



eHEALTH INITIATIVE

Real Solutions. Better Health.

2011 REPORT ON HEALTH INFORMATION EXCHANGE

THE CHANGING LANDSCAPE

● ● ● ● EXECUTIVE SUMMARY ● ● ● ●

FULL REPORT

CHART BOOK

MARKET REPORT & HIE VENDOR LIST

SUSTAINABILITY REPORT

WORKFORCE DEVELOPMENT REPORT

*Based on Results from eHealth Initiative's Eighth
Annual Survey of Health Information Exchange*

About eHealth Initiative

eHealth Initiative (eHI) is a Washington D.C.-based, independent, non-profit organization whose mission is to drive improvements in the quality, safety, and efficiency of healthcare through information and information technology. eHI is the only national organization that represents all of the stakeholders in the healthcare industry. Working with its membership, eHI advocates for the use of health IT that is practical, sustainable and addresses stakeholder needs, particularly those of patients.



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I | INTRODUCTION

eHealth Initiative (eHI) fielded the first eHealth Initiative Health Information Exchange (HIE) Survey in 2004. Over the last decade, eHI has been monitoring the progress of health information technology (HIT) and health information exchange (HIE). During this time there has been enormous growth for both HIT and HIE. In 2004, there were a few dozen HIE initiatives; today there are approximately 255.

While the last decade has seen growth and change, the past year has been transformational for health information exchange. The results from this year's *2011 Report on Health Information Exchange: The Changing Landscape* demonstrate that exchange is no longer an experiment or a project that initiatives and hospitals can dabble in or take years to develop. In order to survive, HIE initiatives and health systems must jump whole heartedly into advanced health information exchange with workable business models. Due to the changing healthcare environment, they no longer have the luxury of taking their time to experiment with HIE and pilot projects.

IS POLICY CHANGING THE LANDSCAPE FOR EXCHANGES?

One of the factors pushing the transformation of the HIE field is the Health Information Technology for Economic and Clinical Health (HITECH) Medicaid and Medicare Electronic Health Record (EHR) Incentive Program. While the Stage 1 Meaningful Use requirements for the actual electronic exchange of health information were relatively low, requiring only a single test of the capability to exchange, the proposed Stage 2 requirements establish higher conditions, which will potentially begin in 2013 for those attesting to Stage 1 in 2011.

NOUN VERSUS VERB

The HIT Policy Committee's recommendations for Stage 2 of Meaningful Use expand the historical definition of health information exchange from a noun to a verb. The requirements eliminate the test of the ability to exchange, and instead require specific use cases that focus on health information exchange as a verb. HIE the verb refers to the "act" of exchanging health information between two or more entities. It does not require any formal structure or organization to accomplish the "act" of exchange. HIE the noun refers to a formal exchange organization, typically with a governance structure.

For the sake of making the distinction clear in this report, we utilize the term health information exchange initiatives (or HIE initiatives) to refer to the noun form.

Formal HIE initiatives or organizations can come in multiple forms:

- » State-run HIEs,
- » Community-based for-profit or non-profit HIEs, or
- » Integrated Delivery Network/Health System HIE (also known as an Enterprise HIE).

It appears that the federal government is attempting to align the various incentive programs as much as possible. This alignment will propel health information exchange forward. In addition to the changes in Stage 2 requirements, the Patient Protection and Affordable Care Act (PPACA) is pushing transformation in the healthcare system, specifically with the Medicare Shared Savings Program for Accountable Care Organizations (ACOs). The ACO program in its current form requires a high level of care coordination, and therefore a high level of health information exchange, the verb. Some ACOs will partner with existing HIE organizations to accomplish this; others may build out systems through proprietary networks or IDNs. Our survey results show that nearly a quarter of existing HIE initiatives plan support with an ACO. In addition, there has been a noticeable uptick in health systems announcing plans to create an HIE within their network; some are planning to include providers in their geographic area who are outside of their network.

PERFECT STORM

The push towards a transformed healthcare system has led to a perfect storm for HIE initiatives and exchange. It is understood that a transformed system must have robust health information exchange, which is a positive development. However, the market has been shifting over the last year, and HIE initiatives must quickly adapt to these changes. Initiatives that cannot adapt quickly will face major challenges in a transformed healthcare system. HIE initiatives must move beyond simple exchange to more advanced value-add services, to maintain relevancy in a market that is shifting towards enterprise HIE initiatives that are run by an integrated delivery network (IDN) or a health system. Since many IDNs have been performing advanced analytics, quality reporting, and other value-add services internally for years, this may not be a challenge for them. However, many of these functions have been deployed in the inpatient setting. As IDNs begin to offer these services in the ambulatory setting, they may face the same challenges of community-based initiatives. However, for community-based HIE initiatives that are just entering the market place, providing these advanced services is more challenging.

HIE initiatives must realize that the healthcare system is rapidly evolving, and to remain in business, they must quickly grow their service offerings and move swiftly through the eHI Stages of Development (see Figure 1 on page 7).

The *2011 Report on Health Information Exchange: The Changing Landscape* will discuss survey results in the context of the changing healthcare environment, including:

- » Overview of the exchange landscape
- » Stakeholders taking the lead
- » Changing business models
- » Transforming healthcare with functionality and services
- » Incorporating the Direct Project
- » Patient services
- » Enhancing patient privacy
- » Recommendations for moving forward

II | KEY FINDINGS

Over the last decade, eHealth Initiative has been monitoring the progress of health information technology (HIT) and health information exchange (HIE). *The 2011 Report on Health Information Exchange: The Changing Landscape* discusses survey results in the context of the changing healthcare environment. Key findings from the report are highlighted below.

- » While there has been some consolidation in the health information exchange market, there has been net growth of 9% in the number of initiatives, as the number of new efforts has more than offset consolidation among existing initiatives. At least 10 HIE initiatives have closed or consolidated in the last year.
 - ▶ The known number of initiatives increased by 9% from 234 in 2010 to 255 in 2011.
 - ▶ 46 new respondents completed the survey.
 - ▶ 85 initiatives are in the advanced stages of development, up from 73 in 2010.
 - ▶ 24 initiatives report they are “sustainable”, up from 18 in 2010.
 - ▶ 4 initiatives consolidated into other HIE initiatives.
 - ▶ 4 initiatives closed operations.
 - ▶ 2 for-profit organizations were purchased, and HIE operations closed.
- » Initiatives are developing complex privacy controls for patients, even in the absence of new federal requirements.
 - ▶ In 2011, 46 initiatives report offering opt-out at a data type level (lab, radiology results, etc.), compared to 13 in 2010 offering opt-in or opt-out.
 - ▶ 9 initiatives offer opt-in and 40 offer opt-out at the data field or individual data element level (i.e. demographic information).
 - ▶ 28 initiatives offer opt-in, and 36 initiatives offer opt-out for sensitive data.
- » In addition to struggling with business models and value, initiatives are facing new challenges including addressing technical aspects and systems integration.
 - ▶ The number of initiatives indicating that systems integration was a major or moderate challenge increased from 97 in 2010 to 117 in 2011.
- » The top 4 types of data exchanged by the advanced initiatives are: laboratory results for Meaningful Use Stage 1 (64), medication data (56), outpatient lab results for Meaningful Use Stage 2 (54), and radiology results (54).

- » The top 3 types of functionalities provided by advanced initiatives are: connectivity to EHRs (60), a Master Patient Index (60), and results delivery (47).
- » Behavioral or mental health providers are providing and viewing more data through exchanges.
 - ▶ In 2010, 10 initiatives indicated they were providing data; in 2011, behavioral or mental health providers provided data in 18 initiatives.
 - ▶ In 2010, 27 initiatives had behavioral health providers viewing or receiving data; in 2011, 32 initiatives indicated providers could view or receive data.
- » Advanced initiatives receive revenue from 3 key stakeholder groups, and use multiple revenue models, with membership fees being the most utilized model.
 - ▶ Most advanced initiatives spread their funding over multiple stakeholders, with hospitals, payers, and provider practices being the main sources of funding.
 - ▶ 65 are dependent upon the federal government for funding, up from 62 in 2010.
- » Advanced initiatives are more prepared to support meaningful use. The majority of advanced initiatives are offering at least one service that supports Meaningful Use requirements for Stage 1 and 2. All but one functionality showed an increase from 2010.
- » Initiatives are weighing their options about involvement with ACOs. A quarter of the respondents indicated that they will support an accountable care organization.
- » Advanced initiatives are offering more support services and value-add services to clinicians and hospitals. The following saw major increases from 2010 to 2011.
 - ▶ Workflow modification guidance for clinicians increased from 35 to 48.
 - ▶ Technical assistance for implementation in hospitals increased from 37 to 42.
 - ▶ Providing aggregation of administrative transactions increased from 3 to 23.
 - ▶ Providing access to provider and provider related databases increased from 6 to 22.
 - ▶ Offering billing services increased from 6 to 22.
 - ▶ Providing credentialing services increased from 3 to 18.
- » A majority of initiatives (113) plan to incorporate the federal Nationwide Health Information Network's (NwHIN) Direct Project into their service offerings.

III | OVERVIEW OF THE EXCHANGE LANDSCAPE

HOW MANY INITIATIVES ARE THERE?

eHealth Initiative (eHI) has identified 255 known health exchange initiatives in 2011, and through the survey process has collected data on 196 initiatives. Respondents to the *2011 Annual Survey on Health Information Exchange* included state grantees, state designated entities (SDEs), statewide HIE initiatives, community-based HIE initiatives, integrated delivery networks (IDNs), and health systems.

KEY FINDING

While there has been some consolidation in the health information exchange market, there has been net growth of 9% in the number of initiatives, as the number of new efforts has more than offset consolidation among existing initiatives.

STATE-LEVEL HIE INITIATIVES

Under the State HIE Cooperative Agreement program, 56 states and U.S. territories received funding to support HIE in their state or territory. States are taking multiple approaches to the program. This year 48 states, SDEs, and statewide HIE initiatives that are part of the State HIE Cooperative Agreement Program responded to the 2011 survey. For more information on the approaches states are taking, see the eHI and Thomson Reuters paper *Governance Models for HIE*. The eHealth Initiative will also release a special report on the survey results from the state-level initiatives later this year.

HOW ADVANCED ARE INITIATIVES?

In 2005, eHI developed a framework for assessing and tracking health information exchange development. eHI identified seven stages of development that most initiatives will move through, at varying paces. For 2011, eHI updated the stages of development to reflect the advanced services that some initiatives are offering. Stage 7 has been updated to reflect that an initiative is not only sustainable, but has also expanded its service offerings to include value-add services, such as analytics, quality reporting, Picture Archiving and Communication System (PACS) reporting, etc. See Figure 1 for the seven stages of development.

HEALTH INFORMATION EXCHANGE STAGES OF DEVELOPMENT

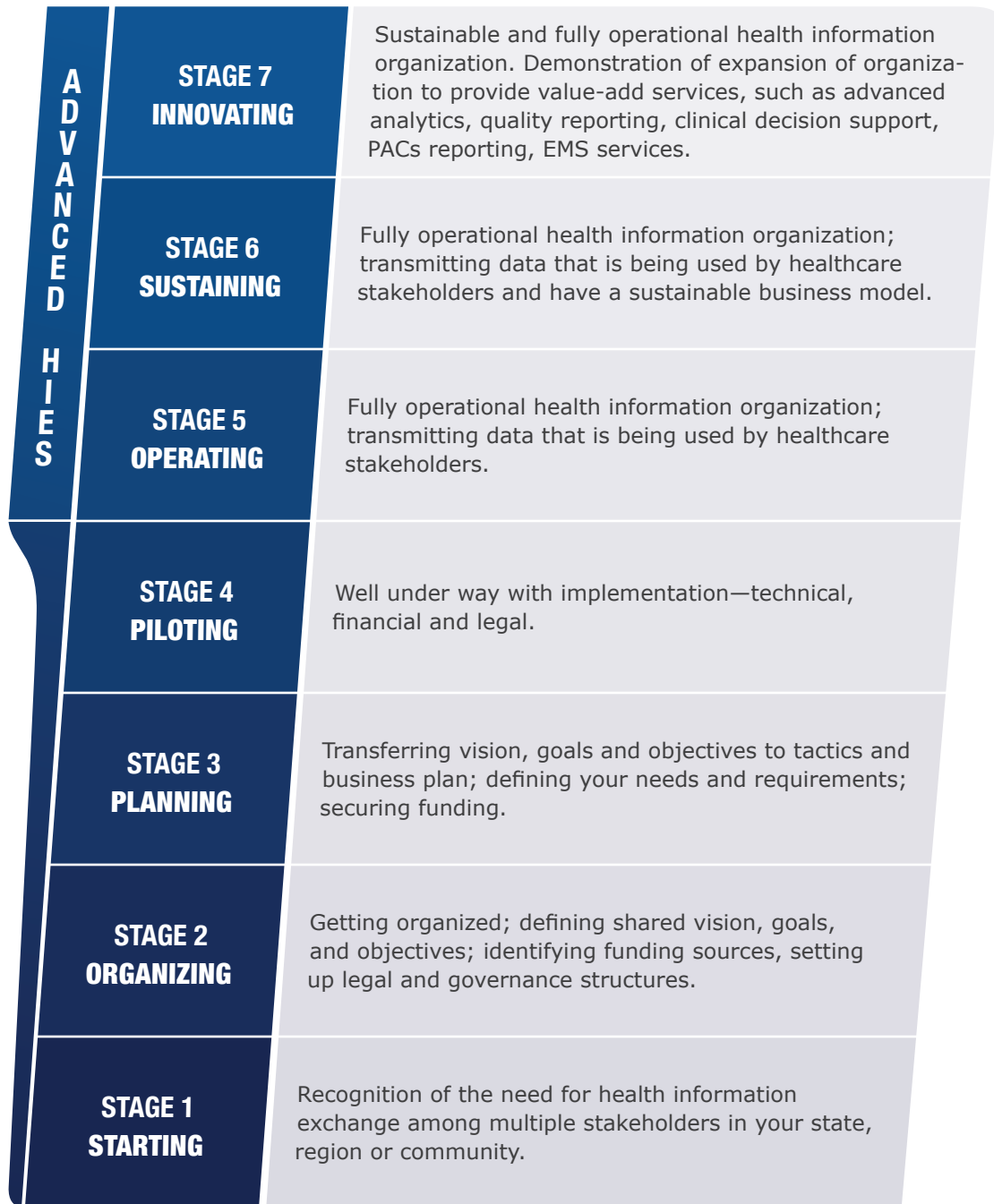


Figure 1: eHI Stages of Development



This year the number of advanced HIE initiatives (those who identified themselves as Stages 5, 6, or 7) continued to grow. To be considered advanced, initiatives must at a minimum, be transmitting data that is being used by healthcare stakeholders. In 2011, 75 initiatives indicated they are advanced initiatives. A total of 10 advanced initiatives that responded to the 2010 survey, did not complete the 2011 survey. eHI confirmed that the 10 initiatives are still operating, bringing the total number of advanced initiatives to approximately 85. Figure 2 below, shows the ever increasing number of advanced HIE initiatives from 2004 when eHI first began surveying the field.

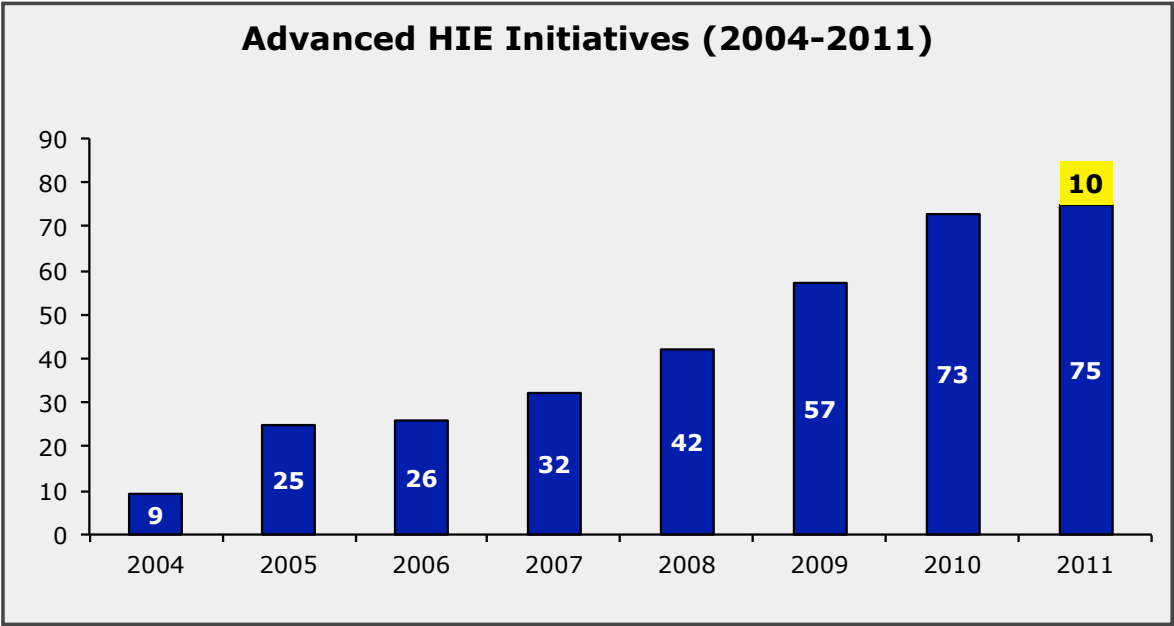


Figure 2: Advanced Initiatives 2004-2011
(Note: The additional 10 initiatives in 2011 were 2010 respondents that were verified to still be operating.)

Similar to 2010, this year, most HIE initiatives are in the intermediate stages of development: Stage 3 (35), Stage 4 (44), and Stage 5 (26). It should be noted that of the 75 advanced initiatives who responded to the survey, 19 reported that they are operating at a Stage 7, innovating level. Twenty-one of the 75 initiatives indicated that it took them only a year to become advanced. Only eight initiatives indicated that it took them four or more years to become advanced.

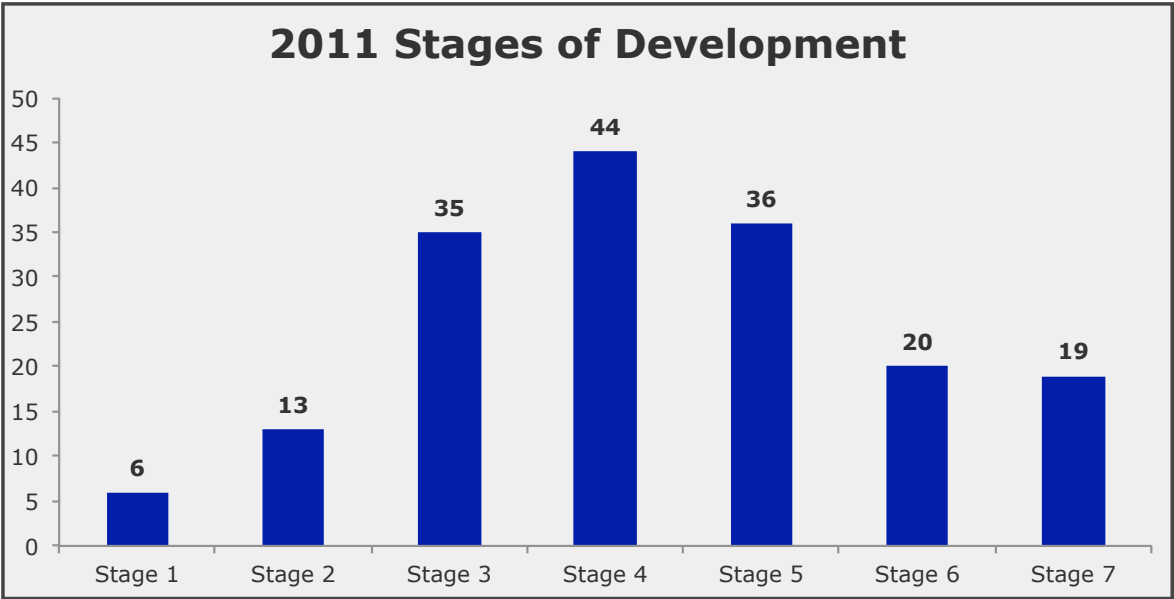


Figure 3: 2011 Initiatives by Stage of Development

Twenty-four organizations meet the eHealth Initiative’s definition of sustainability in 2011, up from 18 in 2010. To be considered sustainable, organizations must be in an advanced stage (5, 6, or 7), not dependent upon federal funding, and sustaining themselves through operational revenue alone.

WHAT MAJOR CHALLENGES ARE INITIATIVES FACING?

While HIE initiatives continue to report that developing a sustainable business model and defining value are their biggest challenges, this year has seen some new challenges emerge. Similar to previous years, 144 initiatives indicated that sustainability was a very difficult or moderately difficult challenge. Interestingly, defining value ranked second, with 134 initiatives reporting it was very difficult or moderately difficult. Since defining value is a key factor in developing a sustainable business model, it stands to reason that initiatives would find it difficult as they struggle to become sustainable.

A new top challenge cited by initiatives is addressing technical aspects, which rose from 118 to 131. Another rising challenge is the concern over systems integration; the number of initiatives identifying it as a challenge increased from 97 to 117 among this year’s respondents. As interoperability becomes more important, initiatives face mounting pressure to integrate disparate systems. Not surprisingly, engaging practicing clinicians increased as a challenge from 101 initiatives in 2010 to 116 in 2011.

KEY FINDING

In addition to struggling with business models and value, initiatives are facing new challenges including addressing technical aspects and systems integration.

It is interesting to note that obtaining state charter/authorization decreased from 54 initiatives in 2010 to 37 in 2011, which could reflect that many of the statewide HIEs and SDEs have already obtained authorization. Figure 4 details the top challenges initiatives face.

TOP CHALLENGES FACED BY INITIATIVES		
	2010	2011
Developing a sustainable business model	137	144
Defining value	129	134
Addressing government policy and mandates	131	132
Addressing technical aspects including architecture, applications and connectivity	118	131
Addressing privacy and confidentiality issues - HIPAA and other	127	127
Systems integration	97	117
FOR A FULL LIST OF THE CHALLENGES INITIATIVES ARE FACING, PURCHASE THE FULL SURVEY REPORT.		

Figure 4: Top Challenges Faced by All Initiatives

IV | STAKEHOLDERS TAKING THE LEAD

WHO ARE THE KEY STAKEHOLDERS INVOLVED IN GOVERNANCE?

The stakeholders involved in governing initiatives have not changed much over the last few years. The top five stakeholders remain the same, although there has been some movement around which stakeholders take the top spot. Overall, hospitals (161) and primary care physicians (132) have seen a large increase in their involvement in governance. Additionally, more initiatives (79) are including consumers in governance compared to 2010 (71). Figure 5 below provides a comprehensive list of the major organizations involved in governance.

KEY STAKEHOLDERS INVOLVED IN GOVERNANCE IN ALL INITIATIVES		
	2010	2011
Hospitals	138	161
Primary care physicians	123	132
Specialty care physicians	82	87
Community and/or public health clinics	99	86
Payers	86	82
Consumers	71	79
Local Public Health Department	79	76
Employers or health care purchasers	68	75
Patient or consumer groups	67	72
Behavioral or mental health providers	61	60
FOR A FULL LIST OF STAKEHOLDERS INVOLVED IN GOVERNANCE, PURCHASE THE FULL SURVEY REPORT.		

Figure 5: Key Stakeholders Involved in Governance

WHICH STAKEHOLDERS ARE EXCHANGING DATA?

The last year has seen an increase in stakeholders providing and receiving data. As more initiatives become advanced and care coordination becomes more important, it is expected that these numbers will continue to increase.

Interestingly, while hospitals continue to be the leading provider of data, more primary care physicians (PCPs) are viewing more data. There is one notable new trend. The number of initiatives with behavioral or mental health providers exchanging data has seen the largest increase. Figures 6 and 7 on the following page show the increase from 2010 to 2011 in stakeholders providing and receiving data.

KEY FINDING

More behavioral and mental health providers are viewing or receiving data.



STAKEHOLDERS PROVIDING DATA IN ADVANCED INITIATIVES		
	2010	2011
Hospitals	138	161
Primary care physicians	123	132
Specialty care physicians	82	87
Community and/or public health clinics	99	86
Payers	86	82
Consumers	71	79
Local Public Health Department	79	76
Employers or health care purchasers	68	75
Patient or consumer groups	67	72
Behavioral or mental health providers	61	60
FOR A FULL LIST OF STAKEHOLDERS PROVIDING DATA, PURCHASE THE FULL REPORT.		

Figure 6: Stakeholders Providing Data in Advanced Initiatives

STAKEHOLDERS VIEWING OR RECEIVING DATA IN ADVANCED INITIATIVES		
	2010	2011
Primary care physicians	58	68
Hospitals	61	65
Specialty care physicians	53	58
Community and/or public health clinics	51	51
Long-term care providers	33	36
Outpatient/ambulatory surgery centers	37	35
Behavioral or mental health providers	27	32
Skilled nursing facilities	28	31
Local Public Health Department	28	30
Independent radiology centers	20	22
FOR A FULL LIST OF STAKEHOLDERS VIEWING DATA, PURCHASE THE FULL REPORT.		

Figure 7: Stakeholders Viewing or Receiving Data in Advanced Initiatives

ARE INITIATIVES PLANNING ON SUPPORTING ACCOUNTABLE CARE ORGANIZATIONS (ACOs)?

For the past few months, ACOs have been in the spotlight. The healthcare industry eagerly waited for the release of the notice or proposed rulemaking (NPRM). Since its May 2011 release, there has been much discussion of the rule's finer points.

KEY FINDING

Initiatives are weighing their options about involvement with ACOs, a quarter of the respondents indicated that they will support an accountable care organization.

The Centers for Medicare and Medicaid Services (CMS) have received innumerable comment letters from across the industry over the last few months. While it is unclear what the final rule for ACOs will look like, it is clear that care coordination and exchange will be keys to a successful ACO. Patients involved in the program are not required to stay within a specific network. Therefore, hospitals and providers in an ACO will need to exchange information, not just within their own network or practice, but also with those outside of their organizations. They will need information from other providers and hospitals, and from community health resources. Hospitals and providers will need a holistic view of their patients to ensure they can manage and improve the quality of patients' care while reducing costs.

Some HIE initiatives may be positioned to act as an intermediary between disparate systems and support ACOs. When asked if they plan on participating in an ACO, 48 initiatives indicated that they will participate, and 38 indicated they would not participate. The majority of HIE initiatives, 110, are unsure of whether they will participate.



V | CHANGING BUSINESS MODELS

HOW DEPENDENT ARE INITIATIVES ON FEDERAL FUNDING?

The majority of HIE initiatives (115) reported that they were not dependent on federal funding in the last fiscal year; 65 respondents indicated that they were dependent on federal funding. The responses indicate that there has not been much movement since the 2010 survey. In 2010, 107 respondents were not dependent on federal funding, while 62 were dependent. In 2011, of the 75 advanced initiatives, 20 were dependent on federal funding, while 54 responded that they were not. Last year, only 48 advanced initiatives indicated they were not dependent on federal funding, while 27 were dependent on federal funding.

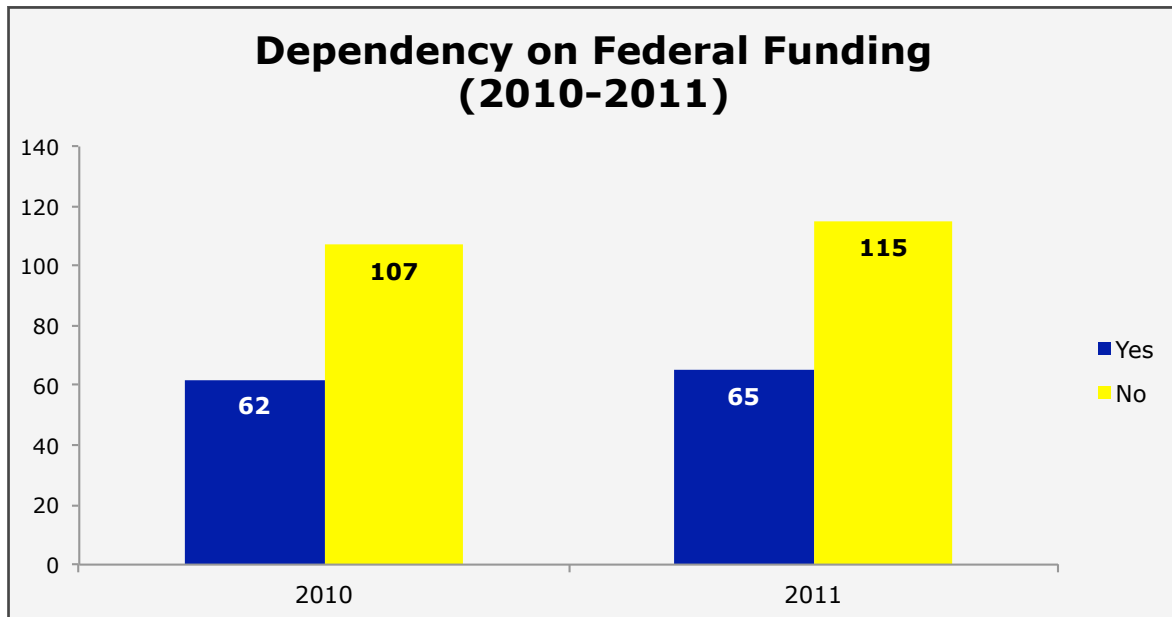


Figure 8: Dependency on Federal Funding (All Initiatives)

HOW MANY INITIATIVES ARE SUSTAINABLE?

Using the same criteria as in 2010, eHI identified 24 sustainable initiatives in 2011. Sustainable initiatives are those that reported that they are advanced (Stages 5, 6, or 7), were not dependent on federal funding in the last fiscal year, and broke even through operational revenue alone. eHealth Initiative will release a special report on the survey results provided from the sustainable initiatives later this year.

VI | TRANSFORMING HEALTHCARE THROUGH FUNCTIONALITY & SERVICE

HOW PREPARED ARE INITIATIVES TO SUPPORT MEANINGFUL USE REQUIREMENTS?

One way that HIE initiatives can move towards sustainability is by providing services desired by customers. Initiatives must then offer those services faster, cheaper, and more reliably than their competitors. The Meaningful Use program provides a roadmap for HIE initiatives on which services will be in demand over the next years. Initiatives seem to be paying attention.

KEY FINDING
Advanced initiatives are more prepared to support meaningful use.

This year has seen a significant increase in the number of respondents providing services that fall under Meaningful Use Stage 1 and the HIT Policy Committee recommendations for Stage 2. Figure 9 details which functionalities are Stage 1 and proposed Stage 2 requirements, and the number of HIE initiatives providing those functionalities. Figure 10 details the data advanced initiatives are exchanging and denotes which data is Stage 1 and proposed Stage 2 requirements.

KEY FINDING
The top 3 types of functionalities in 2011 for advanced initiatives are connectivity to EHRs (60), a Master Patient Index (60), and results delivery (47).

CURRENT FUNCTIONALITIES OF ADVANCED INITIATIVES	
	2011
Stage 1 Meaningful Use Items	
Connectivity to electronic health records	60
Electronic Prescribing	32
Alerts to providers-Drug-to-Drug	31
Alerts to providers-Drug-to-Allergy	29
Clinical decision support	25
Additional Stage 2 Proposed Meaningful Use Items	
Results delivery (e.g. laboratory or diagnostic study results)	47
Provider Directory	36
Disease registries	18
Image exchange	18
Reminders	16

CURRENT FUNCTIONALITIES OF ADVANCED INITIATIVES	
	2011
Additional Functionalities	
Master Patient Index	60
Health summaries for continuity of care	43
Record Locator Service	38
Clinical documentation	36
Alerts to providers	36

Figure 9: Current Functionalities of Advanced Initiatives

KEY FINDING
The top 4 types of data exchanged by the advanced initiatives in 2011 are laboratory results (64), medication data (56), outpatient lab results (54), and radiology results (54).

DATA EXCHANGED BY ADVANCED INITIATIVES	
	2011
Stage 1 Meaningful Use Items	
Laboratory Results	64
Care Summaries (demographics, encounter history, medications, etc.)	52
Emergency Department episodes/discharge summaries	50
Retail pharmacy	19
Additional Stage 2 Proposed Meaningful Use Items	
Outpatient laboratory results	54
Radiology results	54
Inpatient discharge summaries	49
Physician notes	45
Laboratory Ordering	30
Additional Data	
Medication data (including outpatient prescriptions)	56
Allergy info	53
Inpatient diagnoses & procedures	51
Pathology	43
Outpatient episodes	42

Figure 10: Data Exchanged by Advanced Initiatives
(Note: Not all of the Advanced initiatives responded to this question)

ARE INITIATIVES OFFERING NON-CLINICAL AND VALUE-ADD SERVICES?

As HIE initiatives move through the stages of development, they must continue to offer additional value-add services, including those services that are administrative in nature such as billing services, credentialing, or technical assistance. By offering these services, they can increase the value-proposition for HIE stakeholders participating in their organization. Initiatives have increased the number of value-add services they are offering. The number of HIE initiatives providing workflow modification guidance for clinicians and hospitals has grown in the last year among support functions. Non-clinical value-add services have also seen much growth across most of the service offerings. Figures 11 and 12 below indicate which non-clinical and value-add services initiatives are offering.

KEY FINDING

Advanced initiatives are offering more support services and value-add services to clinicians and hospitals.

SUPPORT FUNCTIONS ADVANCED INITIATIVES PROVIDE		
	2010	2011
Technical assistance for implementation with clinicians	49	49
Workflow modification guidance for clinicians	35	48
Technical assistance for implementation in hospitals	37	42
Hosting a support hotline for providers	30	38
Liaison between public and private health IT efforts in service area	36	37
Workflow modification guidance for hospitals	23	35
FOR A FULL LIST OF SUPPORT FUNCTIONS, PURCHASE THE FULL REPORT.		

Figure 11: Support Functions Advanced Initiatives Provide

NON-CLINICAL VALUE-ADD SERVICES PROVIDED BY ADVANCED INITIATIVES		
	2010	2011
Aggregation of Administrative Transactions	3	23
Billing Services	6	22
Charges for providing access to provider and provider related databases	6	22
Credentialing services	3	18
Distribution services, such as distributing reports to physicians	21	17
Electronic medical record hosting or EHR-Lite	N/A	17
FOR A FULL LIST OF NON-CLINICAL VALUE-ADD SERVICES, PURCHASE THE FULL REPORT.		

Figure 12: Non-Clinical Value-Add Services Provided by Advanced Initiatives



VII | INCORPORATING THE DIRECT PROJECT

In March 2010, an initiative, called the Direct Project, was launched by the Office of the National Coordinator (ONC). The goal of the Direct Project is to support use of internet protocols, for an easy-to-use secure method to replace mail and fax transmissions between providers and stakeholders,

such as other providers, labs, and public health departments. Additionally, the Direct Project aims to alleviate the need to build EHR-specific custom interfaces due to the lack of interoperability between EHRs. This effort is part of the Nationwide Health Information Network (NWHIN), developed to specify a simple, secure, scalable, standards-based way for participants to send authenticated, encrypted health information directly to known, trusted recipients over the internet. HIE initiatives that serve providers that are paper-based or have EHRs that are not certified may be able to use the Direct Project through the initiative to meet their health information exchange needs.

While the Direct Project is currently in a pilot phase, HIE initiatives will be able to incorporate it into their service offerings. In fact, initiatives under the Cooperative Agreement Program had to detail how they will incorporate it in order for their operating plans to be approved by ONC. In 2011, 113 initiatives responded that they will be incorporating Direct into their service offerings. Only seven initiatives do not plan to include it. Respondents were also asked what use cases they are or will be using for Direct.

KEY FINDING

Initiatives are preparing to incorporate the Direct Project into their service offerings.



VIII | PATIENT SERVICES

While most HIE initiatives do not interact directly with patients, a few are offering functional support services. Currently, 17 initiatives allow patients to access their health information through the exchange. Eighteen will offer access in the next year, and an additional 40 initiatives will offer it in the next two years. With Stage 2 of Meaningful Use focusing more on patient interactions, the number of initiatives offering services such as adding health information or viewing summaries of care should increase over the next three to four years.



IX | ENHANCING PATIENT PRIVACY

The last year has been a waiting game for updates to the Health Insurance Portability and Accountability Act (HIPAA) regulations to be finalized. Under HITECH, the Office of Civil Rights (OCR) was required to update the HIPAA regulations. For example, the business associate requirements need to be expanded, and the accounting for disclosures requirements need to be improved.

Although the HIPAA Privacy Rule does not require express patient consent or authorization for the exchange of health information for many routine purposes, HIE initiatives have typically implemented policies that promote patient privacy by giving patients some choice about whether or not their health information is included in or can be exchanged through the initiative. Further, state laws often require specific consent or authorization for the disclosure of all or certain types of health data. Providing patients with the right to either opt-in (typically consent provided before the information is included in or exchanged by the initiative) or opt-out (assuming the patient’s information is part of the exchange initiative unless the patient expressly opts-out) may be required by applicable law, or providing some choice can assist providers and initiatives in complying with such laws. 2011 saw more HIE initiatives providing patients with choice at a more granular level than just “all in” or “all out.”

LEVEL OF OPT-IN / OPT-OUT CHOICE

Initiatives were asked at what level they offer either opt-in consent or opt-out consent. Opt-out consent is still the predominant type of consent. Additionally, the majority of HIE initiatives provide consent options at the provider or organization level. See Figure 13 below for details on the level of consent provided by initiatives.

KEY FINDING

Initiatives are developing complex privacy controls for patients, even in the absence of new federal requirements.

2011 LEVEL OF OPT-IN/OPT-OUT CHOICE		
	Opt-in	Opt-out
By provider	39	70
By data type (lab, radiology results, etc.)	11	46
By encounter	15	44
By sending organization (hospital, lab, etc.)	25	52
By data field or individual data element (demographic information)	9	40
Sensitive Data (mental health, HIV, etc.)	28	36

Figure 13: Level of Opt-in or Opt-out Choice

X | RECOMMENDATIONS FOR MOVING FORWARD

For many, the last year has been a waiting game for policy related to HIE initiatives. The updated privacy regulations, Medicare Shared Savings Program, and Meaningful Use Stage 2 have all been looming for the past months. Some initiatives have been hesitant to move forward until the changes to the healthcare system are more concrete. However, the time for waiting seems to be over. HIE initiatives should consider the following as they move forward.

GET MOVING-TIME IS NOT YOUR FRIEND

The wait is coming to an end on the final Medicare Shared Savings Program rules, privacy regulations, and the recommendations for Stage 2 Meaningful Use. Additionally, the path forward to Stage 3 of Meaningful Use is beginning to emerge. HIE initiatives no longer have the luxury of moving slowly through the stages of development. They must find a way to quickly support stakeholders in meeting ever increasing requirements.

COMPETING TIMEFRAMES MEAN TOUGH CHOICES

Initiatives have multiple competing policy timeframes to work within to modify their systems – including Meaningful Use, HIPAA 5010, ICD-10, changes to the eRx Incentive Program, potential state certification/accreditation requirements, the NWHIN NPRM, and possible new requirements on metadata standards that were suggested in the President’s Council of Advisors on Science and Technology report released in early 2010. HIE initiatives must upgrade their systems to meet the new requirements of HIPAA 5010 and ICD-10 standards. In addition, the eRx Incentive Program is moving from an incentive to a requirement for providers. Those who do not meet the requirements will face penalties. Initiatives need to be able to support providers in meeting the requirements of this program. ePrescribing is also a requirement of Meaningful Use. Grantees of the State HIE Cooperative Agreement Program are required to support providers in ePrescribing in order to maintain their funding. A number of states have implemented certification or accreditation standards for HIE initiatives that operate in the state. Others are still considering these requirements. Initiatives must prepare to meet the necessary requirements that will be laid out in their state. Initiatives must also consider the coming NWHIN NPRM that will lay out the standards initiatives should use for health information exchange. Finally, ONC has announced they will be releasing an NPRM on metadata standards. It is unknown what the timeframe will be for implementing the standards, but initiatives must consider modifying their systems to meet the metadata standards.



USE THE POLICY PRESSURES TO YOUR BENEFIT

HIE initiatives can use the Meaningful Use Stage 2 and 3 HIT Policy Committee recommendations and the proposed ACO requirements under the Medicare Shared Savings Program as a road map for their service offerings. Both programs are transforming the healthcare system by increasing care coordination and patient involvement; both of which require health information exchange. Initiatives can be a trusted partner between competing organizations that will need to work together in an ACO. Providers also want to be able to assure their patients that they are exchanging health information in a way that can be trusted. Initiatives that can move quickly and offer services to support these programs will increase their value to their stakeholders

QUICK INNOVATION IS REQUIRED TO OVERCOME COMPETITION

Rather than waiting, initiatives need to offer more advanced services now, less expensively than competing providers can. Community-based and state initiatives are increasingly competing with IDN based initiatives. Since many IDNs have been exchanging data internally for years, they are well positioned to provide value-add services, such as analytics, quality reporting, wellness programs and education, PACs reporting, and emergency medical services data exchange. Some of these value-add services are pivotal for care coordination and consequently the transformed healthcare system the nation is moving towards. Initiatives that cannot provide these services in the very near future risk being left behind by networks that are already positioned to support these services.

CONTINUE TO RAMP-UP PRIVACY CONTROLS

Privacy and security issues continue to be in the spotlight. Initiatives are currently working on HIPAA 5010 requirements which begin in January 2012. A final rule with additional updates to HIPAA will be released by the end of 2011, and a NPRM for accounting of disclosures has also been released. Congress is also taking notice of privacy issues. There are a number of bills currently being considered by congress that concern consumer privacy that may have implications on the healthcare industry. If patients are to be engaged in their care, they have to trust that their information can be securely exchanged. One way of many to build this trust framework, initiatives need to offer patients more than a global consent model. Initiatives need to consider much more complex consent levels than global or organizational. Offering patients a consent model that gives patients some control over sensitive health information will help build trust.



WORK WITH WHAT YOU HAVE

Since initiatives need to rapidly innovate and move through the stages of development quickly, they need to consider working with the existing infrastructure in their geography. In some areas a well developed, Stage 7 community-based initiative is already operating. IDNs and hospitals should strongly consider working with them rather than reinventing the wheel. In other areas, there are well developed IDNs or health systems that community-based or state initiatives can work with. Initiatives should determine ways that they can work together to use existing infrastructure to support providers inside and outside of the IDN's network. While competition can be good for innovation, in the current rapidly changing healthcare market, competition may not be the best option for sustainability.

XI | METHODOLOGY

The 2011 *Eighth Annual Survey of Health Information Exchange* was launched on May 17, 2011 and closed on June 20, 2011. Announcement of the survey was communicated through newsletters, mailing lists, and meetings to a wide range of audiences in order to elicit responses from national, state, regional, enterprise, and community-based initiatives working on health information exchange.

Each response was reviewed carefully, and significantly incomplete responses, duplicates, or responses from organizations not directly involved with health information exchange were excluded. Responses to the survey were self-reported by participants. While responses were reviewed by eHealth Initiative staff for reasonableness, in most cases they were not verified.

After review, a total of 196 initiatives were included in the results. It should be noted that not all respondents answered each question, so a selection bias may exist. To view a list of initiatives, please visit www.ehealthinitiative.org.

Repeated attempts were made to contact all of the organizations who participated in the 2009 and 2010 *Annual Surveys of Health Information Exchange*. Personal emails were sent to individuals listed as organizational contacts, and follow-up phone calls were made to organizations that did not respond prior to the survey completion deadline. eHealth Initiative's staff was able to verify that an additional 59 initiatives that either responded in previous years or were provided by a State HIT Coordinator or vendor, are still pursuing HIE. Additionally, staff members were able to verify through phone calls and emails that 10 advanced initiatives that responded to the 2010 survey are still advanced in 2011.

To incentivize organizations to take the time to participate in and complete the survey in its entirety, participants were entered in a random drawing for one of two 16 GB Apple® iPads™.

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