2012 REPORT ON HEALTH INFORMATION EXCHANGE:

SUPPORTING HEALTHCARE REFORM

eHEALTH INITIATIVE
Real Solutions. Better Health.

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Introduction

Health information exchange (HIE) is the electronic mobilization of healthcare information or data across organizations within a state, region, community or hospital system. HIE moves clinical information among disparate healthcare information systems while maintaining the integrity of the information during the exchange. Formal organizations, like community-based organizations and statewide initiatives providing this service are known as health information exchange organizations. However, healthcare data exchange also occurs in many organizations that are not formal health information exchange organizations, such as between a hospital and affiliated independent practices. This report covers both types of data exchange, using the term "HIE initiatives" or HIE interchangeably.

Since 2004, eHealth Initiative (eHI) has fielded a comprehensive survey assessing the current state of data exchange within the United States. Over the years, this survey has grown from one that examined the nascent stages of HIE, into one that provides insight into the overall progress and growth of health information technology (HIT) and HIE throughout the country. Health information exchange organizations have been in existence for many years, but only a handful were surveyed in 2004. The number of exchanges has grown each year since then, and in 2009, as part of the American Recovery and Reinvestment Act (ARRA), the federal government helped fund several new and existing initiatives through the State Health Information Exchange Cooperative Agreement Program (SHIECAP). This support provided additional momentum for health information exchange nationwide. This year, eHI identified approximately 222 HIEs in the United States and territories.

The Era of Healthcare Reform

In the last few years, new legislation and federal requirements have helped underscore the importance of data exchange. Following the passage of the Affordable Care Act (ACA) in 2010, two new care delivery models have emerged that critically depend upon successful data exchange: accountable care organizations (ACOs) and patient-centered medical homes (PCMHs). In contrast with the traditional volume-based healthcare reimbursement model which calculates payment around the episodes of care provided, ACOs instead compensate providers according to the quality of care delivered, measurable improvements in population health, and achievements in cost containment – a goal that is alternatively referred to as the Triple Aim. By realigning payment incentives, ACOs leverage a teams-based approach towards integrating providers at disparate healthcare settings into a unified network responsible for the totality of a patient's care. A patient-centered medical home is a team-based model of care led by a personal physician who provides continuous and coordinated care throughout a patient's lifetime to maximize health outcomes.[1] Although ACOs and PCMHs have the potential to improve the coordination and value of care delivered, they depend on the timely, complete, and secure exchange of patient information between providers, facilities, and operations within and beyond participating networks. The results of the 2012 survey indicate that 47 HIE initiatives are currently participating in an ACO and 62 are participating in a PCMH. An additional 63 HIEs plan to participate in one or both of these models in the future. The success of ACOs and PCMHs in providing value-based services to patients is contingent on a robust and interoperable HIE infrastructure that can support coordination across the care continuum, data exchange between disparate sources, and evidence-based practices and clinical guidelines for care.

The Direct Project is a standards-based transport mechanism that sends authenticated, encrypted health information directly to an authorized entity

The recent release of the Centers for Medicare and Medicaid Services (CMS) Electronic Health Record (EHR) Incentive Program (otherwise known as Meaningful Use) Stage 2 requirements further emphasizes the importance of data exchange as a core element of healthcare reform. HIE-related requirements for Meaningful Use Stage 1 are minimal, requiring only a single test of the capability to exchange a patient's information. However, Stage 2 establishes more rigorous requirements, such as the use of specified data standards to enable interoperability, the creation of a patient summary of care record, and the inclusion of the Direct Project. As a result, some

[1] Definition provided by the American College of Physicians (www.acponline.org)

HIEs must improve their existing functionality and expand their service offerings to assist in the overall realization of nationwide health information exchange.

The *2012 Report on Health Information Exchange* will discuss the survey results in the context of health reform, including:

- Overview of the exchange landscape
- Stakeholder participation
- Health reform
- Data exchange
- Financing/Sustainability

Key Findings

The 2012 Report on Health Information Exchange discusses the survey results in the context of the American Recovery and Reinvestment Act (ARRA) and the Patient Protection and Affordable Care Act (ACA). Key findings from the report are highlighted below.

- **Data exchange is increasing.** In 2012, 322 organizations were solicited to take the survey an increase from the 255 in 2011. 107 respondents completed the survey in 2012 that also completed the survey in 2011.

- **The environment is ripe for new health information exchange organizations to form and persevere.** 54 new respondents completed the survey in 2012. 88 initiatives are in the advanced stages of development (Stages 5, 6 or 7 on the eHealth Initiative's HIE development scale), an increase of 13 from 2011.

- **Data exchange is playing a key role in healthcare reform efforts.** More than half (109) of the initiatives reported that they are currently supporting ACOs and/or Patient-Centered Medical Homes (PCMHs), and 63 indicated that they plan on doing so in the future. 91 HIEs indicated that they are supporting ACOs or PCMHs by either providing technical infrastructure (the functionality to exchange data between entities) or analytics (the functionality to analyze data for cost efficiencies and/or quality improvement).

- **Federal funding is still supporting many advanced initiatives.** The single most substantial source of financial support in 2012 was federal funding, as indicated by 27 of the advanced HIEs surveyed. Out of those 27 respondents, 22 were classified as state-designated entitles (SDEs).

- **Organizations are "bullish" about surviving without federal funding.** 37 SDEs (of 39 responding) believe it is 'very likely' or 'likely' that they will remain operational after HITECH funding expires. 31 SDEs also reported that it is 'very likely' or 'likely' they will be financially sustainable three years from now, assuming no additional federal funding is appropriated.

- **Support of Direct is growing.** 59 HIE organizations currently offer Direct and 53 plan to support Direct in the future. Only 25 HIEs offered Direct at the time of the 2011 survey. The most common use cases for Direct are transitions of care and/or the exchange of laboratory results.

- **Competition is increasing.** In addition to sustainability, funding, privacy, and confidentiality issues, initiatives are facing the additional challenge of competition in the marketplace from other HIE initiatives, vendors, or other stakeholders.

Methodology

The 2012 *Survey of Health Information Exchange* was launched on July 16, 2012 and closed on October 1, 2012. The survey was announced and links to the instrument were communicated through eHI's newsletter, mailing lists, personal phone calls, and meetings. A wide range of audiences were contacted in order to elicit responses from national, state, regional, enterprise, and community-based initiatives working on health information exchange.

In this year's survey, some questions differed from those in past years as the emphasis was on maturity and scope of exchange, stakeholder involvement, data exchange, and sustainability. Reflecting the changing landscape of HIE, new questions explored areas previously unaddressed in past surveys, such as the effect that HITECH may have on sustainability, the potential for HIEs to remain operational and sustainable when HITECH funding expires, and the role that HIEs are playing in healthcare reform. Where possible, we made comparisons between the data collected in 2011 and 2012 to demonstrate trends over time. However, in some cases, response options in 2012 were altered to make the survey easier to complete and provide new insight into the evolving activities of HIEs across the nation. For example, in past years, respondents could select from a lengthy list of the types of data that HIEs are exchanging in both inpatient and ambulatory settings. In 2012, we aggregated some of the data types in this list in order to provide a broader understanding of the data being exchanged. In this case, we feel it is more valuable to understand how many HIEs are exchanging public health reports overall, rather than the specific public health data elements that one or two HIEs might share. Respondents were not required to address every question, and in some cases, answers were left blank even when the survey was completed in its entirety. HIEs that started the survey and did not complete it (partial responses) were not included in our tabulations. Based on findings from past years, most HIEs that only complete a portion of the survey are either in too nascent of a state to adequately address most of the questions, or are not facilitating data exchange. Responses to the survey were self-reported by participants. While responses were reviewed by eHealth Initiative staff (eHI) for reasonableness, in most cases they were not verified.

322 HIEs were solicited for a response to the survey. Of these 100 organizations were discarded because they do not facilitate information exchange. In total, 161 HIEs responded, which equates to an approximately 73% response rate. One possible explanation for the difference in the number of responses in 2011 and 2012 is that eHI did not count partial responses this year. Additionally, there are respondents who completed the survey, but may have opted to pass on a specific question, which may have introduced selection bias into the results.

Repeated attempts were made to contact all of the organizations who participated in the 2010 and 2011 HIE surveys. 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. Based on responses to the survey, at least 107 initiatives that responded in previous years are still pursuing HIE. Forty advanced initiatives that responded to the 2011 survey reported that they are still advanced in 2012.

Demographics - An Overview of HIE in the United States

Key Findings:

1. *161 HIE initiatives responded to the 2012 Annual Survey.*
2. *There are 88 advanced initiatives in 2012, an increase of 13 since 2011.*

Since the passage of ARRA and launch of the State Health Information Exchange Cooperative Agreement Program (SHIECAP) several years ago, the HIE ecosystem has grown to become more vibrant and diverse than ever. As 2012 comes to a close, some HIEs have ceased operations or merged, new HIE initiatives have started, and others have evolved to exchange additional types of data, achieve a sustainable business model that is not dependent upon federal funding, or offer value-add services beyond the immediate functionalities required for basic HIE. The expanding reach of HIE initiatives has also begun to attract and integrate new stakeholder entities such as mental health and long-term care providers within the greater health system.

How many initiatives are there?

Based on responses to past surveys and research, eHealth Initiative identified approximately 322 possible HIE initiatives to participate in the survey. Of these 322, 100 were removed from the study sample either because they responded to the survey and indicated that they did not facilitate information exchange, or they did not respond to repeated contact attempts and further review was unable to verify whether the initiative was functional. Of the remaining 222, 16 declined to participate and 43 could not be reached after numerous attempts. Two responses were duplicates and subsequently removed, leaving a total of 161 HIE initiatives that completed the survey.

Who are they?

Respondents to the 2012 Annual Survey predominantly described themselves as health information exchange organizations (101)[2], statewide HIEs or state designated entities (39), or healthcare delivery organizations (28). Other responses (25) included nongovernmental organizations or policy/advocacy groups, academic institutions, technology vendors, public health departments, and state government. Figure 1 displays the types of initiatives.

[2] Includes regional and community based health information exchanges

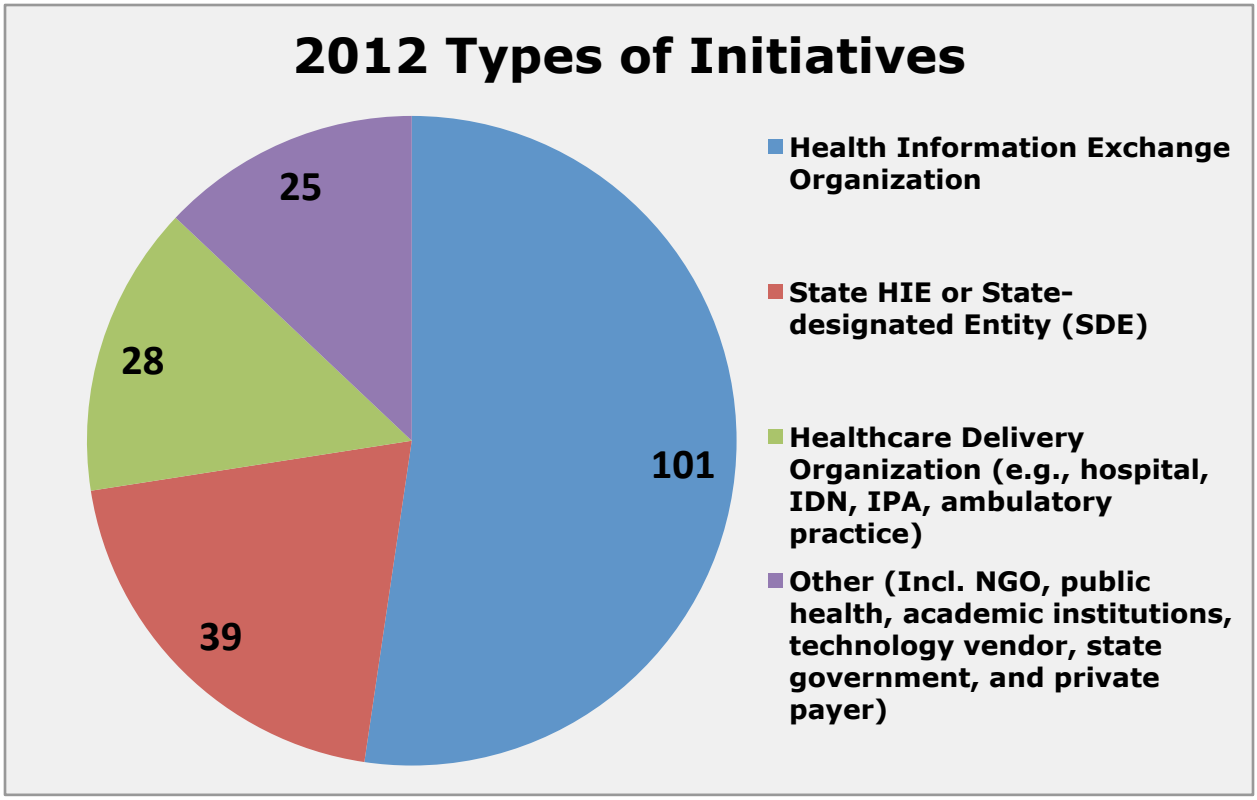

Figure 1: Types of Initiatives
(Note: Respondents could select more than one option)

Most HIE initiatives reported themselves as established, independent organizations (106) and operate as non-profit corporations (111). HIEs that operate within other organizations (49) were most often part of healthcare provider organizations (16) or government (12). Only 20 HIEs operate under a for-profit or limited liability company, trust, or partnership legal model. Additionally, most initiatives (123) do not restrict participation in the exchange for competing entities provided they meet requirements to participate (e.g. pay membership fees). Fifteen HIEs responded that they are private or enterprise HIEs and therefore restrict which stakeholders can participate.

Where are they?

Federal investment and the growing need for electronic health exchange have stimulated the growth of HIEs across the country, but some states have had more initiatives develop over the past few years than others. Figure 2 demonstrates a list of the states with the highest concentration of HIE initiatives, including state-level initiatives.

Top States for HIE		
State	**Number of HIEs 2011**	**Number of HIEs 2012**
California	10	22
New York	17	16
Florida	12	9
Michigan	10	9
Oklahoma	8	9
Texas	17	9
North Carolina	9	8
Illinois	7	7
Georgia	6	6
Massachusetts	4	6
Wisconsin	2	6

Figure 2: Top States for HIE

Figure 3: eHI Stages of Development

Development

Since 2005, eHealth Initiative has used a framework for assessing and tracking HIE development based on seven stages of development (see Figure 3). As in past years, the stage of development reported by survey respondents follows a relatively normal distribution. However, the center of the distribution has shifted in 2012, indicating that initiatives have become slightly more advanced overall. Figure 4 shows the distribution of stage of development in 2011 and 2012.

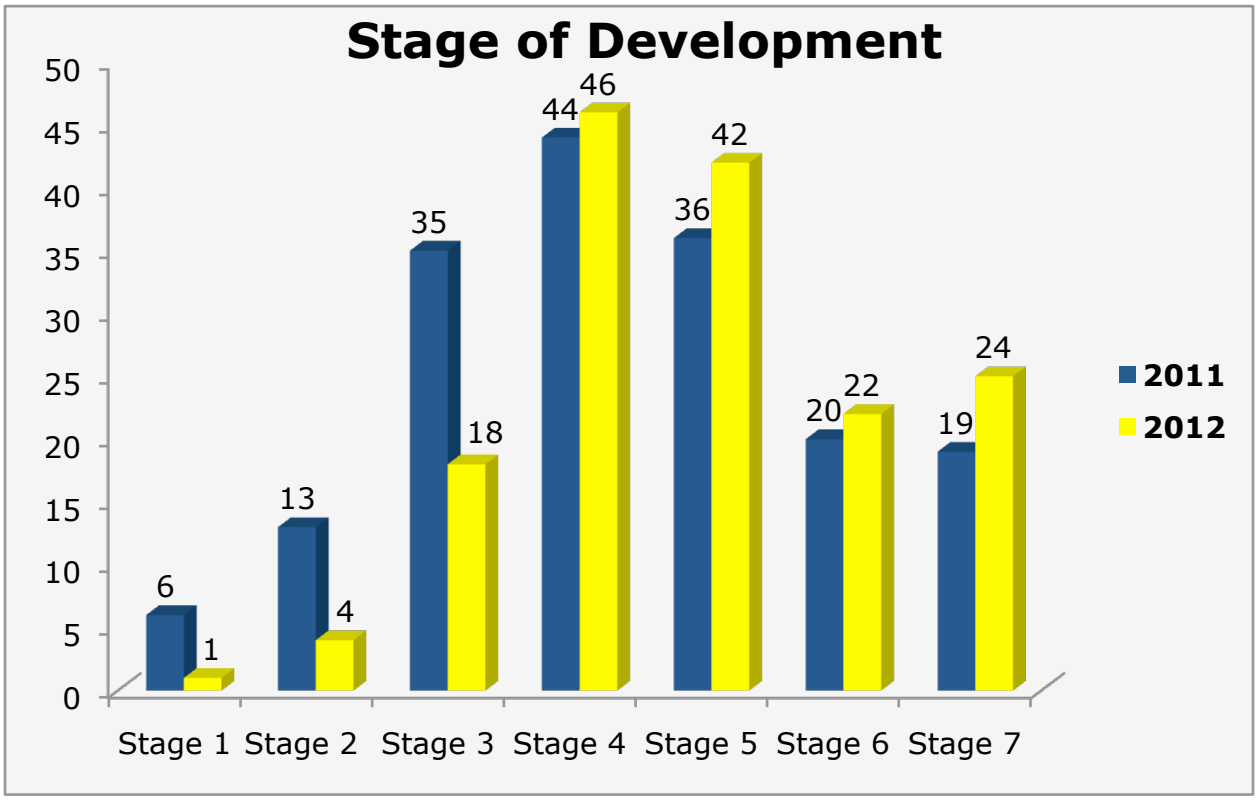

Figure 4: Stage of Development

According to eHI's framework, "advanced" initiatives are those that have reached the operating, sustaining, or innovating phases (5, 6, or 7) of development. These organizations, at a minimum, are actively transmitting data between stakeholders. In 2011, there were 75 advanced initiatives. In 2012, 88 responded that they had reached stages 5, 6, or 7. Of note, 24 of these initiatives have reached the highest stage in 2012, an increase of five since 2011. Figure 5 shows the growth in the number of advanced initiatives since eHI began the annual survey.

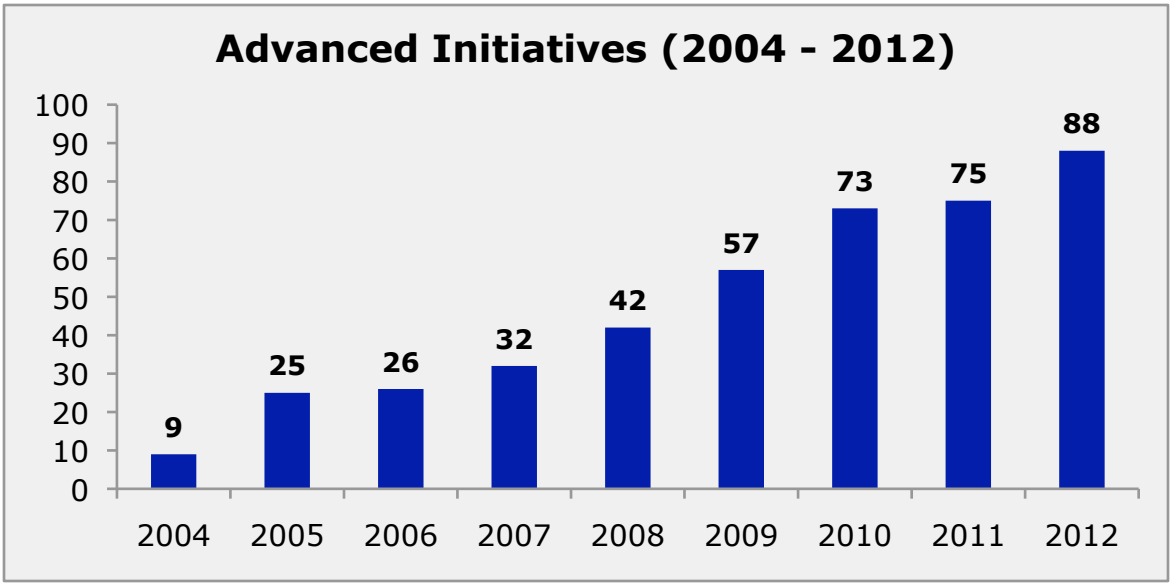

Figure 5: Advanced Initiatives 2004-2012

Figures 6 and 7 show the geographic distribution of advanced HIEs in 2011 and 2012, respectively. New York continues to have the most advanced initiatives (11). California witnessed a large increase in the number of advanced initiatives responding to the survey, from five in 2011 to ten in 2012. Twenty-one states have four or more advanced initiatives, and every state excluding the US territories and Arkansas have at least one.

States with Advanced HIE Initiatives 2011

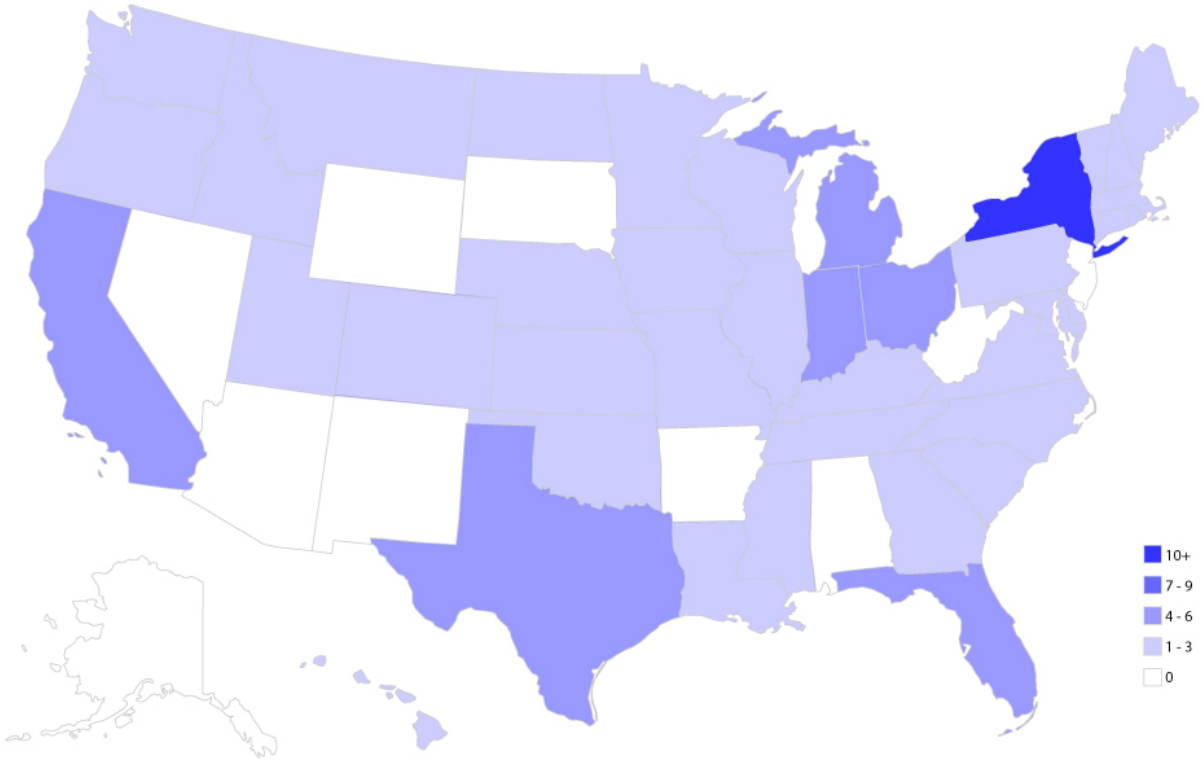

Figure 6: States with Advanced Initiatives 2011

States with Advanced HIE Initiatives 2012

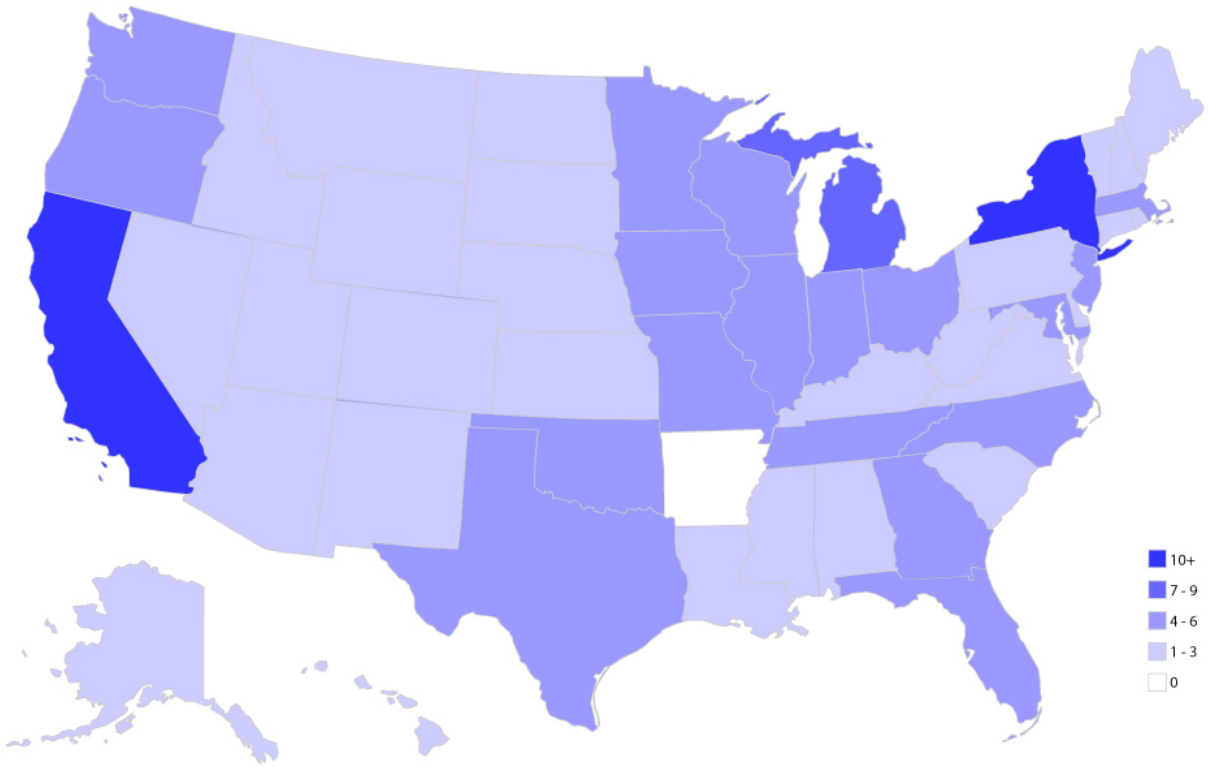

Figure 7: States with Advanced Initiatives 2012

Finally, the size of HIE initiatives can also reflect their level of development, as many initiatives launch with a core group of providers and expand over time. HIEs covering a greater number of stakeholders have a larger base from which to draw revenue, potentially increasing the chances that the HIE can reach sustainability. Similarly, the more stakeholders an HIE covers, the more likely it is that the organization was able to convince those stakeholders that there is value in data exchange. The majority of HIE initiatives report between 1-20 hospitals and 1-50 ambulatory practices are participating in the exchange. Figure 8 shows the number of hospitals and Figure 9 shows the number of individual ambulatory practices providing or viewing data among all initiatives.

Number of Participating Hospitals Providing or Viewing/Receiving Data within an HIE		
Number of hospitals	**Providing**	**Viewing/ Receiving**
0	6	13
1-20	70	66
20-40	11	8
40-60	6	4
60+	2	2

Figure 8: Number of hospitals providing or viewing/receiving data

Number of Participating Ambulatory Practices Providing or Viewing Data Within an HIE		
Number of Ambulatory Practices	**Providing**	**Viewing/ Receiving**
0	15	8
1-50	44	41
50-100	15	13
100-150	5	8
150-200	2	2
200-250	1	2
250-300	1	1
300-350	1	1
350-400	2	2
400-450	1	0
450-500	0	0
500+	2	8

Figure 9: Number of ambulatory practices providing or viewing/receiving data

Additionally, Figure 10 shows the number of hospitals providing or viewing/receiving data and Figure 11 shows the number of ambulatory practices providing or viewing/receiving data within an Advanced HIE.

Number of Participating Hospitals Providing or Viewing/Receiving Data within an Advanced HIE		
Number of hospitals	**Providing**	**Viewing/ Receiving**
0	1	6
1-20	53	53
20-40	10	7
40-60	5	4
60+	2	1

Figure 10: Number of hospitals providing or viewing/receiving data within an Advanced HIE

Number of Participating Ambulatory Practices Providing or Viewing/Receiving Data within an Advanced HIE		
Number of Ambulatory Practices	**Providing**	**Viewing/ Receiving**
0	9	1
1-50	32	30
50-100	12	11
100-150	6	8
150-200	2	2
200-250	1	2
250-300	1	1
300-350	1	1
350-400	1	2
400-450	1	0
450-500	0	0
500+	2	9

Figure 11: Number of ambulatory practices providing or viewing/receiving data within an Advanced HIE

Stakeholder Participation

As HIE initiatives grow and mature in size and scope, new stakeholder organizations are incorporated into entities to increase the volume and diversity of data exchanged.

Which stakeholders are engaged in governance?

The top stakeholders involved in governing initiatives remain consistent with previous years' findings. Ambulatory practices (104), including primary and specialty physicians, and hospitals (97) remain highly engaged in governance. Local and state public health departments, as well as public and private payers, remain consistent in levels of governing initiatives. Pharmacies (17) are less likely to participate than in years past.

Stakeholders Reported to be Involved in HIE Governance[3]		
	2011	**2012**
Ambulatory practice (primary + specialty)	219	104
Hospitals	161	97
Integrated delivery network	N/A	69
Public Health Department (local + state)	132	67
Private Payers	82	53
Public Payers (Medicaid + Medicare)	65	38
Long-term care provider	40	21
Independent laboratory	27	18
Independent pharmacy	42	17
Independent radiology center	18	11

Figure 12: HIEs Reporting Stakeholders Involved in Governance

[3] The sample size of HIEs surveyed in 2011 was larger than in 2012, and a number of categories were combined in 2012, leading to significant differences when comparing the crude numbers above for analysis.

Which Stakeholders are Providing Data?

Hospitals (89), ambulatory practices (79), and independent laboratories retain their position as the top stakeholders providing data to initiatives. Although behavioral health providers (52) showed a large increase in the number providing data between 2011 and 2012, there was a general downward shift in the stakeholders reported across the other categories due to different sample sizes (see footnote below). When looking at the ranking of the crude number of stakeholders reported, fewer public health departments and public and private payers provided data in 2012. Figure 13 shows the types of stakeholders providing data to HIE initiatives.

Stakeholders Providing Data to HIE Initiatives[4]		
	2011	**2012**
Hospitals	125	89
Ambulatory practice (primary + specialty)	204	79
Independent laboratory	82	55
Behavioral health provider	37	52
Integrated delivery network	N/A	48
Independent radiology center	59	37
Public Health Department (local + state)	66	32
Long-term care provider	34	24
Independent pharmacy	50	22
Psychiatric hospitals	N/A	18
Private Payers	38	17
Public Payers (Medicaid + Medicare)	59	16

Figure 13: Stakeholders Providing Data to HIE Initiatives

[4] The sample size of HIEs surveyed in 2011 was larger than in 2012, leading to significant differences when comparing the crude numbers above for analysis. Additionally, some response options for the 2011 survey were combined (as indicated by parentheses) for comparison with 2012 responses.

Which Stakeholders Are Viewing or Receiving Data?

Top stakeholders participating in viewing or receiving data remained consistent with past years. Ambulatory practices (81), hospitals (81), and public health departments (58) remain the most engaged in viewing or receiving data. There was a general downward shift in the stakeholders reported across the other categories due to different sample sizes. When looking at the ranking of the crude number of stakeholders reported, significantly fewer public payers viewed or received data. Figure 14 illustrates which stakeholders are viewing or receiving data from HIEs.

Stakeholders Viewing or Receiving Data through HIE Initiatives[5]		
	2011	**2012**
Ambulatory practice (primary + specialty)	223	81
Hospitals	116	81
Public Health Department (local + state)	105	58
Behavioral health providers	57	55
Integrated delivery network	N/A	55
Long-term care provider	68	45
Independent radiology center	43	29
Independent laboratory	42	23
Psychiatric hospitals	N/A	18
Private Payers	37	18
Public Payers (Medicaid + Medicare)	57	16
Independent pharmacy	36	13

Figure 14: Stakeholders Viewing or Receiving Data

[5] The sample size of HIEs surveyed in 2011 was larger than in 2012, leading to significant differences when comparing the crude numbers above for analysis. Additionally, some response options for the 2011 survey were combined (as indicated by parentheses) for comparison with 2012 responses.

Barriers and Challenges

Key Finding:

In addition to sustainability, funding, privacy, and confidentiality issues, initiatives are facing the challenge of competition in the marketplace from both HIE vendors as well as other HIEs.

Although HIE initiatives continue to report that developing a sustainable business model remains a significant challenge, several new challenges have emerged this year. Similar to previous years, initiatives (116) most often indicated that sustainability was a moderate or substantial challenge. However, financial barriers are not solely limited to long-term sustainability; 103 initiatives reported that a lack of funding in general was a moderate or substantial challenge. Notably, 104 initiatives reported that stakeholder concerns about privacy and confidentiality issues were a moderate or substantial challenge.

In 2012, competition has emerged as a new issue that may be significantly impacting participation in HIEs. Not only did 89 initiatives report stakeholder concerns about competitive position in the market, but competition from HIT system vendors and other HIE efforts were cited as challenges by 68 and 63 initiatives respectively. Given the importance of stakeholder buy-in to sustainability, competition between initiatives and health IT vendors over stakeholder populations could impact future development of HIE overall. Moreover, these findings suggest that some stakeholders may not engage in health information exchange because of concerns surrounding issues such as return-on-investment, privacy, and interoperability. It will therefore be critical for initiatives to build a technical infrastructure and create a framework of governance and policies that clearly establishes the value of participation and allays concerns for all stakeholders.

Other significant challenges that continue to be reported by initiatives include government policy and technical barriers, such as procurement architecture, applications, connectivity, and integration.

Stakeholder Engagement

As initiatives continue to transition from planning into operational stages of development, stakeholder engagement remains a significant barrier to successful data exchange. Seventy-nine HIE initiatives noted a general lack of stakeholder interest in HIE, reflecting survey findings that HIEs had difficulty engaging stakeholders such as health providers, plans, purchasers, laboratories, and hospitals in previous years. More worrisome, perhaps, is the fact that 63 initiatives

cited a lack of agreement on the definition of HIE, suggesting that the role and value of health information exchange needs to be more clearly defined and communicated to stakeholder organizations across the healthcare system. Figure 15 details the top challenges that initiatives face, with "N/A" denoting an issue that was not previously included in the 2011 survey.

TOP CHALLENGES FACED BY INITIATIVES		
	2011	**2012**
Developing a sustainable business model	144	116
Stakeholder concerns about privacy and confidentiality issues – HIPAA and other	127	104
Lack of funding	93	103
Addressing government policy and mandates	132	97
Addressing technical barriers, such as procurement architecture, applications, connectivity, and integration	131	94
Stakeholder concerns about their competitive position in the market	N/A	89
Accurately linking patient data	110	86
Addressing organizational and governance issues	107	84
General lack of stakeholder interest	105[6]	79
Competition from health IT system vendors offering HIE solutions	N/A	68
Ability to hire/retain staff	N/A	65
Lack of agreement on what HIE is/includes	N/A	63
Competition from other HIE efforts	N/A	63

Figure 15: Top Challenges Faced by All Initiatives

When comparing the challenges faced by advanced initiatives with those reported above by all HIEs in 2012, a similar ranking is observed with some minor differences. Results indicate that as initiatives mature into advanced stages, technical barriers and concerns about competitive position become more significant challenges. On the other hand, responses from advanced initiatives indicate that they may be better equipped to alleviate concerns about privacy and confidentiality, lack of funding, and addressing government policy. However, 64 of the 88 advanced initiatives still report that developing a sustainable business model is their organization's top challenge. This concern is also reflected in response to other sections of the survey; more than 30% of advanced initiatives regard federal

[6] This number represents a compilation of two response options on the 2011 survey: "engaging practicing clinicians" and "engaging hospitals".

funding – which is expected to steadily decline over the next several years – as their most substantial source of support. Figure 16 displays the comparison below.

TOP CHALLENGES FACED BY ADVANCED INITIATIVES IN 2012		
	All Initiatives	**Advanced Initiatives**
Developing a sustainable business model	111	64
Addressing technical barriers, such as procurement architecture, applications, connectivity, and integration	90	53
Stakeholder concerns about their competitive position in the market	86	51
Stakeholder concerns about privacy and confidentiality issues – HIPAA and other	98	50
Lack of funding	98	47
Addressing government policy and mandates	91	47
Accurately linking patient data	84	46
Addressing organizational and governance issues	79	45
General lack of stakeholder interest	76	37
Competition from health IT system vendors offering HIE solutions	66	34
Competition from other HIE efforts	58	35
Ability to hire/retain staff	62	29
Lack of agreement on what HIE is/includes	60	27

Figure 16: Top Challenges Faced by Advanced Initiatives in 2012

Data Exchange

Key Finding*:*

The top 5 types of inpatient and outpatient data exchanged by the advanced initiatives in 2012 are results (76), clinical summaries (62), discharge list (62), outpatient problem list (56), and ambulatory medication list (55).

What Types of Clinical Data are Exchanged or Transmitted Electronically between Entities?

As HIE initiatives mature through the seven stages of development towards sustainability, the functionalities and services they offer evolve to meet the needs of participating customer entities. Competing initiatives often follow suit and offer these services as well, leading them to become more common in the marketplace and forcing initiatives to develop to innovate and deliver cheaper, faster, and better services.

DATA EXCHANGED BY ADVANCED INITIATIVES		
	2011	**2012**
Results	**118**[7]	**76**
Inpatient Data	**100**[8]	**70**
Discharge List	49[9]	62
Problem List	51[10]	52
Inpatient Medication List	N/A	44
Physician Notes	45	42
Outpatient/Ambulatory Data	**96**[11]	**71**
Clinical Summaries	52[12]	62
Problem List	N/A	56
Ambulatory Medication List	56	55
Physician Notes	45	40
Referrals	N/A	39
Patient Summary Care Record	52	70
Public Health Reports	N/A	28

Figure 17: Data Exchanged by Advanced Initiatives
(Note: Not all of the Advanced initiatives responded to the question)

[7] Data combines the responses to the "laboratory results" and "radiology results" answer options in the 2011 survey.
[8] Data combines the responses from the "inpatient discharge summaries" and "inpatient diagnoses and procedures" answer options in the 2011 survey.
[9] Data taken from the "inpatient discharge summaries" response from 2011.
[10] Data taken from the "inpatient diagnoses and procedures" response from 2011.
[11] Data combines the "Outpatient Laboratory Results" and "Outpatient Episodes" responses from the 2011 survey.
[12] Data taken from the "Care Summaries" response from the 2011 survey.

Figure 18 shows the percentage of advanced HIEs exchanging each of the main categories of data in 2012 (n=88).

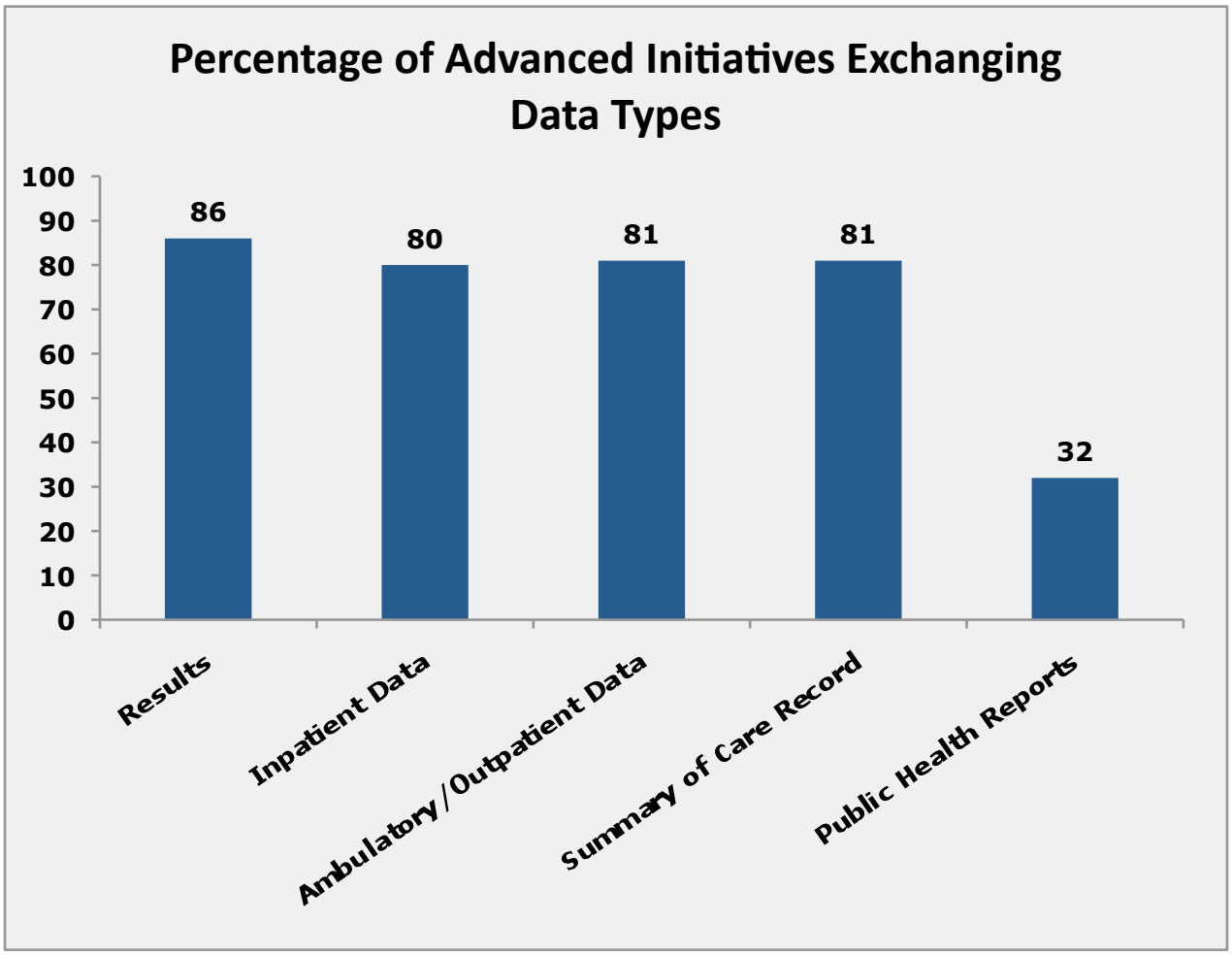

Figure 18: Percentage of Advanced HIEs exchanging data types

Are Initiatives Pushing or Pulling Data to Users?

HIE functionalities have rapidly improved and evolved over time to facilitate bi-directional exchange, which is the ability to both "push" and "pull" information. A push model, seen in Figure 19[13], refers to unidirectional electronic messaging between entities, such as when a clinician requests a colleague at another hospital send a patient's record. The push model has recently been popularized by the Direct project. A pull model is a query/retrieve exchange in which a query is initiated by a participant and data is automatically retrieved from other sources. Bi-directional exchange is critical to the daily needs of providers and hospitals alike, both of which regularly need to push and pull patient data to and from other systems. Today, many HIE initiatives provide both of these capabilities in response to the priorities and needs of participating stakeholder entities. Of the initiatives surveyed, 104 use a push model, 112 use a query model, and 87 report using an end-to-end integration model, which interfaces between systems to enable seamless exchange without any user-initiated effort (e.g. push or query) required.

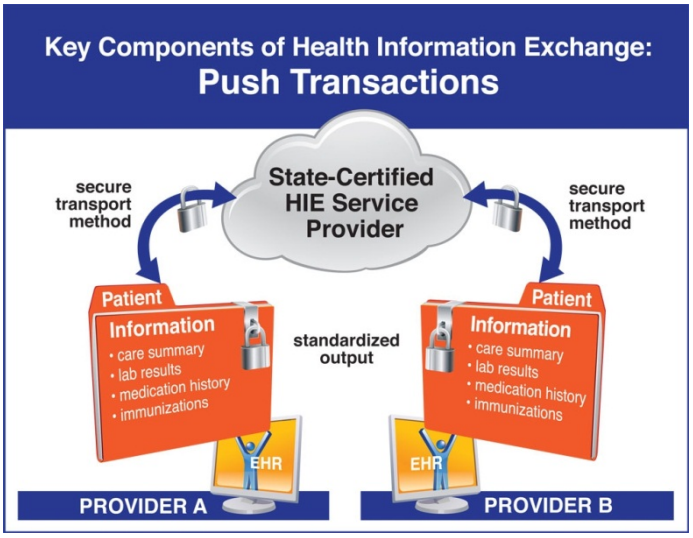

Figure 19: Push Model

[13] Graphic taken from the Minnesota Department of Public Health.

HIEs, Meaningful Use and Health Reform

Key Findings:

1. *More advanced initiatives are prepared to support Meaningful Use in 2012 than in 2011.*
2. *Many initiatives are participating in the State Health Information Exchange Cooperative Agreement Program, which has largely accelerated HIE capability and progress.*
3. *More than half of the initiatives reported that they currently support ACOs and/or PCMHs, and another 30% indicated that they plan on doing so in the future.*
4. *The number of initiatives that are currently offering Direct has almost doubled between 2011 and 2012. The primary purpose of either using or planning to use Direct is for transitions of care (clinical summary from hospital to PCP, PCP to specialist, and specialist to PCP).*

Many HIE initiatives have followed the roadmap set forth by the Meaningful Use program for guidance on the services that are expected to be in demand over the coming years. After the release of the final Stage 1 and Stage 2 Meaningful Use rules, it is clear that advanced initiatives are and have been preparing to support the checklist of required functionalities. Although the proposed and final rules for Stage 3 remain to be released, it is expected that the final stage of Meaningful Use will create an opportunity for significant value-add services for HIE initiatives. Figure 20 below details the Meaningful Use criteria that advanced initiatives currently support.

CURRENT FUNCTIONALITIES OF ADVANCED INITIATIVES[14]		
	2011	**2012**
Implement capability to electronically exchange key clinical information among providers and patient-authorized entities	60	82
Provide summary of care record for patients referred or transitioned to another provider or setting	43	71
Incorporate clinical laboratory test results into EHRs as structured data	47	58
Submit electronic immunization data to immunization registries or immunization information systems	15	35
Generate and transmit permissible prescriptions electronically (ePrescribing)	32	31
Submit electronic syndromic surveillance data to public health agencies	14	25
Submit electronic data on reportable laboratory results to public health agencies	13	24
None	N/A	1

Figure 20: Current Functionalities of Advanced Initiatives

[14] The sample size of HIEs surveyed in 2011 was larger than in 2012, leading to significant differences when comparing the crude numbers above for analysis.

Participation in State Health Information Exchange Cooperative Agreement Program

Under the State Health Information Exchange Cooperative Agreement Program (SHIECAP), 56 states, eligible territories, or qualified State Designated Entities (SDEs) in the U.S. received funding to support HIE within and across states. Regional and state-level HIE capabilities have evolved and expanded over time as more initiatives become involved with participating state or SDE organizations. In 2012, the majority of initiatives responding to the survey (70%) reported active involvement with statewide HIE or SDE efforts. Figure 21 below shows the distribution of participation.

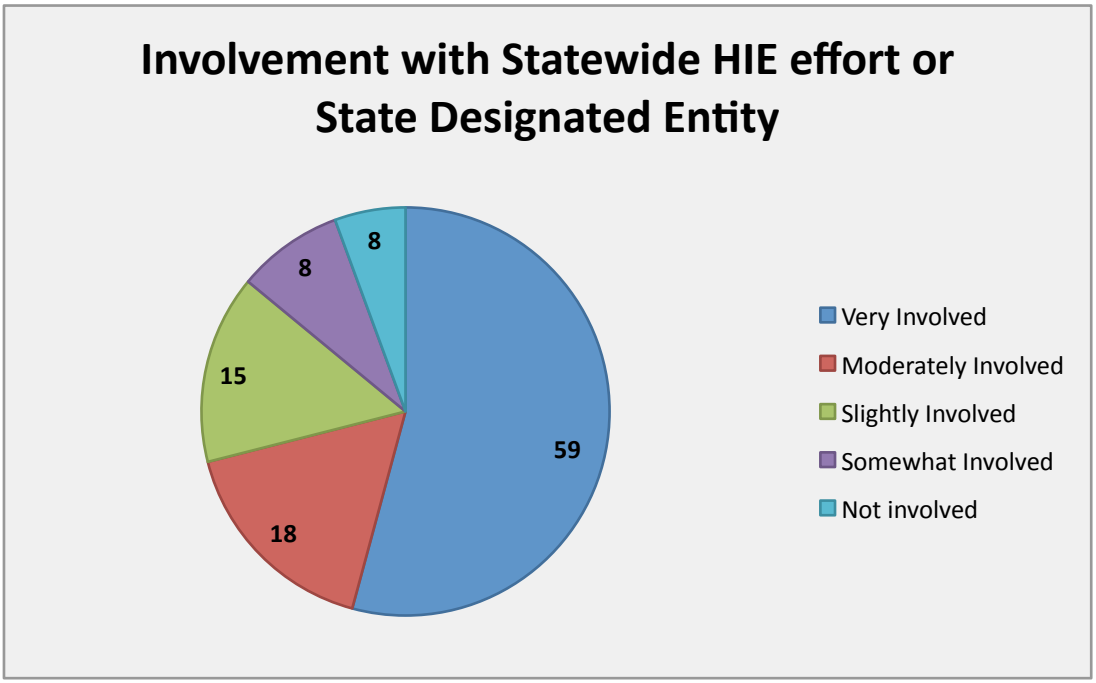

Figure 21: Involvement with State Health Information Exchange Cooperative Agreement Program

Initiatives further reported that not only were many involved with SHIECAP, but that the statewide HIE efforts and SDE activities had also largely accelerated progress. Figure 22 below shows the distribution of impact.

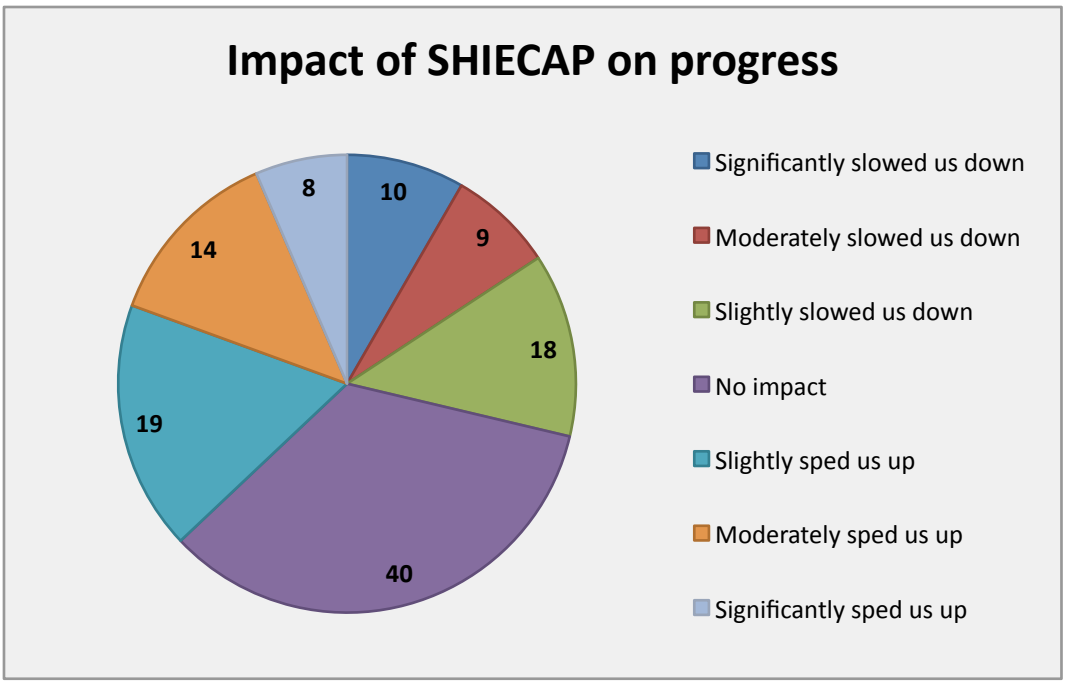

Figure 22: Extent of impact of statewide HIE efforts or SDE activities on progress

Are Initiatives Supporting Delivery System Reform Efforts?

In the face of rising fragmentation and costs, the healthcare system in the U.S. has witnessed the introduction of transformational reform initiatives that are changing the way health care is delivered by emphasizing quality-driven, value-based, and patient-centric approaches. Two models have emerged and proliferated over the past several years that are changing the paradigm of health system performance: Patient-Centered Medical Home (PCMH) and Accountable Care Organization (ACO). The PCMH model emphasizes the role of a primary care practitioner to coordinate continuous patient care across multiple settings over time while reducing costs, improving quality, and integrating a patient-centric approach. An ACO is a provider organization that accepts responsibility for the cost and quality of care delivered to a specific population of patients.

In addition to aligning with specific Meaningful Use incentives, HIE initiatives have also positioned themselves to support delivery system reform efforts by enabling the measurement, collection, and exchange of patient data across EHR systems, administrative databases, and patient and disease registries. More than half of the initiatives reported that they currently support ACOs and/or PCMHs, and another 30% indicated that they plan on doing so in the future. Figure 23 displays below the range of organizations that initiatives support or plan to support.

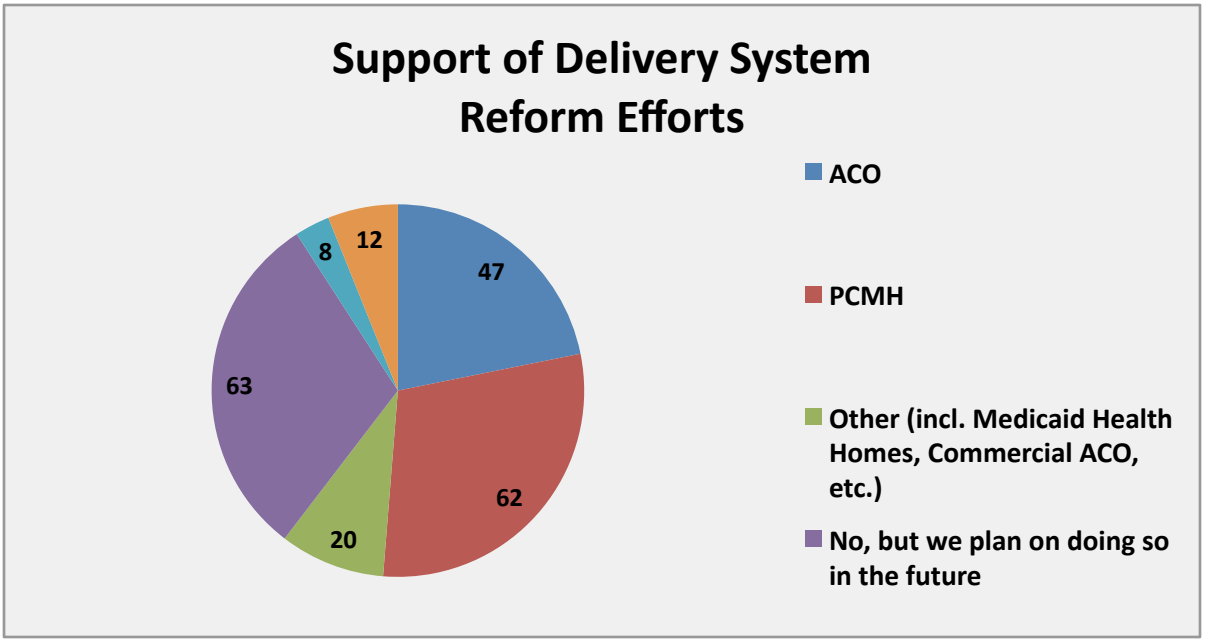

Figure 23: Support of Delivery System Reform Efforts

The measurement of quality and performance are critical to delivery system reform efforts such as ACOs and PCMH. Fifty-four HIE initiatives report that exchange data could be used to profile participating providers on standard quality metrics. However, only 21 initiatives indicated that data are currently being used to measure quality and/or performance of participating providers. Given that many ACOs are still in the nascent stage of development and operation, it is expected that exchange data will continue to be incorporated into daily practice over time as more organizations mature and expand their capabilities.

Incorporating the Direct Project

The Direct Project was launched in 2010 by the Office of the National Coordinator for Health Information Technology (ONC) to support the use of standards-based protocols for an easy-to-use, secure, and scalable method of sending encrypted and authenticated health information over the internet. Essentially conceived as a faster, cheaper, and safer alternative to mail and fax transmissions, the Direct Project also aims to alleviate the need to build EHR-specific custom interfaces due to the lack of interoperability between EHRs. The Direct Project allows health information exchange between providers that are still paper-based or that use EHRs that are not certified. After undergoing a pilot phase in 2011, HIE initiatives are beginning to adopt Direct. More than 100 initiatives report that they are either currently offering Direct (59) or are planning to incorporate Direct (53) into their services. This marks a significant increase in adoption from last year, when only 25 initiatives indicated that they were already using Direct. Of the initiatives surveyed

in 2012, only 8 reported that they did not plan to support Direct. Figure 24 below displays a list of the use cases that HIE initiatives report using or considering for Direct.

Direct Project Use Cases								
	Currently Using		Planning to Use		Considering Whether to Use		Decided Not to Use	
	2011	2012	2011	2012	2011	2012	2011	2012
Transitions of care (Clinical summary from hospital to PCP, PCP to Specialist, Specialist to PCP)	17	32	58	63	22	13	0	0
Exchange of lab results (Lab results from laboratory to PCP)	12	7	43	41	28	15	7	19
Sending information to patients (Health information from PCP to Personal Health Record)	5	6	25	37	42	34	7	10
Public Health Reporting (Immunization data from PCP to public health department)	1	7	46	37	35	32	9	13

Figure 24: Direct Project Use Cases

Sustainability

Key Findings:

1. *Hospitals, ambulatory practices (primary and specialty), integrated delivery networks and private payers are the most common financial supporters of health information exchange initiatives.*
2. *37 advanced initiatives indicated that state or federal funding comprised their most substantial revenue source in 2012.*
3. *Advanced HIEs rely on diverse revenue models, including federal funds (34), membership fees (34), assessment fees (24), and state funds (20).*
4. *A majority of initiatives observed that HITECH had a positive impact on financial sustainability.*

Sustainability is one of the most critical issues faced by health information exchange initiatives. The healthcare system has been slow to adopt electronic data exchange, despite its many benefits. While federal funding through the State HIE Cooperative Agreement Program and other grants has worked to jumpstart HIE development, these funds also represent a readily available source of revenue through which to sustain operations. This has left many HIEs reliant on federal or state dollars to launch their technical infrastructure platforms or expand their service areas/offerings. However, with federally matched cooperative agreement dollars beginning to wind down for SDEs and an uncertain fiscal climate ahead, the future of federal involvement in health information exchange is unclear. Respondents to the 2012 survey were asked a number of questions about financing and sustainability to better understand how HIEs are preparing for this potential loss of revenue from federal funds.

How do HIEs generate revenue?

Advanced HIE initiatives are those that have begun transmitting data, and are thus most likely to have stakeholders contributing revenue. In fact, 29 of the advanced initiatives indicated that entities participating in the exchange covered 100 percent of the HIE's operating expenses (21 of which were SDEs). 44 advanced initiatives reported that participating entities do not cover all of the organization's operating expenses, but of these, nearly half (20) receive contributions of 50 percent or more. Further, 33 of the 44 initiatives expect that they will eventually earn sufficient revenue from participants to cover operating expenses.

Overall, a diverse group of stakeholders support the efforts of HIE initiatives. As Figure 25 shows, hospitals (101), ambulatory practices (73) and integrated delivery networks (58) commonly pay to participate in HIE initiatives.

Stakeholders Paying to Participate – All HIEs	
	2012
Hospitals	101
Ambulatory practice (primary +specialty)	73
Integrated delivery network	58
Private Payers	40
Independent laboratory	31
Long-term care provider	32
Public Health Department (local + state)	30
Independent radiology center	29

Figure 25: Stakeholders Paying to Participate

Public Funding

Still, public funding remains a large portion of the revenue generated by advanced HIEs. Among these initiatives, 27 responded that federal funding represented their most substantial source of revenue in the past year (22 of which are SDEs), with an additional 10 reporting state funding as the most substantial source. Fees for using the exchange, including membership/subscription fees[15] (24), assessment fees[16] (6), and fees for HIE services[17] (5) was the predominant source of revenue for 35 initiatives. Two indicated grants or contracts from non-government sources made up their most substantial revenue source. Figure 26 shows a breakdown of the most substantial revenue sources in the last fiscal year for advanced HIEs.

[15] Flat fee to participate
[16] Fees are charged to the participant based on a particular characteristic such as number of beds per facility or number of hospital discharges
[17] Fees are established for various services (consumer services like PHR portal, advertising/sponsorships, secondary uses of data, etc.) that stakeholders will pay for beyond the basic services they receive

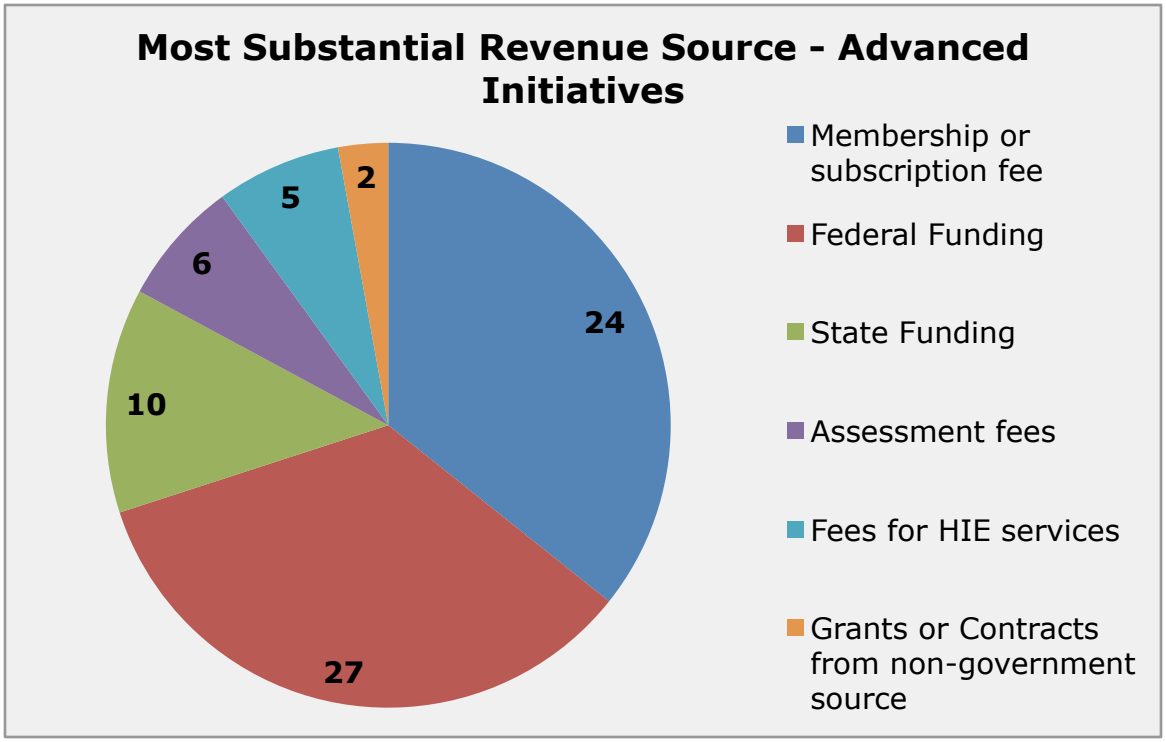

Figure 26: Most substantial source of support in the last fiscal year – advanced initiatives

What revenue models are advanced initiatives using?

To create a sustainable business model, HIEs must determine the type of revenue model they will use. The model(s) chosen will typically reflect the composition of the initiative's stakeholders, and their view of the value of health information exchange. Among advanced initiatives, the most common source of revenue is federal funds (33), followed by membership fees (30), assessment fees (26), and state funds (17). The least used source of revenue is usage/transaction fees[18] (5).

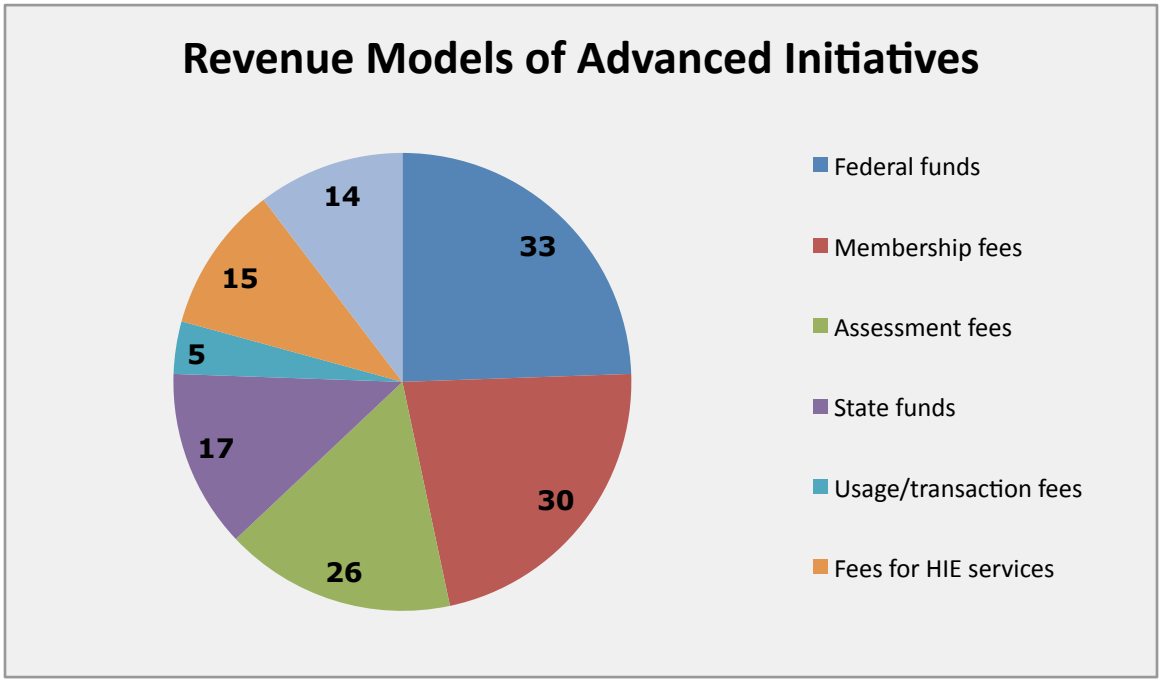

Figure 27: Revenue models of advanced HIE initiatives

Most advanced initiatives use a combination of revenue sources to fund their exchange, but more than half (52) reported that a single source of revenue accounted for 50 percent or more of their total revenue; of these, 26 relied on federal (20) or state (6) funding to do so. This suggests a continuing dependence on public funding even among advanced initiatives. Figure 28 describes the revenue breakdown of various models for advanced initiatives.

[18] Fees are on a transaction basis so the more a participant uses the HIE, the higher the fees are to that stakeholder

2012 Revenue Models of Advanced Initiatives									
	Percentage of Total Revenue							Total Initiatives 2012	Total Initiatives 2011
	0%	1-10%	10-30%	30-50%	50-70%	70-90%	90-100%		
Membership fees	51	5	10	6	3	4	6	34	25
Federal funds	54	5	2	7	10	3	7	34	19
State appropriations/grants	62	1	7	6	3	3	0	20	15
Fees for HIE services	66	7	5	2	1	1	0	16	14
Assessment fees	61	6	4	5	3	3	3	24	12
Usage/transaction fees	81	4	1	0	0	0	0	5	3
Grants/Contracts from non-government source	68	6	7	2	0	1	1	17	N/A

Figure 28: Revenue Models of Advanced Initiatives

Viability of Business Models

Initiatives have varying expectations about how they will achieve sustainability in their vision for the future. Respondents were asked to rate the viability of three business models to sustain HIE efforts. The *fees paid by participants model* includes assessment and membership fees, usage or transaction fees and service fees. The *costs savings model* includes payments based on projected operational costs saved or avoided by each stakeholder from their participation in the HIE. *Public funding through state or federal government* includes government grants or appropriations and taxation. In 2012, a majority (71) of HIEs stated that *fees paid by participants* was the most viable business model.

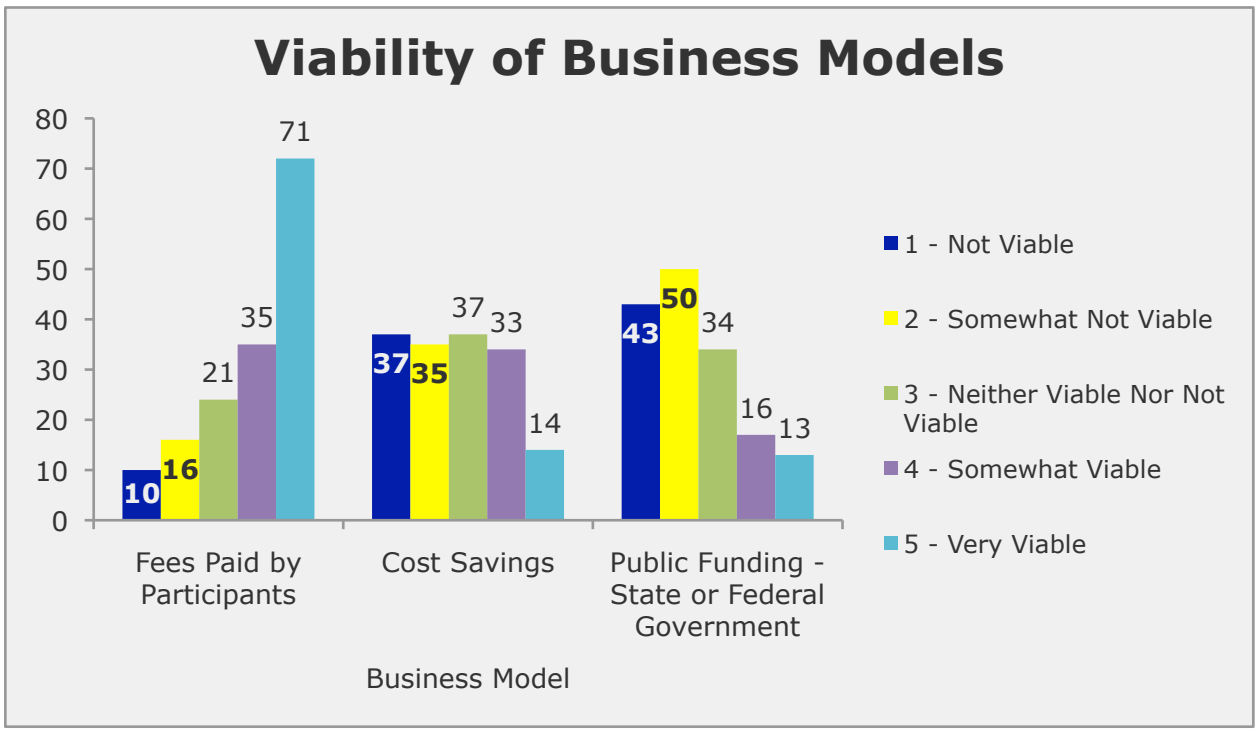

Figure 29: Viability of Business Models

Future Expectations of Sustainability

Initiatives' future expectations for financing and sustainability are mostly positive. Thirty-seven SDEs (out of the 39 identified in the report) indicated they fully expect to be operational three years from now, after State HIE and Cooperative Agreements end, assuming no further funding. This indicates a great deal of confidence that they can continue operations even without federal dollars. A smaller majority of SDEs (31) responded that it is very likely or likely that they will be financially sustainable in three years without further funding. Out of all of the HIEs surveyed (161), 93 feel that it is highly likely they will be operational in three years

and 64 believe they will be financially sustainable, even though 45 of these HIEs depend on federal funding as their primary revenue source. Figure 30 highlights the future expectations of these HIEs.

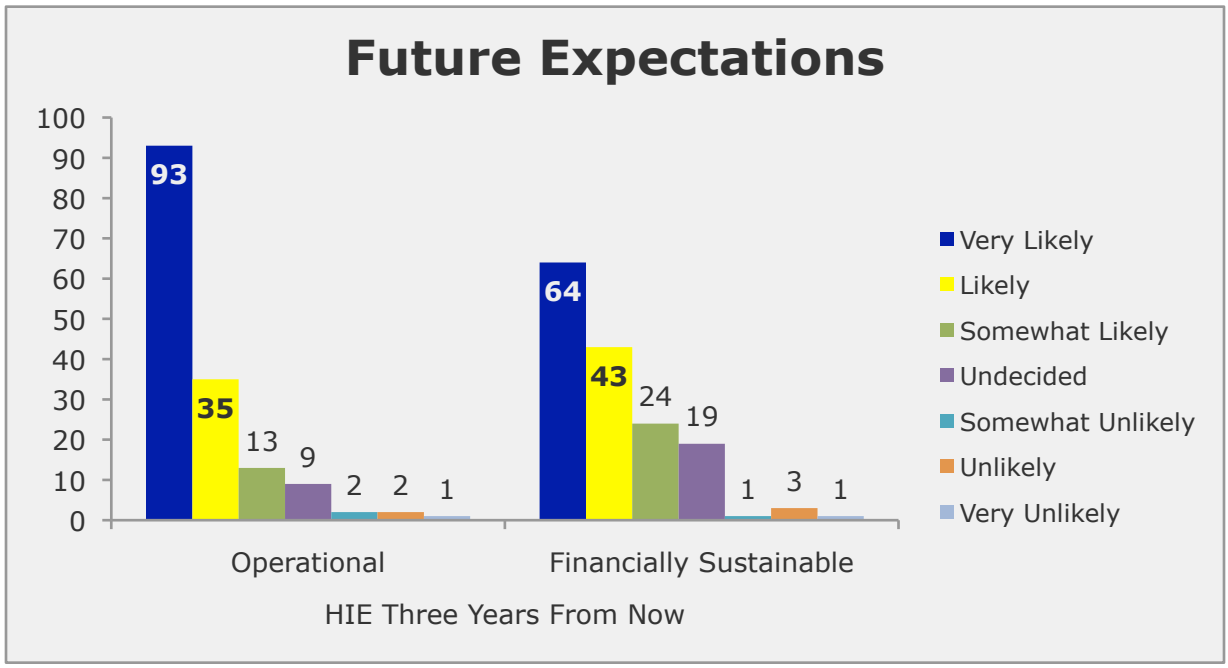

Figure 30: Future Expectations of HIEs

How has HITECH Impacted the Financial Sustainability of Initiatives?

By the very nature of its focus on health IT and data exchange, the HITECH Act created financial incentives for many HIE initiatives when previously, issues of cost and difficulty demonstrating return on investment stymied development. In fact, in 2012, a majority of initiatives observed that HITECH had a positive impact on financial sustainability; 81 initiatives (28 of which were SDEs) reported that HITECH has made it easier to become sustainable, while only 5 noted that it had made it harder to become sustainable. While no SDEs responded that HITECH made it harder to become sustainable, ten reported the legislation had no impact on sustainability. Figure 31 below shows the distribution of responses in regards to the impact of the legislation.

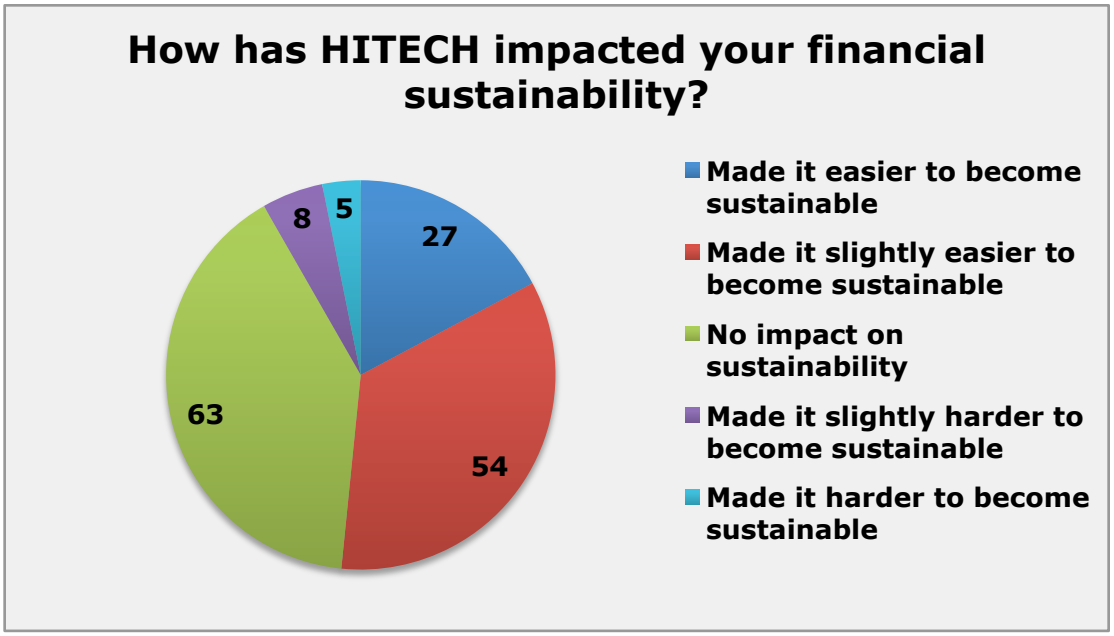

Figure 31: Impact of HITECH on financial sustainability

Conclusions and Recommendations for Moving Forward

Over the past year, there has been maturation in health information exchange initiatives even as federal funding under HITECH begins to sunset. This is due to the following factors:

- The utilization of HIE has reached a critical point at organizational, local, and state levels across the country following the passage of the Stage 2 Meaningful use requirements;
- The acceleration of new care delivery models under health reform; and
- The emphasis on clinical quality outcomes and increased efficiencies in care.

Exchanging key patient information among providers and between disparate settings is essential to meeting the goals of the Triple Aim, improving quality, improving efficiency and reducing costs. HIEs are integrating themselves into the new models of care brought about through healthcare reform legislation, while examining ways to achieve financial sustainability.

Data Exchange is Critical to the Success of Healthcare Reform

The Patient Protection and Affordable Care Act (ACA) requires ACOs to:

- Manage patients across the entire continuum of care at different institutional settings, including ambulatory care, inpatient hospital care and possibility post-acute care.
- Link payments to improved care and cost reductions.
- Support comprehensive, valid and reliable performance measurement.

Data exchange is crucial for an ACO or PCMH to achieve the necessary degree of patient-centered care coordination to successfully meet these needs. HIE will be used to connect providers who are rendering care to patients in these models, provide valid, complete and useful information at the point of care, enable communication between patient and provider participants, and assist both providers and patients in managing care. By connecting physicians with disparate clinical systems and enabling patient-centered care, HIE becomes a vital contributor to the success of an ACO and/or a PCMH.

In 2012, a large majority of HIEs indicated that they are either participating in ACO or PCMH efforts or intend to in the near future. In addition to connecting providers and facilitating data exchange, HIEs provide technical infrastructure and analytic capabilities, consulting on design and/or operational approach, and other services (such as patient engagement) for ACOs. Given the significance and importance that HIE has to new care delivery efforts, it is vital that exchanges continue to be involved in their development and operation in order to help ensure their success.

Revenue Diversification is a Key to Success

Based on survey results from the past eight years, we believe the most successful HIEs are those who diversified their revenue base and do not depend solely on one source, especially if that source is federal funding. While it is not uncommon for successful HIEs to use public funds to begin development, initiatives must effectively transition to continuous funding sources such as membership and assessment fees to remain viable in the long-term. The 2012 survey results indicate some progress on this front has been made since 2011, but there is still a need for many HIEs to create alternate sources of funding as HITECH funding draws to a close. By engaging multiple stakeholders to whom HIE may prove beneficial, exchanges increase their odds that fees for the use of the HIE will sufficiently cover operational expenses.

Data & Analytics

As HIEs begin to mature and the amount of data exchanged increases in both volume and quality, it is important to understand the content of the data and how analytics can be leveraged to expand the use of healthcare information. HIE initially developed to provide patient information to a provider at the point-of-care so that providers could offer accurate and efficient care based on a patient's entire medical history. While this is still a significant and primary function of HIEs, the data itself provides an important "clinical biography" of a patient that illustrates their history, diagnoses, procedures, medications, lab results and other clinical elements. In aggregate, this data can provide insight into a number of public health issues that may be prevalent within populations served by an HIE at a community, regional, state, or even national level. HIEs will likely play an increasingly large role in aggregating and analyzing this information to assist physicians, public health agencies and other stakeholders devise more effective treatment and management strategies. Additionally, the use of analytics within an HIE can also provide additional advantages, including:

- Comparative effectiveness and clinical utility studies
- Clinical quality measurement and reporting
- Disease surveillance
- Adaptive trials to support personalized medicine

With the growing number of participants in an HIE exchanging and receiving data, and the overall volume of data increasing, it is vital to utilize this data for purposes other than individual clinical encounters.

HIE Benefits Need to be Seen as well as Heard

Our analysis of the challenges faced by HIEs indicate that many are concerned that patients and other stakeholders may choose not to participate in an HIE because of issues with the privacy and security of personal health information. These

stakeholder concerns can hinder the utility of the HIE and undermine its relevance by making it more difficult for initiatives to demonstrate the value of data exchange. As a result, HIEs must focus on highlighting the benefits to both patients and stakeholders in a manner that they can both see and understand. Some of these benefits may include:

- An increase in patient safety brought about by offering providers current information on a patient's medical status, their current medications and lab results, and their list of allergies and contraindications to medication to prevent adverse events.
- Improvement in quality outcomes through enabling providers to consult with other providers or specialists to determine the appropriate course of action based on the information they received.
- Providing patients with access to their health information so they can stay engaged in the care process and have more productive conversations with their physician.

If patients and providers can both learn the benefits of an HIE and see those same benefits being applied in the course of care, HIEs are more likely to remain viable and become sustainable in the future.

List of Advanced HIE Initiatives[19]

Alaska Regional HIO
Atrius Health
Big Bend Regional Healthcare Information Organization
Brooklyn Health Information Exchange (BHIX)
Camden Health Information Exchange
Carolina Health Information Exchange
Central Georgia Health Exchange (Central Georgia Health Network)
ChathamHealthLink
Chesapeake Regional Information System for our Patients (CRISP)
ClinicalConnect
Coastal Carolinas Health Alliance (Coastal Connect HIE)
Community Health Information Collaborative (CHIC)/HIE-Bridge
ConnectVirginia
CORHIO
Crescent City Beacon Community - LA - Louisiana Public Health Institute
DC Regional Health Information Organization (DC RHIO)
Delaware Health Information Network (DHIN)
Dignity Health
Dominican Hospital
Douglas County Hospital HIE
East Kern County Integrated Technology Association (EKCITA)
GOCHC HIE
Great Lakes HIE (formerly Capital Area RHIO)
Greater Dayton Area Health Information Network
Greater Tulsa Health Access Network
GRIPA Connect Clinical Integration
Health Information Exchange of New York (HIXNY)
Health Information Technology Oversight Council (HITOC)
HealthBridge
Healthcare Access San Antonio (HASA)
HealtheConnections RHIO Central New York
HEALTHeLINK - the Western New York clinical information exchange
Healthix
HealthLINC
Hoag Memorial Hospital Presbyterian
Huntington Memorial Hospital
Idaho Health Data Exchange
Indiana Health Information Exchange
Inland Northwest Health Services
Integrated Care Collaboration - Icare (ICC)
Jackson Community Medical Record
Kansas Health Information Exchange, Inc (KHIE)
Kansas Health Information Network (KHIN)

[19] All initiatives on this list self-reported as stages 5, 6, or 7 on the 2012 survey. eHI did not verify whether these organizations had reached these stages.

Kentucky Health Information Exchange
Lewis and Clark Information Exchange (LACIE)
Louisiana Health Information Exchange/LHCQF
Marshfield Clinic Telehealth Network
Medical Information Network - North Sound
Memorial Healthcare System
Michiana Health Information Network
Michigan Health Connect
Michigan Health Information Network (MiHIN)
NC DETECT
Nebraska Health Information Initiative (NeHII)
New England Healthcare Exchange Network (NEHEN)
New York eHealth Collaborative (NYeC)
Norman Physician Hospital Organization
North Carolina Healthcare Information and Communications Alliance (NCHICA)
North Coast Health Information Exchange
NYC Syndromic Surveillance
NYU Langone Medical Center
Oklahoma Association of Optometric Physicians (SMRTSight)
OneHealthPort (Washington HIE)
PinnacleHealth System
Primary Care Coalition of Montgomery County/Metro DC HIE (MeDHIX)
Quality Health Network
RAIN Central Coast
Redwood MedNet
Rhode Island Quality Institute
Rochester RHIO
SAFE Health
Santa Cruz Health Information Exchange
SMRTNET
South Dakota Health Link
Southern Tier HealthLink
Strategic Health Intelligence
SunCoast RHIO, Inc.
Taconic Health Information Network and Community (THINC), Inc.
Telligen (IFMC)
Texas Association of Community Health Centers
University of California at Davis Health System
Utah Health Information Network (UHIN)/Clinical Health Information Exchange (cHIE)
Vermont Information Technology Leaders, Inc. (VITL)
Washington County Regional medical center
Whatcom Health Information Network (HINet)
Wisconsin Health Information Exchange (WHIE)
WNC Health Network
Wright State HealthLink