# EVALUATION OF THE STATE HIE COOPERATIVE AGREEMENT PROGRAM

# Final Report: Executive Summary

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# Abbreviations

| Acronym | Description |
|---|---|
| **ACA** | Patient Protection and Affordable Care Act |
| **ACO** | Accountable Care Organization |
| **ADT** | Admission, Discharge, Transfer |
| **AHA** | American Hospital Association |
| **AHRQ** | Agency for Healthcare Research and Quality |
| **API** | Application Program Interfaces |
| **ARRA** | American Recovery and Reinvestment Act |
| **CAH** | Critical Access Hospital |
| **CCD** | Continuity of Care Document |
| **C-CDA** | Consolidated Clinical Document Architecture |
| **CFR** | Code of Federal Regulations |
| **CHIP** | Children's Health Insurance Program |
| **CHPL** | Certified Health IT Product List |
| **CLIA** | Clinical Laboratory Improvement Amendments |
| **CMS** | Centers for Medicare & Medicaid Services |
| **CRM** | Customer Relationship Management |
| **DoD** | U.S. Department of Defense |
| **DURSA** | Data Use and Reciprocal Support Agreement |
| **ED** | Emergency Department |
| **EHI** | eHealth Initiative |
| **EHR** | Electronic Health Record |
| **ELR** | Electronic Laboratory Reporting |
| **FOA** | Funding Opportunity Announcement |
| **FQHC** | Federally Qualified Health Center |
| **GAO** | Government Accountability Office |
| **HCIA** | Health Care Innovation Award |
| **HHS** | U.S. Department of Health and Human Services |
| **HIE** | Health Information Exchange |
| **HIMSS** | Health Information Management Systems Society |
| **HIO** | Health Information Organization |
| **HIPAA** | Health Insurance Portability and Accountability Act |
| **HISP** | Health Information Service Provider |
| **HITECH** | Health Information Technology for Economic and Clinical Health Act |
| **HITRC** | Health Information Technology Research Center |
| **ICD-10** | International Statistical Classification of Diseases and Related Health Problems, 10th revision |
| **IDN** | Integrated Delivery Network |
| **IIS** | Immunization Information Services |
| **IT** | Information Technology |

| Acronym | Description |
|---|---|
| **LOINC** | Logical Observation Identifiers Names and Codes |
| **MACRA** | Medicare Access and CHIP Reauthorization Act of 2015 |
| **MIPS** | Merit-Based Incentive Payment System |
| **MMIS** | Medicaid Management Information System |
| **MSA** | Metropolitan Statistical Area |
| **MU** | Meaningful Use |
| **NATE** | National Association for Trusted Exchange |
| **NEHRS** | National Electronic Health Record Survey |
| **NORC** | NORC at the University of Chicago |
| **NPP** | Notice of Privacy Practices |
| **NwHIN** | Nationwide Health Information Network |
| **ONC** | Office of the National Coordinator for Health Information Technology |
| **OSCAR** | Online Survey, and Certification and Reporting |
| **PCMH** | Patient-Centered Medical Home |
| **PIN** | Program Information Notice |
| **PPS** | Prospective Payment System |
| **REC** | Regional Extension Center |
| **RFP** | Request for Proposal |
| **RWJF** | Robert Wood Johnson Foundation |
| **S&I** | Standards and Interoperability Framework |
| **SIM** | State Innovation Model |
| **SNOMED** | Systematized Nomenclature of Medicine |
| **SNOMED CT** | SNOMED Clinical Terms |
| **SDE** | State Designated Entity |
| **VA** | U.S. Department of Veterans Affairs |

# Executive Summary

## I. Introduction and Context

As part of the 2009 American Recovery and Reinvestment Act (ARRA), Congress passed the Health Information Technology for Economic and Clinical Health (HITECH) Act, to promote "the electronic movement and use of health information among organizations using nationally recognized interoperability standards."[1] The HITECH Act provided $564 million to the Office of the National Coordinator for Health Information Technology (ONC) in the U.S. Department of Health and Human Services (HHS), to enable rapid development of health information exchange (HIE) across the nation.[i] The State Health Information Exchange Cooperative Agreement (State HIE) Program was created to achieve this objective via tailored, state-level solutions. Organizations in all 56 states and territories submitted strategic and operational plans; and during the four-year program, they received funding and ongoing ONC guidance for development and implementation of their plans. The HITECH Act also mandated an annual evaluation of program activities; grantees completed self-evaluations; and in 2010, ONC awarded a contract for an independent program evaluation to NORC at the University of Chicago (NORC).

Multiple approaches are available to accomplish information exchange; and the funding opportunity announcement (FOA) offered grantees flexibility in selecting their approaches, recognizing the need for distinct models depending on the state/territory and its relevant ecosystem.[2] Exchange can occur through secure email or messaging (directed exchange), drawing information from a dataset (query-based exchange), or communication between electronic health records (EHRs). Ideally, this means patients, families, caregivers, and health care providers can send and receive health-related information securely; authorized parties can access and use the information; and providers can interact with the greater health care ecosystem to support population health outcomes and contribute to the learning health care system.[3]

Increasing availability and use of systems for exchange was a central goal of the State HIE Program, and a central question in the evaluation. Developing systems for exchange is also a stepping stone to achieving health system–wide interoperability—the ability of two or more systems or components to exchange information, so recipients can use the information in a meaningful way.[4] Although not a central program goal, interoperability was a frequent theme throughout the evaluation and remains a long-term federal objective of ONC, the Centers for Medicare & Medicaid Services (CMS), and other agencies engaged in health information technology (health IT)–related initiatives and delivery system reform.

### Program and Evaluation Overview

The overarching goal of the State HIE Program was to rapidly build HIE capacity by: (1) ensuring every provider has at least one option for meeting the HIE requirements of meaningful use (MU)[ii]; (2) fostering creation and use of networks of exchange through which information can flow; (3) filling existing gaps in exchange capacity (e.g., overcoming technical barriers, lack of services); and (4) ensuring exchange can occur across networks. Given the program's design as a one-time investment over a four-year period, ONC recognized it would be challenging "for states to implement and operate comprehensive statewide HIE services" using HITECH funds alone.[5] As such, states were encouraged to fill service gaps, leverage

[i] Initial awards were made in February and March 2010; the program ended in February 2014

[ii] Under CMS' EHR Incentive Programs, eligible providers must demonstrate "meaningful use" of certified EHR technology in order to receive incentive payments.

existing information exchange, and coordinate with key stakeholders in pursuit of sustainable HIE solutions.

NORC conducted an independent program evaluation, funded by ONC, which focused on three aims:

**AIM 1: Characterize the Approaches Taken to Enable HIE and How They Evolved over Time.** This included identifying the technical and operational models grantees selected, factors that influenced their approach selection, and how these approaches evolved in the context of state-level priorities and pressures.

**AIM 2: Characterize HIE Levels at Baseline and How They Changed over Time.** Following the initial characterization of state approaches to HIE, Aim 2 focused on how state-level measures of EHR adoption and HIE participation and activity progressed over the course of the program.

**AIM 3: Assess Overall Program Effectiveness.** Finally, over the course of the four-year program, what were the factors (contextual and programmatic) that influenced HIE progress? What were the program impacts?

## II. Methods

NORC developed a mixed-methods approach to obtain a comprehensive understanding of the planning, implementation, operation, and impact of the program. The evaluation consisted of a variety of qualitative and quantitative evaluation activities occurring between 2011 and 2014. We designed these activities to explore different dimensions of the states' implementation approaches; different stakeholder perspectives; and state-level challenges, barriers, and lessons learned.

## III. AIM 1: Characterize Approaches Taken to Enable HIE and How They Evolved

In AIM 1 of the evaluation, we focused on three key research questions: 1) What approaches did grantees take to enable HIE services? 2) What was the rationale for the approach chosen? 3) How did grantee approaches evolve over the program?

### What Approaches Did Grantees Take to Enable HIE Services?

Grantees were able to select state-specific implementation approaches, given varied market dynamics.

***Leadership and Organizational Structure.*** HITECH authorized ONC to provide program funding and leadership authority to states and state designated entities (SDEs), which led to development of three models for disseminating program funds and leading implementation: state-led approach, SDE-like approach, and "true" SDE approach. Each approach presented its own advantages and drawbacks, as discussed in Chapter I (Introduction and Context) and Chapter III (AIM 1).

***Technical Approaches.*** ONC allowed grantees leeway in developing their technical approaches in response to local needs and, in some cases, existing infrastructure. In spite of wide variation in overall technical approach, many grantees either: (1) established or leveraged a single statewide organization for exchange, or (2) connected local or regional nodes in a "network-of-networks" approach. A majority of grantees used a single organizational entity to provide technical services across the state, rather than engaging with multiple organizations to do so. In general, grantees' services aligned strongly with the Medicare and Medicaid EHR Incentive Programs' MU priorities.

***Legal and Policy Approaches.*** Most grantees selected "opt-out" consent models, allowing providers to exchange patient health information unless the patient explicitly requests otherwise. Many encouraged HIE participation via legal and policy levers. These levers included mandating provider participation in the statewide HIE system; enacting legislation to promote HIE participation, EHR adoption, or both; and

accrediting or certifying health Information organizations (HIOs) or health information service providers (HISPs) to increase stakeholder trust in HIE efforts and organizations.

### What Was the Rationale for the Approach Chosen?

The level of HIE activity prior to HITECH affected grantee selection of leadership and organizational approach. State characteristics—including population size and urbanicity, local use cases, and presence of HIOs and other hospital systems engaging in exchange—influenced grantees' selected technical approach. Privacy and security concerns, combined with existing legislation related to health information disclosure and use, influenced state selection of a consent model.

### How Did Grantee Approaches Evolve over Time?

Given the ongoing evolution of both the health care market and the health IT landscape, as well as the availability of exchange via organizations outside the State HIE Program, many grantees shifted their approach during the program to strengthen the capacity of existing networks of exchange instead of positioning themselves as the state's central HIE service provider. Throughout the program, grantees' priorities shifted from Stage 1 MU requirements and services emphasized by the initial State HIE Program Information Notice (PIN)[6] (e.g., electronic prescribing [e-prescribing], receipt of structured laboratory results, sharing of patient care summaries, and public health reporting) towards Stage 2 MU requirements related to HIE.

Grantee perspectives shifted on the uses and utility of types of exchange as well. After enabling or increasing availability of query-based exchange, grantees recognized the importance of ensuring high data quality to build trust and amass users. Grantees began to view directed messaging as a short-term solution—or a solution with specific use cases (e.g., exchange of behavioral health information)—with query-based exchange as the preferred solution but (for many) a long-term goal.

## IV. AIM 2: Characterize HIE Levels at Baseline and How They Changed over Time

AIM 2 focused on two research questions: (1) What was the baseline level of HIE across states? (2) How did HIE progress over the program period? Since the primary data collection did not include direct measures of HIE at the grantee level, AIM 2 relies on national and state-level data from secondary sources. Given the numerous public and private efforts operating concurrently that also influenced HIE, we cannot attribute changes in HIE levels directly to the program. Isolating program efforts from broader health IT and other delivery system reform efforts is also a challenge.

### What Were HIE Levels at Baseline and How Did They Progress over the Program?

To assess baseline HIE levels and progress we look at measures of HIE capability and activity. Our measures of HIE capability show increased access to, and opportunity for, exchange throughout the program. While most measures reflect gains in HIE activity, they must be taken in the context of the baseline—grantees started with a modest amount of exchange at program inception (with the exception of a limited number of states), which grew to more robust levels. However, there is considerable room for service expansion and improvements in overall participation and use.

***Measures of HIE Capability.*** To assess capacity for exchange we analyzed: (1) the capacity to exchange based on available HIOs, and (2) the extent to which hospital and ambulatory providers actively shared patient-level clinical data through an HIO. From 2010 to 2015, the number of HIOs fluctuated but saw a 41 percent net growth nationally.[7] Hospital and ambulatory practice exchange of clinical data through an HIO increased twofold and threefold, respectively; however, overall participation numbers remained low, with 30 percent of hospitals and 10 percent of ambulatory care practices[8] sharing data in 2012.

We also measured grantee participation in directed and query-based exchange, as well as the capacity of clinical laboratories to exchange laboratory results. Acute care hospital participation in directed exchange increased from just over 124 to just under 938 in 2013, while participation of ambulatory entities increased from 4,500 in 2012 to 21,000 in 2013. The number of acute care hospitals participating in query-based exchange increased from less than 400 in 2011 to 2,000 in 2013 (nearly a threefold increase), while participation of ambulatory entities increased from 2,200 to 8.800 (a fourfold increase). In addition, 67 percent of clinical laboratories reported the capability to send structured laboratory results electronically in 2012, again with significant variation across states.

***Measures of HIE Activity.*** These measures included the overall volume of directed and query-based transactions, hospital and office-based physician electronic exchange of PIN priority MU measures (i.e., measures of e-prescribing, receipt of structured laboratory results, sharing of patient care summaries, and public health reporting), and a composite measure of HIE activity.

- **National Levels of HIE Activity.** As reported by grantees, the total number of directed transactions increased more than threefold, while total number of patient record queries increased more than fourfold from 2011 to 2013.[9] Although these numbers represent considerable growth, national averages of participation were driven by a small number of top performing states, rather than by high participation across all states.
- **PIN Priority MU Measures.** HIE levels related to PIN priority MU measures increased over the program period (i.e., measures of e-prescribing, receipt of structured laboratory results, sharing of patient care summaries, and public health reporting). The average share of physicians actively using an EHR to e-prescribe via Surescripts increased by 28 percentage points from 2011 to 2014.[10] However, only 22 grantees reported providing or enabling e-prescribing as an operational service in 2013.[11] The average increase in care summary exchange from a hospital to another hospital outside the system was 38 percentage points over the same period.[12] In 2014, 85 percent of eligible hospitals were reporting, without exclusion, to the Medicare EHR Incentive Program on at least one public health measure.[13] In the same year, 72 percent of participating Medicare professionals who vaccinate reported electronically to an immunization information system, up from 51 percent in 2011.[14]
- **Summary of HIE Activity.** As part of the evaluation, NORC developed a composite HIE score made up of seven measures within three of the PIN priority MU domains (e-prescribing, laboratory results exchange, and care summary exchange).[iii] Our results showed positive change on multiple dimensions. The national composite HIE score increased from 36 to 79 percent from 2010 to 2014—an increase that was reflected in each of the seven measures making up the composite. In 2014, the level of HIE activity ranged from 51 percent (Nevada) to 97 percent (Minnesota). The gap between hospital-to-hospital and hospital-to-ambulatory care provider exchange also narrowed over the period—by 9 and 13 percentage points, respectively, for clinical care summary and laboratory results exchange.

Together, these results indicate a positive trend in HIE adoption and use, across the program years, states, and multiple services. Nonetheless, adoption and use varies heavily by state and many opportunities for expansion remain.

[iii] The composite HIE score was derived from seven measures: percent of hospitals sharing laboratory results electronically with hospitals outside their system, percent of hospitals sharing laboratory results electronically with ambulatory providers outside their system, percent of office-based physicians able to view laboratory results electronically, percent of office-based physicians able to send laboratory orders electronically, percent of hospitals exchanging clinical care summaries with hospitals outside their system, percent of hospitals exchanging clinical care summaries with ambulatory providers outside their system, percent of physicians actively using an electronic health record to e-prescribe via Surescripts (SS) network

## V. AIM 3: Assess Program Effectiveness

AIM 3 focused on two research questions: (1) What were the factors (contextual and programmatic) that influenced HIE progress? (2) What were the overall program impacts? Contextual factors are state-specific demographic and market characteristics (e.g., health system characteristics, and EHR adoption level), which often affected decisions regarding program factors (e.g., governance structure, technical and consent model, and supportive legislation) during implementation. We defined impact as the extent to which the program achieved its objectives to: (1) establish HIE infrastructure, (2) expand HIE adoption and reduce the cost and complexity of participation in exchange, and (3) help providers meet MU requirements.

### What Were the Factors (Contextual and Programmatic) that Influenced HIE Progress?

Qualitative and quantitative evaluation findings suggest that program factors such as technical, leadership, and consent models significantly influenced the grantees' trajectories, and that the influence of the State HIE Program increased over time. During the early program stages, contextual factors were of primary importance. For example, states with high levels of EHR adoption prior to HITECH had higher levels of exchange. In other words, states with experience in EHR adoption had a head start in HIE implementation and participation.

Over the four-year program, quantitative findings show that program approaches selected by states drove most of the changes in state HIE. Qualitative and quantitative findings also show that program and contextual factors worked together synergistically to support higher levels of exchange across the program years. Overall, states with a solid HIE foundation experienced greater success; these states were able to accelerate their progress with State HIE Program support. States with little foundation in HIE struggled to establish themselves in the early program years and only made measurable advances in the later years. In later program years, states with state-led HIE showed more success with HIE than true SDE or SDE-like models.

### What Were the Overall Program Impacts?

Based upon qualitative evidence, the State HIE Program impacted areas related to engaging stakeholders, aligning with Medicaid and public health programs, expanding HIE services and adoption, reducing the cost and complexity of exchange, helping providers meet MU requirements, raising awareness and acceptability of HIE, and creating infrastructure that can be leveraged by delivery system reform efforts.

Importantly, the program did not operate in a vacuum. Because it funded all 56 states and territories—and because grantees were encouraged to pursue solutions based on their own local needs, stakeholders, contexts, etc.—implementation variation among states is high, making the confounding factors numerous.

Finally, many program investments are likely to pay dividends in the coming years, as HIE becomes more established, more widely available, and more interoperable. As a result, additional program impacts may emerge downstream that cannot be captured at present.

## VI. Lessons Learned: Key Drivers, Challenges, and Solutions

A central goal of the evaluation was to extract important lessons from grantee implementation, to guide and inform similar efforts and provide an opportunity for grantees to learn from one another's experiences.

### Lessons Learned

Across grantee reports, several common key drivers eased the implementation of HIE, encouraged participation by hospitals and providers, and accelerated progress:

- Involvement of diverse stakeholders was of great value to build relationships, establish trust, improve acceptance, align goals, leverage existing HIE assets, and create a sense of ownership for all those involved.
- Initial service offerings played an important role in driving momentum for HIE by building services based on provider needs and demand, rather than building a service or standard and then trying to recruit adopters.
- Governing bodies varied in their official responsibilities, legal authority, membership, and affiliation with government—all of which had implications for the design, pace of development, and sustainability of HIE.
- Starting simply, rolling out services incrementally, and layering on complexity over time in response to growing provider demand, allowed states to demonstrate immediate value and gain buy-in for HIE.
- Delivery system reform has played, and will continue to play, a role in HIE expansion. The State HIE Program has facilitated provider efforts to meet the requirements of MU, and existing HIE infrastructure will play an important role supporting delivery system reform efforts.

### Challenges

- Developing and implementing HIE infrastructure and services was more resource intensive (in time, money, and effort) than grantees anticipated.
- Common standards and incentives were needed to achieve interoperability.
- Grantees encountered barriers in their relationships with EHR developers and HIE vendors, as well as lack of developer readiness to accommodate the needs of HIE stakeholders.
- Sustainability was a persistent concern among grantees.

### Sustainability

The State HIE Program catalyzed HIE through a substantial, one-time infusion of funds. Many factors will contribute to the sustainability of HIE services, whether state-led or otherwise—including diverse stakeholder engagement, a flexible infrastructure, continued marketing of benefits, and clear and consistent policies and regulation. Grantees expressed concerns about the financial sustainability of their HIE efforts, wondering whether they would be able to secure the necessary financial investment to continue operating in the short term—needed to demonstrate long-term value to stakeholders. Post-program, seven grantees are no longer operational. Grantees who continue to operate reflected that they may require more examples of the value-add of HIE to motivate continued stakeholder commitment and investment. Long-term sustainability requires that grantees seek out new financial contributors (including payers, ACOs, and long-term care providers) and offer them reasonably priced services that address their needs and priorities for exchange.

## VII. Policy Implications

With the conclusion of the State HIE Program and sweeping changes to the health care delivery system, HIE requires continued support at the federal, state, and community levels. Informants[iv] reported a desire for facilitation on multiple fronts, to maintain the program's momentum and to leverage its efforts for current and future HIE initiatives.

[iv] Informants included interviewees from Round 1 and 2 case studies, stakeholder discussions, and summative key informant interviews, as described in the Methods and Policy Implications chapters.

### State Role

- **Leadership and coordination,** particularly in convening stakeholders; policy development and delivery system reform; and conducting ongoing state-level needs assessments.
- **Engaging in future HIE efforts vis a vis Medicaid and social services,** given Medicaid's growing population creates a growing role for HIE and Medicaid's strength and influence as a payer and licensing body means its participation would lend strong support to HIE sustainability.
- **Creating and maintaining the Health IT Coordinator role,** given the value of having a dedicated official focused on health IT/HIE opportunities in the state with access to different levers and collaborators to prompt state action (e.g., Medicaid, state insurance, state employer program, state public health department). The Health IT Coordinator can act as a liaison/initiator for ongoing federal-state partnership opportunities to advance HIE.
- **Driving/sustaining demand for HIE and leveraging existing HIE investments under delivery system reform,** for example, engaging in pre-Stage 3 MU "marketing" to communicating the value of HIE and reinforcing the state's commitment; leveraging investments formerly supported by the State HIE Program for delivery system reform; and pursuing HIE-supportive policies (e.g., promote ACOs and other models that leverage technology and potential incentives).

### Federal Role

- **Crucial guidance around HIE governance and technical standards.** Informants called for continued ONC leadership on privacy and security; assistance creating user agreements, trust agreements, and policy frameworks; policies on secondary data use; as well as data standards to mobilize electronic information from diverse providers, and for research. Informants also requested leadership on difficult technical issues (e.g., patient matching algorithms, certification criteria for the Certified Health IT Product List [CHPL] for MU); and dissemination of lessons learned from the program and best practices to guide those newly interested in HIE.
- **Provide strong leadership and support for interoperability,** especially to extend the scope to settings that are critical to care transformation (e.g., long-term care, behavioral health, and home health); and to emphasize open standards, interfaces, and protocols, and coordination with MU.
- **Align HIE efforts across agencies,** pursuing aligned "policy push" with federal incentives for standards of information; coordinating with MU and other initiatives; and leading consensus-building around development, dissemination, and use of standards.
- **Emphasize HIE as part of delivery system reform activities**, such has including HIE use in changes to payment structure; continuing HIE-supportive initiatives, such as SIM and Medicaid 90/10 funding; and expanding efforts like CMS quality initiatives to encompass health IT/HIE.

### Shared Needs and Responsibilities

- **Continue to assess how technical solutions evolve in different markets, and develop and disseminate best practices (state and federal role).** States can support best practices put forward by ONC and tailor solutions to their local needs—enacting supportive legislation that removes barriers to information flow (e.g., policies for data ownership and use, protections against data breaches and unauthorized access), and aligns more closely with federal laws such as HIPPA.
- **Monitor best practices and funding opportunities (provider organization role).** Increasingly difficult requirements for MU mean grantees and others will need financial and technical support. Providers should keep informed of useful findings and funding opportunities related to delivery system reform initiatives (e.g., SIM awards, Health Care Innovation Awards [HCIA], Medicaid 90/10 funding, ACO incentives and development grants).

## Conclusions

HITECH funding, including awards made under the State HIE Program, created and expanded HIE-related infrastructure—both in the technical sense of services and infrastructure and in the legal, governance, consent, and policy structures to support it. This HIE infrastructure is now available and delivery system reform efforts are likely to leverage it. Our evaluation findings demonstrate that there is no one-size-fits-all solution with HIE; instead, development and use of HIE is predicated on the state and local environments within which it exists. That said, certain factors influence HIE and are helping some states gain traction. These factors and exemplar states may serve as lessons learned for HIOs, grantees, and state and federal policy makers interested in continuing HIE development.

Throughout the program, grantees overcame many challenges to HIE, and new challenges emerged in the process. Some states were more successful than others in navigating these challenges and in enabling exchange. Though not all such challenges have been resolved, there is now more HIE capacity than before the program, as well as a path forward toward greater data liquidity for both exchange and interoperability.

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