

April 3, 2015



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National Coordinator for Health Information Technology
Acting Assistant Secretary of Health
U.S. Department of Health and Human Services
Hubert H. Humphrey Building
200 Independence Avenue, SW
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Dear Dr. DeSalvo:

The members of the Strategic Health Information Exchange Collaborative (SHIEC) and our colleagues in partner HIE groups and organizations across the country, including the Mid-States Consortium of Health Information Organizations (Mid-States), applaud ONC in preparing the critically important *Connecting Health and Care for the Nation: Shared Nationwide Interoperability Roadmap*. We embrace the Roadmap's vision as a shared national framework. We are eager to work with ONC to take immediate action to advance mission-critical collaboration for Health IT that enables transformation of health and healthcare. Our comments focus on collaboration with ONC, your federal colleagues and partners, and with the ultimate "customers" of interoperability: our nation's citizens and the organizations dedicated to improving the equity and quality of their health and wellness.

SHIEC is the national trade association for Health Information Exchange Organizations, but it is in and across local communities that our impact is felt. The *Dartmouth Atlas* documents that the vast majority of U.S. healthcare delivery is highly localized. Too often, important data about patients' ongoing care resides in multiple unconnected organizations. SHIEC member HIEs use information technology and trusted relationships in their service areas to enable secure, authorized exchange of patient information among disparate providers, other organizations, patients, and families. By providing enhanced access to all available and relevant patient data, SHIEC HIE members aim to improve the quality, coordination, and cost-effectiveness of health care provided in their communities.

Mid-States is a volunteer consortium collaborating to address data exchange challenges. The consortium's core objectives include advocating for more robust forms of health information exchange (HIE), such as query-based HIE, and for health information to appropriately follow patients that require health care services outside of their home town or home state. Mid-State members are also addressing the challenges and unique needs of rural areas related to health information technology (HIT) and HIE.

We are pleased to submit these joint comments, reflecting the perspective of 38 HIEs serving millions of patients across 24 states. The *Roadmap* provides a framework for how we can link all of our communities, regions, states, systems, and systems of systems together to implement the cross-boundary, cross-domain information supply chain required for a Learning Health System.

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We embrace your invitation to participatory democracy in the governance and operation of interoperable critical national infrastructure that 1) is person-centric, 2) serves the continuum of health, public health, healthcare, research, and human services, and 3) is vendor-, payer-, and institution-agnostic. We have already begun work with colleagues and allies across many domains to help ONC ensure that responses to your Call to Action on Governance reflect the broadest possible national interests. We look forward to collaborating with you to solve these critical issues and ensure health and wellness for all Americans.

Dick Thompson, SHIEC Board Chair

Jeffrey S. Messer, Mid-States Consortium of HIOs

Robert Steffel, SHIEC Executive Director

Overarching Comments:

SHIEC and Mid-States members vigorously applaud the Federal actions to support interoperability summarized in B.1.1-B.1.11 in Table 2 of the *Roadmap*. This commitment recognizes federal partners as customers of interoperability (not just as regulators). It invites private partners to join HHS's long-term strategic vision for interoperable data exchange that is "baked into" routine business practice. The cost of interoperable exchange should ultimately be borne in equal measure by all of its participants and beneficiaries. SHIEC and Mid-States members and our many state government partners share that vision. We actively support emerging delivery and payment system innovations that will enable us to achieve the goal of ubiquitous interoperability.

We believe the *Roadmap's* Call to Action on Governance with uniform policies, operations, and standards is central to the success of everything we must do as a nation to achieve the Triple Aim. We recognize that it is no accident that governance interdependencies reverberate through seven of the *Roadmap's* Business and Technical Requirements. Getting governance right is as critical as it is challenging.

We believe that interoperability governance must reflect a "whole is greater than the sum of its parts" information supply chain that includes the rich and abundant data from across the health, healthcare, human services, health research, and personal health & wellness ecosystem. However, a national information supply chain operating at scale requires a vendor-, payer-, and institution-agnostic governance process.

We urge ONC to adopt a broad definition of the interoperability ecosystem, reflecting the goal of a Learning Health System. We must collaborate across communities, states, and domains to address the scope and significance of this effort and its essential national importance to health, wellness, and cost.

This coordinated collaboration and governance must be durable, repeatable, and extensible across many organizations, institutions and applications. To ensure the equity and integrity of this critical national infrastructure, it must be organized through a process that is vendor-, payer-, and institution-agnostic and reflects all of the domains of HIT's diverse constituencies.

Those domains include but are not necessarily limited to:

- Data generators and users, including
 - patients and families,
 - providers: individuals, institutions, and organizations across the care, services, health & wellness continuum;
 - Federal providers of healthcare services and federal senders/receivers of data (DoD, VHA, IHS, CDC, CMS... the members of the Federal Health Architecture);
- State, county, local, territorial, and tribal governments and agencies;
- Health IT and IT system vendors and integrators, their trade groups and associations;
- Health Information Exchange and data aggregation and analytics organizations and services;

- Clinical research and the pure and applied sciences communities;
- Champions of transparency, value, and quality of healthcare delivery and financing; and
- Cross-cutting individuals and organizations that provide support to those working both within and working across these domains.

We believe that the best approach is an iterative, agile series of steps designed to:

- engage and convene cross-domain constituencies of collaborators;
- define shared values by articulating clusters of use cases that reflect common patterns across domains; and
- produce a set of recommendations in early fall 2015 for specific actions steps that can be taken within each domain, including government, to inform ONC and partners about the next steps we as states/organizations/individuals can take together through self-organizing collaboration.

We recognize this is no small task, but the alternative is to continue the unacceptable chaos that characterizes the *status quo* of interoperability. A powerful approach for comprehensive collaboration is to capitalize upon and leverage the self-organizing impulses of affinity groups and entities acting on particular aspects of interoperability.

This process can reflect the particular interests of diverse communities across the ecosystem while defining common ground across those communities. Its outcomes cannot be pre-ordained: the governance structures will emerge “in the rearview mirror,” based on the outcomes of subsets of collaborative activities. That said, those diverse, self-organizing activities responding to interoperability’s challenges will be best served by using the *Roadmap* as the organizing framework for large-scale collaboration.

We are too large and complex a nation for a “one size fits all” infrastructure. Governance—in the form of effective, comprehensive, nation-wide collaboration—will enable “networks of networks” and modular, distributed, cross-boundary services to flourish. The key is making it easier by removing barriers, which is in everyone’s long-term interest.

Interoperability must be governed with a commitment to open and unbiased exchange, organized and operated for the public good, and not subsidizing a limited institutional or corporate business model. Such exchange can and will be conducted by both private commercial, private non-profit, and public entities, united to serve the nation. That outcome is possible because the digital landscape of health data is best characterized by abundance—even overabundance—not by scarcity. Distilling information and knowledge out of that abundance will benefit many, many organizations and individuals.

It is critical not to let construction of an ideal governance solution impede immediate progress. It will take a long time to fully instantiate a durable, persistent governance collaboration process that enables the shape of “the elephant of interoperability” to emerge. Even very recent history is littered with multiple, failed efforts to define “the right governance” and roadmap for HIT.

SHIEC and Mid-States members believe that these failures are the result of approaching the problem from too narrow a perspective. We urge the National Coordinator to think big

and look to the wisdom of General and President Dwight D. Eisenhower, who said “Whenever I run into a problem I can't solve, I always make it bigger. I can never solve it by trying to make it smaller, but if I make it big enough, I can begin to see the outlines of a solution.”

Specific SHIEC & Mid-States Actions on the Role of HIEs to support Interoperability

We applaud the *Roadmap* as it takes the vision of HIT far beyond EHRs and points to a much broader strategy: interoperability is neither solely about Eligible Providers and Eligible Hospitals, nor solely about the doctors’ and hospitals’ EHR vendors. Much of the most critical data about the nations’ most expensive and at-risk individuals live in systems that are not EHRs. Interoperability requires business and technical functionalities that operate across institutional, community, and jurisdictional boundaries.

We wholeheartedly endorse “[o]ne of the guiding principles for the *Roadmap*, ...the notion of modularity: complex systems are more durable under changing circumstances when they are divided into independent components that can be connected together.” (page 86)

As a verb, HIE is a communication of health information from one provider to another via any number of methods – fax, mail, in-person delivery, a secure electronic connection, etc. As a noun, HIE is a trusted organization that allows a patient’s body of clinical information to follow that patient wherever he or she seeks treatment, linking multiple health care entities that are involved in a patient’s care. It is a secure portal designed to ensure only those providers authorized to see a patient’s information have access to it.

HIEs and related data-sharing infrastructure play a unique role in enabling the creation and operation of the information supply chain across health, health care, and human services systems, organizations, providers, payers, and individuals. HIEs 1) provide high-value content- and format-agnostic tools, 2) facilitate bi-directional, cross-organizational information sharing, and 3) serve as neutral content and format transformation engines that spare users from the burden of maintaining interoperability in “edge” systems.

Over time, a picture of the architecture of the ultra-large-scale, complex “systems of systems” and “networks of networks” will emerge – through collaboration. SHIEC members and an emerging group of partners, including state health reform and HIT leadership, the Collaborative Health Network project of the Network for Regional Healthcare Improvement, the Learning Health Community, the Cure Project, and the Stewards of Change Institute, are committing to collaborative leadership. Together with ONC, other federal partners, and others, we can harness the strategic will to ensure mission-critical collaboration for interoperability to:

- Enable delivery and payment system transformation focused on person-centered health and wellness, empowering individuals and families in their health decisions and care coordination by improving cross-boundary communication across the continuum of care;
- Enhance quality, transparency, and accountability of care and services;
- Empower knowledge by connecting clinical, claims, research data, public health, and human services data; and over time
- Build the digital infrastructure of the Learning Health System.

SHIEC Responses to Roadmap Questions

1 General

1.1 *Are the actions proposed in the draft interoperability Roadmap the right actions to improve interoperability nationwide in the near term while working toward a learning health system in the long term?*

On the whole, yes. The *Roadmap* provides a “table of contents” of “the manual” for building the interoperable, timely, secure, information-rich health and healthcare future to which we aspire. SHIEC’s role is to step up to the table with willing partners, to begin the collaborative process of writing the “chapters,” requirement by requirement. The only thing that stands in the way of SHIEC and allies proceeding is the question of how this process is to be orchestrated. The Draft Version 1.0 *Roadmap* extends an honest invitation to the nation to answer that question. The final Version 1.0 would do well to point to a collaborative orchestration process, recognizing the work SHIEC and partners have begun.

1.2 *What, if any, gaps need to be addressed?*

ONC has focused on clinical data exchange between providers, and the *Roadmap* reflects that focus. ONC has an opportunity to work with partners to expand the *Roadmap* scope to address the needs of payers, purchasers, and novel delivery and payment structures. Claims and administrative data, including stakeholders such as All Payer Claims Databases and Qualified Entities, must be included in the ecosystem of interoperability. Similarly, while setting a Learning Health System as the goal, the *Roadmap* gives short shrift to the implications of near-term health research activities, including but not limited to the Patient Centered Outcome Research (PCOR) initiatives and networks, pharmaceutical clinical trials, and genomic data exchange.

1.3 *Is the timing of specific actions appropriate?*

SHIEC believes it is less important to focus on predicting and dictating the specific timing of actions in the *Roadmap*. Rather, *Roadmap* implementation should focus on enabling a common framework for beginning to prioritize and sequence interdependencies. Activities already “in flight” with SDOs, vendors, and others need to be tracked, understood and integrated into future implementation steps. Such complexity cannot be managed through top-down structures or dictates; the best that can be accomplished is comprehensive, ecosystem-wide awareness that creates the opportunities for collaboration and alignment.

1.4 *Are the right actors/stakeholders associated with critical actions?*

As noted above, the *Roadmap*’s view of actors and stakeholders must be expanded.

2. *Priority Use Cases*

2.1 *Appendix H lists the priority use cases submitted to ONC through public comment, listening sessions, and federal agency discussions. The list is too lengthy and needs further prioritization. Please submit 3 priority use cases from this list that should inform priorities for the development of technical standards, policies and implementation specifications.*

SHIEC is collaborating with the above mentioned groups to use the Stewards of Change (SOC) Institute's 10th Annual National Symposium (June 22-24 at Johns Hopkins University) to test the prioritization of clusters of cross-boundary use cases which share common patterns, stories, and personas across settings.

An example is the cluster of related use cases supporting care and service coordination by: a) state agencies managing children in foster care, b) parents coordinating care for children with special health needs, chronic disease, or behavioral disorders, c) patients and families participating in clinical drug trials, and d) both active-duty and retired military personnel negotiating care across both government and private sector provider settings. Such shared narratives can be used to create story boards that refocus technical discussions into human stories about communication that can be improved by cross-boundary interoperability.

3. *Governance*

3.1 *The draft interoperability roadmap includes a call to action for health IT stakeholders to come together to establish a coordinated governance process for nationwide interoperability. ONC would like to recognize and support this process once it is established. How can ONC best recognize and support the industry-led governance effort?*

Our comments above address this question at length. Our additional comment here regards the phrase "industry-led governance effort." The Wi-Fi Alliance is an excellent example of industry coming together to solve shared interoperability challenges, but the complexity and scope of health, healthcare, health research, human services, and personal health interoperability demands a substantially larger response than "industry."

Expressed a different way: the scope and perspective of ONC's FACA Committees and the industries they represent are an important subset, but only a subset, of the scope of interoperability. (The HIT Standards Committee's feedback that "NIEM does not belong in the Roadmap," a statement that flies in the face of health to human services interoperability, is an example of their parochial perspective.) An approach to governance that fails to recognize the need to expand the conversation beyond "industry" to all stakeholders is doomed to achieve the current, skewed results.

A coordinated governance process will require a comprehensive portfolio management structure, complete with sophisticated project and knowledge management, across loosely-coupled, self-organizing collaborative activities. It is complicated, but far from impossible. It is long past time for public and private partners to marshal their resources, using the *Roadmap* to transform the current “random walk” toward interoperability into purposeful, aligned action.

4. *Supportive Business, Cultural, Clinical and Regulatory*

4.1 *How can private health plans and purchasers support providers to send, find or receive common clinical data across the care continuum through financial incentives? Should they align with federal policies that reinforce adoption of standards and certification?*

Private plans should be encouraged to require their provider networks to support specific use cases designed to enhance cross-boundary information-sharing, such as clinical alerting and electronic care coordination, in partnership with Medicare and Medicaid multi-payer payment and delivery system reforms.

5. *Privacy and Security Protections for Health Information*

5.1 *What security aspects of RESTful services need to be addressed in a standardized manner?*

Structure, policies, and business practices for secure, authorized access to (an increasing set of standardized) data from EHRs and other clinical infrastructure, including shared enabling and location services, must be standardized to ensure its availability to patients and their authorized agents across the ecosystem.

6. *Core Technical Standards and Functions*

6.1 *Which data elements in the proposed common clinical data set list need to be further standardized? And in what way?*

6.2 *Do you believe the approach proposed for Accurate Individual Data Matching will sufficiently address the industry needs and address current barriers?*

We applaud publication of the *2015 Interoperability Standards Advisory: Best Available Standards and Implementation Specifications*, will be responding to its request for comments, and looks forward to participating in the ongoing collaborative process its publication has begun.

7. *Certification and Testing*

7.1 *In what ways can semantic interoperability be best tested? (e.g., C-CDA content and semantics)*

Testing must be done in the context of real-world implementation. HIEs provide an infrastructure that ONC could utilize as part of a collaborative effort to ensure Certified products perform “in the wild” as promised in development and on the test

bench. SHIEC and Mid-State look forward to exploring with ONC and the community how our assets can be leveraged to promote the transparency and equitable performance of certified products.

8. *Measurement*

- 8.1 *Does the measurement and evaluation framework cover key areas? What concepts are missing?*
- 8.2 *Which concepts from the framework are the most important to measure? What types of measures should be included in a "core" measure set?*
- 8.3 *Should measurement focus on certain use cases, priority populations or at certain levels of the ecosystem (e.g., encounter, patient, provider, organization)?*
- 8.4 *What other types of metrics have been successfully used at the local or regional level that might be considered for nationwide use? Would stakeholders be willing to propose novel metrics and provide "test beds" to assess the potential for nationwide use?*
- 8.5 *What measurement gaps should be prioritized and addressed quickly?*
- 8.6 *What other available data sources at the national level could be leveraged to monitor progress?*
- 8.7 *Are the potential mechanisms for addressing gaps adequate? What are other suggestions?*
- 8.8 *How should data holders share information to support reporting on nationwide progress?*
- 8.9 *What are appropriate, even if imperfect, sources of data for measuring impact in the short term? In the long term? Is there adequate data presently to start some measurement of impact?*

The most meaningful measure of interoperability will be its widespread adoption. While metrics are of value to some constituencies, too often the call for better measurement signals a motivation to slow down and attempt to control the disruptive change ubiquitous information sharing will bring to the landscape. Patients, family members, and clients of "the system" stand on one side of the healthcare industrial complex, purchasers and payers stand on the other. Both currently have unmet expectations for data transparency and equity.

By the time measurement is perfected, the market will have voted with its feet. That is the power and democratizing strength of interoperability: all nodes are equal. The strength and power of a national interoperability *Roadmap* is to organize, accelerate, and energize the democratizing process of appropriately-, securely- but freely-shared information.

Appendix 1

SHIEC Members

- Arizona Health-e Connection
- etHIN, East Tennessee Health Network
- Greater Dayton Area Health Information Network
- HealtheConnections RHIO Central NY
- HEALTHeLINK - Western NY
- Healthix – New York
- HealthLINC – Bloomington IN
- HealthlinkNY
- HealthShare Exchange of SE Pennsylvania Inc
- Indiana Health Information Exchange
- Nebraska Health Information Initiative
- NYU Langone Medical Center
- Santa Cruz Health Information Exchange
- Quality Health Network, Grand Junction CO
- Rochester NY RHIO
- Stony Brook University Hospital
- The Health Collaborative (formerly HealthBridge)
- Utah Health Information Network
- Western Connecticut Health Network

Mid-State Members

- Colorado Regional Health Information Organization
- Community Health Information Collaborative (Minnesota)
- Coordinated Care Oklahoma (Oklahoma Physician Health Exchange)
- Health Information Network of Arizona
- HealthShare, Montana, Inc.
- Idaho Health Data Exchange
- Illinois Health Information Exchange
- Iowa Health Information Network
- Kansas Health Information Network, Inc.
- Lewis and Clark Information Exchange (Kansas City, Mo.)
- Michiana Health Information Network (northern Indiana and southern Michigan)
- Missouri Health Connection
- MyHealth Access Network, Inc. (Oklahoma)
- Nebraska Health Information Initiative
- North Dakota Health Information Network
- Quality Health Network (Colorado)
- SMRTNET (Tulsa, Okla.)
- South Dakota Health Link
- Southeast Texas Health System
- Tiger Institute Health Alliance (Columbia, Mo.)
- Utah Health Information Network
- Wisconsin Statewide Health Information Network