

State Engagement on the Interop & Exchange Roadmap

Summary Report and Findings

Highlights from the State Engagement process

- States see establishment of a national approach to governance for interoperability and health information exchange and federal leadership essential to realizing significant progress over the next few years.
- States have significant concerns about vendor behavior that limits interoperability and encourage ONC to take action against vendors with business practices that create barriers to exchange.”
- States support better defined and constrained content standards such as the consolidated Clinical Data Architecture for summary of care records, to enable true semantic interoperability and actionable information at the point of care.
- States support including clinical and administrative data, and payers, in the roadmap.
- States encourage reliance on more infrastructure “in the middle” to support interoperability and exchange across the care continuum instead of relying primarily on EHRs and Health Information Service Providers.
- States want information from human and community based services to be integrated into the health IT ecosystem to enable new models of care and holistic management of health and health care.
- States want to have an on-going relationship with ONC to work on the implementation of the Interoperability Roadmap, which ONC fully supports.

Document Overview

States had significant, substantive feedback for ONC about both the roadmap itself and, as importantly, about their desire to play an ongoing collaborative role with ONC and other Federal partners in its implementation. Their feedback is grouped into five areas of focus:

1. What role could/should States play in advancing interoperability and exchange?
2. What do States view as the priority use cases and factors for enabling successful interop and exchange?
3. What are core services and key technical assets States believe need to be leveraged?
4. What are the significant challenges and barriers to interoperability and exchange?
5. Other suggestions and recommendations to ONC
6. A set of next steps and opportunities for follow up is included as a sixth section.

Context

In early July, representatives of the States with whom ONC has worked throughout the State HIE Cooperative Agreement program and other State officials were invited to come to a meeting in Washington to provide feedback to the National Coordinator and ONC staff on State perspectives on the Interop & Exchange Roadmap. A series of five pre-meeting calls and a shared online discussion forum were utilized to prepare the group, refine its focus, and ensure a productive meeting discussion. Over 90 individuals from a total of 38 states participated in the process, with representatives from 18 states attending the August 27 meeting in person and at

least 10 additional states dialed in by phone for at least a portion of the day-long meeting. This document is the public output from the State Engagement process.

1. States' Roles in Interoperability & Exchange

States want to partner and collaborate on roadmap implementation. First and foremost, States were very clear in voicing their concern that they be considered ongoing partners with ONC – as well as with CMS and other HHS agencies – to ensure the success of the interoperability roadmap agenda. Indeed, during the preparatory calls, it became clear that States did not want to have a “once and done” meeting for their input. Rather, they demonstrated their ownership of interoperability issues and the need to work together to achieve shared goals. States noted not always having felt that there was a positive, two-way dialog with ONC in the past, but many commented that one immediate, positive result of this Engagement process was to “reset” the State/ONC relationship.

States see clear role for government in health, health care, and human services interoperability. There was mutual agreement that this is a moment in history when government leaders have an obligation to accelerate and ensure the success of interoperability, that the scope is larger than health care services *per se*, that it includes public health, human services, and ensuring the needs of all citizens are met by a comprehensive system of information exchange and sharing. State leaders noted the importance of public health and human services data to inform delivery and payment system reform, particularly in addressing the social determinants of health.

States see critical role for Federal leadership in interoperability. States made it clear that they look to Federal level leadership to help establish a baseline for interoperability policies, standards, and governance to ensure a healthy environment for national exchange. Participants pointed both to immediate cross-border issues where health care markets span state lines, requiring national state-to-state consistency, as well as the often cited “State A resident presents unconscious in an emergency department in State B, halfway or further across the country” scenario. In both of those cases, States and Federal policy makers must work together to ensure a governance and technical framework that enables interoperability.

States concerned about ensuring the public good in interoperability. States also noted that while health care is largely a private endeavor – notwithstanding the significant role of public payers like Medicare, Medicaid, and the VHA – the behavior of both health care provider organizations and their HIT vendors is not always consistent with (or at least sufficiently attuned to) the public good. As such, State/Federal partnership is of particular importance in the context of supporting positive, beneficial behavior on the part of actors who might otherwise focus on more narrow interests. Both with respect to broad information sharing across organizations and the interoperability of HIT solutions themselves, States were consistent advocates of the need for government to play a “guard rail” role in ensuring fair and equitable exchange, asserting that ONC should play a convener role to harmonize conflicts between states and providers and the

HIT industry. Here too, they spoke to the beneficial aspects of State/Federal collaboration to ensure that the variability and diversity of health care markets, organizations, and structures across jurisdictions is adequately represented both in the national interoperability discussion and in solutions for interoperability governance.

2. Priority Use Cases and Factors for Enabling Success

Value-based payment & team-based medicine are key. States unanimously identified new payment models and delivery system configurations (designed to highlight performance based accountability and improved quality and financial outcomes) as the leading driver of interoperability and exchange. While noting that we are still in the early days of such transformation, there was broad agreement that these financial incentives are *the* animator of increased information sharing. That said, they noted that both technical and policy challenges to interoperability must be overcome in order to make good on the promise of these efforts. Until exchange is easy from a technical and process point of view, it remains convenient for reluctant players to blame technology for their failure to share data more expansively.

Providers need information about patient activity from across the community ecosystem. A high priority use case as we transition to accountable care is alert notification. States are very clear about the value both of “traditional” Admission Discharge and Transfer (ADT) alerting and many spoke about the emerging use of eCQMs to support more clinically specific alerts to support decision support and more targeted, clinically focused interventions. The use of ADT alerts, enabled by comprehensive Master Persons Index and sophisticated Entity and Individual Level Provider Directory functionality, is clearly seen by States as an essential component of effective case management and care coordination across disparate organizations in the ecosystem.

Services for payers looking for clinical data add to sustainability. States noted that increasingly, payers are looking to HIEs for more robust, timely data than they can derive from claims submissions. Alerts and notifications fit into this category, but insurance carriers in some states are seeing value in many forms of clinical data sent directly from provider EHRs both via Direct and pushed through query-model HIE infrastructure. While largely still at a developmental stage, payers – and purchasers – are also interested in both eCQMs and reports compiled from same. Because of the localized nature and specificity of these services, States again echoed the point that the national interoperability and exchange strategies need to reflect the diversity of the state and regional marketplaces.

Learn from the standardization of administrative data. State leaders with experience in the implementation of HIPAA and the exchange of claims and administrative data pointed to lessons that could be learned from those challenges. One theme from that aspect of the discussion was the utility model of clearinghouses, which evolved to translate and normalize diverse data types “in the middle” instead of trying to normalize and standardize transport protocols “at the edges.”

3. Core Services and Key Technical & Enterprise Assets

Provider and Patient Identity Management is essential. As noted in the Alerting use case example above, sophisticated Provider Directory functionality, well beyond “Direct address white pages,” is seen as an essential core state – or in larger states, regional – service. It is worth noting here that “State service” can mean either infrastructure operated directly by the State, infrastructure operated on behalf of the State by a State Designated Entity (SDE), or a hybrid of the two where, for instance, an SDE might partner with a State Medicaid Agency to leverage State Enterprise Systems to support either a statewide HIE or regional HIOs. In addition, some states note that even without formally classifying the HIE as an SDE, they enjoy close public/private partnerships between the HIE(s) and State Medicaid and Public Health agencies. Similarly to provider directory services, the capacity to identify and match patients across provider organizations and institutions – including across government systems and those state systems and health care, mental and behavioral health providers, and community based human services organizations – is fundamental to interoperability and to enabling patient/provider attribution for new payment models. States support a Federal role in improving the capacity for patient matching by standardizing a core set of demographic data in a nationally consistent, uniform structure.

State Enterprise Systems themselves are key technical assets. Many States see value in leveraging state systems to support exchange. It was noted that the guidance from CMCS about the use of HITECH and MMIS funding is inconsistent, with regional office and HITECH staff at CMCS not always following through on the much more expansive utilization of Medicaid IT assets and resources which the CMCS Data & Systems Group leadership expresses. Recognizing that there are non-trivial details relating to proper use of CMCS funding authorities, States nonetheless noted the need for better internal communication within CMS about the policies for leveraging State Systems funding to support exchange.

Public Health must be included in the roadmap. States also discussed Public Health IT resources and assets, and there too, noted the opportunity for better alignment and coordination between CDC, ONC, and States. Specifically, States noted the substantial investments made in Public Health registries like immunizations, as well as many the many categorical diseases and vital statistics registries. Participants indicated that there is often a much larger emphasis placed on putting information into those repositories than on getting it out, and that there are substantial backlogs in many states for converting legacy paper files to electronic form. That backlog in digital conversion of records underscores another important area raised by States: the lack of resources at both the state and local level to ensure full engagement by Public Health departments in HIT/HIE. States indicated that problem could be addressed both by increasing overall resources, but also by removing CDC categorical program restrictions that impede data sharing across Public Health programs and silo funds that would otherwise be available to support interoperability and exchange more broadly.

They pointed to the value of making Public Health data more available, both for specific clinical use cases and for informing delivery system planning more broadly. It was noted that there is sometimes a missed opportunity when it comes to the integration of the public health definition of *population health* with the more narrow health of *populations under management* in the context of accountable care and other risk based management of populations of covered lives. It was suggested that ONC and CDC could work together to address the problem of “public health data hoarding.”

Interoperability is not limited to health care. States spoke to the data assets within their human services (both state-level and community-based) organizations as being of critical importance to health care transformation, given the information on social determinants of health available from those resources. As such, they chafed at the suggestion that the governance of interoperability, as well as technical standards addressing same, needs to be limited in the near term to health care interoperability. “We’re doing it now” was the sentiment expressed by State officials actively engaged in the blending of health, health care, and human services data, and they voiced frustration at the challenges they face in making full use of those information assets absent interoperability across those domains. States urged ONC to work closely with HHS partner agencies to accelerate a unified technical and governance framework for health, health care, and human services.

Alignment of governance is essential to successful interoperability. In a related comment on the challenge of multiple governance constructs (e.g., the SIM grant governance requirements, HIE governance, and various HHS agency directives related to data governance and stewardship at the State level), States again pointed to the benefit of ONC playing a coordinating role across Federal partners to help rationalize a landscape that will almost without question involve ever increasing demands to share and “mash up” data across domains frequently defined by Federal funding authorities.

4. Key Challenges and Barriers Identified by States

- **Content standards must be better defined, constrained, and the standards standardized.**
- **Transport standards must be improved.** There are two standards for Direct and there are no requirements for vendors to choose which one (and even if they choose both, there remains a trust problem because of the lack of a clear national governance framework). Moreover, traditional HL7/IHE profile exchange that was in place long before Direct, has little place in MU2, which is supposed to advance interoperability. Care summary exchange in MU2 is a “check the box” requirement divorced from providers’ actual workflow that’s actually antagonistic to the role of centralized and federated HIE. Direct standards are affecting patient safety. Docs don’t know if their messages are arriving. Messages are being dropped because of trust relationships.

- **Consent continues to be a challenge.** There are a host of issues related to consent, including contradictory models (opt in vs. opt out) in different states, and the challenges with sharing sensitive data, including that covered by 42 CFR Part 2 and FERPA. There is a critical need for automated consent management and authorization, but the notion of “granular” consent is terribly problematic in the near term because of the expense and technical challenges particularly with scaling this capability. . There is a challenge because we need to look at what consumers want but balance that with providers who don’t want filtered “swiss cheese” health records. If granular consent does become feasible, patients records should be clearly flagged to let clinicians know when a patient has opted to withhold access to some of their data. “Freedom and responsibility go together. Don’t want to share all data? Fine, but your recourse to find providers liable for treatment based on incomplete data should be limited.” It was also noted that “team based care” changes the context of providing consent and that consent for use of data for specific research purposes (e.g., asthma research for those diagnosed with asthma) can provide motivation for sharing data.
- **Liability concerns among providers.** Some providers resist HIE because they fear being held liable for data that was available that they didn’t see, but many supported evolving to a standard of care where the liability burden is on not using data when and where it’s available. That requires defining the right subset of “all” health data clinicians should be expected to access.
- **Patient matching is a challenge.** There need to be common approaches to patient matching supported by standards for how patient demographics are recorded, stored, and transmitted. States also reinforced the need for standards, policy, architecture & governance for sophisticated Provider Directories. The need to automate attribution of clinician and patient is critical to new payment models and impossible to achieve without improved standards and processes of identity management. States working on integrating public health and human services data with clinical data noted the need to align NIEM and health care data models.
- **Certification problems are real.** There are significant opportunities for improvement in EHR Certification, particularly:
 - A testing process that demonstrates “real world” applicability, as many products apparently meet the criteria to pass certification in a lab / workbench environment but do not actually provide interoperability in practice.
 - Determine a way to prevent vendors’ compliance of the CEHRT regulations that meet only the minimum level necessary to pass certification, completely missing the broader policy intent and spirit. They are limiting how cCDAs can be transmitted and charging unreasonable prices. There’s also a need to monitor and act on deceptive trade practices like “voiding the warranty” when customer tries to implement functionalities on their own that they thought they purchased with the product but which are only available with up-charges and customization.

- Create an ONC interoperability test tool where vendors can test post implementation and demonstrate that they are adhering to this every day. States urged ONC to apply principles of modularity more aggressively in the CEHRT process: instead of recreating multiple instances of the same functionality in every EHR, there are many opportunities to centralize functionality “in the middle.”
- **Single sign-on is not widespread yet.** In most states, it is tremendously burdensome for providers to navigate without single sign-on and authentication across systems. State noted providers often need 10 or more different passwords to interact with different, siloed systems (e.g., provider portals for viewing clinical records, portals for various mandatory reporting, payer portals to check eligibility, prescription drug monitoring program portals, advance directives registry portals, etc., etc., etc.)
- **National alignment needed on governance.** State to state variation in privacy and security laws and approaches to governance as well as lack of alignment with federal rules and incentives, needs to be addressed on a national level. States want a consistent, national-level governance and policy framework. ONC should put together an operational framework for governance that takes into account how state and national governance of health information exchange will interact with each other as a part of the interoperability roadmap.
- **Patient Engagement in Health IT is critical but problematic.** Many states pointed to the model of multiple patient portals tethered to EHRs actually hindering patient access to data if they have to log into multiple portals to see their data siloed in multiple provider’s systems. The vision should be a system where patients have access to all their information in one spot, including explanation of benefits (EOB) notices. Facilitating patient engagement should be a more rational process. ONC should conduct or commission scientific research in patient interests and then identify what needs to be done rather than building expensive systems and waiting to see who shows up wanting to use them. Another challenge is that although the power of the patient is recognized, there is certain volume and value that is available now and doctors still can’t get the info and upload it to patient portal. Then there are the questions about what information you allow patients to see, when (e.g. when can the patient know about a cancer or HIV diagnosis?).

5. Other Suggestions & Recommendations for ONC

- **Clinical and Claims data.** There should be a focus on the integration with the claims data infrastructure, “bringing HIPAA and HITECH worlds together.” The role of payers is missing from the vision document. CMS, Medicaid, commercial—these are the ones paying for exchange. As we transition from FFS to value base payments, insurers still play an absolute role and the **vision paper/roadmap** should understand that this will drive payment reform. Payers will have a need to access clinical data, and it is important to

think of payers needs and roles in the roadmap. Payers realize they can't advance risk payment models without underlying data infrastructure for robust performance measurement. **eQMs: great promise, troubling implementation.** We need "end-to-end" eQM functionality and the supporting data infrastructure to ensure consistency and reliability of this critical capability for delivery system and payment reform.

- **Standardize the standards.** Need to standardize codes along with content.
- **Bust silos.** Need to get rid of the silos that are jeopardizing the vision of Triple Aim.
- **Leverage State Coordinators.** There is ambiguity about the definition of State Health IT Coordinators; their roles differ in each state. For the State HIE Cooperative Agreement program ONC required a state to name a coordinator, but that is not a recognized term in every state terminology; and there are no standards or requirements for the coordinator. If strategy is to work with the states through HIT Coordinators, then there is a problem if there is not a definitive role across the board in all states for the ongoing role of Health IT Coordinators.
- **Leverage collective wisdom.** Collect lessons learned and develop a mechanism to share across states to develop one voice to educate and inform policy makers.
- **Make coming together easier.** A single annual ONC meeting instead of multiple meetings is helpful for strained state budgets and limited travel resources. Tagging onto other meetings state officials attend (such as HIMSS) would also help stretch tight resources.
- **Help educate new State executives.** Provide states advice on how to deal with new state governors and new politically appointed leaders to educate them on HIT; leverage the NGA new governors' "boot camp."
- **Enable self-assessment and gap analysis.** Create a map of gaps for states to identify them and better utilize funding to address them. Help states compare their assets and environment with peers.
- **Medicare should not be a "free rider."** Medicare as source of funding should be included in roadmap. Medicare should also be actively involved in funding discussions related to HIE.
- **Need more tactical details.** States want to know what ONC's role within the five building blocks is so states can have better clarity on how to support implementation. Who do the states look to if they have problems with standards and who is the lead? Is the vision now that the umbrella is the national umbrella, or the ecosystem umbrella?
- **Need better definition of scope.** States want to know where the definition of health IT starts and stops in regards to the roadmap. Parameters should be defined in the strategic plan. Is the roadmap a strategic plan meant to address problems of implementation for HIT/providers or is it meant to identify opportunities for improvements

in a short three year time frame? Or all of the above? Where does state learning fit into the roadmap?

6. Opportunities for Follow-up and Next Steps

- **States want situational awareness:** knowledge across the states about the current state of interoperability and exchange in each state. One suggestion is to have states create self-assessments/report cards with baseline measures and include implementation policies/models for states to compare with one other. Example: what vendors are in place, what standards are used, and which standards were tested at certification; how many queries are being done, how many HL7 messages? What is the model for Direct in the state? (Varies widely). What have you actually implemented? What are your problems and where have you solved it? Are HIE services available for their providers in new care and payment models? But the metrics have to be useful.
- **Create a series of State Policy Academies.** States supported the idea of creating State Policy Academies with travel support that states can apply to participate in where they would come together to focus on a series of specific issues. Among those suggested: pairing topics of patient matching “end to end” eCQM functionality, and state policy levers that can be used to promote exchange.
- **Learn from past five years.** Need to have a candid conversation, a post mortem on the “not so bright spots” of the grant program and create a “top ten list” of lessons learned from the HIE program.
- **Move to action.** A pilot or pilots focused on sophisticated Provider Directory implementation and how a national federation of PDs would work at a technical, policy, and governance level, potentially focused on how PDs support alerting use cases.