



eHEALTH INITIATIVE

Real Solutions. Better Health.

# 2011 REPORT ON HEALTH INFORMATION EXCHANGE

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## THE CHANGING LANDSCAPE

● ● ● ● **FULL REPORT** ● ● ● ●

EXECUTIVE SUMMARY

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 4 on page 9).

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.

### OTHER HIE INITIATIVES

The last year has seen significant change in the health information exchange market place. There were 255 HIE initiatives in 2011, up from 234 in 2010. Despite the rise in initiatives, a total of 10 initiatives are no longer operating due to several reasons. Some initiatives have closed down operations (4), and others have consolidated into other HIE initiatives (4). There were two for-profit organizations which were purchased, and HIE operations have closed.

However, there are also a number of brand new HIE initiatives that are just starting out. Forty-six initiatives that responded in 2011 indicated that they had not responded to a previous eHI survey. An additional 10 groups declined to complete the 2011 survey since they were in a very nascent stage (approximately 10).



While there are HIE initiatives across the entire U.S. and its territories, some states have a particularly high level of HIE activity. See Figure 1 for a list of the ten states with the highest concentration of initiatives, including state-level initiatives.

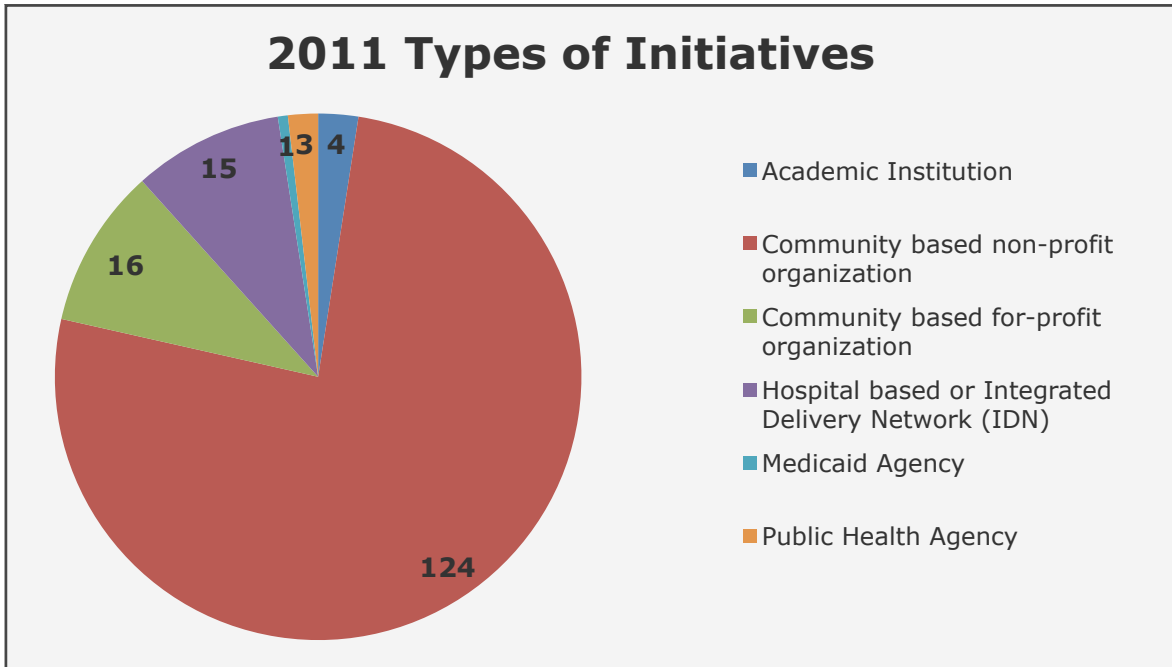
| TOP TEN STATES FOR HIE |                |
|------------------------|----------------|
| State                  | Number of HIEs |
| New York               | 17             |
| Texas                  | 17             |
| Florida                | 12             |
| California             | 10             |
| Michigan               | 10             |
| New Jersey             | 9              |
| North Carolina         | 9              |
| Ohio                   | 9              |
| Washington             | 9              |
| Oklahoma               | 8              |

Figure 1: Top States for HIE

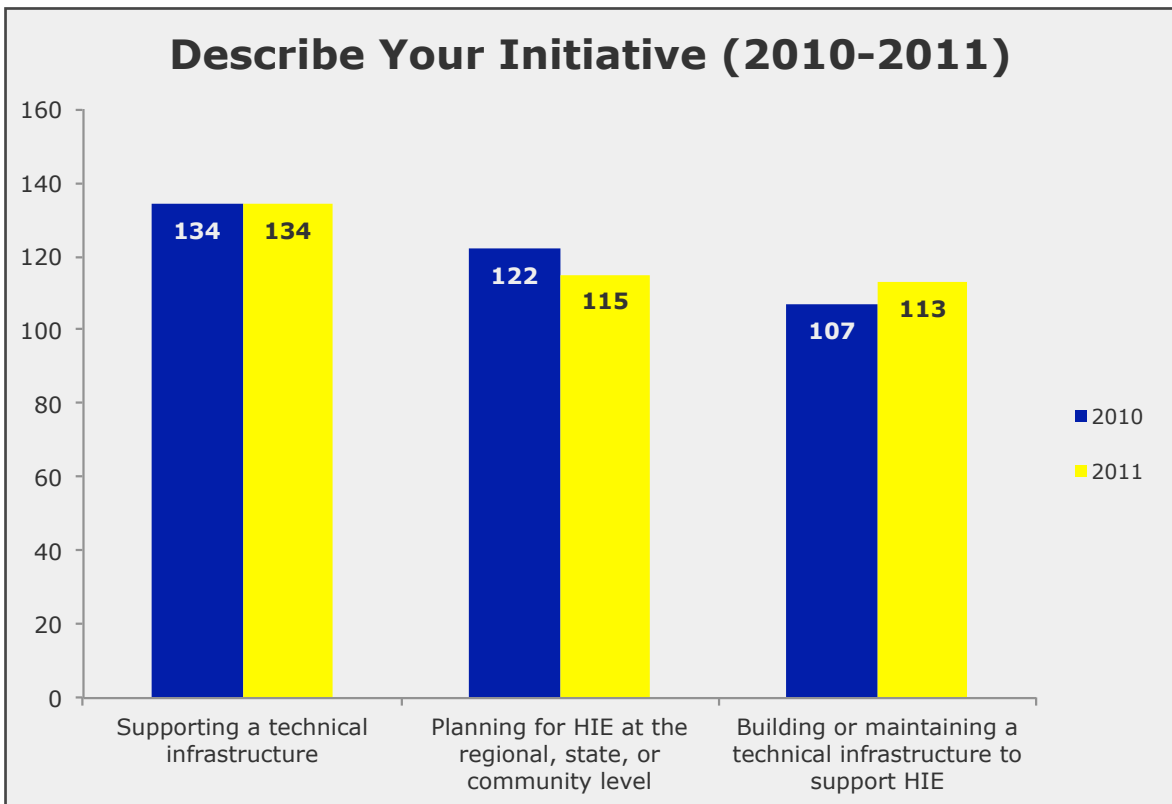
## WHAT TYPES OF INITIATIVES ARE PREVALENT?

The predominant type of initiative continues to be community-based non-profit organizations (124). This year however, saw a small increase in community-based for-profit organizations. In 2010, there were 13 for-profit HIE initiatives that responded to the survey; this year the number of community-based for-profits that responded increased to 16. Additionally, this year 15 hospital based or IDN organizations responded to the survey. While the number of IDN organizations responding to the survey increased in 2011, they are still under-represented in the survey results due to the fact that they are private and/or proprietary in nature. See Figure 2 below for a breakdown of the types of organizations that responded to this year’s survey.

As in 2010, the majority of initiatives (134) reported that they are “supporting a technical infrastructure that enables health information exchange between at least two different stakeholders, such as a hospital and physician practice, at the regional, state, or community level.” Many initiatives (115) reported that they are “planning for health information exchange at the regional, state, or community levels,” and 113 are “building or maintaining a technical infrastructure to support health information exchange.” See Figure 3 below.



*Figure 2: Types of Initiatives  
(Note: Respondents could only choose one option.)*



*Figure 3: Describe Your Initiative  
(Note: Respondents could choose more than one option.)*

# HEALTH INFORMATION EXCHANGE STAGES OF DEVELOPMENT

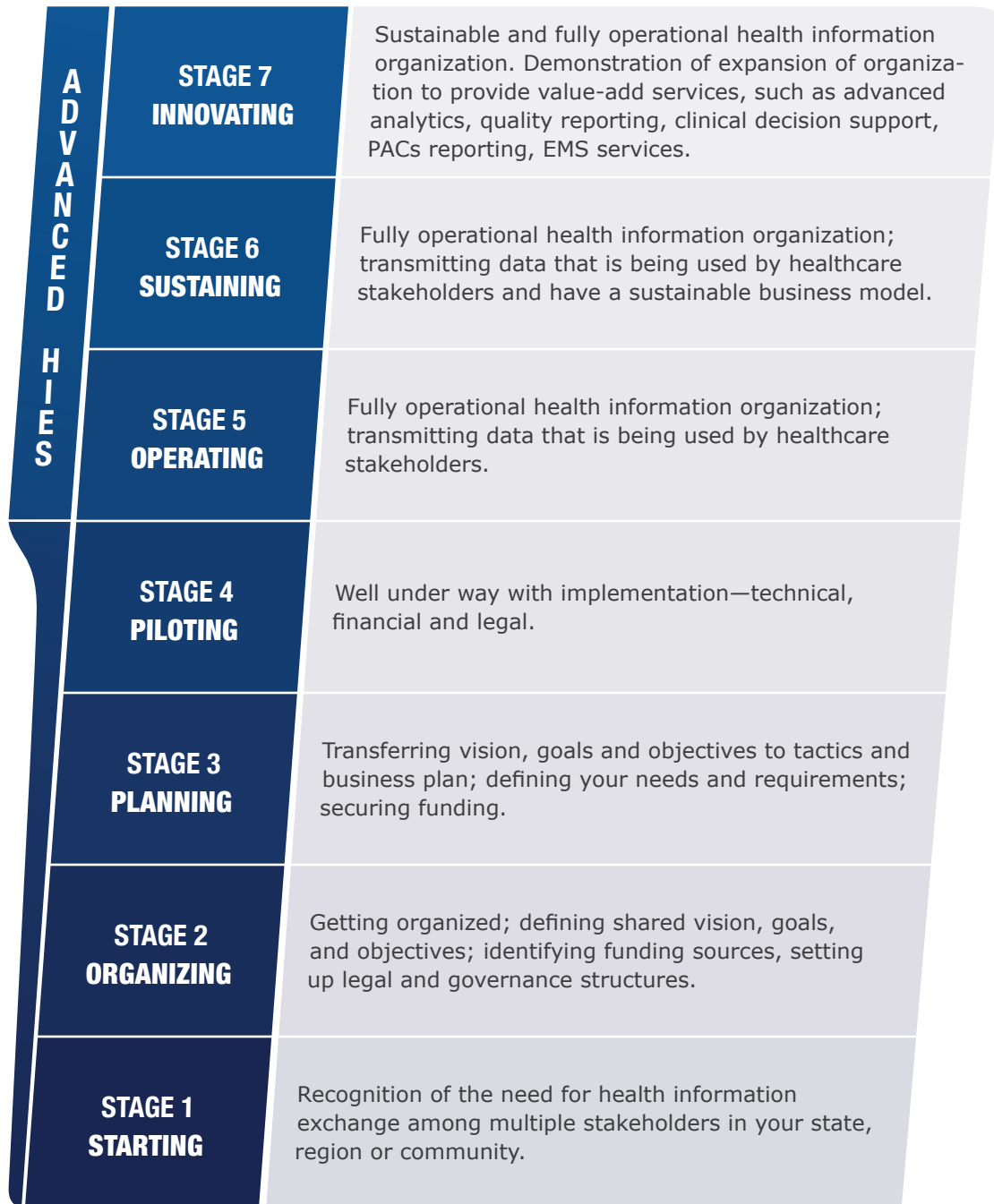
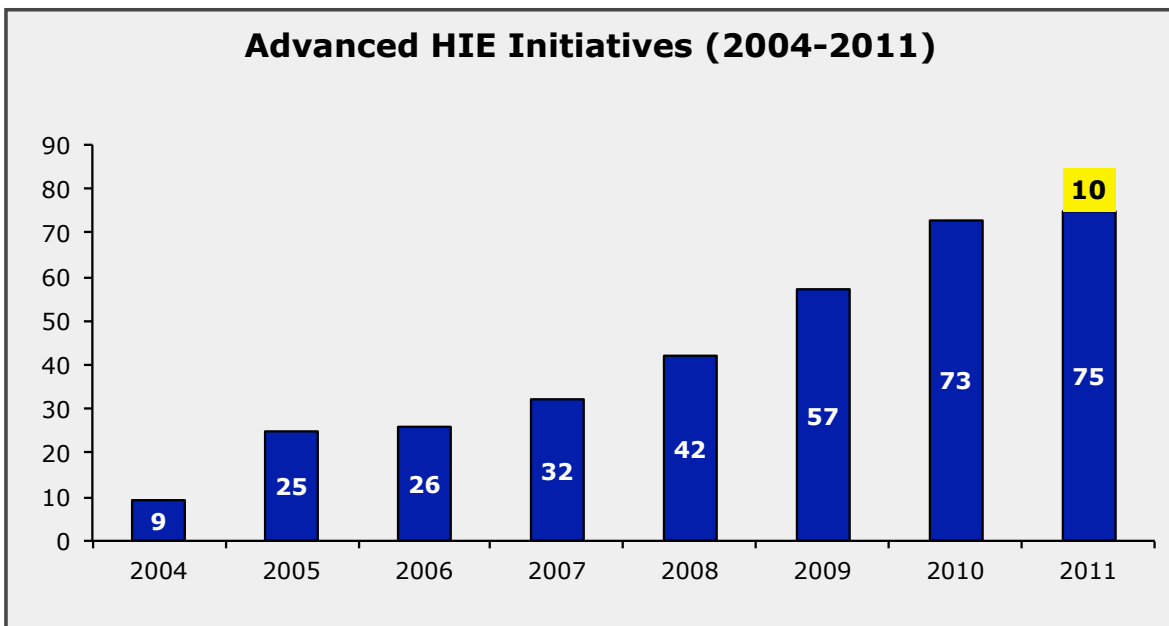


Figure 4: eHI Stages of Development

## 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 4 for the seven 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 5 below, shows the ever increasing number of advanced HIE initiatives from 2004 when eHI first began surveying the field.



*Figure 5: 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.

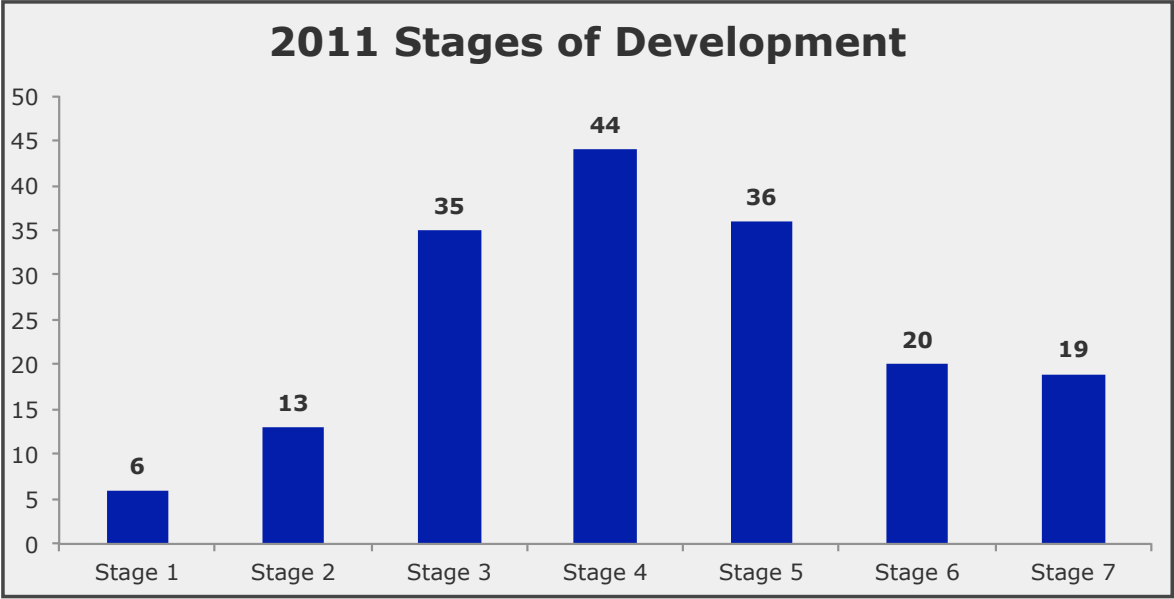


Figure 6: 2011 Initiatives by Stage of Development

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.

Geographically, the location of advanced HIE initiatives has remained consistent since 2010. New York still has the highest number of advanced initiatives (15). Twenty-eight states have two or more advanced initiatives, and 13 states and one U.S. territory have at least one advanced initiative. Ten states and four U.S. territories have zero advanced initiatives in their borders. Figure 7 illustrates the current geographic spread of the advanced initiatives that participated in the 2011 survey.

## States with Advanced HIE Initiatives 2011

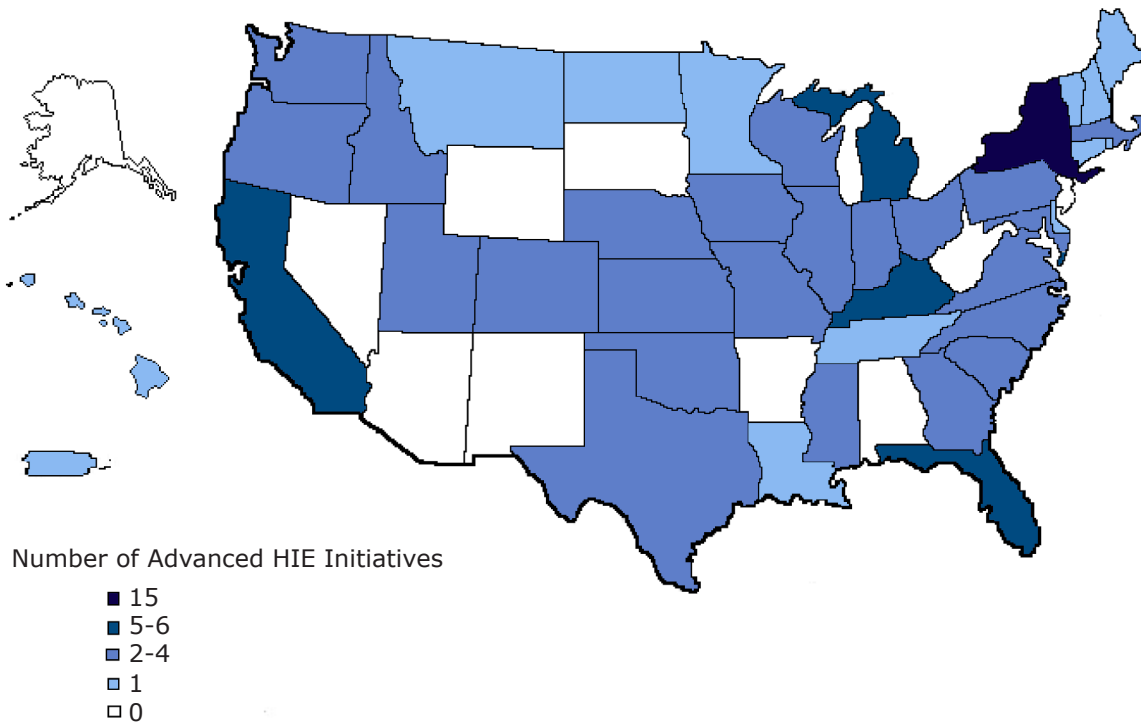


Figure 7: States and US Territories with Advanced Initiatives

### 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 8 details the top challenges initiatives face.

| <b>TOP CHALLENGES FACED BY INITIATIVES</b>   |             |             |
|--|-------------|-------------|
|  | <b>2010</b> | <b>2011</b> |
| 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         |
| Engaging practicing clinicians   | 101         | 116         |
| Accurately linking patient data  | 105         | 110         |
| Addressing organization and governance issues                                      | 117         | 107         |
| Addressing other legal issues  | 110         | 104         |
| Engaging health plans  | 105         | 104         |
| Engaging purchasers  | 101         | 99          |
| Engaging laboratories  | 95          | 95          |
| Securing upfront funding   | 82          | 93          |
| User management  | 82          | 91          |
| Managing growth  | 80          | 91          |
| Engaging hospitals   | 84          | 86          |
| System/technology procurement  | 69          | 68          |
| Securing tax-exempt status   | 29          | 30          |
| Obtaining state charter/authorization  | 54          | 37          |

*Figure 8: Top Challenges Faced by All Initiatives*

## TOP GOVERNANCE CHALLENGES

In addition to the above challenges, initiatives were asked to identify their top three governance challenges. Lack of board knowledge continues to be a challenge for many initiatives, with 50 initiatives indicating it is their biggest challenge. Forty-two initiatives cite conflicts of interest among board members as a challenge; in a multi-stakeholder organization, conflicts of interest could be a more prevalent issue. Interestingly, nearly twice as many initiatives are more concerned about too much board involvement than board disinterest. Figure 9 below details the governance challenges initiatives are facing.

| GOVERNANCE CHALLENGES                 |      |
|---------------------------------------|------|
|                                       | 2011 |
| Lack of board knowledge in HIE        | 50   |
| Conflicts of interest                 | 42   |
| Micro management decisions            | 19   |
| Board disinterest                     | 9    |
| Poor management-board communication   | 8    |
| Difficulty recruiting board members   | 6    |
| High board turnover                   | 4    |
| Lack of adherence to by-laws or rules | 0    |

*Figure 9: Governance 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 10 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   |
| State Public Health Department                             | 64   | 56   |
| Medicaid   | 61   | 55   |
| State - Governor's Office                                  | 61   | 47   |
| Quality Improvement Organizations                          | 56   | 45   |
| Pharmacies   | 38   | 42   |
| Long-term care providers                                   | 43   | 40   |
| Outpatient/ambulatory surgery centers                      | 41   | 39   |
| Independent laboratories                                   | 28   | 27   |
| Skilled nursing facilities                                 | 27   | 24   |
| Independent radiology centers                              | 28   | 18   |
| Healthcare IT suppliers                                    | 23   | 17   |
| Military and/or VA medical facilities                      | 14   | 17   |
| School-based clinics                                       | 15   | 12   |
| Medicare   | 9    | 10   |
| Pharmacy benefit management companies                      | 14   | 9    |
| Indian or Tribal Health Centers                            | 17   | 9    |
| Center for Disease Control                                 | N/A  | 3    |

Figure 10: Key Stakeholders Involved in Governance



## HOW MANY STAKEHOLDERS ARE INVOLVED?

When trying to become sustainable, having a critical mass of stakeholders is very important. While the vast majority of initiatives have ten or less stakeholders in each category, some indicated that they have large numbers of stakeholders involved in their organization. Figure 11 details the number of stakeholders involved in HIE initiatives.

| 2011 NUMBER OF STAKEHOLDERS INVOLVED IN ALL INITIATIVES |      |       |       |       |       |       |     |                   |
|---|------|-------|-------|-------|-------|-------|-----|-------------------|
|   | 0-10 | 11-20 | 21-30 | 31-40 | 41-50 | 51-60 | 61+ | Total Initiatives |
| Hospitals   | 109  | 29    | 8     | 3     | 4     | 5     | 5   | 163               |
| Primary care physicians                                 | 57   | 10    | 3     | 7     | 5     | 2     | 72  | 156               |
| Specialty care physicians                               | 68   | 8     | 7     | 4     | 2     | 5     | 53  | 147               |
| Independent laboratories                                | 134  | 3     | 1     | 0     | 0     | 0     | 1   | 139               |
| Behavioral or mental health providers                   | 121  | 13    | 3     | 0     | 0     | 0     | 1   | 138               |
| Payers  | 135  | 3     | 0     | 0     | 0     | 0     | 0   | 138               |
| Consumers   | 112  | 5     | 1     | 0     | 0     | 0     | 17  | 135               |
| Employers or health care purchasers                     | 126  | 4     | 2     | 0     | 0     | 0     | 3   | 135               |
| Independent radiology centers                           | 128  | 4     | 2     | 0     | 0     | 0     | 0   | 134               |
| Long-term care providers                                | 120  | 8     | 0     | 1     | 3     | 0     | 1   | 133               |
| Outpatient/ambulatory surgery centers                   | 117  | 9     | 1     | 1     | 2     | 1     | 2   | 133               |
| Pharmacies  | 114  | 3     | 4     | 2     | 1     | 1     | 8   | 133               |
| Skilled nursing facilities                              | 120  | 6     | 2     | 0     | 0     | 0     | 0   | 128               |
| School-based clinics                                    | 120  | 2     | 0     | 0     | 0     | 0     | 0   | 122               |

Figure 11: Number of Stakeholders Involved in All Initiatives



## 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 12 and 13 below 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.

| <b>STAKEHOLDERS PROVIDING DATA IN ADVANCED INITIATIVES</b> |             |             |
|--|-------------|-------------|
|  | <b>2010</b> | <b>2011</b> |
| 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          |
| State Public Health Department                             | 64          | 56          |
| Medicaid   | 61          | 55          |
| State - Governor's Office                                  | 61          | 47          |
| Quality Improvement Organizations                          | 56          | 45          |
| Pharmacies   | 38          | 42          |
| Long-term care providers                                   | 43          | 40          |
| Outpatient/ambulatory surgery centers                      | 41          | 39          |
| Independent laboratories                                   | 28          | 27          |
| Skilled nursing facilities                                 | 27          | 24          |
| Independent radiology centers                              | 28          | 18          |
| Healthcare IT suppliers                                    | 23          | 17          |
| Military and/or VA medical facilities                      | 14          | 17          |
| School-based clinics                                       | 15          | 12          |
| Medicare   | 9           | 10          |
| Pharmacy benefit management companies                      | 14          | 9           |
| Indian or Tribal Health Centers                            | 17          | 9           |
| Center for Disease Control                                 | N/A         | 3           |

*Figure 12: Stakeholders Providing Data in Advanced Initiatives*





| <b>STAKEHOLDERS VIEWING OR RECEIVING DATA IN ADVANCED INITIATIVES</b> |             |             |
|---|-------------|-------------|
|   | <b>2010</b> | <b>2011</b> |
| 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          |
| Independent laboratories  | 18          | 21          |
| Payers  | 24          | 21          |
| State Public Health Department  | 17          | 18          |
| Pharmacies  | 21          | 17          |
| Military and/or VA medical facilities                                 | 16          | 17          |
| School-based clinics  | 13          | 14          |
| Consumers   | 13          | 14          |
| Medicaid  | 8           | 13          |
| Quality Improvement Organizations                                     | 13          | 10          |
| Employers or health care purchasers                                   | 10          | 9           |
| Indian or Tribal Health Centers                                       | 11          | 8           |
| Medicare  | 9           | 6           |
| Patient or consumer groups  | 6           | 6           |
| Center for Disease Control  | N/A         | 4           |
| Pharmacy benefit management companies                                 | 4           | 3           |
| State - Governor's Office   | 1           | 3           |
| Healthcare IT suppliers   | 6           | 1           |

*Figure 13: Stakeholders Viewing or Receiving Data in Advanced Initiatives*

## HOW MANY STAKEHOLDERS ARE INVOLVED IN THE ADVANCED INITIATIVES?

The advanced initiatives have roughly the same ratio of stakeholders involved in their initiatives. Figure 14 below provides a breakdown of the number of stakeholders involved in the advanced initiatives.

| 2011 NUMBER OF STAKEHOLDERS INVOLVED IN ADVANCED INITIATIVES |      |       |       |       |       |       |     |                   |
|--|------|-------|-------|-------|-------|-------|-----|-------------------|
|  | 0-10 | 11-20 | 21-30 | 31-40 | 41-50 | 51-60 | 61+ | Total Initiatives |
| Hospitals  | 41   | 16    | 4     | 1     | 4     | 3     | 3   | 72                |
| Primary care physicians                                      | 13   | 4     | 2     | 5     | 2     | 2     | 44  | 72                |
| Specialty care physicians                                    | 67   | 2     | 1     | 0     | 0     | 0     | 1   | 71                |
| Independent laboratories                                     | 23   | 3     | 3     | 3     | 1     | 3     | 35  | 71                |
| Behavioral or mental health providers                        | 63   | 3     | 2     | 0     | 0     | 0     | 0   | 68                |
| Payers   | 54   | 9     | 2     | 0     | 0     | 0     | 1   | 66                |
| Consumers  | 59   | 3     | 1     | 0     | 0     | 0     | 3   | 66                |
| Employers or health care purchasers                          | 56   | 6     | 0     | 1     | 2     | 0     | 1   | 66                |
| Independent radiology centers                                | 54   | 6     | 1     | 1     | 1     | 1     | 2   | 66                |
| Long-term care providers                                     | 65   | 1     | 0     | 0     | 0     | 0     | 0   | 66                |
| Outpatient/ambulatory surgery centers                        | 60   | 4     | 2     | 0     | 0     | 0     | 0   | 66                |
| Pharmacies   | 50   | 1     | 4     | 1     | 0     | 0     | 8   | 64                |
| Skilled nursing facilities                                   | 51   | 2     | 0     | 0     | 0     | 0     | 10  | 63                |
| School-based clinics   | 59   | 2     | 0     | 0     | 0     | 0     | 0   | 61                |

Figure 14: Number of Stakeholders Involved 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.

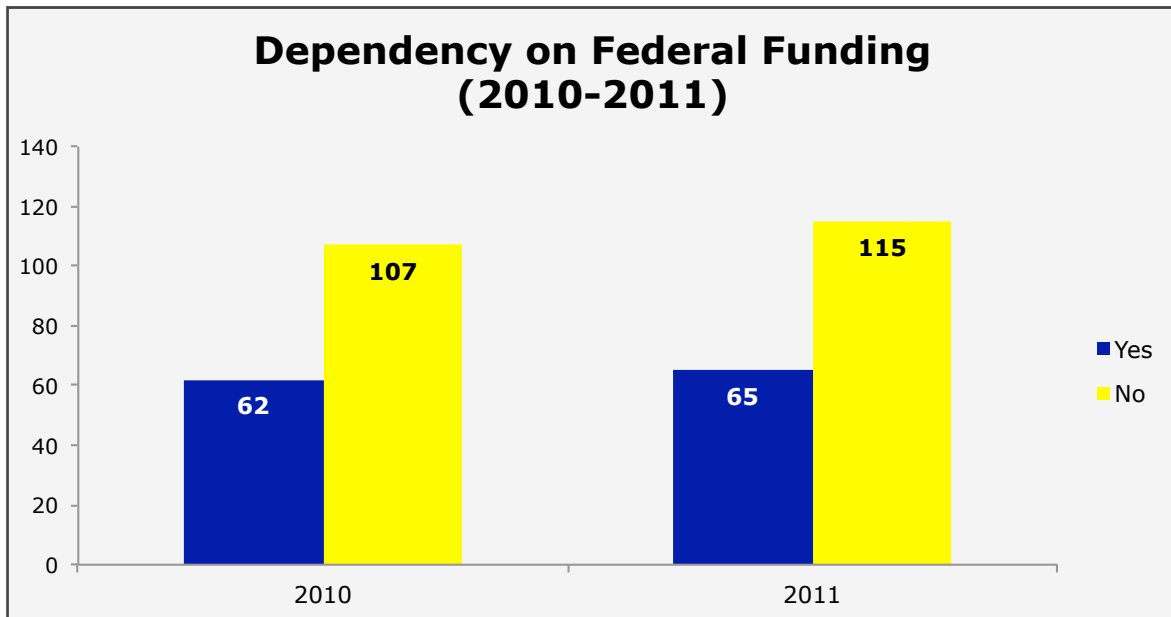


Figure 15: Dependency on Federal Funding (All Initiatives)

This year initiatives were also asked if they were “federally funded under the State Health Information Exchange Cooperative Agreement Program.” Fifty-one initiatives indicated that they were receiving funding under the program. States are not all following the same path to statewide HIE. While some states, such as Delaware have a single statewide entity for HIE, other states are subcontracting the HIE services to multiple initiatives in their state. For example, Texas is awarding contracts to sixteen regional HIE 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.

## WHO IS FUNDING THE ADVANCED INITIATIVES?

As federal funding decreases, it is important that initiatives identify other revenue sources. Of the 75 advanced initiatives, 56 have received funds from a customer, and 14 initiatives have not. Interestingly, the advanced initiatives are more likely to charge hospitals and payers to participate in the exchange than physicians. In 2010, initiatives were asked if they charge physicians to access information and 35 of the 75 responded that they do. This year, the number of advanced initiatives charging physicians increased to 42. Figure 16 details which groups the advanced initiatives are charging to participate.

| 2011 ADVANCED INITIATIVES CHARGING GROUPS TO PARTICIPATE |     |    |
|--|-----|----|
|  | Yes | No |
| Physicians   | 42  | 30 |
| Hospitals  | 51  | 19 |
| Payers   | 32  | 21 |

Figure 16: Advanced Initiatives Charging Groups to Participate

In the most recent fiscal year, 34 of the advanced initiatives earned more than \$1 million in revenue, two of which earned more than \$30 million. This is a 30 percent increase from 2010, where only 26 advanced initiatives had more than \$1 million in revenue. Figure 17 shows how much the advanced initiatives are charging physicians, hospitals, and payers annually to participate. Hospitals and payers carry the heavier burden in comparison to physicians.

| AVERAGE ANNUAL CHARGE PER GROUP (ADVANCED INITIATIVES) |     |         |           |           |             |               |                |               |
|--|-----|---------|-----------|-----------|-------------|---------------|----------------|---------------|
|  | \$0 | \$1-100 | \$101-250 | \$251-500 | \$501-1,000 | \$1,001-5,000 | \$5,001-10,000 | Over \$10,000 |
| Per physician  | 28  | 9       | 8         | 8         | 10          | 3             | 1              | 1             |
| Per hospital   | 16  | 1       | 0         | 1         | 0           | 5             | 6              | 40            |
| Per payer  | 18  | 1       | 0         | 0         | 0           | 2             | 3              | 27            |

Figure 17: Average Annual Charge per Group (Advanced Initiatives)

The initiatives were also asked to detail what percentage of their revenue comes from each stakeholder group. Many of the advanced initiatives are earning revenue from multiple sources, and only nine initiatives draw 100% of their revenue from one source: federal funds (1), hospitals/health systems (5), payers (1), or state funds (1). Figure 18 presents the revenue sources of advanced HIE initiatives by the percentage of total revenue.

**KEY FINDING**

Advanced initiatives spread their revenue sources over multiple stakeholders and use multiple revenue models, with membership fees being the most utilized model.

| <b>2011 REVENUE SOURCES OF ADVANCED INITIATIVES</b> |                                    |              |               |               |               |               |             |
|---|------------------------------------|--------------|---------------|---------------|---------------|---------------|-------------|
|   | <b>Percentage of Total Revenue</b> |              |               |               |               |               |             |
|   | <b>0%</b>                          | <b>1-20%</b> | <b>21-40%</b> | <b>41-60%</b> | <b>61-80%</b> | <b>81-99%</b> | <b>100%</b> |
| Federal Funds                                       | 39                                 | 7            | 2             | 6             | 2             | 1             | 1           |
| FQHCs   | 49                                 | 7            | 2             | 0             | 0             | 0             |             |
| Hospitals/Health system                             | 16                                 | 13           | 9             | 6             | 9             | 0             | 5           |
| Labs  | 50                                 | 6            | 2             | 0             | 0             | 0             | 0           |
| Long term care facilities/agencies                  | 52                                 | 6            | 0             | 0             | 0             | 0             | 0           |
| Medicaid  | 51                                 | 5            | 1             | 0             | 0             | 1             | 0           |
| Payers  | 39                                 | 11           | 3             | 4             | 0             | 0             | 1           |
| Pharmacies  | 57                                 | 1            | 0             | 0             | 0             | 0             | 0           |
| Private grant funds                                 | 49                                 | 8            | 1             | 0             | 0             | 0             | 0           |
| Provider practices                                  | 36                                 | 14           | 4             | 2             | 2             | 0             | 0           |
| Radiology services                                  | 56                                 | 2            | 0             | 0             | 0             | 0             | 0           |
| State funds   | 36                                 | 6            | 3             | 4             | 5             | 2             | 2           |

*Figure 18: Revenue Sources of Advanced Initiatives  
(Note: Not all initiatives responded to this question.)*

## WHAT TYPES OF REVENUE MODELS ARE ADVANCED INITIATIVES USING?

To create a sustainable business model, HIE initiatives must determine the type of revenue model they will use. The model(s) chosen will typically reflect the initiative's stakeholders, and their view of the value of health information exchange. While some initiatives use one model exclusively, many use a combination of different models to create a sustainable business model. The most common revenue model is membership fees, with 25 initiatives indicating membership fees are part or all of their revenue model. Figure 19 describes the average percent of total revenue for each type of model advanced initiatives use.

| REVENUE MODELS OF ADVANCED INITIATIVES |                             |       |        |        |        |        |      |                   |
|--|-----------------------------|-------|--------|--------|--------|--------|------|-------------------|
|  | Percentage of Total Revenue |       |        |        |        |        |      | Total Initiatives |
|  | 0%                          | 1-20% | 21-40% | 41-60% | 61-80% | 81-99% | 100% |                   |
| Membership fees                        | 27                          | 7     | 3      | 1      | 3      | 6      | 5    | 25                |
| Federal funds                          | 33                          | 6     | 3      | 6      | 1      | 1      | 2    | 19                |
| State appropriations/grants            | 37                          | 4     | 3      | 2      | 3      | 1      | 2    | 15                |
| Fees for HIE services                  | 38                          | 7     | 3      | 1      | 2      | 0      | 1    | 14                |
| Assessment fees                        | 40                          | 3     | 1      | 5      | 1      | 2      | 0    | 12                |
| Usage/transaction fees                 | 49                          | 1     | 1      | 0      | 0      | 0      | 1    | 3                 |
| Taxation                               | 50                          | 0     | 1      | 1      | 0      | 0      | 0    | 2                 |
| Cost savings                           | 52                          | 0     | 0      | 0      | 0      | 0      | 0    | 0                 |

Figure 19: Revenue Models of Advanced Initiatives  
(Note: not all initiatives responded to this question)

## VI | TRANSFORMING HEALTHCARE THROUGH FUNCTIONALITY & SERVICE

### ARE INITIATIVES GOING TO SUPPORT CCD EXCHANGE AND BI-DIRECTIONAL EXCHANGE?

As the nation moves towards a transformed healthcare system, two capabilities are becoming more important. One capability is the ability to exchange health information bi-directionally. The second important functionality is the exchange of a continuity of care document or CCD.

Bi-directional exchange is the ability to push and pull information (send and request/receive). Providers and hospitals not only pull (request/receive) data from other systems, but they need to be able to push (send) data out to those systems. One hundred and sixteen initiatives responded that they currently have the ability to push and pull information.

The exchange of a CCD or CCR is important for Meaningful Use. While different standards may be used to accomplish this, HIE initiatives can use Integrating the Healthcare Enterprise (IHE) standards to exchange a CCD and will be able to support providers and hospitals in qualifying for Meaningful Use. Only one HIE initiative indicated that they do not intend to support CCD exchange using IHE standards. While 16 initiatives were unsure, 88 percent or 127 initiatives will be supporting standardized CCD exchange.

### 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 20 details which functionalities are Stage 1 and proposed Stage 2 requirements, and the number of HIE initiatives providing those functionalities.





The table includes data from the 2009 and 2010 HIE surveys. N/A denotes a functionality that was not in the 2009 or 2010 list of choices. Figure 21 details the data advanced initiatives are exchanging and denotes which data is Stage 1 and proposed Stage 2 requirements. The table includes data from the 2009 and 2010 HIE surveys. N/A denotes a functionality that was not in the 2009 or 2010 list of choices.

**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).

| <b>CURRENT FUNCTIONALITIES OF ADVANCED INITIATIVES</b>            |             |             |             |
|---|-------------|-------------|-------------|
|   | <b>2009</b> | <b>2010</b> | <b>2011</b> |
| <b>Stage 1 Meaningful Use Items</b>                               |             |             |             |
| Connectivity to electronic health records                         | 29          | 49          | 60          |
| Electronic Prescribing  | 16          | 27          | 32          |
| Alerts to providers-Drug-to-Drug                                  | N/A         | 25          | 31          |
| Alerts to providers-Drug-to-Allergy                               | N/A         | 22          | 29          |
| Clinical decision support   | 13          | 18          | 25          |
| Medication Reconciliation   | N/A         | 12          | 22          |
| Alerts to providers-Drug-to-Food Allergy                          | N/A         | 18          | 21          |
| Ambulatory order entry  | 12          | 14          | 20          |
| Connectivity to other HIEs, IDNs, RHIOs, etc                      | N/A         | N/A         | 19          |
| Immunization Registry   | N/A         | 11          | 15          |
| Public health: syndromatic surveillance reporting                 | 7           | 7           | 14          |
| Public health: electronic laboratory reporting                    | 6           | 7           | 13          |
| <b>Additional Stage 2 Proposed Meaningful Use Items</b>           |             |             |             |
| Results delivery (e.g. laboratory or diagnostic study results)    | 31          | 39          | 47          |
| Provider Directory  | N/A         | N/A         | 36          |
| Disease registries  | 14          | 9           | 18          |
| Image exchange  | N/A         | N/A         | 18          |
| Reminders   | 9           | 17          | 16          |
| Patient access to information through the exchange/patient portal | 7           | 9           | 10          |
| Patient-provider communication - other                            | 3           | 3           | 8           |
| Populate PHRs   | N/A         | N/A         | 8           |

| <b>CURRENT FUNCTIONALITIES OF ADVANCED INITIATIVES (CONT.)</b> |     |     |    |
|--|-----|-----|----|
| <b>Additional Functionalities</b>                              |     |     |    |
| Master Patient Index   | N/A | N/A | 60 |
| Health summaries for continuity of care                        | N/A | 35  | 43 |
| Record Locator Service   | N/A | N/A | 38 |
| Clinical documentation   | 24  | 30  | 36 |
| Alerts to providers  | 22  | 28  | 36 |
| Consultation/referral  | 16  | 28  | 33 |
| Analytics  | N/A | N/A | 26 |
| Electronic referral processing                                 | 16  | 24  | 28 |
| Disease or chronic care management                             | 13  | 19  | 21 |
| Claims or eligibility checking                                 | N/A | 18  | 19 |
| Quality improvement reporting for clinicians                   | 10  | 15  | 16 |
| Visiting nurses accessibility                                  | N/A | N/A | 16 |
| Medical Device Interoperability                                | N/A | 2   | 9  |
| Emergency Medical Services (EMS) connectivity                  | N/A | N/A | 9  |
| Public health alerts   | N/A | 8   | 8  |
| Patient-provider clinical data exchange                        | 6   | 6   | 6  |
| Quality performance reporting for purchasers or payers         | 6   | 7   | 6  |
| Public health: case management                                 | 9   | 4   | 5  |
| Patient-provider email   | 4   | 3   | 4  |
| VA connectivity  | N/A | N/A | 4  |
| Home Monitoring  | N/A | 1   | 4  |

*Figure 20: 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).

| <b>DATA EXCHANGED BY ADVANCED INITIATIVES</b>                       |             |             |             |
|---|-------------|-------------|-------------|
|   | <b>2009</b> | <b>2010</b> | <b>2011</b> |
| <b>Stage 1 Meaningful Use Items</b>                                 |             |             |             |
| Laboratory Results  | 49          | 68          | 64          |
| Care Summaries (demographics, encounter history, medications, etc.) | 34          | 47          | 52          |
| Emergency Department episodes/discharge summaries                   | 36          | 58          | 50          |
| Retail pharmacy   | 20          | 24          | 19          |
| <b>Additional Stage 2 Proposed Meaningful Use Items</b>             |             |             |             |
| Outpatient laboratory results                                       | 45          | 62          | 54          |
| Radiology results   | 39          | 54          | 54          |
| Inpatient discharge summaries                                       | 32          | 52          | 49          |
| Physician notes   | N/A         | N/A         | 45          |
| Laboratory Ordering   | 49          | 26          | 30          |
| Advance Directives  | N/A         | 16          | 16          |
| Radiology images  | 18          | 17          | 16          |
| <b>Additional Data</b>  |             |             |             |
| Medication data (including outpatient prescriptions)                | 48          | 63          | 56          |
| Allergy info  | N/A         | N/A         | 53          |
| Inpatient diagnoses & procedures                                    | 35          | 51          | 51          |
| Pathology   | 32          | 42          | 43          |
| Outpatient episodes   | 43          | 56          | 42          |
| Cardiology  | 27          | 39          | 39          |
| Dictation / transcription   | 31          | 34          | 38          |
| Pulmonary   | 23          | 33          | 34          |
| Gastroenterology  | 22          | 32          | 31          |
| Enrollment / eligibility  | 25          | 30          | 26          |
| Claims: pharmacy, medical, and/or hospital                          | 27          | 30          | 20          |
| Elder care information  | N/A         | N/A         | 12          |
| Patient-reported data   | 13          | 13          | 10          |
| VA data   | N/A         | N/A         | 4           |

*Figure 21: 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 22 and 23 below indicate which non-clinical services initiatives are offering.

### KEY FINDING

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



| <b>SUPPORT FUNCTIONS ADVANCED INITIATIVES PROVIDE</b>                                |             |             |
|--|-------------|-------------|
|  | <b>2010</b> | <b>2011</b> |
| 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          |
| Providing implementation guides for health information exchange                      | 39          | 33          |
| Vendor-neutral advice on purchasing decisions  | 30          | 33          |
| Dissemination of best practices and research   | 26          | 32          |
| Provide patient or provider data management services                                 | N/A         | 19          |
| Recommendations for specific vendors   | 18          | 19          |
| Coordinating financial incentives within the market                                  | 16          | 18          |
| Supporting quality improvement or performance reporting for purchasers and/or payers | 19          | 17          |
| Group purchasing   | 15          | 11          |

Figure 22: Support Functions Advanced Initiatives Provide

| <b>NON-CLINICAL VALUE-ADD SERVICES PROVIDED BY ADVANCED INITIATIVES</b>                |             |             |
|--|-------------|-------------|
|  | <b>2010</b> | <b>2011</b> |
| 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          |
| Hosting Nationwide Health Information Network (NwHIN) Gateway/Connecting EHRs to NwHIN | N/A         | 16          |
| Patient identity management reports  | N/A         | 16          |
| Performing analytics for stakeholders  | N/A         | 13          |
| Printing services  | 2           | 10          |
| Provider directory services  | N/A         | 7           |
| Providing access to clinical trial database  | 1           | 7           |

Figure 23: 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,

### KEY FINDING

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

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. See Figure 24 below for a list of the use cases being used or considered.

| 2011 DIRECT PROJECT USE CASES   |                 |                 |                            |                    |
|---|-----------------|-----------------|----------------------------|--------------------|
|   | Currently Using | Planning to Use | Considering Whether to Use | Decided Not to Use |
| Transitions of care (Clinical summary from hospital to PCP, PCP to Specialist, Specialist to PCP) | 17              | 58              | 22                         | 0                  |
| Exchange of lab results (Lab results from laboratory to PCP)                                      | 12              | 43              | 28                         | 7                  |
| Sending information to patients (Health information from PCP to Personal Health Record)           | 5               | 25              | 42                         | 7                  |
| Public Health Reporting (Immunization data from PCP to public health department)                  | 1               | 46              | 35                         | 9                  |

Figure 24: Direct Project Use Cases



## 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. Figure 25 provides a view of the services currently being offered, and details the services HIE initiatives are planning to offer in the future.

| SERVICES OFFERED TO PATIENTS BY ALL INITIATIVES         |      |
|---|------|
|   | 2011 |
| Authorize the sharing of their healthcare information   | 31   |
| Review audits of access to their healthcare information | 17   |
| Access educational information on health and healthcare | 15   |
| Review their health data                                | 12   |
| Download their health information                       | 10   |
| Electronic interactions with their care providers       | 9    |
| Add information on their health status                  | 9    |
| Request or refill prescriptions                         | 8    |
| Request referrals                                       | 8    |
| Review appointment history                              | 8    |
| Make new appointments                                   | 7    |
| Check eligibility                                       | 5    |
| Review progress for chronic diseases                    | 4    |
| Schedule lab tests                                      | 3    |

Figure 25: Services Offered to Patients by All Initiatives

## 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 26 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 26: Level of Opt-in or Opt-out Choice*



## **WHAT TYPES OF CHOICES DO INITIATIVES OFFER TO PATIENTS AND HOW ARE PATIENTS INFORMED OF THESE OPTIONS?**

With the wait for updated HIPAA regulations continuing, many HIE initiatives have not changed their privacy policies over the last year. Additionally, many initiatives are waiting for laws to be passed in their state legislatures.

Most initiatives (67) rely on the Notice of Privacy Practices (NPP) signed by patients at the point of care to notify them that their data is available to others through the exchange. While 48 initiatives do not offer any additional patient choice (beyond what is required by HIPAA), more than half of initiatives do provide more patient choice. HIE initiatives responded affirmatively to providing the following types of choice:

- » Patient consent required before clinical information can be shared with another provider for treatment purposes (57).
- » Patient consent required before clinical data deemed to be sensitive (e.g., mental health, STD, AIDS) can be shared with another provider for treatment purposes (55).
- » Patient consent required to share clinical information for healthcare operations purposes (31).
- » Patient may impose restrictions upon uses or disclosures to carry out treatment, payment, or health care operations in addition to those restrictions patients are entitled to impose under applicable laws (29).
- » More stringent restrictions than HIPAA are in place for use and disclosure for research (27).
- » Patient consent required to share aggregated or de-identified information (21).
- » More stringent restrictions are in place for use and disclosure for public health activities (11).

## **WHO IS RESPONSIBLE FOR SECURING CONSENT?**

Many initiatives rely on providers and their staff to educate patients about their choices and to obtain their opt-in or opt-out consent, if applicable. However, in 2011, a number of HIE initiatives (58) responded that they are responsible for managing consumer consent, while 69 initiatives responded that they are not responsible. The initiatives were also asked if they have an electronic means for obtaining consent. Fifty-six initiatives indicated that they do have an electronic means, while 76 said they do not.

## 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](http://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™.



## XII | ACKNOWLEDGEMENTS

A report of this depth and breadth would not be possible without the support and contributions from numerous HIE experts. Our sincere thanks go to the following individuals who volunteered their time and expertise:

- » Scott Afzal, Program Director, CRISP
- » Deb Bass, Bass and Associates, Executive Director NeHII
- » Doug Dietzman, Executive Director, Michigan Health Connect
- » Dale Emerson, President, Hielix
- » Vicki Estrin, Principal, C3 Consulting
- » Gerry Hinkley, Co-Chair, Health Care Industry Team, Pillsbury Winthrop Shaw Pittman
- » Laura Kolkman, President, Mosaica Partners
- » Jerry Malone, Vice President, Sandlot
- » Trudi Matthews, Director of Policy and Public Relations, HealthBridge
- » Laura McCrary, Executive Director, Kansas Health Information Network
- » Gina Bianco Perez, MPA, President, Advances in Management Inc.
- » Todd Rowland, Executive Director, HealthLinc
- » Cheryl Stephens, Executive Director, Community Health Information Collaborative
- » Micky Tripathi, PhD, President and CEO, Massachusetts eHealth Collaborative

The following staff contributed to the development of the survey, collection of the results, data analysis, and the writing of this report: Jennifer Covich Bordenick, Genevieve Morris, Susan Silberman, Katinka Canning, Alex Kontur, and Katie Reedy.

eHealth Initiative is grateful to a number of organizations for their support of the dissemination of the survey results, including: Axolotl now part of OptumInsight, GE Healthcare, and Siemens.

