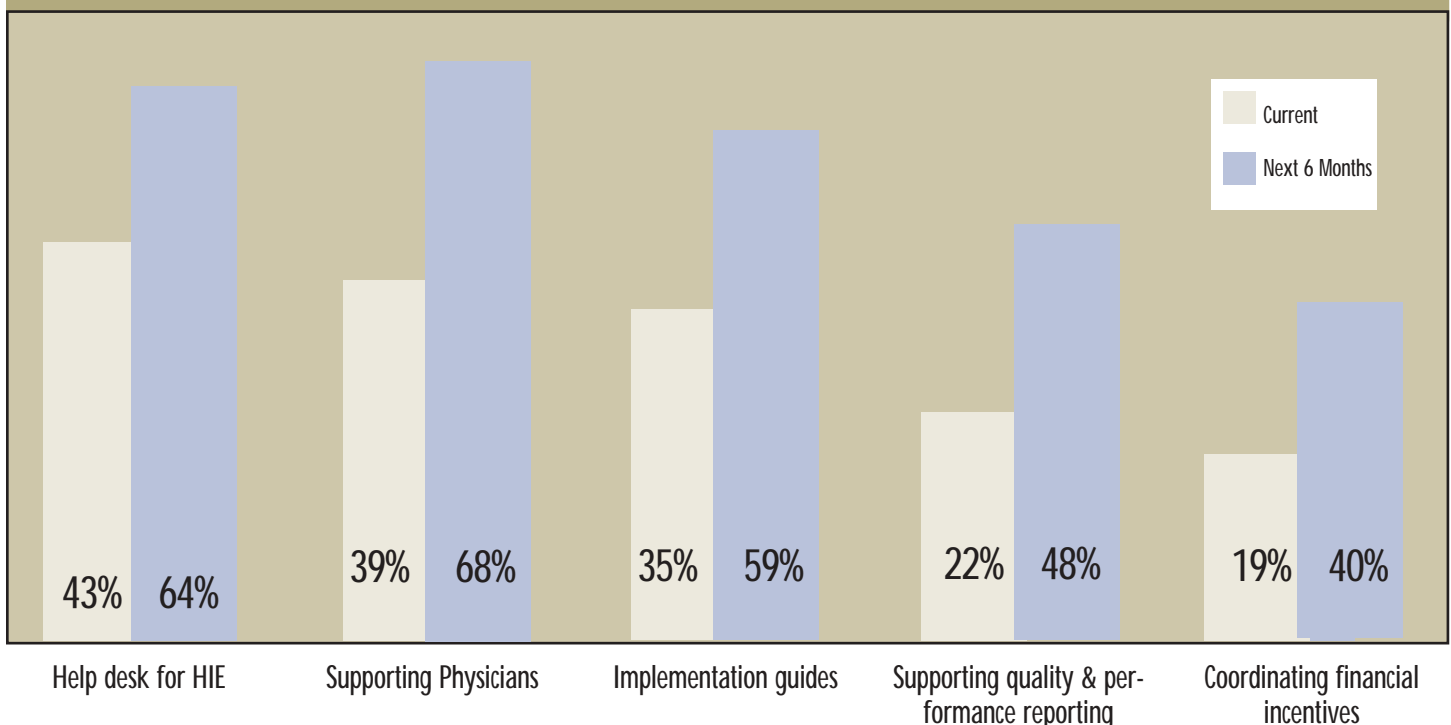
A comparison of this year's results to those from 2004 indicates a clear progression towards the use of funding sources outside of the federal government, with a specific focus on those entities that will derive value from the access of data to support their various functions within the health-care system (e.g. providers, purchasers and payers, etc.)

Expansion of Services Evident in Advanced Stage Efforts

Recognizing the need to deliver value and support the actual integration of the health information exchange network into existing healthcare processes, increasingly HIE initiatives and organizations are providing or planning to provide within the next six months a number of "support" functions. Of the 63 advanced stage organizations:

- 43 percent are offering help desk functions for HIE activities (either phone or computer based) while 21 percent plan to do so within the next six months;
- 39 percent are supporting practicing clinicians with the adoption of EHRs or other applications while 29 percent plan to do so within the next six months;
- 35 percent are providing implementation guides for HIE while 24 percent plan to do so within the next six months;
- 22 percent are supporting quality improvement or performance reporting for purchasers and/or payers while 26 percent plan to do so within the next six months; and
- 19 percent are coordinating financial incentives within the market while 21 percent plan to do so within the next six months.

Expansion of Services: Advanced Stage, Current and Within Next 6 Months



Finding #8:

Funding sources for both upfront and ongoing operational costs still rely heavily upon government funds but alternative funding sources for ongoing sustainability are beginning to emerge.

Forty-six percent of all respondents cited federal government grants and contracts as a current revenue source for upfront funding, while 48 percent of advanced stage initiatives cited this as a revenue source for ongoing operations. Increasingly, HIE efforts are looking towards alternative funding sources for sustainability, with advanced stage initiatives relying upon advance payments from hospitals (38 percent), physician practices (33 percent), public health (19 percent), laboratories (15 percent), payers (15 percent), and purchasers (9 percent) to support ongoing operations.

MOVING FORWARD

Where Do We Go From Here?

The survey results identify many of the challenges facing HIE efforts, and shed light on areas where progress has been made by many to address these challenges. As noted in the overview section of this report, the eHealth Initiative Foundation is convening national experts, multiple and diverse stakeholders, and “on-the-ground” implementers to develop common principles, policies, and standards to help stakeholders navigate the organizational, legal, financial, and technical complexities related to using HIE to support improvements in health and healthcare. Insights gained from this survey as well as other research and working group activities are providing input into an emerging set of guides and tools for HIE that will be released to support the field in the third quarter of 2005.

The following summarizes a series of steps that are needed to support and accelerate the mobilization of data to support patient care through HIE across the United States.

- **Without the alignment of financial and other incentives with both quality and efficiency goals as well as electronic health information exchange capabilities, efforts to accelerate the mobilization of information to support patient care will continue to move at a slow pace.** Achieving ongoing sustainability was cited as a significant challenge by 31 percent of all respondents, and 84 percent cited this barrier as either a very difficult or moderately difficult challenge. Recent efforts by members of Congress, the Administration and the private sector hold promise for beginning the migration of our outdated payment system to one which rewards quality and efficiency goals and the processes and functions (such as HIE) that support their achievement.
- **Innovative programs designed to facilitate public and private sector seed funding of emerging health information exchange efforts must be developed and implemented if goals related to widespread interoperability are to be achieved.** Securing upfront funding is the most challenging issue for HIE initiatives, with 59 percent of all respondents citing “securing upfront funding” as a very difficult challenge and 91 percent citing this barrier as either a very difficult or moderately difficult challenge. While federal efforts can play a critical role in addressing this challenge, they should be designed to stimulate investment by the private sector as well as state and local government agencies to facilitate widespread interoperability.
- **More work is needed to support the engagement of the multiple and diverse stakeholders within healthcare in health information exchange efforts, including consumers, laboratories, health plans, purchasers, and consumers.** Of all constituencies, providers are playing the most visible role in the governance of HIE efforts, with survey results revealing that hospitals (61 percent), primary care physicians (48 percent), specialty care physicians (37 percent), and community health clinics (35 percent) are involved in the governance in these efforts. The survey data also shows that while there is a trend toward including other stakeholders in these efforts, more work is needed to continue to engage their involvement. For instance, survey results reveal that only 37 percent of health plans, 27 percent of employers or purchasers, 26 percent of patient or consumer groups, 12 percent of healthcare IT suppliers, and 7 percent of laboratories are currently engaged in the governance of HIE efforts.

- **States are increasingly becoming involved in health information exchange efforts, but their role should be expanded and clarified.** Increasingly, states are playing a role in supporting the work of local efforts related to HIE within their boundaries with 53 percent of all respondents indicating state involvement. The state can play a pivotal role in either promoting or impeding the progress of HIE initiatives. Given their multiple roles as purchaser, payer, regulator, and funder, their participation and support of these efforts is critical. More work needs to be conducted to explore and define an expanded role for states.
- **National efforts designed to achieve consensus on and promote the adoption of standards could not be more timely.** HIE initiatives are in the midst of engaging in the difficult work related to getting organized; engaging stakeholders; defining goals, objectives, and priorities; and developing sustainable business models. As this work continues to migrate towards the implementation of technical networks, leadership on both the development of new and communication of the many existing standards at the national level will be critical to enable interoperability across markets.

Over the coming months, eHI will use the survey results to continue its work with leaders at the state, regional and community levels to build multi-stakeholder collaborations focused on mobilizing healthcare information across organizations to improve the quality, safety and efficiency of care. eHI will incorporate the survey findings and recommendations into a rich set of tools and resources to support the various aspects of HIE and the results will be shared for use by the more than 100 HIE initiatives across the U.S.

eHealth Initiative Foundation's Expert Working Groups and Programs Offer Support to HIE Efforts

The eHealth Initiative Foundation's approach to driving change is to engage the multiple, diverse stakeholders within healthcare at the national, state, regional and local levels to develop common principles, policies and standards for improving the quality, safety and efficiency of healthcare through health information technology (HIT) and HIE. The initiatives and programs which support these goals include the following:

eHI Working Groups

Working Group for Connecting Communities. Co-chaired by Mark Frisse, MD, MBA, director, Regional Health Initiatives, Vanderbilt Center for Better Health and head of Tennessee's Volunteer eHealth Initiative and J. Marc Overhage, MD, PhD, CEO, Indiana Health Information Exchange, this coalition of more than 100 state, regional and community-based efforts to support HIT and HIE adoption supports the development, sharing, and implementation of principles, policies, standards, and strategies to address the organizational, financial, legal and technical challenges of mobilizing health information across organizations within regions and communities.

Working Group for Financing and Incentives. Co-chaired by Marianne E. DeFazio, director, Global Health Benefits, IBM and John Glaser, PhD, vice president and chief information officer, Partners HealthCare System, this Working Group has developed consensus among multiple, diverse stakeholders on a set of principles and framework for aligning incentives with quality and efficiency goals, as well as the health information infrastructure required to achieve those goals, within the physician practice and across regions and communities. The primary deliverable of this Working Group is eHealth Initiative's Parallel Pathways for Quality Healthcare framework, which can be viewed at www.ehealthinitiative.org.

Working Group on HIT for Small Medical Practices. Co-chaired by Peter Basch, MD, medical director, eHealth, Medstar Health, and co-chair of PEHRC, and David Kibbe, MD, director, Center for Information Technology, AAFP and co-chair of PEHRC, this Working Group is developing practical work products and strategies to improve the value proposition of and support the adoption of EHRs and other HIT products and services aimed at the small and medium sized ambulatory care sector, to support clinicians in improving quality, enhancing safety, and increasing efficiency within their practices. Key deliverables include a roadmap for achieving connectivity between labs and small physician practice EHRs, a set of tools and resources to support practice redesign, and standard tools to assist physician practices with the purchase of EHRs.

eHI Employer Purchaser Advisory Board. Co-chaired by Dale Whitney, corporate health and welfare manager, United Parcel Service and Dolores Mitchell, executive director of the Group Insurance Commission, Commonwealth of Massachusetts, this Working Group is engaging employers and other healthcare purchasers in taking action to support improvements in health and healthcare through the use of HIT and HIE. Key deliverables of this Working Group included a tool-kit to support employers and purchasers in aligning incentives with both quality and efficiency goals and electronic HIE capabilities as well as resources to support consumer (employee-beneficiary) messaging around the importance of HIT in addressing quality, safety and efficiency goals.

Working Group for the Leadership in Global Health Technology Initiative. Chaired by Susan Penfield, vice president of Booz Allen Hamilton, this Working Group is facilitating learning, information sharing, and collaboration globally regarding the basic requirements, key barriers, and strategies for implementing HIT and HIE to support better health and healthcare in other parts of the world.

eHI Policy Working Group. Chaired by Bob Doherty, senior vice president of public affairs and policy, American College of Physicians, this Working Group is educating policy makers and driving policy change to support a higher quality, safer and more efficient healthcare system through HIT.

eHI Partnerships with Public Sector Entities

eHI's Connecting Communities for Better Health Program. Conducted by the eHealth Initiative Foundation in cooperation with HRSA/OAT, this program is providing seed funding and technical support to state, regional and community-based HIE efforts across the U.S.

eHI State and Regional HIT Policy Initiative. Conducted by eHI, with support from the Vanderbilt Center for Better Health, and in collaboration with the Agency for Healthcare Research and Quality National Resource Center for Health Information Technology, this initiative is comprised of a series of activities that bring public and private sector stakeholders together at the state and regional levels to assess their environment, facilitate collaboration around HIT, and develop principles, priorities and plans to support the achievement of an interoperable health information environment within their boundaries.

AHRQ National Resource Center for Health Information Technology. The eHealth Initiative Foundation is a partner in a collaborative effort supporting the Agency for Healthcare Research and Quality (AHRQ) National Resource Center for Health Information Technology, a growing resource which is currently providing support to 107 AHRQ HIT-related grantees/contracts, many of which are involved in HIE. This collaboration is led by the National Opinion Research Center (NORC) and includes Burness Communications, the Center for Information Technology Leadership, Computer Sciences Corporation, the eHealth Initiative Foundation, Regenstrief Institute/Indiana University, and the Vanderbilt Center for Better Health.



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