



From Siloes to Solutions:

Getting to Interoperability in Health and Human Services

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CONTENTS

EXECUTIVE SUMMARY	3
BACKGROUND	5
Life Isn't Lived in Siloes and Our Data Shouldn't Either	5
Interoperability Defined Across Four Different Layers	7
OUR APPROACH	9
Expert Interviews	9
Exploratory Search and Review	9
Coding with Key Components of Interoperability	10
FINDINGS	11
High-level Conclusions	11
ANALYSIS AND INTERPRETATION	13
The Data Element	13
The Human Element	15
The Systems Element	17
THEMES ABOUT PROGRESS AND CHALLENGES	19
Progress Found in Increased Awareness of and Capacity for Interoperability	19
Barriers to Progress Range from the Technical to the Cultural	19
CONCLUSIONS	21
APPENDIX A. INTERVIEW PROTOCOL	25
APPENDIX B. CODING	26
APPENDIX C. ADDITIONAL RESOURCES	30
ACKNOWLEDGMENTS	31

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 cautions 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, and more efficient data sharing across the sectors that influence health and well-being can significantly improve people’s lives, particularly those who are at-risk and underserved, as long as their data is secure and appropriate privacy protections are in place.

When we use the term “interoperability,” we refer to the ability to collect, review, share, and use information seamlessly across organizations and systems. Our primary goal in this report is

to inform future collaborative multi-sector work that builds on shared experiences of what works and integrates ongoing work by our NIC partners and other stakeholders. We hope that the report can provide a foundation for developing a common set of technical and leadership skills, a shared knowledge base, organizational structures, teaming models, and other considerations that will be key to success with complex interoperability efforts.

Methods and Approach

To conduct our assessment, we did a systematic online search of technical documents and toolkits that promote interoperability and provide guidance about how to share and integrate information from different sources. We also interviewed interoperability experts from health, education, public health, and human services systems; held discussion sessions with the NIC advisory group members; and presented our preliminary findings at the first NIC Symposium, an invitational meeting with 125 attendees in March 2018.

Building on our previous multi-sector work conducted for federal agencies and foundations,¹ we defined nine key sectors that correspond to organizational structures, missions, and sources of funding. They included health, human services, public health, emergency response, education, transportation, information technology (IT), energy, and national security.²

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/edmforum>) and the Community Health Peer Learning Program (<http://www.academyhealth.org/chphealthit>), AcademyHealth has defined key sectors and domains that intersect 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/>).



Nine Components of Interoperability



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.

Nine Sectors



- Among the most challenging barriers to integration are the need for consensus about data exchange standards, the need for more systems thinking rather than organization-specific interests, and the lack of incentives to share data.
- Legislative and regulatory complexities about sharing and protecting data are the most vexing and challenging barriers.

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 lay person -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.

BACKGROUND

Life Isn't Lived in Siloes and Our Data Shouldn't Either

All across the country, health and human services programs are making connections so they can provide more coordinated approaches to health and well-being in their communities. The drive to build collaborations comes from a sense of urgency about overcoming the separated, “siloe” approaches to health and social care that have evolved under different sources of funding, leadership, agency and organizational cultures, and jurisdictions, and these hinder efforts to coordinate and share information effectively.

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 individuals, their families, and their neighbors more effectively and efficiently, and often more quickly as well.

Our focus for this report will be on the health and human services ecosystem and the available guidance to build an information infrastructure that supports multi-sector collaboration.

Despite their best intentions, however, different organizations and agencies often have different priorities due to separation of their functions and missions, funding streams and sources, different legal and statutory authorities, geographic and cultural variations in local resources and assets, and many other reasons. These institutional and programmatic separations, and even the perceptions of differences in constituencies and objectives, can lead to duplication of effort, gaps, and disappointing and preventable errors and delays in getting the right information to deliver the right care and services at the right time.

We are interested in the ways that critical information can be shared better, faster, and more efficiently across health and human services systems to promote health and well-being for individuals, families,

and communities. Our focus for this report will be on the health and human services ecosystem and the available guidance to build an information infrastructure that supports multi-sector collaboration.

Many initiatives are underway to share and integrate information across health and human services programs, as well as other sectors (e.g., education, transportation, criminal justice, etc.). Generally speaking, the social, economic, and environmental factors that influence people's health and well-being can be placed into two categories:

Individual-level factors, such as level of education or income, access to health care, housing, healthy food and parks, and languages spoken at home; and

Community-level factors, such as availability of transportation, public safety, quality education, affordable, healthy food in local grocery stores, or exposure to air pollution, contaminated water, or lead paint in an apartment building or playground.

The comprehensive perspective and approach to integrating health and social care is described by a number of terms in different sectors. Many people use the term “social determinants of health” (World Health Organization, 2018), while others use “population health management” (Massachusetts Medical Society, 2018), “culture of health” (Robert Wood Johnson Foundation, 2018), “service integration” (County Health Rankings & Roadmaps, 2018), “integrated service delivery” (Workforce Training and Education Coordinating Board, 2015), and other terms.

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 combined to support various program components (Academy-Health, 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).

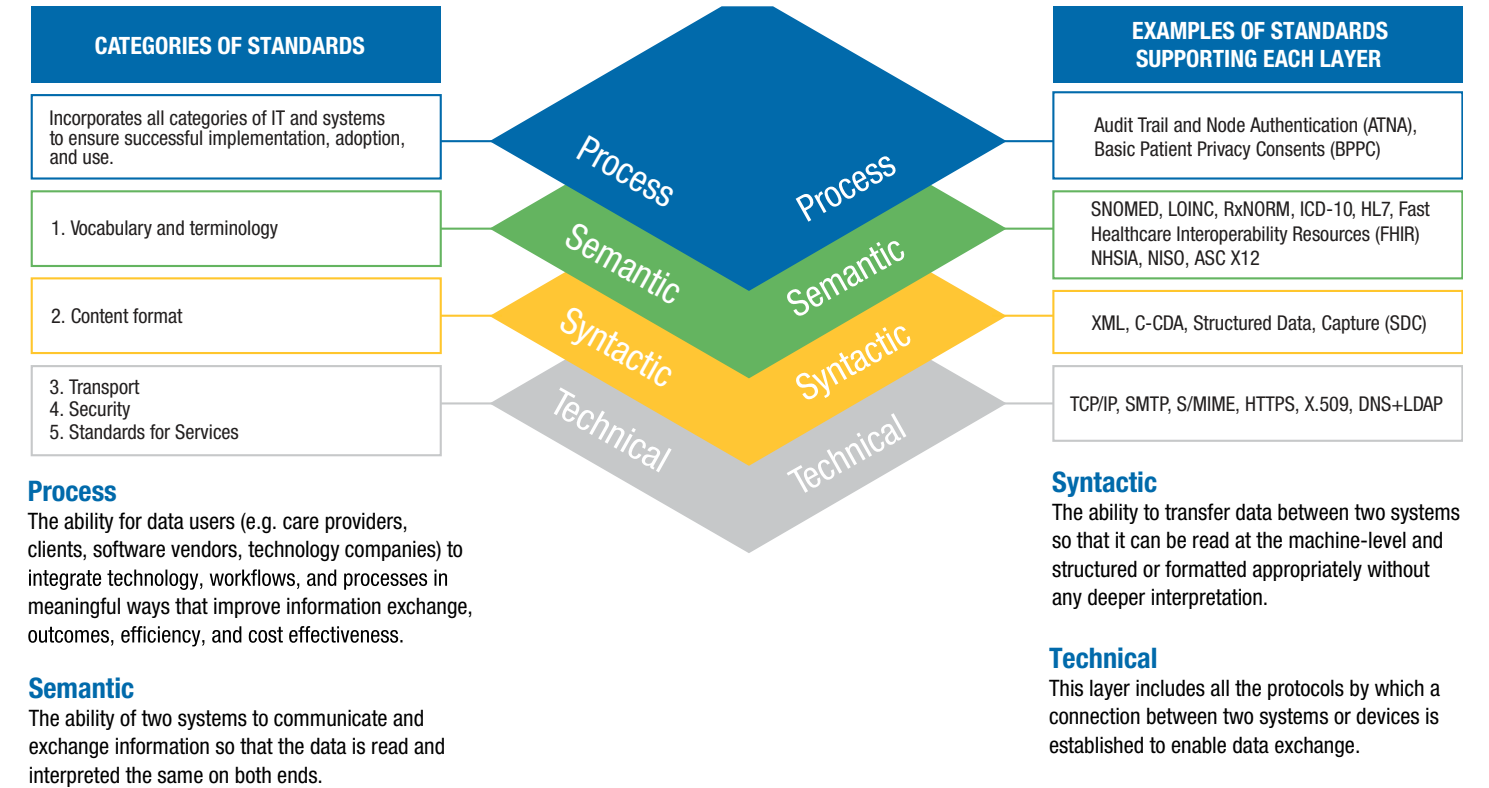
Figure 1. Social Determinants of Health

Economic Stability	Neighborhood and Physical Environment	Education	Food	Community and Social Context	Health Care System
Employment Income Expenses Debt Medical bills Support	Housing Transportation Safety Parks Playgrounds Walkability Zip code / geography	Literacy Language Early childhood education Vocational training Higher education	Hunger Access to healthy options	Social integration Support systems Community engagement Discrimination Stress	Health coverage Provider availability Provider linguistic and cultural competency Quality of care

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



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.

Syntactic

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.

Technical

This layer includes all the protocols by which a connection between two systems or devices is established to enable data exchange.

Figure 2 Source: Adapted from Padgham, D., Edmunds, M., Holve, E. (2016) Toward Greater Health Information Interoperability in the United States Health System. Issue Briefs and Reports. Issue 20. <http://www.academyhealth.org/node/2316>.

Particularly in the public sector, budget limitations often require agencies 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.

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).

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.”

Source: Institute for Electrical and Electronics Engineering (IEEE). *IEEE Standard Computer Dictionary: A Compilation of IEEE Standard Computer Glossaries* (New York, NY: 1990).

“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.”

Source: Healthcare Information and Management Systems Society. What is Interoperability? Retrieved from HIMSS: himss.org/library/interoperability-standards/what-is

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.)”

Source: CoSN (2017). Working Together to Strategically Connect the K–12 Enterprise: Interoperability Standards for Education. <https://cosn.org/focus-areas/it-management/interoperability-standards>

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.”

Source: U.S. Department of Education. Digital Systems Interoperability. Retrieved from ED: <https://www.ed.gov/open/plan/digital-systems-interoperability>

“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).”

Source: Office of the National Coordinator for Health IT. Interoperability. Retrieved from HealthIT.gov: <https://www.healthit.gov/topic/interoperability>

“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.”

Source: Administration for Children & Families. Interoperability. Retrieved from U.S. Department of Health & Human Services: <https://www.acf.hhs.gov/about/interoperability>

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.”

Source: Information Sharing Environment (2014). ISE Information Interoperability Framework: National Security through Responsible Information Sharing.

https://www.dni.gov/files/ISE/documents/DocumentLibrary/FINAL---ISE_I2F_v0-5.pdf

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=20) were further excluded due to either lack of relevance or because they were not accessible (e.g. broken URL); and the remaining resources (n=29) 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.

Key Considerations

The search string used – (*interoperab* AND data system guidance*), or (*interoperab* 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.

FINDINGS

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 helps 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.

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 touching upon nearly all of the key components (Figure 5).

The systematic search yielded the largest number of guidance resources from the health sector, which was unsurprising given heavy federal investments in health information infrastructure in the last decade (specifically, the Health Information Technology for Economic and Clinical Health (HITECH)), part of the American Recovery and Reinvestment Act of 2009 (ARRA). The Patient Protection and Affordable Care Act (ACA), enacted by Congress the following year, had several provisions intended to encourage multi-sector collaboration in service of better outcomes and improved operational efficiency, and we found some comprehensive interoperability guidance developed by experts in human services and education about reaching out to health organizations. NHSIA is an example of one such guidance document prepared by the Administration for Children and Families/DHHS to apply the ACA goals.

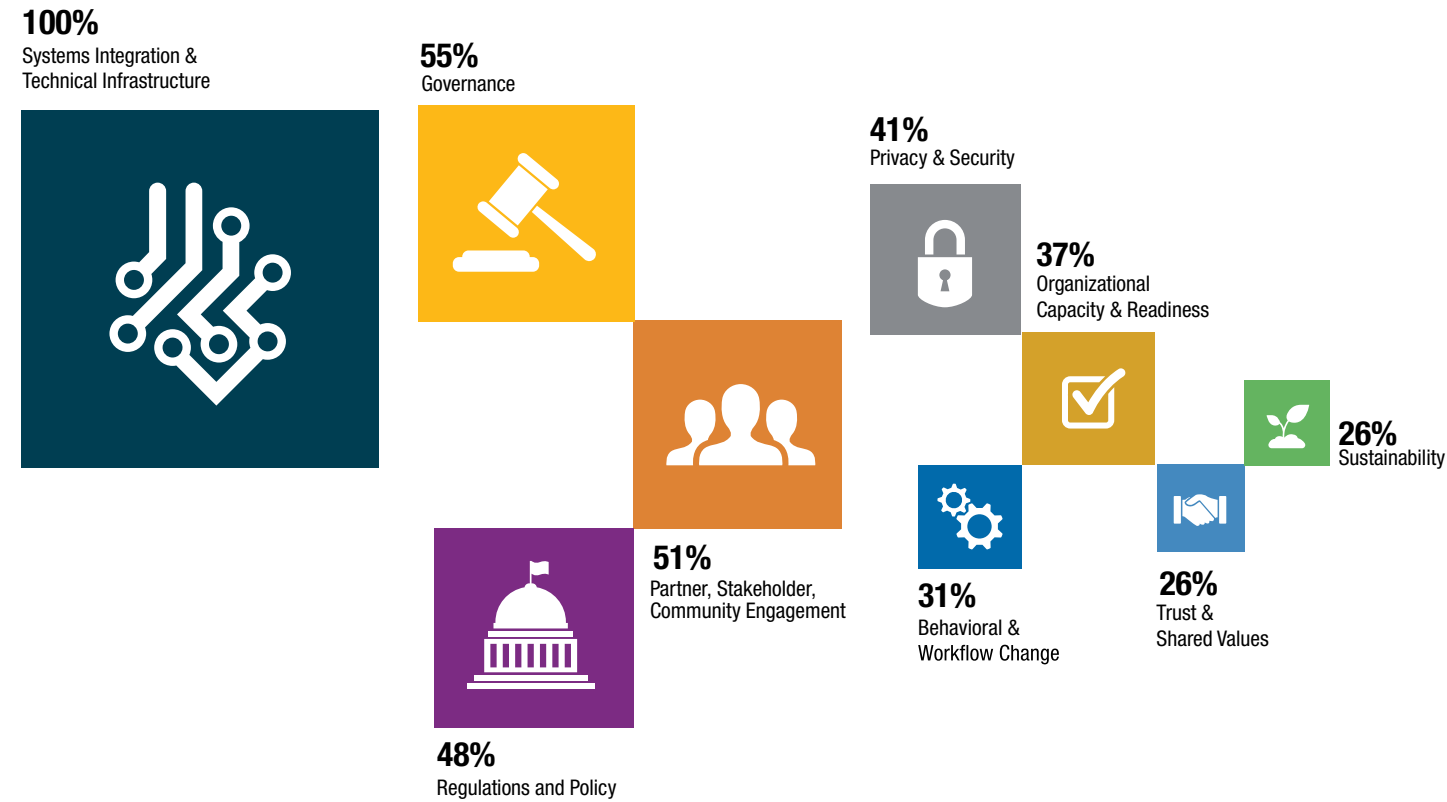


Of the sectors represented, the emergency response and health sectors had the largest number of guidance documents that emphasized behavior and workflow change management, and also sustainability. National security / defense sector focused more on trust and shared values, and partner, community and stakeholder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

Figure 3. Guidance Documents Emphasized the Data and Policy Elements of Interoperability
 In the below graphic, the icon size corresponds to how often that component was addressed in interoperability guidance.



All 29 coded guidance documents addressed Systems Integration & Technical Infrastructure. Sixteen documents addressed Regulations & Policy; 15 addressed Partner, Community, & Stakeholder Engagement; 14 addressed Governance; 12 addressed Privacy & Security; 11 addressed Behavior & Workow Management; 8 addressed Trust & Shared Values; and 8 addressed Sustainability.

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 when education data systems do not use interoperability standards to enable easy and secure exchange of information, educators miss out on opportunities to use data for improved and personalized learning, and leaders cannot aggregate data to improve the quality and effectiveness of their tools and resources (Office of Educational Technology, 2017; Consortium for School Networking, 2017).

In addition, four of the five experts we interviewed raised the importance of standards, citing the need to ensure that systems have the ability to enter, send, and receive data in an understandable and actionable

format. Interestingly, one expert made a point of clarifying this did not mean it would be necessary to have a centralized system coordinating in the middle, but rather a distributed but coordinated, common infrastructure (“federated model”) to facilitate the exchange process.

Another interviewee emphasized, in particular, the need for *consensual standards* – noting that it is not that there is a need for new software and data standards, but rather a need for a shared understanding and consensus on which existing standards to use in contracts, regulations, or reporting requirements.

One guidance document regarding interoperability of health information, noted that “regardless of the EHR’s 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.

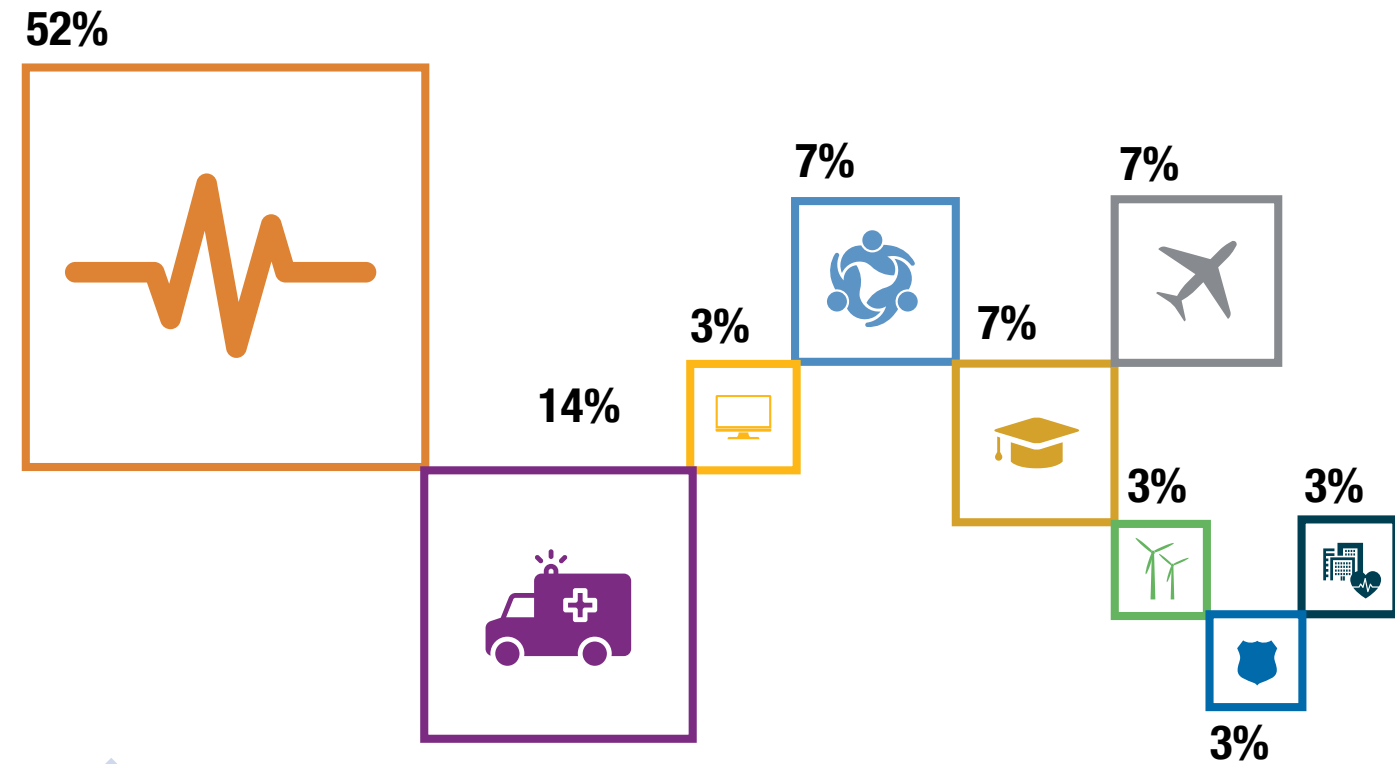
Privacy and Security

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.

Almost half of the guidance we reviewed touched on privacy and security (Appendix B), and the need for appropriate mechanisms to protect individuals’ personal information while also ensuring necessary data elements can be shared and used appropriately in a timely manner. This can be difficult, particularly as organizations begin thinking about using and sharing newer types of data, and “there remains a need to consider the balance of risk between privacy breaches and enabling beneficial uses (and reuses) of greater data sharing,” (EDM Forum Community, 2016).

Figure 4. Most Guidance was from the Health Sector

In the below graphic, the size of each icon corresponds to how many documents that sector authored.



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.

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

Figure 5. Sectors with the Most Comprehensive Guidance Included Health, Education, Emergency Response, and Human Services

The below grid shows which sectors addressed which components of interoperability.

		Components of Interoperability								
										
Sectors		■	■	■	■	■	■	■	■	■
		■	■	■	■	■	■		■	■
		■	■	■	■	■	■	■		■
		■	■	■	■	■	■	■	■	
		■	■		■	■				
		■		■					■	
		■	■			■				
		■			■					
		■		■						

common security and business practices” (Office of the National Coordinator for Health Information Technology, 2014).

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.

Behavior and Workflow Change Management

A total of nine documents highlighted the need for behavioral change and workflow processes (Appendix B) to enable interoperability. Generally, guidance promoted an inclusive approach to training and capacity-building tailored to data producers and users (United Nations Statistics Division; Global Partnership for Sustainable Development Data, 2017). An inclusive approach can support behavioral and culture change management, minimizing the barriers to adoption of new systems.

One white paper suggested that data users should be engaged in supported processes and workflows that integrate technology in a way that meaningfully improves “information exchange, outcomes, efficiency, and cost effectiveness...” (EDM Forum Community, 2016). The emergency response sector provided thorough guidance on developing training materials and exercise programs to practice “communications interoperability” to ensure the technology is responsive and properly utilized by the end-user (U.S. Department of Homeland Security, n.d.).

One guidance document discussed the need to assess current workflows, processes, and systems that will be affected by the adoption of interoperability practices at the outset when transitioning to more interoperable systems. In addition, as more technology and tools are included, plans for ongoing business process improvement analysis should be in place to ensure that operational needs are well-known and inform the design of future versions of systems and software (Colorado Department of Human Services, 2014).

The Systems Element

Even with successful alignment of all of the data and human elements necessary for interoperability, it is not possible to achieve interoperability without the proper regulatory frameworks and structures in place at a systems level. Interoperability is not just about exchanging data within and across organizations. It also requires an alignment of policies and protocols. Federal and state laws intended to protect privacy may have the unintended consequence of restricting data sharing, depending on how they are interpreted by leadership at an organizational or institutional level. In other cases, proprietary data is not shared because it might provide a competitive advantage to others.

Laws, Regulations, and Policies

Roughly half of the guidance documents we reviewed addressed the role of federal and state laws and regulations (Appendix B) in supporting interoperability efforts. The systems and structures that are in place play a huge role in shaping how interoperability efforts are approached. For example, *Supportive Business, Clinical, Cultural, and Regulatory Environment* is a core building block of ONC’s 10-Year vision for achieving an interoperable health IT infrastructure, with the understanding that it will be necessary to reduce and remove regulatory and business barriers that prevent data flow.



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 (Administration 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 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.

Often, local network technology costs are recovered through state or federal funding, grant funding, or user fees, such as in the membership fee for participation in a health information exchange. In its review of 18 initiatives, the GAO found that fees can be charged based on the type of participant, such as an individual physician or a hospital, or the volume of data exchanged through a network (United States Government Accountability Office, 2015).

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.

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 waiting 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., enter-

ing 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.

- **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.

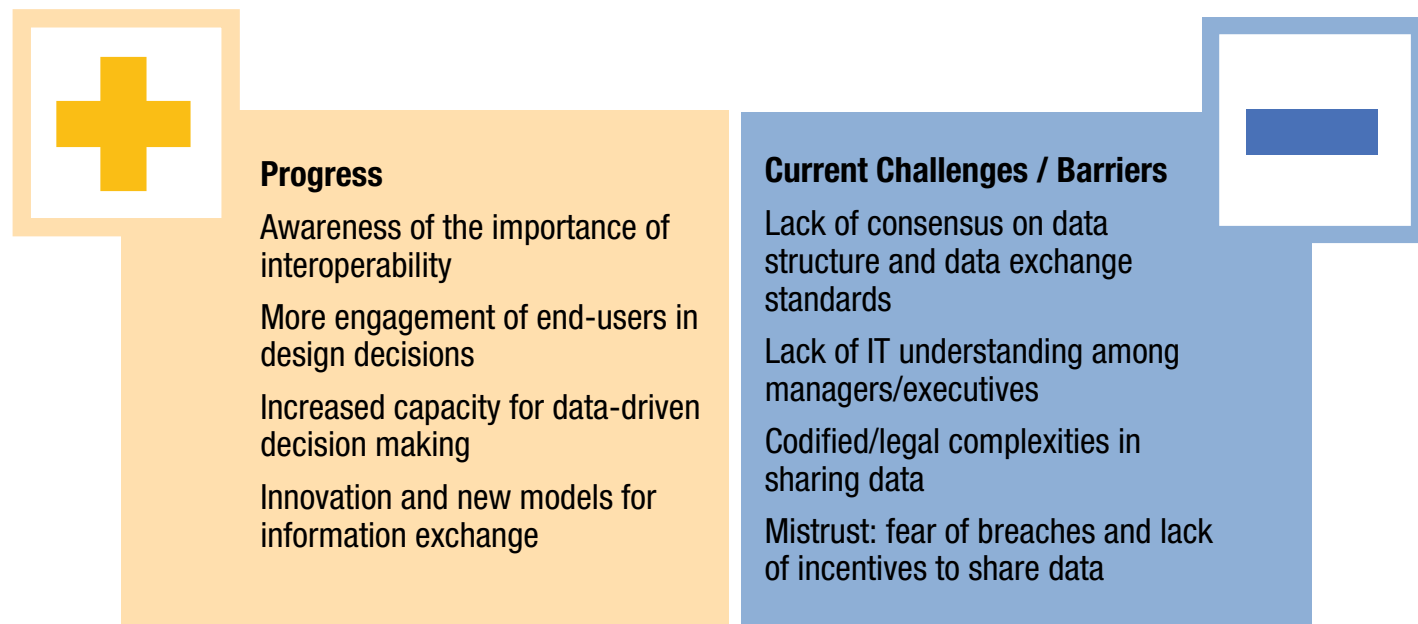
In our view, the combination of these three factors — increased awareness, greater user engagement, and increasing capacity to use data for decision-making — is creating an increased demand by decision-makers for better-functioning systems. This is in turn driving innovation and rapid change in the information 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-

Figure 6. PROGRESS IS BEING MADE, BUT CHALLENGES REMAIN



ments, and other infrastructure to be in place. In contrast, newer ‘NoSQL’ database technologies, which run Healthcare.gov and many security agencies, don’t require similar data structures and can handle and index both structured and unstructured information for rapid retrieval, similar to the internet.

- **Lack of consensus on data exchange standards.** Every organization customizes its data for its own use. While that clearly benefits local users, it makes it much harder to exchange information with other entities unless there is a contractual or legal requirement to report and exchange information in a set format. The ideal way to enhance data exchange and interoperability is to agree on which industry standards will be used, either through a data-sharing agreement, memorandum of understanding, or other kind of agreement about how data will be structured and exchanged. Currently, however, in most sectors there are philosophical and technical disputes about which standards are best or most appropriate for which applications; a lack of awareness about standards or disregard for using standards; and a lack of tools and mechanisms to support voluntary adoption of standards. There is no current framework or single organization with the authority and responsibility to set standards for health and human services systems, which would be a massive undertaking.
- **Lack of technology literacy and systems thinking among decision-makers.** Tech-savvy leaders tend to form cross-function teams that consider user needs as a best practice in designing systems and implementing data and information systems. In many if not most cases, however, the responsibility for making

purchasing and implementation decisions about software is in the hands of people who don’t have a background in information technology, computer sciences, informatics, or related fields. Often they don’t have the time or resources to get trained, don’t have access within their organization to people who do have the right training, and don’t have a budget to bring in expert consultants who can oversee development projects. For example, agencies in the public sector typically lack technology staff and have vacancies in technology positions because the private sector pays so much better.

- **Legal/statutory complexities about sharing and protecting data.** Organizations must adhere to industry standards as well as privacy and security laws in order to protect sensitive personal information from breaches, identity theft, and other threats. The federal Health Insurance Portability and Accountability Act (HIPAA) regulates sharing and use of personal health information, and the Family Educational Rights and Privacy Act (FERPA) sets standards for how students’ data is stored, transmitted, and accessed, as well as how permissions to release data are given. Both laws are highly complex, technical, and subject to widespread variations in interpretation. In some cases, states may enact requirements that are more stringent than the federal ones. As a result, an unintended consequence of the legal privacy protections is a reluctance to make any data available outside of the system where it is stored and curated.
- **Mistrust and lack of incentives to share data.** Fears about data breaches are not the only reason agencies and organizations may be reluctant to share data. Other reasons include a

sense of ownership of data; fear that loss of control will lead to inaccuracies, diminish authority, or cause a loss of competitive advantage; misperceptions about what is allowable; and lack of clarity about the specific data elements to be included, how the data will be used, and who will be able to access it. Many of our experts talked about the importance of shifting to data-sharing as the norm, rather than the exception, and creating a culture of collaboration that serves the public interest.

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 (e.g., vision documents and timelines) so everyone involved will know when they’ve arrived. Whenever possible, they should show an ongoing individual commitment to the process and also have good team-building skills to help ensure continuity throughout management transitions.
- **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 within and across organizational functions and goals. In particular, the design and implementation teams need to be committed to the vision communicated by top leadership and buy in to the successful achievement of that vision. Consensus about technical standards should be an integral part of the decision-making process.

- **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.
- **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.

NEXT STEPS

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 collaboration. 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 aspirational 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:

- **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.
- **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 understood 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

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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.

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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:
Position Title:

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 “siloes” 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?
 - a. What is the difference between data sharing and interoperability?
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

Source	Title	Year	Sector	Key Components								
				Governance	Trust & Shared Values	Partner, Community, and Stakeholder Engagement	Behavior and Workflow Change Management	Systems Integration and Technical Infrastructure	Organizational Capacity and Readiness	Sustainability	Privacy and Security	Regulations and Policy
Administration for Children and Families (ACF)	Confidentiality Toolkit - A resource tool from the ACF Interoperability Initiative	2014	Human Services	1	1	1	1	1	1	1	1	1
American Health Information Management Association (AHIMA)	Data Standards, Data Quality, and Interoperability	2013	Health			1		1				1
Bipartisan Policy Center	Improving Health Through Interoperability and Information Sharing: Advancing Medical Innovation for a Healthier America	2015	Health			1		1		1		1
Centers for Disease Control and Prevention (CDC); Healthcare Information and Management Systems Society (HIMSS)	CDC Connecting to Healthcare through Interoperability	2012	Health			1		1				1
Centers for Disease Control and Prevention (CDC)	Standards and Interoperability Enterprise Services	-	Public Health					1			1	1
Centers for Medicare & Medicaid Services	The Merit-based Incentive Payment System (MIPS) Advancing Care Information Prevention of Information Blocking Attestation: Making Sure EHR Information is Shared	2017	Health				1	1				
Centers for Medicare & Medicaid Services (CMS), Office of the National Coordinator for Health Information Technology (ONC)	State Health IT 1115 Toolkit - Key Questions with Detailed Background (1.0)	-	Health	1	1			1		1		1
Cerner	The Building Blocks of Nationwide	-	Health			1		1				1
Colorado Department of Human Services	Colorado Client Information Sharing System Interoperability	2014	Human Services	1	1	1	1	1	1	1	1	1
Consortium for School Networking (CoSN)	Working Together to Strategically Connect the K-12 Enterprise:	2017	Education	1				1		1	1	
EDM Forum Community	Toward Greater Health Information Interoperability in the United	2016	Health				1	1		1	1	
ICF	Standards and Interoperability in Electric Distribution Systems	2016	Energy			1		1				
Marcos, Gonzalez-Ferrer, Peleg, Caverio	Solving the interoperability challenge of a distributed	2015	Health					1				
NY State Government	New York: 2014 Statewide Communication Interoperability	2014	Emergency Response	1		1	1	1	1	1	1	1
Office of Educational Technology	Reimagining the Role of Technology in Education: 2017	2017	Education		1	1		1		1	1	1
Office of the National Coordinator for Health Information Technology (ONC)	Health IT Enabled Quality Improvement: A Vision to Achieve Better Health and Health Care	-	Health			1		1			1	1
Office of the National Coordinator for Health Information Technology (ONC)	Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap	2015	Health	1				1			1	1

APPENDIX B. CODING (Continued)

Source	Title	Year	Sector	Key Components								
				Governance	Trust & Shared Values	Partner, Community, and Stakeholder Engagement	Behavior and Workflow Change Management	Systems Integration and Technical Infrastructure	Organizational Capacity and Readiness	Sustainability	Privacy and Security	Regulations and Policy
Office of the National Coordinator for Health Information Technology (ONC)	2016 Interoperability Standards Advisory	2016	Health					1				1
Office of the National Coordinator for Health Information Technology (ONC)	DRAFT - Trusted Exchange Framework and Common Agreement	2018	Health	1	1			1		1		1
Office of the National Coordinator for Health Information Technology (ONC)	Connecting Health and Care for the Nation: A 10-Year Vision to Achieve an Interoperable Health IT Infrastructure	2014	Health	1	1	1	1	1		1		1
RAND Corporation	Chapter 2: A Broad Definition of Interoperability	2000	National Security / Defense		1	1		1				
Sittig & Wright	What makes an EHR "open" or interoperable?	2015	Health					1				
State of Oregon	Oregon Statewide Communication Interoperability Plan (SCIP)	2016	Emergency Response	1		1	1	1		1		
U.S. Department of Homeland Security	Interoperability Continuum - A Tool for Improving Emergency Response Communications and Interoperability	-	Emergency Response	1		1	1	1		1		
U.S. Department of Homeland Security Office of Emergency Communications	National Interoperability Field Operations Guide	2011	Emergency Response	1				1				
U.S. Department of Transportation Federal Highway Administration	ITS Research 2015-2019: Interoperability White Paper	-	Transportation	1				1			1	
U.S. Department of Transportation Federal Highway Administration	Guidance on State Safety Data Systems	2016	Transportation					1				1
U.S. Government Accountability Office	Nonfederal Efforts to Help Achieve Health Information Interoperability	2015	Health	1	1	1		1		1		1
United Nations Statistics Division (UNSD) and Global Partnership for Sustainable Development Data (GPSDD)	Multi-stakeholder meeting on data interoperability for the SDGs	2017	IT	1			1	1				
				14	8	15	9	29	11	8	12	16

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/CDPHLGALegBriefingPHWeekPublicHealth2035.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.svrtdt.org/>
- State of California Health and Human Services Data Playbook
<https://chhsdata.github.io/dataplaybook/>

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