



CALIFORNIA HEALTHCARE FOUNDATION



# Ten Years In: Charting the Progress of Health Information Exchange in the US

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## About the Foundation

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## Introduction

Efforts to digitize the nation's health care system and make it possible to electronically exchange health information have been underway for more than a decade. Three major federal initiatives have shaped these efforts:

1. **Executive Order 13335**, released in April 2004, established the position of National Coordinator for Health Information Technology (HIT) and charged it with implementing a nationwide interoperable HIT infrastructure.<sup>1</sup>
2. **The Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH)** created incentives for electronic health record (EHR) adoption and health information exchange (HIE) with federal stimulus funds.<sup>2</sup>
3. **The Patient Protection and Affordable Care Act of 2010 (ACA)** established health care system payment reforms and is leading to new models of care delivery that further encourage health care providers to engage in HIE.<sup>3</sup>

This paper describes the HIE landscape as it stands today, nearly 10 years after the creation of the Office of the National Coordinator (ONC) and 5 years after the passage of HITECH. It takes stock of the nation's efforts to encourage HIE through three lenses: (1) EHR adoption; (2) standards, certification, and incentives for HIE; and (3) governance. The paper also outlines current opportunities and challenges as described by nine experts in the fields of health care and HIT. (A list of interviewees can be found in Appendix A.)

## Background

The modern era of HIE-related public policy activity dates back to May 2004, with the appointment of the first national coordinator for HIT and the release of the federal government's first comprehensive HIT strategy document, *The Decade of Health Information Technology: Delivering Consumer-Centric and Information-Rich Health Care — Framework for Strategic Action*.<sup>4</sup> At that time, federal support for HIT did not have the benefit of significant funding and, as a result, focused primarily on mobilizing the private sector.

## HITECH: Federal Dollars Spur Adoption and Use

By 2009, Congress had united behind the concept of HIT as an enabler of better health care, leading to the passage of HITECH as part of the American Recovery and Reinvestment Act of 2009 (ARRA). HITECH set out a framework to leverage significant ARRA funds to create a nationwide HIT infrastructure intended to enable the electronic exchange and use of health information.

HITECH's cornerstone was the Medicare and Medicaid EHR Incentive Programs, which provided eligible hospitals and professionals with financial incentives for the "meaningful use" of certified EHR technology to improve patient care. In 2015, the Medicare EHR Incentive Program will transition from offering incentives to imposing penalties on eligible hospitals and professionals who are not meaningfully using certified EHRs. The Congressional Budget Office estimated that spending for the Medicare and Medicaid EHR Incentive Programs would total \$30 billion between 2011, the year incentive payments began, and 2019.<sup>5</sup>

The US Department of Health and Human Services (HHS) originally envisioned that the Meaningful Use Incentive Program would evolve incrementally through three stages over five years, but proposed to extend the timeline by two years in December 2013.<sup>6</sup> Stage 1 focuses on adoption of EHRs, basic electronic data capture, and medication ordering. HHS set up future stages to become gradually more rigorous by requiring providers not only to adopt EHRs but to use them to exchange health information and, ultimately, to achieve improvements in care, efficiency, and population health.<sup>7</sup> Through rulemaking, HHS has established the specific objectives and criteria for meaningful use that eligible hospitals and professionals must meet to receive incentive payments.<sup>8</sup>

In addition to establishing the EHR Incentive Programs, HITECH also allocated more than \$2 billion for new HIT and HIE infrastructure programs designed to support and accelerate HIT adoption and use, advance standards adoption, create a network of regional extension centers to help providers implement and use certified EHRs, and fund demonstrations and research projects to develop, evaluate, and disseminate best practices.

## Health Reform

In many ways, HITECH was a prologue to the far-reaching changes that were introduced with passage of the ACA, which brought with it a panoply of new payment and delivery system initiatives, almost all of which, in some measure, require the development and widespread adoption of better HIE systems. As the health care industry strives to reorganize itself around new ways of doing business through primary care medical homes, accountable care organizations, and other arrangements, many of the planning efforts are focusing on the technology and methods for collecting, integrating, sharing, and analyzing health information to support better health outcomes and more cost-effective ways of delivering care.

Today, the nation's HIT policy is in transition. One of the principal reasons for the bipartisan support HITECH received was the shared conclusion that the health care marketplace had failed to provide a business case for investment in new and powerful ways of sharing, analyzing, and using health information. Policymakers did not believe that market stagnation in the HIE arena could be overcome without government support. Now, after HITECH's investments, the primary question many experts are struggling with is: What constitutes the right mix of government HIT programs versus market forces to continue development of an HIT infrastructure that can support higher quality, more cost-effective health care?

## Electronic Health Record Adoption

HITECH was based on the premise that EHR adoption is a critical first step to electronic sharing of information to support better care coordination and improved health outcomes. Since the implementation of HITECH in 2010, adoption of basic EHR systems has increased dramatically.

For hospitals, the adoption rate was 44% in 2012, which had increased from 17% in 2011 and nearly tripled from what it was in 2010.<sup>9</sup> As of February 2014, HITECH's Regional Extension Center (REC) program, designed to assist small health care providers in selecting, implementing, and using EHR systems, has succeeded in working with over 136,000 (nearly half) of the nation's primary care providers, helping 90% (more than 123,000) of those providers adopt an EHR system and 62% (more than 85,000)

demonstrate Stage 1 meaningful use.<sup>10</sup> According to 2013 data from the annual National Ambulatory Medical Care Survey, nearly 80% of office-based physicians used some type of EHR system.<sup>11</sup> About half of office-based physicians surveyed reported using a "basic system."<sup>12</sup> As of December 2013, 435,000 eligible professionals and 4,690 eligible hospitals have signed up for the Medicare and Medicaid EHR Incentive Programs.<sup>13</sup> Over 335,000 professionals and 4,400 hospitals have received incentive payments, totaling almost \$19 billion under the programs.<sup>14</sup>

## Adoption Gaps

Despite the widespread increase in EHR adoption, however, gaps remain. Providers in rural and low-income areas have lower rates of EHR adoption compared to their colleagues in urban and high-income areas. Long term care and behavioral health providers also have lower rates of EHR adoption than the general provider population, mainly because these providers were ineligible for HITECH's incentive programs.<sup>15</sup>

Experts disagree about how worrisome these adoption gaps are. For some, it is natural that new technologies would be adopted sooner in some parts of the health care delivery system than in others. Others worry that a "digital divide" may be developing. Some experts are concerned that the ineligibility of long term care providers to receive EHR incentives is creating a potentially dangerous dearth of health care data from the post-acute sphere of the health care system at a time when care coordination has been identified as a top priority.

## Meaningful Use Program

Some experts also raised concerns that the "meaningful use" paradigm, which is generally viewed as having been an effective policy lever during Stage 1, is in danger of impeding further EHR adoption and effective use. They worry that Stage 2 may be proceeding too quickly and that Stage 2 requirements may be too complex. These experts fear that providers may struggle to keep pace with meaningful use requirements as well as requirements related to the ACA, ICD-10 (the 10th revision of the World Health Organization's medical classification list), and the Health Insurance Portability and Accountability Act (HIPAA).

Other experts questioned whether meaningful use prevents providers from using EHRs to their full potential by promoting a “check the box” mentality in which achievement of improved health outcomes becomes secondary to achievement of the Meaningful Use Program’s required steps. One expert interviewed believed that there are too many meaningful use measures, that they are too tactically focused, and that this has caused providers to focus on what they need to do to achieve meaningful use rather than on how to use HIT to improve patient care. Another interviewee noted, “Everyone is enamored with the idea that good things will happen through EHRs, and we don’t step back to think about whether it will actually make a difference. From a doctor’s perspective, if you don’t tell us something we do not already know about our patients, then what is the point?”

Some experts also cautioned against overemphasis on the role of EHRs in care coordination and analytics. According to these individuals, the provision of care, by definition, happens in multiple places and requires sophisticated processing capabilities to make information meaningful and actionable to a caregiver. The technology located in a caregiver’s office is simply one tool, and many innovative developments in care management may happen outside of EHR systems altogether. For example, innovations have been developed to use data to support treatment decisions in obesity and other chronic diseases, and new consumer health tools have emerged that better enable patients with chronic diseases to adhere — long-term — with their treatment regimens.

Finally, experts expressed differing opinions on the impact of meaningful use on the EHR vendor market. It was generally acknowledged that meaningful use has led to a consolidation of the market, especially on the inpatient side, and that many smaller vendors are not able to keep pace with meaningful use certification requirements. Two vendors dominated the large hospital market in 2012, with Epic and Cerner winning 75% of new EHR contracts for large hospitals.<sup>16</sup> Some experts were concerned that a consolidated EHR market raises the specter that vendor market power will “trap” provider data by making it costly for a provider to exchange data with other providers who are not running the same EHR system. Others, in contrast, thought that having a critical mass of health care providers running the same EHR systems could lead to interoperability more quickly because there will be fewer competing standards, and the cost and complexity

of connectivity will be reduced. One expert stated, “As we’ve seen in other industries, you generally don’t get standardization until there is a shake-out among the early adopters; we are seeing this both in the health care marketplace in general (i.e., consolidation among hospitals and health care providers) and in the EHR market.”

## Health Information Exchange Standards, Certification, and Incentives

As it was 10 years ago, achieving interoperability — generally speaking, the ability of two health care providers to exchange data and subsequently present the data in a manner that can be understood by a patient — continues to be an important HIT policy goal, and the issue of how to achieve interoperability continues to spark debate.<sup>17</sup> According to one expert, there is no common expectation of interoperability today. There is, however, general agreement that a lack of widely adopted standards, failure to use existing standards, and flexibility in the way that standards are implemented have contributed to the high cost of exchange in today’s health care market.<sup>18</sup>

There is also debate about the federal government’s use of incentives to encourage development of HIE capabilities that are configured to deliver discrete data to entities who are known to each other (referred to as “push” or “direct” exchange) versus those that are configured to support the ability of authorized users to “pull” data from multiple systems in response to queries (referred to as “pull” or “query-based” exchange). For some, focusing on direct exchange is setting the bar too low in terms of what should be expected from HIE. In their view, direct exchange does not support the type of analytics or decision support necessary to improve health care quality and lower health care costs. For others, direct exchange is simpler, costs far less than query-based exchange, and solves the need for providers to securely exchange progress notes, discharge summaries, and other clinical documents electronically. Both forms of exchange are still in the early stages of development, and as the HIE market develops, each is expected to be used to address different needs.

## Standards and Certification Activities

The federal government, states, and other purchasers and users of HIE systems, recognizing the need for common standards to reduce the costs of HIE, have initiated different efforts to accelerate the pace of standards development and adoption.

### Federal Government Efforts

The federal government's standards-setting activities began in 2005 with the efforts of the Health Information Technology Standards Panel and the American Health Information Community, both of which focused on adoption of content and vocabulary standards. HITECH established new structures and processes for standards adoption, including the formation of two committees under the Federal Advisory Committee Act: the Health IT Policy Committee and the Health IT Standards Committee. The Health IT Policy Committee is required to recommend and prioritize the areas in which standards, implementation specifications, and certification criteria are needed for the electronic exchange and use of health information, in alignment with a strategic plan developed by ONC. The Health IT Standards Committee is required to recommend to ONC a set of standards, implementation specifications, and certification criteria that align with the priorities set by the Health IT Policy Committee as well as with ONC's strategic plan.

Initially, the federal government required that EHRs be certified by the Certification Commission for Healthcare Information Technology (CCHIT), a private, nonprofit organization created by health care IT industry associations. In 2010, ONC expanded the pool of organizations able to certify EHRs; these organizations are referred to as accredited testing laboratories (ATLs) or authorized certification bodies (ACBs). For a health care provider to receive incentive payments for achieving meaningful use, the provider must have EHR certification identification from the Centers for Medicare & Medicaid Services (CMS), which confirms that the provider possesses the required capabilities of a complete EHR.

The initial set of standards, implementation specifications, and certification criteria under HITECH focused only on the standards required for certified EHR technology to support Stage 1 meaningful use, including data content standards (i.e., requirements for defining data elements captured in EHRs in a standard way) associated

with laboratory results, medications, problems, and procedures. Data transport standards (i.e., methods required for moving EHR information), which are critical to the success of health information exchange, were not included in the initial set. Despite the inclusion of standards in the Meaningful Use Program, the health care system has still not achieved interoperability. Among other explanations, experts cited the slow standards development process and difficulty in reaching consensus. Another challenge is that there are no incentives or penalties to ensure compliance by ancillary organizations that use and supply data to providers, such as clinical laboratories and pharmacies, which are not subject to the EHR certification process under the Medicare and Medicaid EHR Incentive Programs.

The current federal strategy for the development and adoption of HIE standards is articulated in a June 2013 report to Congress from ONC.<sup>19</sup> According to this report, ONC's high-level approach to meeting its responsibilities and fostering interoperable HIT products and systems includes the following:

- ▶ **Supporting flexible, incremental, and modular standards.** ONC acknowledges that it has not attempted to develop a centralized or top-down approach to interoperability. Instead, through the Standards & Interoperability Framework Initiative, ONC supports the development of flexible, modular standards and harmonizes a portfolio of standards, services, and policies that provide flexible ways for different systems in different settings to interact and exchange information with one another.
- ▶ **Selecting standards that work for the future.** ONC states that its work advancing interoperability continually and deliberately considers the need for the HIT infrastructure to be adaptable, so that it can meet today's needs but still accommodate new policies, payment models, care models, and technologies in the future.
- ▶ **Making incremental changes with community feedback.** ONC takes an incremental, iterative approach that engages the community to help identify problems and quickly develop solutions. ONC uses feedback from real-world pilots to help refine and improve the standards available for health information interoperability and exchange.

► **Supporting implementation and pre-certification testing.** ONC notes that HIT interoperability standards, specifications, and services are successful when vendors and providers are able to effectively, efficiently implement and use these resources. ONC acknowledges that supporting implementation and pre-certification testing efforts is critical both to learning what helps to accelerate incremental improvement of interoperability resources and to helping the HIT vendor and user communities succeed in information exchange and use.

Many experts believed that it would be difficult to determine the right pace for standards-setting because doing so involves weighing what the market is ready to accommodate. According to these experts, the reason for the lack of progress on standards is the lack of a clear business case for standards in the first place. Several experts noted that they think standards for HIE will only evolve once the HIE market is more mature and once different types of organizations see connecting with each other as a compelling business imperative.

### Private Sector and State-Based Efforts

State and private sector players have also contributed to standards development activities. These efforts have often helped speed up the process of standards adoption and have focused on the development of standards to support types of activities that the federal government had not yet begun to address (e.g., standards for query-based exchange).

In February 2011, a coalition of states, joined by other HIE purchasers, users, and vendors, launched the EHR/HIE Interoperability Workgroup to leverage existing standards and to develop consistent implementation guides for interoperability between HIE software platforms and the applications that interface with them.<sup>20</sup> The workgroup consists of 19 states and 43 EHR/HIE vendors. In 2013, the EHR/HIE Interoperability Workgroup released its first set of functional, technical, and test specifications, which included those related to direct as well as query-based exchange.<sup>21</sup>

In March 2013, a coalition of EHR vendors banded together to address the problem of interoperability. This group, known as the CommonWell Health Alliance, consists of representatives from Allscripts, athenahealth, Cerner, CPSI, Greenway, McKesson, and Sunquest. The alliance will initially certify core interoperability services

and standards for vendors to embed within their own software.<sup>22</sup> The services the alliance will test in its initial proof-of-concept phase, estimated to last 18 to 24 months, include:

- Cross-entity identity management services: the ability to identify patients as they move from setting to setting, regardless of the underlying software system
- Patient consent and data access management: a HIPAA-compliant, patient-controlled means to simplify the management of consents and authorizations for data sharing
- Patient record locator and directed query services: the ability to deliver a history of recent patient care encounters and, with appropriate authorization, patient data across multiple providers and episodes of care

### HIE Incentives

In addition to requiring certification of compliance with various technological standards, the federal government has sought to encourage HIE through payment incentives, beginning with the meaningful use requirements of the EHR Incentive Programs and now including the payment reform provisions of the ACA.

### Meaningful Use

As implemented, HITECH specified the following three components of meaningful use:

- Use of certified EHR technology in a meaningful manner (e.g., e-prescribing)
- Use of certified EHR technology for the electronic exchange of health information to improve the quality of health care
- Use of certified EHR technology to submit clinical quality measures and other such measures selected by HHS

As implemented by CMS and ONC, the Medicare and Medicaid EHR Incentive Programs feature a phased approach across three stages, designed to reflect, in turn, data capture and sharing, advanced clinical processes, and ultimately, improved health outcomes.

Meaningful use Stage 1 requirements included e-prescribing, the capability to submit electronic data to

immunization registries or to provide electronic syndromic surveillance data to public health entities, as well as the testing of other data exchange capabilities. Unlike the first stage, Meaningful Use Stage 2 was designed to encourage routine data exchange between entities not under common control. Expectations for information exchange in Stage 2 include more demanding requirements for e-prescribing, incorporation of structured laboratory results, and expectations that providers will electronically transmit patient care summaries to each other and to patients in order to support transitions in care. (See Table 1.)

A study in the *American Journal of Managed Care* provides a portrait of physicians' exchange capabilities nationally as of Stage 1 of the Meaningful Use Program and a baseline for monitoring progress as new policies and initiatives to accelerate HIE are implemented — in particular, Stage 2.<sup>23</sup> According to the study, in 2011, more than half of all US physicians (55%) reported that their practices had computerized capability to e-prescribe. A majority of physicians (67%) reported that they were able to view lab results electronically, but fewer physicians (42%) were able to incorporate lab results into their EHR. More than one-third reported that they were able to send lab orders electronically. The computerized capability to provide clinical summaries to patients was reported by 38% of physicians. Among those physicians who reported exchanging clinical summaries with other

providers (31%), approximately three-fourths reported both sending and receiving clinical summaries.

## Payment and Care Model Reforms

Since Stage 2 meaningful use measures are just beginning to be implemented, it is too early to assess their impact on the HIE marketplace. Experts agreed, however, that widespread HIE will not occur until new payment approaches such as bundled payment options, accountable care organizations, and medical home initiatives create the business case for information exchange.<sup>24</sup> Fee-for-service payments that reward volume of care, and not quality or efficiency, give providers little incentive to share electronic information to support better patient care.<sup>25</sup> According to many experts, HITECH was meant to be coupled with ACA-style payment reform provisions.

The ACA includes a series of new payment and delivery system initiatives, and almost all, in some measure, require the development and widespread use of better HIT systems. A significant part of the planning efforts for these new care delivery models focus on the technology and methods for collecting, integrating, sharing, and analyzing health information to support better health care outcomes and more cost-effective care delivery. For ACO arrangements to function successfully, for example, participants need timely access to the following data: (1) performance metrics, such as care cost and quality; (2) patient events, such as a visit to the emergency

**Table 1. Key Health Information Exchange Requirements for Meaningful Use Stages 1 and 2**

	DESCRIPTION
<b>Electronic exchange of lab results</b>	Providers receive and use lab results, supplying critical information to make diagnoses, track treatment of chronically ill patients, and assess quality of care.
<b>Care and discharge summaries</b>	When a patient is referred to a specialist or discharged from a hospital, care and discharge summaries are shared with the patient's primary care provider to enable the provider to make effective diagnoses, follow up with the patient in a timely and appropriate manner, prescribe appropriate medications, and avoid unnecessary services so that patient transitions are safer and more effective.
<b>Public health reporting</b>	Providers report key events relevant to public health (immunizations delivered, contagious diseases found), supporting improved population health.
<b>Quality reporting</b>	Providers measure and share information about the quality of the care they deliver, creating critical feedback loops.
<b>Sharing information with patients</b>	Providers share care summaries, reminders, and other key information with patients, improving care coordination and engaging patients in their own care.

Source: Claudia Williams et al., "From the Office of the National Coordinator: The Strategy for Advancing the Exchange of Health Information," *Health Affairs* 31, no. 3 (March 2012): 527–536, [content.healthaffairs.org](http://content.healthaffairs.org).



department or a failure to show up for an appointment; and (3) patient status, as in a hospitalization in a member hospital with a specific discharge destination.

Generally, experts believed ACOs, payment bundling, and other payment and service delivery innovations under the auspices of the Center for Medicare & Medicaid Innovation, all could be seeds of a business case for exchange. According to one expert, demand to participate in HIE in the state of Massachusetts has become nearly universal among hospitals, in large part due to ACA payment incentives. Some small practices may choose not to engage in HIE, but they will not survive in the world of accountable care, said this expert. This individual also predicted that in the next few years, 80% of health care providers will be exchanging health information electronically, thanks to new methods of payment that encourage care coordination and management across disparate providers.

The proliferation of ACOs, with their well-defined membership structures and targeted patient populations, has been noted as a contributing factor to larger health systems' desire to build or procure their own private HIEs. As of July 2013, there were 488 ACOs, of which 52% were engaged in a contract with CMS to provide care to Medicare beneficiaries through the Medicare Shared Savings Program or the Pioneer ACO Model.<sup>26</sup> And this number continues to grow: For example, CMS announced 123 new ACOs under Medicare on December 23, 2013.<sup>27</sup> State efforts to redesign their Medicaid programs to reward more efficient and coordinated care have also been noted drivers of HIE.

## Health Information Exchange Governance

From the start, governance has been recognized as critical to the success of HIE. ONC's first strategic plan, issued in 2004, observed that "an interoperable infrastructure requires coordinated and secure HIE, including the business, governance, and technical delivery mechanisms to support it."<sup>28</sup>

HIE governance refers to the establishment and oversight of a common set of behaviors, policies, and standards that enable trusted HIE among a set of participants. Policymakers and stakeholders have emphasized the need for a governance mechanism to advance the

goals of interoperability, decrease the cost and complexity of exchange, and mobilize trusted exchange among stakeholders to support patient care. While the need for governance is widely recognized, the last 10 years has not led to a clear consensus on the nature and extent to which governance is required at the national, state, regional, or community levels. A review of various governance-related efforts is intended to help inform future HIE policy and business efforts.

## National Governance Efforts

There have been a variety of efforts to establish governance mechanisms for HIE at the national level. None of these efforts, however, have led to the establishment of a national HIE governance mechanism. Prior to HITECH, in 2005, ONC awarded contracts to four consortia to develop prototypes for the Nationwide Health Information Network (NHIN), which ONC hoped would evolve into a common framework and national governance structure. Over time, however, the NHIN concept was abandoned and replaced by a different set of policy priorities that focused on more nimble, local, and regional governance.

Another significant federal effort to launch a nationally governed network was the creation of the eHealth Exchange. The eHealth Exchange was launched in February 2009 with the first live exchange of data between the Social Security Administration and a private, nonprofit regional health information organization, MedVirginia, followed by the US Department of Veterans Affairs and Kaiser Permanente later that year. In October 2012 the operations of the eHealth Exchange were transferred from the federal government to Healtheway, a private, nonprofit organization. While the eHealth Exchange is one of three federally recognized mechanisms to meet meaningful use Stage 2 transitions in care and referral measures, it currently operates independently of the federal government. Participants in eHealth Exchange, whose membership has grown to approximately 40 organizations, share information under a common trust agreement, using a common set of technical requirements, policies, and testing processes.<sup>29</sup>

With the passage of HITECH, Congress required the National Coordinator for Health Information Technology to establish a governance mechanism for the NHIN.<sup>30</sup> ONC issued a request for information in May 2012 seeking public input on a potential regulatory approach to

spell out “conditions for trusted exchange” (safeguards, and technical and business practices) through rule-making, and to establish a voluntary accreditation and certification process for validating organizations as legitimate participants in the NHIN.<sup>31</sup> Public feedback on this request suggested that market conditions were not right (i.e., lack of general support and sufficient agreement on implementation strategies) for the creation of a formal national governance process, and consequently, ONC decided instead to focus on defining general principles for supporting HIE at whatever level of organization it is being pursued.<sup>32</sup>

Accordingly, in May 2013, ONC released a “Governance Framework for Trusted Electronic Health Information Exchange.”<sup>33</sup> The framework outlined four categories of principles for HIE governance:

- ▶ Trust principles guide HIE governance entities on patient privacy, meaningful choice, and data management in HIE.
- ▶ Business principles focus on responsible financial and operational policies for governance entities, and emphasize transparency and the patients’ best interests.
- ▶ Technical principles express priorities for the use of standards to support the trust and business principles as well as furthering the execution of interoperability.
- ▶ Organizational principles identify approaches for good self-governance.

Most experts agreed that the idea of nationwide governance for HIE (i.e., a governance mechanism that can facilitate cross-state and cross-regional exchange) would be “nice to have” but not necessary at the present time. There is not enough “felt need” for HIE that is national in scope. While national HIE may make sense for large, regionally dispersed health care systems like the Mayo Clinic or Kaiser, these organizations are few and far between. Nationwide governance will be necessary when there is a need to solve the practical problems that can only be addressed through collaboration across political entities and across marketplaces.

Other experts pointed out that there are significant legal barriers to national governance of HIE. For example, HIPAA does not preempt state privacy and security laws, and accordingly, any national governance structure would need to accommodate those laws. Since privacy

and security requirements vary widely from state to state, this task may be too great to reconcile at the federal level. One expert said that it would be great to see national policy and governance with consistency across the states, but because of the lack of preemption and the different definitions among various stakeholders of what is necessary to establish trust, governance of HIE will exist only at the local and state level for some time.

## State-Level Governance Efforts

In addition to national efforts, there have also been a number of state-level HIE governance initiatives. One major effort to seed the establishment of state-level governance mechanisms was launched in 2009 through the State Health Information Exchange Cooperative Agreement program. Under this program, ONC provided \$564 million in HITECH funds to states and state-designated entities to develop strategic and operational plans to address statewide policy, governance, technical infrastructure, and business practices in support of HIE.<sup>34</sup>

The program’s focus on state governance of HIE was spurred in part by the fact that many of the policy issues that need to be aligned to facilitate effective HIE are controlled by state governments, such as privacy and security practices and the participation of Medicaid in HIE efforts. ONC’s support for these initiatives is winding down as ONC made funding available for a four-year period beginning in 2010 and ending in 2013. The future of these initiatives will rest on whether states or health care stakeholders see enough value in the exchanges to merit providing them with continued financial support. In January 2013, the governor of New York, for example, proposed to contribute over \$50 million in state funding to support the ongoing operation of the state’s HIE network (the Statewide Health Information Network for New York), which was originally built using cooperative agreement funding.

States have followed different pathways in trying to facilitate HIE. Some have developed consistent statewide policies to facilitate exchange, others have supported community-based HIE efforts, and still others have formed regional consortia.<sup>35</sup> Following ONC’s lead, many states initially focused on implementing direct exchange. A handful of states aggressively pursued both direct and query-based exchange, with some seeking to launch statewide HIE “public utilities” and requiring participation through statute or regulation.<sup>36</sup> According to the

progress reports submitted by states under the HITECH HIE Cooperative Agreement Program, in the second quarter of 2012, both direct and query-based exchanges were broadly available in the majority of states. Thirteen states made only direct exchange available, while three states made only query-based exchange available.<sup>37</sup>

Experts agreed that query-based exchange poses far more complex governance, policy, and business issues — including those relating to privacy and security, legal liability, data usage, and financial sustainability — than direct exchange. States that have pursued query-based exchanges have sought to standardize the policy, business, and technical components of HIE, believing that this standardization will increase the value and reduce the cost of participating in an exchange more so than leaving the development of HIE to the private marketplace. States pursuing this approach believe that individuals have a right to easy access to their own health care data and that a public exchange, in which all participants agree to share information with each other based upon an open and transparent set of requirements, is essential to ensuring that neither vendors nor providers create barriers to HIE.

## The Future of HIE Governance

At this juncture, there is no overarching governance model to accelerate the development of HIE. Instead, it appears that the role of the federal government will, for the time being, continue to revolve primarily around standards-setting, certification, and administration of the Meaningful Use Programs, and the role of states will vary depending on the strategy each state elects to pursue.

In addition, day-to-day HIE activities in many parts of the country may increasingly take place through private HIE entities formed by different groups of private stakeholders for the purpose of supporting a specified business initiative, such as an accountable care organization. In fact, the presence of private HIE is on the rise. The number of private HIEs increased from 52 in 2010 to 161 in 2011, growing two to three times faster than public HIEs.<sup>38</sup>

Despite the governance issues, there has been a growth in HIE overall. A 2012 survey found that 1,398 US hospitals (30% of US community hospitals) participated in HIE efforts, compared to 14% in 2010.<sup>39</sup> Similarly, in 2012, 23,341 ambulatory practices (10% of US practices)

participated in the 119 operational HIE efforts; this is more than triple the number of practices (3%) that participated in 2010. This growth reflects a shift in mindset among hospital and practice administrators who are recognizing the importance of HIE in solving fundamental business problems. As several experts noted, it is becoming increasingly rare to encounter a provider who doesn't see the need for HIE on some level and who isn't already thinking about HIE requirements, both strategically and tactically.

## Conclusion

Nearly a decade after the establishment of the ONC and five years after the passage of HITECH, the United States is moving forward with creating a health care system that is harnessing the power of health information to support more cost-effective and better quality care. For some, this journey is taking longer than originally anticipated and involves more twists in the road than predicted at the outset. But there is little denying that the combination of government initiatives and market forces is propelling the nation forward to a time when the creation, sharing, and use of electronic health information to improve health care decisionmaking and management will be commonplace.

In the years ahead many important health policy decisions will need to be confronted, given the trajectory of health reform and the winding down of HITECH funding. Will a national HIE governance mechanism be implemented? How will the country overcome barriers to sharing health information across state lines? Will more regulation be required to ensure that stakeholders and vendors don't restrict data exchange that is in the best interests of patients? What steps will need to be taken to ensure that all health care stakeholders, including long term care providers and behavioral health providers, and providers serving rural areas and low-income populations, fully participate in HIE? Will the combination of meaningful use incentives and ACA payment and delivery system reform initiatives be sufficient — and sufficiently coordinated — to continue stakeholder interest in supporting HIE? What steps will be taken to ensure that health information is used to support better health care outcomes? How will we ensure that patients are given meaningful access to their own health information?

The experts interviewed for this paper were asked: If you had a magic wand and could have one wish granted, what would you ask for that would accelerate the use of HIE to improve our health care system? A wide-ranging list of requests emerged:

- ▶ Full implementation of the ACA
- ▶ More support for adoption of HIT by long term care, mental health, and social service providers
- ▶ Accelerated development of key technical infrastructure standards for HIE
- ▶ A national patient identifier
- ▶ Technical assistance and financial support for rural and safety-net providers
- ▶ More focus on health care outcomes and less focus on compliance-focused regulations that may inhibit innovation
- ▶ Federal preemption of state privacy laws; the establishment of a national framework for privacy and security
- ▶ Funding to ensure that the necessary innovation and transformation actions can take place

These requests reflect the multitude of “lessons learned” that we have encountered in the 10 years since the federal government made adoption of EHRs and HIE a national priority. In years to come, how we respond to these types of requests will influence the speed and success of our path forward.

## Appendix A: Interviewees

David Blumenthal, MD, MPP

President

The Commonwealth Fund

Mark Frisse, MD, MS

Accenture professor, Biomedical Informatics

Vanderbilt University

John Glaser, PhD

Chief executive officer, Health Services Business Unit

Siemens Healthcare

John Halamka, MD, MS

Chief information officer

Beth Israel Deaconess Medical Center

Arien Malec

Vice president, Data Platform Solutions

Relay Health

David Pryor, MD

President and chief executive officer

Ascension Clinical Holdings, Ascension

Lonny Reisman, MD

Chief medical officer

Aetna

Mark Savage, JD

Director of Health IT Policy and Programs

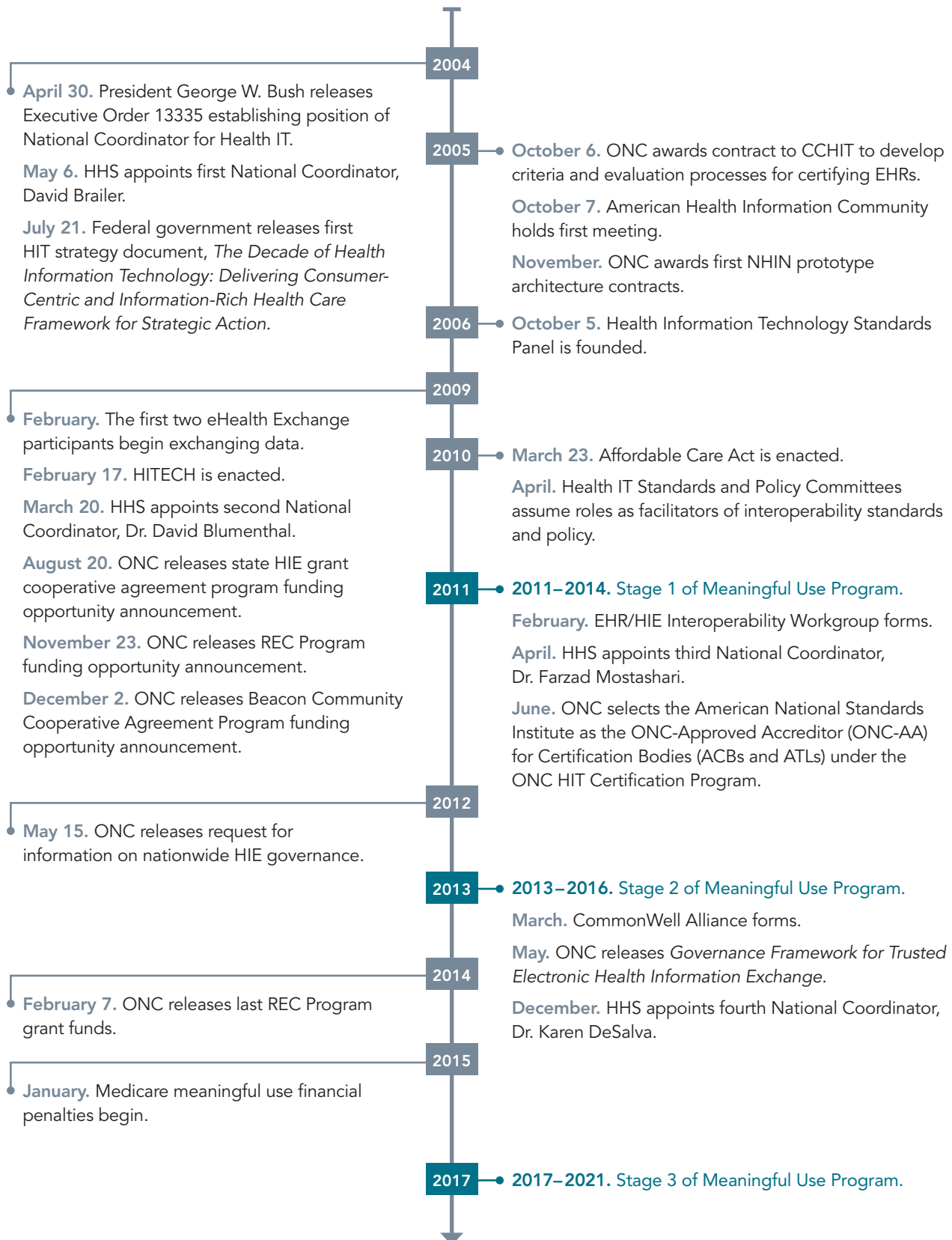
National Partnership for Women & Families

Micky Tripathi, PhD, MPP

President and chief executive officer

Massachusetts eHealth Collaborative

## Appendix B: Key HIE Milestones



## Endnotes

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