From Siloes to Solutions: Getting to Interoperability in Health and Human Services

July 2018
EXECUTIVE SUMMARY

Background
Health and human services agencies and organizations across the country are engaging in a variety of initiatives and innovations to share and integrate information about programs and the people they serve. It might seem obvious that sharing information is a good thing for organizations as well as the people they serve, by making better use of resources, improving efficiencies, saving time, and reducing costs of unnecessary duplication.

While there are many positive benefits to interoperability, there are also significant technical and cultural barriers as well as caution about information-sharing. These include technical issues with the governance, structure and flow of data; confidentiality and privacy protections; legal and regulatory restrictions; and organizational opposition for proprietary or other reasons.

When we use the term “interoperability,” we refer to the ability to collect, review, share, and use information seamlessly across organizations and systems.

The National Interoperability Collaborative (NIC) is a “community of networks” co-led by Stewards of Change Institute and AcademyHealth, aimed at identifying and advancing strategies and practices for overcoming those barriers. As a part of that effort, AcademyHealth conducted an environmental scan to assess existing guidance about sharing critical information within and across organizations and sectors. We conclude that better, faster sharing electronic health data (AcademyHealth, n.d.). The components are: systems integration and technical infrastructure; governance, structure and flow of data; confidentiality and privacy protections; legal and regulatory restrictions; and organizational opposition for proprietary or other reasons.

We also categorized the information covered by the interoperability guidance into nine components, based on our previous work on sharing electronic health data (AcademyHealth, n.d.). The components are: systems integration and technical infrastructure; governance, regulations and policy; partner, stakeholder, and community engagement; privacy, security, and confidentiality; organizational capacity and readiness; behavioral and workflow change; sustainability; and trust and shared values. Later on, we grouped these components into three key elements – data, human, and systems – to create a framework for organizing our analysis.

1. Through its work directing the Electronic Data Methods (EDM) Forum (http://www.academyhealth.org/edinforum) and the Community Health Peer Learning Program (http://www.academyhealth.org/chphealthit), AcademyHealth has defined key sectors and domains that interest with data sharing and interoperability.

2. The National Interoperability Collaborative, in a separate process, has defined six domains: human services, education, public health, public safety, health information technology, and emergency services (https://nic-us.org/nic-collaboration-hub).
Four advisory committees, which yielded the following insights:

We also conducted expert interviews and held discussions with our stakeholders across most sectors that we think is meaningful and useful. We also conducted expert interviews and held discussions with our stakeholders across most sectors that we think is meaningful and useful. From a systems perspective, it might seem obvious that different entities serving the same people should want to be collaborating to address different dimensions of their clients’ patients’, and constituents’ lives. For health and human services organizations and systems, a broader perspective and knowledge about a person’s life circumstances can often produce insights about how to help an individual, their families, and their neighbors more effectively and efficiently, and often more quickly as well.

Conclusions, Recommendations, and Next Steps

We were pleased to find a shared understanding of the benefits and components of interoperability across sectors and to find similar challenges across sectors, which bodes well for future cross-sector problem-solving and collaboration. In addition to addressing technical, policy, and organizational challenges, several of our discussions involved leadership development and the technical and management expertise needed for systems integration and upgrades.

Based on what we have learned, we recommend the following next steps:

- Build and promote multi-sector forums and platforms for collaboration and information sharing to address complex problems such as data exchange standards.
- Provide more layperson-friendly guidance and training on privacy, confidentiality, and information security.
- Develop guidance to promote a culture of information-sharing and interoperability to promote the public interest.

Full interoperability is a lofty, long-term goal. Multi-sector collaboration and data sharing are more practical and realistic goals that may actually achieve similar outcomes in the long run. We acknowledge those who have already started to work across existing human and technical connections and identified shared values, and who seek to build an ecosystem in which collaboration becomes the new normal. We look forward to contributing to those multi-sector collaborations.

Key Findings

While taking into account the large proportion of health documents about interoperability, we found some common ground across most sectors that we think is meaningful and useful.

- Every document addressed systems integration and technical infrastructure issues.
- Slightly more than half of the documents addressed governance (55%) and stakeholder engagement, (51%) and slightly under half (48%) addressed regulations and policy issues.
- The most comprehensive guidance documents were found in the education, emergency response, health, and human services sectors.
- Guidance about governance and organizational capacity and readiness was the most detailed and specific, often including model documents such as data use agreements.
- The health sector produced more interoperability guidance documents than any other sector (51% of the total), but that may have been an artifact of the large recent federal investments in Health IT. It also might reflect our focus on the search term “interoperability,” since some sectors use other terms (e.g., integrated delivery systems).

We also conducted expert interviews and held discussions with our advisory committee, which yielded the following insights:

- There is an increasing awareness of the benefits and importance of interoperability, including improving the client/patient/clinician experience and making systems more efficient.
- There is also an increasing awareness of the importance of including end users of information systems in their design and redesign.
- Data-driven decision-making by management and operations requires better access to current information, and this is beginning to drive technology integration across sectors.

Most of the initiatives to address social determinants and/or to integrate service delivery reflect activities at the community level, but their funding may come from multiple sources, including state, federal, philanthropic, or other sources, and sources may be combined to support various program components (AcademyHealth, 2018) (McGinnis, Crumley, & Chang, 2018). All of these funding sources may add their own reporting requirements, with different formats and standards (Brodt, Kang, & Rein, 2017). Consequently, this broader approach to addressing social determinants of health usually requires collecting and organizing different types of information about an individual, family, or community from different sources.
These data sources may be part of the same system (e.g., different programs within a county) or they may be completely separate, even if they are geographically nearby (e.g., city to county, or county to county within a region). Either way, different organizations are likely to create and keep their information using different software systems, with their own formats, protocols for access, and security procedures.

Because of concerns about protecting privacy, it is usually difficult to access or use information from outside an organization, even when there is a pre-existing collaborative relationship. For example, a school nurse may want to coordinate care of an asthmatic child with the parents and pediatrician’s office, but usually cannot access or contribute clinical information directly to the child’s electronic health record (EHR).

Fortunately, the technology exists to overcome these challenges of separation across agencies and organizations. When we build information systems from scratch, we have the opportunity to map out the relationships and flow of information that support shared decision-making, ensure information is collected once and can be reused several times (rather than collecting the same information over and over again), and generally make it easier to work together across departments, agencies, and organizations. This may be referred to as systems redesign (e.g., U.S. Department of Veterans Affairs, 2018).

Since building new systems is less common than working with existing ones (“legacy systems”), one more readily available technology option is using Application Programming Interfaces (APIs) that make it easier and more efficient to exchange information effectively across programs (Forbes Technology Council, 2017). A fuller discussion of system upgrades is beyond the scope of this report, but where interoperability is concerned, management decisions may revolve around integrating new components into the existing system or replacing systems entirely (Wachter & Goldsmith, 2018; Weldon, 2015).

In today’s data-driven world, the realities are that we usually need to accommodate working with legacy information systems, most of which were originally built for other purposes. For example, many proprietary healthcare providers such as hospitals had been doing electronic billing for some time, and then responded to HITECH financial incentives by purchasing clinical information systems without involving clinicians and other end-users in software purchasing decisions. The difficulty in using some of these poorly-designed, patched-together software systems has been blamed for high levels of physician burnout (Wachter & Goldsmith, 2018).

Figure 1. Social Determinants of Health

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community and Social Context</th>
<th>Health Care System</th>
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<tr>
<td>Employment</td>
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<td>Literacy</td>
<td>Hunger</td>
<td>Social integration</td>
<td>Health coverage</td>
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<td>Language</td>
<td>Access to</td>
<td>Support systems</td>
<td>Provider availability</td>
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<td>Safety</td>
<td>Early childhood</td>
<td>healthy options</td>
<td>Community engagement</td>
<td>Provider linguistic</td>
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<td>education</td>
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<td>Playgrounds</td>
<td>Vocational training</td>
<td>Quality of care</td>
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Health Outcomes
- Mortality
- Morbidity
- Life Expectancy
- Health Care Expenditures
- Health Status
- Functional Limitations

Figure 2. Mapping the Layers of Interoperability to Categories of IT Standards

Interoperability also means that the information in different systems is structured such that computers can automatically “read” information from another system. That capability is known as “syntactic” interoperability, and because it is built in to the software, it is usually invisible to most people using the system to enter or access information, or to prepare reports.

The next layer is “semantic” interoperability. For our purposes in health and human services, that layer includes standardized coding systems that providers use to record and keep track of their encounters for clinical, service, research, and billing purposes. For example, clinicians use diagnostic codes derived from the International Classification of Diseases and Related Health Problems (ICD) list. Payment systems require the use of standard diagnostic coding for payment.

The most familiar and visible aspect of interoperability for most people has been described as “process interoperability,” which refers to “the ability for data users (e.g., care providers, patients, EHR vendors, technology companies) to integrate technology workflows and processes in meaningful ways that improve information exchange, outcomes, efficiency, and cost-effectiveness” (EDM Forum Community, 2016).

**Process**

- The ability for data users (e.g., care providers, clients, software vendors, technology companies) to integrate technology, workflows, and processes in meaningful ways that improve information exchange, outcomes, efficiency, and cost-effectiveness.

**Semantic**

- The ability of two systems to communicate and exchange information so that the data is read and interpreted the same on both ends.

**Technical**

- The ability to transfer data between two systems so that it can be read at the machine level and structured or formatted appropriately without any deeper interpretation.

**Syntactic**

- The ability for data users to work with legacy systems — old hardware and old versions of software — that are not designed for interoperability. The inefficiencies of these agencies and frustrations they create have not been as well documented, but they are well-recognized nonetheless.

**Interoperability Defined across Four Different Layers**

The ability to collect, review, share, and use information seamlessly across organizations and systems is known as “interoperability.” Not to be confused with data sharing, or the electronic or physical exchange of information between two entities, colloquially, interoperability means that information systems can “talk to” each other (see Figure 2 below). And in this context, electronic data sharing is a fundamental component of interoperability, but is not exactly the same.

Functionally, interoperability means that the technical protocols for exchanging electronic information already are worked out, usually following agreed-upon industry standards or other technical requirements. This technical capability usually is described as the foundational “layer” of interoperability.


Information Exchange is Key to Interoperability

Interoperability is “the ability of two or more systems or components to exchange information and to use the information that has been exchanged.”


“In healthcare, interoperability is the ability of different information technology systems and software applications to communicate, exchange data, and use the information that has been exchanged.”


The education sector aims for “digital content interoperability,” or “seamless access to digital content and software for students and teachers, generally through a student learning platform or learning management system (LMS).”


According to the U.S. Department of Education, “achieving more secure, interoperable digital systems, including those that manage student information, learning materials and financial data...has been a design goal for many system architectures and standards groups for decades.”


“The term ‘interoperability,’ with respect to health information technology, means such health information technology that—(A) enables the secure exchange of electronic health information with, and use of electronic health information from, other health information technology without special effort on the part of the user; (B) allows for complete access, exchange, and use of all electronically accessible health information for authorized use under applicable State or Federal law; and (C) does not constitute information blocking as defined in section 3022(a).”


“Interoperability refers to the ability of two or more systems or components to exchange information and to use the information to make better decisions. The term is often used in a technical engineering sense and also in a broader sense, taking into account social, political, and organizational factors that impact performance.”


Information interoperability is defined as the “ability to transfer and use information in a uniform and efficient manner across multiple organizations and information technology systems. It is the ability of two or more systems or components to exchange information and to use the information that has been exchanged.”


OUR APPROACH

To inform this report, the project team conducted an environmental scan of interoperability guidance. The goals of the scan were to:

- Define the stakeholders and systems that comprise an interoperability ecosystem that spans across health and human services sectors;
- Identify guidance documents on interoperability to better understand the scope of existing resources and help foster implementation among users within and across sectors;
- Identify standards and best practices to disseminate high-level learnings and recommendations from experts;
- Analyze gaps in available guidance to help focus attention on where there is a need for additional resources and assistance; and
- Inform development of a plan for NIC and its partners to work with stakeholders and other experts in the field to address these gaps with new resources and investments.

In summary, anywhere that information flows across systems, or where different information systems are combining and using information from different sources, interoperability is the goal.

The environmental scan was conducted in two parts in order to capture a broad snapshot of the field: (1) semi-structured interviews with five content experts on their experiences and recommendations regarding interoperability practices; and (2) a limited search and review of available guidance, including grey literature (non peer-reviewed white papers, issue briefs, and reports), toolkits, and other publicly available information.

Expert Interviews

In early 2018, based on the recommendations of NIC partners and advisory board, the authors conducted interviews with five individuals with extensive experience and knowledge of data sharing and interoperability using a semi-structured interview guide (Appendix A). These included thought leaders from health, public health, and human and social services.

Exploratory Search and Review

The exploratory internet search of grey literature and peer-reviewed literature (specifically within eGEMs, Journal of the American Medical Informatics Association, and Applied Clinical Informatics) yielded an initial sample of resources to which the following inclusion criteria were applied:

- Nationally applicable or replicable;
- Published within last 7 years (2011-2018);
- Documentation of best practices, challenges, etc. pertaining to data interoperability
- Not commentary, such as blog posts, news articles, opinion pieces; and
- Published by an established organization or institution (in existence for at least 10 years with well-defined governance structure).

In order to ensure guidance was broadly applicable, documents that focused on the following themes were excluded from analysis:

- Medical device interoperability
- Electronic Health Record (EHR) certification guides
- Local/regional Health Information Exchange guides
- Case studies
- International sources

The initial search yielded 49 documents; a smaller subset of resources (n=29) were further excluded due to either lack of relevance or because they were not accessible (e.g. broken URL); and the remaining resources (n=20) were coded.

After the initial search, the project team collected additional resources suggested by advisors or content experts (see Appendix C). These additional resources were not analyzed systematically due to time limitations, but we note them here as additional contributions to the interoperability ecosystem.
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Key Considerations
The search string used – (interoperable AND data system guidance), or (interoperable AND data system toolkit) – likely introduced a health sector bias in the search as well as in the results and subsequent analyses, as “interoperability” is a complicated term which, while growing in popularity in the last decade, is interpreted differently by various stakeholders. The term is used extensively by the health sector, which has received a substantial amount of federal funding and support to undertake initiatives for sharing health data. Other sectors may be publishing relevant guidance focused on “information sharing” or “integration” that do not mention the term “interoperability” and therefore did not appear in our search results. The scan also excludes guidance and documentation related to data sharing generally, which is a core component of interoperability but is too broad a term to use for the purposes of this analysis.

Coding with Key Components of Interoperability
In reviewing the full-text resources identified in the search, it was important to develop a framework against which the content could be assessed. Building on prior AcademyHealth work conducted for the Agency for Healthcare Research and Quality (AHRQ) and the Office of the National Coordinator for Health IT (ONC) (AcademyHealth, n.d., Community Health Peer Learning Program) (AcademyHealth, n.d., Electronic Data Methods Forum), we identified nine key components of interoperability to be used in our coding. Each resource was reviewed and coded for inclusion of language or guidance relevant to each of the below key components, with the intent of identifying common themes and gaps.

1. Behavioral and Workflow Change: Change management with respect to adoption of new technology and change in workflow among end users.
2. Governance: Organizational and legal agreements among key members of leadership and institutions about shared decision-making processes, policies, resource allocations, joint products and services, and operations, including data use agreements (DUAs), memoranda of understanding (MOUs), etc.
3. Organizational Capacity and Readiness: The ability to adopt the socio-technical aspects of interoperability at the institutional level, C-suite decision-making, considerations for ROI.
4. Partner, Stakeholder, Community Engagement: Approach, model, or framework for engaging various community partners and stakeholder groups, or talks about presenting a value proposition.
5. Privacy and Security: Technical or policy aspects of ensuring exchanged data and information exchanged is secure and unidentified.
6. Regulations and Policy: State and federal policy/ guidelines (e.g. HIPAA, FERPA, 42 CFR Part 2).
7. Sustainability: Financial, organizational, and technical mechanisms, resources, and infrastructure to support the work: continuing, including ongoing training, updating systems as technology and requirements change, and broadening the user base.
8. Systems Integration and Technical Infrastructure: Technological aspects of enabling interoperability and information exchange, including technical requirements and standards.
9. Trust and Shared Values: Building shared understanding and trust among partners and stakeholders.

Limitations of our Approach
We would like to note two key and related limitations of the scan. First, we focused our search on terms specific to “interoperability” after preliminary searches with related but broader terms such as “information sharing,” “data sharing” and “data integration” yielded far too many documents to include in the scan. This means that we also did not use the search term “integrated data systems,” which we later learned is more commonly used in the social and human services and education sectors. Given the significant amount of recent federal investments to promote adoption and use of electronic health records, our findings may be more a reflection of the lack of standardized terms across sectors and comparatively greater public availability of guidance documents in the health sector than of actual cross-sector differences.

Our examination of interoperability guidance and expert interviews confirmed that interoperability is complex and challenging, but well worth the effort. It has the power to significantly improve systems and help providers’ serve populations better and more efficiently. This is true both within and across sectors, given that all sectors attempt to address the data, human and systems elements of interoperability.

FINDINGS
Guidance focuses more on systems integration and technical infrastructure than other components of interoperability.

High-level conclusions from review of guidance documents
- Guidance focuses more on systems integration and technical infrastructure than other components of interoperability.
- All 29 documents included guidance around systems integration and technical infrastructure, with a strong focus on the importance of using data exchange standards (Figure 3). A relatively small number of documents mentioned sustainability, or trust and shared values. This suggests that there is an opportunity to collect best practices and approaches to building trust and sustainability – two of the most significant barriers to enabling interoperability.
- Guidance around governance and organizational capacity and readiness is the most specific.
- These documents provided examples of data use and data sharing agreements, as well as best practices and guidelines about establishing governance protocols. In regards to organizational capacity and readiness, some documents discussed how to involve leadership in interoperability efforts and even provided decision-making models to understand which standards were worth adopting. One resource also discussed members of leadership who should be at the table to accelerate progress.
- Guidance lacks specific “how to” information in key areas. Gaps in detailed guidance were identified for the following components of interoperability: regulations and policy, partner, community, and stakeholder engagement; and privacy and security.
- The health sector contributed the most guidance followed by the emergency response sector (Figure 4), and the emphasis on different components of interoperability varied across sectors. Emergency response and health provided the most guidance around behavior and workflow change management and sustainability, while education and human services released guidance that covered the most breadth in terms of addressing nearly all of the key components (Figure 5).

Of the sectors represented, the emergency response and health sectors had the largest number of guidance documents that emphasized behavior and workflow change management, and also sustainability. National security/defense sector focused more on trust and shared values, and partner, community, and stakeholder engagement.

Even though relatively few education documents met our inclusion criteria, those we did review had rich information that was applicable across most of the key components we coded, with the exception of behavior and workflow change management. The same was true of documents from the human services sector, which covered almost all of the key components of interoperability, with the exception of sustainability. In our search results, only the health sector published guidance that covers every component of interoperability.
Analysis and Interpretation

Taking a closer look at our findings from the document search and expert interviews, three key interoperability elements emerged: data, human, and systems. In the following sections, we discuss the challenges and opportunities around interoperability from these three perspectives.

The Data Element
Data and the ability to share, understand, and use it are at the core of interoperability, so it is no surprise that all reviewed guidance included language about systems integration and technical infrastructure.

Standards
Two-thirds of the literature we reviewed emphasized or mentioned the importance of standards to interoperability (Appendix B). This goes back to the syntactic and semantic levels of interoperability (Figure 2), and ensuring that despite differences between systems, relevant information is structured or can be re-structured to fit a specific, common format so that it is readable and usable by other systems. We found this to be true both within and across sectors.

This commitment to standards is universal across sectors. For example, the first building block of the Office of the National Coordinator for Health IT (ONC)’s 10-year vision toward achieving interoperable health IT infrastructure is Core Technical Standards and Functions. ONC is committed to using standards and certification processes to establish standard vocabularies and structure essential information (Office of the National Coordinator for Health Information Technology, 2014).

In another example, the Office of Educational Technology noted that “regardless of the EHRs internal selection of database technology (e.g., relational, hierarchical, or object-oriented), data exchange with another application requires significant effort to transform the data into an agreed-upon format with agreed-upon meaning,” (Sittig & Wright, 2015). This topic also came up several times at the NIC Symposium, where participants agreed lack of standards is not the issue, and instead called for having “an honest conversation” about standards in a neutral environment.

Privacy and Security
Confidentiality and privacy rules, as well as security protections, apply differently depending on whether the information exchange is for purposes of research, policy, and/or care or case management. Personally identifiable information is needed for care and case management, but research and policy activities involve de-identified and aggregated data, which have different regulatory requirements for sharing and usage.

One guidance document regarding interoperability of health information, noted that “regardless of the EHRs internal selection of database technology (e.g., relational, hierarchical, or object-oriented), data exchange with another application requires significant effort to transform the data into an agreed-upon format with agreed-upon meaning,” (Sittig & Wright, 2015). This topic also came up several times at the NIC Symposium, where participants agreed lack of standards is not the issue, and instead called for having “an honest conversation” about standards in a neutral environment.
The health sector contributed 15 documents; emergency response contributed 4; IT, human services, and education sectors each contributed 3; and energy, national security, and public health sectors each contributed 1.

The emphasis on privacy and security included a call for better provider and client education about the importance of information sharing and the necessary privacy protections that are in place (Colorado Department of Human Services, 2014). Guidance also noted a need to support greater transparency so that individuals understand how their data is used (Office of the National Coordinator for Health Information Technology, 2014). ONC’s Trusted Exchange Framework also calls for identity proofing, two-factor authentication, and compliance with breach notification regulations (Office of the National Coordinator for Health Information Technology, 2018). To assist with the educational process with providers and administrators, the Administration for Children and Families has released examples of memoranda of understanding (MOUs) and data security agreements for governing security and privacy during data exchange (Administration for Children and Families, 2014).

Two of the experts we interviewed also mentioned privacy, but their focus was not on the technical aspects of securing information. Instead they focused on the human element, noting that privacy regulations are influenced by variations in their interpretation by different stakeholders.

Additional privacy concerns include pushback from individuals who are not comfortable sharing personal information that may be sensitive, and organizations that are risk-averse, fearing legal repercussions. In particular, one interviewee noted difficulties around sharing education data because of parents’ concerns about making information about their children widely available. According to that expert, it is largely the “interpretation of privacy rules that really restrict our ability to make progress.” He recommended working in smaller circles with existing partners to build on existing collaborations where trust about data sharing is already established.

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The Human Element

From a technological standpoint, interoperability is becoming more achievable due to advancements and investments in computer science and training, but leadership, organizational commitments to shared goals, and commitment of adequate resources will ultimately determine the feasibility and appropriateness of establishing truly interoperable systems. Ignoring human-controlled components will make it much harder to implement the necessary infrastructure to enable interoperability.

Organizational Capacity, Leadership, and Readiness for Change

Eleven documents mentioned organizational capacity and readiness (Appendix B) as crucial to enabling interoperability. One document from the education sector provided key steps in determining organizational capacity, including: “Knowing how many and what kinds of devices will be supported, current network capacity, and the types of resources available to fund a transition to greater use of technology (Office of Educational Technology, 2017).” Others addressed the importance of making a business case for interoperability with a realistic assessment of implementation costs.

Assessing capacity also means determining business model maturity and readiness through tools such as the Medicaid Information Technology Architecture (MITA) State Self-Assessment tool. While tools are helpful in prioritizing action, it’s also essential to demonstrate the value of interoperability efforts to leadership and key decision-makers – not by focusing on the technical specifications and capabilities, but in terms of how the new system will impact outcomes and produce better results.

Technological and social components of a system should influence the design of the system and help to cultivate a culture around the use of technology that will “advance clinical and administrative processes, workflows, tools, and policies.” For example, Geisinger Health System has addressed cultural and organizational processes through adopting a dual operational framework that addresses both culture and organizational processes, not just technological issues (EDM Forum Community, 2016).

Governance and Community Partnerships

Fourteen documents cited establishment of a governance structure at the outset as being integral to improving the overall policies and processes that will enable successful interoperability (Appendix B). From a strategic standpoint, governance structures “provide the framework in which stakeholders can collaborate and make decisions that represent a common objective,” (U.S. Department of Homeland Security, n.d.). The governing body should be focused on forming consensus around the policies and standards that should be adopted to inform further decision-making around systems and platforms (Consortium for School Networking, 2017).

Guidance documents strongly emphasized the need for a governance structure across the board, but fewer suggested approaches for fostering agreement around organizational policies related to security, data use, technical standards, privacy, etc. (United States Government Accountability Office, 2015). The few guidance documents that did highlight approaches for fostering agreement often included sample memoranda of understanding and data use agreements that may be adapted for use by other organizations (Administration for Children and Families, 2014).

Several documents emphasized that the governing body should be comprised of a diverse group of stakeholders who reflect all levels of government, health and/or human services personnel, and community interests. However, the size of the governing body (number of organizations involved) could create significant challenges around trust and varied approaches to data-sharing policies among organizations (United States Government Accountability Office, 2015).

Two guidance documents explicitly advocated for the inclusion of patients or patient advocates in the governance body (United States Government Accountability Office, 2015) (Cerner, n.d.). While it was not coded specifically, the concept of end user engagement goes beyond the health sector, as inclusion of end users helps to actively address issues around privacy and consent so that systems are designed in a user-centered way. Focus on the user experience applies not only to program staff, administrators, and clinicians, but also to clients, patients, caregivers, and consumers.

One guidance document highlighted “trust communities” as governance bodies that form around a particular technology or use case (Office of the National Coordinator for Health Information Technology: CMS, n.d.). Educating community partners about the purpose, vision, and goals of the interoperability plan, as well as how it will be implemented and operationalized, can help to foster trust (Colorado Department of Human Services, 2014).

Yet another document suggested developing a “shared vision” and establishing a process of regular information sharing with stakeholders to foster ongoing engagement and understanding around the effort (Administration for Children and Families, 2014). A third guidance document discussed the implications of fostering trust across different communities, stating, “Scaling trust across communities requires assurance that each adheres to a minimum set of
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The below grid shows which sectors addressed which components of interoperability.

### Components of Interoperability

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<th>Components of Interoperability</th>
<th>Sectors</th>
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### The Systems Element

Focusing more on leadership, another document emphasized the importance of including “proactive champions” who are on the ground doing the work and who can inform the advancement of achieving interoperability through translating technical issues for management and helping address other organizational issues (Office of Educational Technology, 2017).

In sum, the majority of guidance included specific discussions about the structure and composition of advisory groups. Some documents also addressed the human elements of collaboration, including shared vision, shared values, and trust-building with communities, organizations, and other stakeholders in order to promote interoperability.

### Laws, Regulations, and Policies

At the federal level, guidance specifically addressed the Health Insurance Portability and Accountability Act (HIPAA), which regulates data privacy and security for protected health information, 42 CFR Part 2, which limits disclosure of patient records related to drug and alcohol abuse, and the Family Education Rights and Privacy Act (FERPA), which protects student education records (Administrative for Children & Families 2014; Cerner, n.d.). The Confidentiality Toolkit produced by the Administration for Children and Families also reviews federal laws and regulations for Temporary Assistance for Needy Families, Child Care, Child Welfare, Child Support, Supplemental Nutrition Assistance Program (SNAP), and Low Income Home Energy Assistance Program (LIHEAP), and the specific language that dictates the sharing of those data elements. Two content experts we interviewed highlighted the need for federal guidance to achieve interoperability, with one noting that a lack of national, coordinated and consistent guidance coupled with multiple interpretations and viewpoints of existing regulations make consensus unlikely at this time.
However, going beyond federal laws and regulations, the Government Accountability Office (GAO) report noted that variation in state-level privacy rules is a significant barrier to implementation of interoperable systems (United States Government Accountability Office, 2015). States play a critical role in shaping and advancing the legal, business, and technical incentives of information exchange at the local level, and stakeholders must think about both the federal and state-level context when designing their interoperability efforts.

**Sustainability**

Less than one-third of the guidance documents we reviewed addressed sustainability and the necessary mechanisms for ensuring that the information infrastructure for interoperable systems can be maintained (Appendix B). However, those that did emphasized the need to build in plans for continued financing or funding as part of a long-term strategy. Consideration of sustainable financing is necessary for not only building and maintaining the technical part of long-term strategy. Consideration of sustainable financing is necessary for not only building and maintaining the technical infrastructure necessary for interoperable information systems, but also for knowing how to fund data sharing models.

According to CMS, “Federal and State funding coupled with State policy can advance provider infrastructure build outs for Health IT. The vision is that the State will develop and adopt a strategy to fund providers to adopt Health IT infrastructure and software” (Office of the National Coordinator for Health Information Technology, CMS, n.d.). One of the content experts we interviewed echoed these thoughts, noting that dedicated funding through federal grants or state funds would allow local health departments to update their systems when otherwise the costs of infrastructure upgrades are usually not included in local budgets.

**Less than one-third of the guidance documents we reviewed addressed sustainability and the necessary mechanisms for ensuring that the information infrastructure for interoperable systems can be maintained.**

**Increasing capacity to use data for strategic decision-making.**

Data-driven decision-making is a buzzword, a philosophy, and a trend in business intelligence, but it also applies widely to health and human services policy makers, program directors, and analytics teams. Leaders who are accountable for their decisions need current, accurate information to make rapid and long-term decisions, whether they need to find a foster care placement for an individual child or sign a data sharing agreement with a counterpart agency in another jurisdiction. Increasing technology integration into decision-making is a sea change in management and operations, across the board.

In our view, the combination of these three factors — increased awareness, greater user engagement, and increasing capacity to use data for decision-making — is creating an increased demand by decision-makers for better-functioning systems. This is in turn driving innovation and rapid change in the information ecosystem. We anticipate and hope for continuing and effective transformation to a more collaborative and interoperable approaches.

**Barriers to Progress Range from the Technical to the Cultural**

We also heard quite a bit about the following barriers and challenges:

- **Lack of agreement on how to structure data.** A quick Google search will yield countless examples of “why data sharing is hard to do.” Data sharing is often the first step toward interoperability, but it is not as simple or straightforward as it might seem. As shown in Figure 2, interoperability requires a consistent data format (often described as a common data model, or CDM) for data to be easily shared. When data elements are structured in different formats by older technology, such as relational databases, they need to be run through an exchange or data warehouse to be restructured and integrated. That structural transformation takes time, money, workflow changes, data sharing agree-

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**THEMES ABOUT PROGRESS AND CHALLENGES**

**Progress Found in Increased Awareness of and Capacity for Interoperability**

Throughout the process of planning and conducting this scan, we consulted with experts from health and human services communities and other sectors, including members of the NIC advisory group and partners. Early on, we conducted a small number of semi-structured interviews with five experts in health and human services programs, systems design, and information exchange (Appendix A). Among other questions, we asked them to identify areas where they thought progress toward interoperability had been made in the past 3-5 years.

After summarizing the themes, we presented them at the first National Interoperability Symposium, held in Sacramento in late March 2018, and received informal feedback that we incorporated in this section.

The following high-level, overarching themes emerged across sectors.

- **Increasing awareness that interoperability is important.** Its benefits include:
  - Improving the client/patient experience by reducing wait times, avoiding administrative duplication and errors, contributing to better outcomes
  - Increasing agency efficiency and reducing response time
  - Making better use of funding and resources
  - Getting more accurate and more comprehensive information to decision-makers

- **Greater acknowledgement of the need to design information systems with users in mind.** Systems that don’t meet the needs of their users and are difficult to navigate not only decrease efficiency; they contribute to poor morale and user frustration, will not be adopted, and end up costing money and time. There are many examples of poorly designed systems, but savvy decision-makers and information officers are forming cross-function design teams that include technical experts and program experts, thus engaging the people who will be using systems (e.g., entering data, generating reports) to help design them. This approach is known as agile software development, and it involves user-centered design principles, modular procurement, incremental design, and ongoing focus on what system users need.

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Progress
Awareness of the importance of interoperability
More engagement of end-users in design decisions
Increased capacity for data-driven decision making
Innovation and new models for information exchange

Current Challenges / Barriers
Lack of consensus on data structure and data exchange standards
Lack of IT understanding among managers/executives
Codiﬁed/legal complexities in sharing data
Mistrust: fear of breaches and lack of incentives to share data

CONCLUSIONS

We are encouraged to see a growing recognition of the value of interoperability, despite its many deﬁnitions and interpretations. While it is more an end goal than an operational one, its components – information sharing, shared governance, integrated data systems, aligned policies and values, coordinated care and case management, program integrity and effectiveness – are becoming increasingly accepted and better understood in more organizations and environments.

In addition to the technical aspects of interoperability, dynamic leadership and skilled management are absolutely critical. Based on our discussions with content experts, members of our advisory group, participants in the NIC Symposium, and our review of guidance documents, we conclude that the following ingredients are essential for managing a successful transition to interoperability.

Top leadership needs to provide a clear and compelling description of the vision that is to be achieved. Ideally, leaders should be tech-savvy, clear about where they’re going, able to explain why they’re doing what they’re doing, open to strategic risk-taking, and willing to set achievable and transparent goals.

Change should be driven by a team with the right skills. Experienced top and middle management work with technical experts and programmatic teams during the design and implementation phases. Internal workgroups ensure collaboration and articulation to achieve the overarching vision as well as reach milestones along the way. Another option might be to convene a cross-sector meeting of data exchange experts, software vendors, and programmatic stakeholders to discuss common approaches to integrate health and social care data. Funding may be incremental, but leadership needs to plan for achievable milestones.

From Silos to Solutions: Getting to Interoperability in Health and Human Services

Progress is being made, but challenges remain.

It was heartening to encounter a shared sense of the components of interoperability across sectors and to ﬁnd that sectors were experiencing similar barriers, which bodes well for future cross-sector collabora-
tion. However, we also encountered some flashpoints where there are philosophical and technical disagreements, long-standing sensitivities, and a lack of consensus, particularly in the area of standards.

In keeping with our intent, we are interested in balancing aspira-
tional goals with realistic and pragmatic approaches. Based on what we have learned, we believe the following steps would be useful for the health and human services sectors.

1. The organizational change management strategy should be included from the outset. The teams involved in design and implementation need to collaborate on key milestones and to ensure that transitions are planned at every appropriate level of the system or organization. They need to engage end-users of the system in its design from the beginning.

2. Financial systems/investments need to be sufﬁcient and sustainable. Achieving multi-sector collaboration requires an adequate commitment of up-front financial resources that cover technical infrastructure, attract the right talent and expertise, and put in place a sustainable structure that allows coordination and articulation to achieve the overarching vision as well as reach milestones along the way. Another option might be to convene a cross-sector meeting of data exchange experts, software vendors, and programmatic stakeholders to discuss common approaches to integrate health and social care data. Funding may be incremental, but leadership needs to plan for achievable milestones.

3. Increase the availability of neutral forums and platforms to share knowledge, strategies, documents, and toolkits. Positive change often happens faster when people are connected by shared goals and values and want to work together to achieve something practical and realistic within the near term.

4. Provide more guidance and training on conﬁdentiality, privacy, and security in plain language. Currently, most data sharing practices are developed and governed by agency attorneys and technical experts in data exchange, whose language is not always accessible or understandable by program leadership and staff.
Convene groups who can have an "honest and informed conversation about standards," voluntary compliance in the standards area has not been effective in promoting interoperability and data exchange. Unless software and technical standards are specified in regulations, reporting requirements, or contracts among entities that will be sharing data, organizations will tend to use what they are already familiar with or ignore standards altogether. A multi-sector conversation involving public and private sector thought leadership on standards would be very valuable.

Develop guidance on how to promote a culture that promotes sharing and interoperability to further the public interest, rather than an organization-specific focus on data ownership. One concrete step toward that culture might be a synthesis of existing measures and metrics to assess readiness for interoperability that can be used at the agency and organizational level. Another option might be to convene a cross-sector meeting of data exchange experts, software vendors, and programmatic stakeholders to discuss common approaches to integrate health and social care data.

Full interoperability is a lofty, long-term goal. Multi-sector collaboration and data sharing are more practical and realistic goals that may actually achieve similar outcomes in the long run. We acknowledge those who have already started to work across existing human and technical connections and identified shared values, and who seek to build an ecosystem in which collaboration becomes the new normal. We look forward to contributing to those multi-sector collaborations.


Office of the National Coordinator for Health Information Technology. CMS. (n.d.). State Health IT 1115 Toolkit - Key Questions with Detailed Background (1.0). Retrieved from https://www.healthit.gov/sites/default/files/1_1115_HIT_Toolkit-Qs_with_Detailed_Background.pdf


From Siloes to Solutions: Getting to Interoperability in Health and Human Services


APPENDIX A. INTERVIEW PROTOCOL

The following list of questions will guide our conversations with subject matter experts. As each interviewee’s background and perspective are varied, so too will be the composition of questions asked during each interview. Where we can add specifics related to the discussion, we may tailor the interview to enhance the richness of discussion.

All interviews will be recorded for notetaking purposes – no identifying information or attributable quotes will be published without permission.

Participant Name:
Program Affiliation:

Context and Rationale

Despite ongoing advances in the fields of health and human services – and, most pointedly, in the numerous areas where those fields converge – a history of operating in “silos” impedes the far-greater progress that could be achieved through enhanced data interoperability and information sharing, both within and across sectors. The purpose of this environmental scan is to identify and document best practices, challenges, and lessons learned with respect to models of data interoperability and implementation guidance and assistance, and to identify gaps and needs for future guidance and technical assistance focused on health and social care integration.

To accomplish this, we will interview subject matter experts about key issues and directions for interoperability, review the peer-reviewed and grey literature providing policy and implementation guidance on interoperability, and assess the contents and impact of recent toolkits and other guidance on promoting interoperability and information exchange.

Interoperability of technology is generally defined as the ability for different systems and software to establish communication channels, accurately and efficiently share data, and use the exchanged information.

1. What is your definition of interoperability? Please provide a brief description based on your experience, including what functional and governance components are needed to successfully achieve interoperability?
2. To successfully achieve interoperability, is it sufficient to receive and relay information through various data sharing mechanisms, or is it also necessary to build a common data infrastructure?
3. Are there any comparable concepts in the human services arena? What are the best examples of information sharing in the social services sector?
4. To what extent would interoperability change workflows or improve outcomes in your sector?
5. From your perspective, in the last 3-5 years, where has your field made the most progress with respect to data interoperability? The least? Where do you see major opportunities?
6. What remaining gaps in knowledge / technology should be addressed to achieve interoperability? In your opinion, what aspects of interoperability are most critical to explore?
7. If we are looking for best practices about data sharing and moving towards interoperability, what are the resources or activities you think would help move the field forward?
## Appendix B. Coding

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APPENDIX C. ADDITIONAL RESOURCES

After the initial search, the project team collected additional resources suggested by advisors or content experts. These additional resources were not analyzed systematically due to time limitations, but we note them here as additional contributions to the interoperability ecosystem.

Additional Resources Not Included in Analysis

- American Public Human Services Association Toolkit: Moving through the Value Curve Stages
  https://aphsa.org/APHSA/Value_Curve_Toolkit/Toolkit__Moving_through_the_Value_Curve_Stage.aspx
- California Department of Public Health GitHub Toolkit
- California Department of Public Health Public Health 2035
  https://www.cdph.ca.gov/Programs/OLGA/PublishingImages/Pages/LegislativeNewsletters/CDPHLAGBrief- ingPHWeekPublicHealth2035.pdf#search=PH2035
- Centers for Medicare and Medicaid Services Guidelines for Accountable Care Organizations
- HIMSS and NACCHO (National Association of County and City Health Officials) Public Health & HIE Toolkit
  http://www.himss.org/public-health-hie-toolkit
- National Human Services Interoperability Architecture (NHSIA)
  https://www.acf.hhs.gov/nhsia-definition
- National Information Exchange Model (NIEM)
  https://www.niem.gov/
- Silicon Valley Regional Data Trust (SVRDT)
  http://www.svrdt.org/
- State of California Health and Human Services Data Playbook
  https://chshdata.github.io/dataplaybook/

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