In the NIC of Time: Six Domains of Primary Focus for the National Interoperability Collaborative

Stewards of Change Institute
Healthcare Information and Management Systems Society

"By failing to prepare, you are preparing to fail."
— Benjamin Franklin

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NIC is a new "Community of Networks" designed to increase collaboration among the sectors that impact health and well-being by improving information-sharing, interoperability, and use of technology. Our goal is to improve outcomes for everyone, particularly vulnerable and under-served members of society. NIC is led by the Stewards of Change Institute and AcademyHealth.

NIC members and other interested parties are encouraged to use this material as the basis for ongoing discussions and interactions on the new NIC website and its collaboration portal. We recognize the complexity of each of the six domains that are summarized here, and encourage active participation – especially on the NIC portal – to delve into topics relevant to your own work and interests. The aim is to identify common themes, needs and areas where collaboration within and among domains could be genuinely valuable.

By providing this unique, explicit look at all six domains, our goal is to enable and support the identification and analysis of common and divergent factors among them – and thereby instigate and accelerate cross-sector information-sharing, interoperability, and collaboration

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Stewards of Change Institute is a national nonprofit organization that provides catalytic leadership to improve the future of children, families and communities by inspiring and initiating transformational change in health and human services at all levels. SOCI's vision is to serve as a driving force for bringing together progressive ideas, cutting-edge tools, and leading innovators from the public and private sectors; conducting, synthesizing and applying research; and providing education, support, training, and advocacy to advance information-sharing and interoperability.

AcademyHealth is a leading national organization serving the fields of health services and policy research and the professionals who produce and use this important work. Together with our members, we offer programs and services that support the development and use of rigorous, relevant and timely evidence to increase the quality, accessibility, and value of health care, to reduce disparities, and to improve health. We bring stakeholders together to address the needs of an evolving health system, inform health policy, and translate evidence into action.

Most of the content in this document was originally researched and written by Stewards of Change Institute for a white paper commissioned by the Healthcare Information Management and Systems Society (HIMSS). The content has been expanded for its use by NIC.

The Healthcare Information and Management Systems Society is a global, cause-based, not-for-profit organization focused on better health through information technology (IT). HIMSS leads efforts to optimize health engagements and care outcomes using IT. HIMSS North America, a business unit within HIMSS, provides thought leadership, community building, professional development, public policy, and events. HIMSS North America represents 64,000 individual members, 640 corporate members, and over 450 non-profit organizations.

We invite input on the content of this document to ensure its accuracy and ongoing usefulness. To ask a question or provide a comment, please send an email to NIC@stewardsofchange.org.

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SECTION I: Introduction and Background

Public and private organizations, as well as thought leaders nationwide, have long recognized that interoperability and information-sharing are at the heart of enabling a genuinely effective approach to addressing virtually any situation affecting multiple organizations, systems, jurisdictions and/or government at all levels.

With this understanding as backdrop, numerous efforts have been made for decades – many of them successful – to improve coordination, communication and collaboration within and among six of the primary domains that operate across the spectrum of care. What this document seeks to accomplish that we believe has not previously been done is to examine the workings of each of the six domains; identify and analyze their successes, problems, commonalities and intersections; and then, based on that learning and additional research by NIC's leader organizations, help them work more cooperatively and interoperatively to deal with a broad array of issues (such as public health crises).

The six domains are: human and social services; public health; public education; public safety; emergency medical services; and health information technology, which differs from the others in that it cuts across domains and is critical to their operations. The mission and work of each domain are summarized in this document, which was researched and written by the Stewards of Change Institute (SOCI), the Healthcare Information and Management Systems Society (HIMSS), and several subject matter experts to whom we are very grateful for the knowledge and guidance they contributed (see Acknowledgements).

SECTION II: Understanding the Six Domains . . . to Connect the Dots

Each of the six domains examined below is in itself a complex, sprawling and diverse field that encompasses numerous agencies, organizations and/or other entities. Each also has its own norms, standards, bureaucracies and internal information-sharing and interoperability challenges. Moreover, each has a full complement of daily and long-term mission responsibilities. It is therefore unrealistic to think they can find a way to broadly exchange data in all circumstances anytime soon, even if the scope were limited to any one issue.

What is possible and what we believe is in these domains' own best interests, however, is to identify particular data sets, processes and other elements of their current work – focused on specific problems (ex., the opioid crisis) – that could be shared. And we believe that doing so would result in better collaboration, services and outcomes in the short term, and increasingly over time. Perhaps most pointedly, to the extent that interoperability and information-sharing among stakeholders is desirable, it clearly needs to be done sooner rather than later, since it would be far more difficult (at best) once an immediate need must be addressed. A deliberately simple example of how this process could be started in a given community: Activities already being conducted in each domain under the umbrella of "preventing opioid addiction" could be identified and enumerated, with answers to questions such as: What data does each domain hold that some or all others do not, and which of them could be of genuine benefit if they were shared?

Answering questions such as these would enable us to "connect the dots," prioritize actions, and then focus on those that could have the greatest impact, the most quickly. Against this backdrop, the next section provides an overview of each of the six domains, including a review of its fundamental functions and structures; its key challenges; and its pragmatic opportunities for taking short-term action. As it develops organizationally and in its on-the-ground activities, NIC's goal is to expand understanding of the domains themselves and, most importantly, to enable them to become more effective -- individually and collectively -- through greater collaboration, information-sharing and interoperability.

Human and Social Services

Mission: Means-tested human services programs, also referred to as social services (or, sometimes, as welfare) comprise about 80 separate federal initiatives that provide a very broad array of benefits and services including: cash and housing assistance, food stamps, medical care, child welfare, human trafficking prevention, energy support, refugee aid, job training, and targeted education assistance for poor and low-income Americans. Individuals and families receive these and other services/benefits from a wide array of providers, based on their specific needs, means and circumstances – all of which can differ greatly and are subject to varying requirements. Furthermore, many recipients use multiple services and providers, again depending on numerous factors.

Today, it is widely recognized that a comprehensive, coordinated set of services is critical to enhancing operational and programmatic efficiencies, as well as outcomes for the people being served. The array of factors that need to be included in creating a holistic, person-centered approach are commonly referred to as the Social Determinants of Health and Well-Being. Indeed, those factors – such as housing, transportation, and jobs, among many others – have the greatest impact. Specifically, research indicates that behavioral and lifestyle choices are responsible for 50 percent of health outcomes; environmental factors and human biology/genetics each contribute 20 percent; and clinical healthcare accounts for only 10 percent.[1]

New healthcare approaches emerging over the past five years, such as Value Based Care Payment Models and Accountable Care Communities, recognize the importance of the Social Determinants and offer incentives to advance coordinated care.[2] Doing so can be very challenging, however, for a host of reasons including: unique and narrow eligibility requirements; legislative requirements and funding silos that restrict spending to specific/narrow purposes; demographic and cultural variability; varying data and technology standards and systems that inhibit data-sharing; and legal hurdles (real or perceived) that also impede Interoperability. This fragmented ecosystem makes coordination cumbersome in the human services field as well as in the other five domains described in this report.

Addressing these complex challenges requires a higher level of planning, alignment and coordination than most systems can achieve within their current constraints. Preventing and addressing major public health problems, for instance, requires the ability to share and use information in a responsible and timely manner to make informed decisions, as well as to gain access to the appropriate types and quantities of services when and where they are needed. However, a cornerstone of preparedness is that communications, system linkages, and trusting relationships among all partners need to be established before a crisis occurs, because trying to accomplish this granular level of coordination and cooperation during an emergency is far more difficult if not impossible.

Infrastructure: Human services assistance/programs are delivered and run by numerous federal, state, local governmental, private, and nonprofit providers across the country. Their systems are made up of a hodge-podge of modern and legacy technologies produced by a variety of vendors that generally operate independently, don't coordinate with each other, and are usually proprietary. They were designed and built in response to specific requirements to serve particular populations, as mandated by enabling (usually federal) legislation and funded by appropriations that often flow from Washington to the state and local levels for implementation. Many of the largest human services systems are directed by federal agencies under congressional statutes that provide policy and funding guidelines for states to build their own programs/systems. These agencies and their main systems include:

[1] Schroeder, SA. (2007). We Can Do Better – Improving the Health of the American People. NEJM. 357:1221-8.
[2] ihttps://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs. html

One of NIC's near-term objectives is to compare the six domains in order to gain insights about them and stimulate communications among them.

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Department of Health and Human Services, Centers for Medicare & Medicaid Services (CMS) – Integrated Eligibility Systems (IES) and Medicaid Management Information Systems (MMIS).

Department of Health and Human Services, Administration for Children and Families – Comprehensive Child Welfare Information System (CCWIS), Temporary Assistance for Needy Families (TANF), Head Start and Child Support Enforcement.

US Department of Housing and Urban Development – Homeless Management Information Systems, Section 8 Housing and Public Housing.

US Department of Agriculture, Food and Nutrition Services – Supplemental Nutrition Assistance Program (SNAP).

There has been a shift toward more interoperability within and among systems over the past decade, driven by innovation in the private sector, the need for greater efficiency and integration, and the availability of increasingly advanced technology. Moreover, thought leaders in and out of government – and, importantly, in the nonprofit sector – have progressively grown to understand the value of interoperability and information-sharing and, as a consequence, have championed coordinating, harmonizing and aligning systems. Some of the key infrastructure innovations that are critical for doing so include:

Standardized Data Exchange Models. The Administration for Children and Families (ACF) established the National Information Exchange Model (NIEM) for human services in 2015 to provide a combination of programmatic, policy, business, and technical expertise. This collaborative work group, overseen and coordinated by ACF, consists of federal,state, local, and non-profit organization representatives.

NIEM has contributed to advances in domain data-modeling and governance; privacy/confidentiality in data exchange; data harmonization; business modeling using Unified Modeling Language to simplify data-exchange implementation; and support for various federal and state data-exchange projects. Rationalizing data definitions and the sharing process would accelerate the exchange of information at times of emergency, when speed and access become particularly critical.

Service-Oriented Architectural. The National Human Services Interoperability Architecture (NHSIA) provides a standardized framework that states and local jurisdictions can use to facilitate information-sharing, improve service delivery, prevent fraud, and improve outcomes for children and families. NHSIA builds off the progress of the Medicaid Information Technology Architecture (MITA), which seeks to create architectural standards and funding requirements for state Medicaid technology systems.

Global Federated Identity and Privilege Management. GFIPM is a solution that offers secure, scalable, and cost-effective technologies for information-sharing within the law enforcement and criminal justice communities. This approach could be utilized by human services programs to ensure identify management when sharing confidential and sensitive information.

Application Program Interfaces. APIs are sets of routines, protocols, and tools for building software applications. Essentially, they specify how software components should interact, so they enable information-exchange. Using API systems facilitates the exchange of information without having to modify underlying technology.

Advances in Hardware and Software Technology. The exponential rate of progress in technology is being fueled by inexpensive and massive cloud storage capacity, faster and more powerful computer processors, enhanced analytical tools, and ubiquitous mobility solutions.

Sources of Funding: The FY 2016 federal budget allocation for human services programs was approximately $350 billion, with an additional $935 billion for federal Medicare and Medicaid expenditures. The ratio of public social spending to GDP in the United States was below the average for the 34 member nations of the Organization for Economic Cooperation and Development. Roughly half of this assistance in our country went to families with children, most of which were headed by single parents.[3] While we are classifying Medicaid within the Public Health domain in this report, it is important to note that it has an enormous impact on the human services ecosystem because of the federal funding available to states that pursue integrating their human service technology with Medicaid systems. The federal government provides a 90 percent match to pay for technology that supports interoperability between Medicaid and human services, if it benefits the administration of Medicaid programs. Medicaid therefore becomes one of the major funding drivers for integration and interoperability between public health and human service programs.[4]

Challenges to Human Services Data-Sharing: Six key federally funded programs for low-income people vary significantly in regard to: eligibility requirements, including age and income; how income is counted; and which benefits are available to whom. Data from FY 2015 show that the federal government spent nearly $540 billion on benefits for these six programs: the Earned Income Tax Credit, Medicaid, the Housing Choice Voucher program, the Supplemental Nutrition Assistance Program (SNAP), Supplemental Security Income (SSI), and Temporary for Needy Families (TANF).[5]

A key challenge for these programs is that they are authorized by different federal statutes, enacted at different times, and in response to different circumstances. Furthermore, other laws – such as those governing how funding is appropriated and spent – also have an impact on federal programs and the rules they need to set. As a result, for example, streamlining eligibility requirements would require changing many laws, as well as coordinating among a variety of lawmakers and congressional committees.

Another challenge is that a different federal agency administers each program. For some, such as TANF, state governments also establish some program rules, making it more difficult to make changes at the federal level within or across these programs. Finally, financial constraints obviously also have a significant impact. If rule changes raise the income eligibility limit in a program, more people could utilize it – and that program's costs presumably would increase.

Despite these challenges, Congress, federal agencies and states have taken some steps in recent years to streamline program administration and rules, including by making greater use of data-sharing where permitted by federal law, and by aligning eligibility processes among various programsso common applications can be used. For example, SSI recipients in most states are automatically eligible for Medicaid, and some states have integrated the SNAP process with other low-income programs through combined applications to streamline eligibility determination.

Workforce: According to the U.S. Census Department's May 2015 data, total national employment in U.S. community and social services organizations is 1,972,140 people. Approximately 53,000 are Executive Managers or trainers in the field.

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[3] Elizabeth H. Bradley, Maureen Canavan, Erika Rogan, Kristina Talbert-Slagle, Chima Ndumele, Lauren Taylor, and Leslie A. Curry. "Variation in Health Outcomes: The Role of Spending on Social Services, Public Health, and Health Care, 2000-09." Health Affairs 35, No.5 (2016):760-768; doi:10.1377/hlthaff.2015.0814.

[4] https://www.acf.hhs.gov/sites/default/files/assets/acf_toolkit_july_2012_final.pdf

[5] Federal Low-income Programs: Eligibility and Benefits Differ for Selected Programs Due to Complex and Varied Rules GAO-17-558: Published: Jun 29, 2017. Publicly Released: Jul 14, 2017.

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Partners for Information Exchange: Historically, human services were organized so that case workers and managers had a more-comprehensive view of the client. There was less fragmentation, partially because people worked in the same office and/or knew each other. Additionally, most activities required in-person meetings, so clients and workers formed relationships. There were also simply fewer services available, so fewer systems were needed to facilitate coordination and communication. Finally, of course, there was less technology, so the work had to be done person-to-person.

Since enactment of the 1965 Social Security Act, however, there has been an explosion of human and health services being offered and utilized by people in every community. As a result, the need of various providers to share information has also grown, and all participants in this domain – clients, patients, clinicians, researchers, payers, and government – have higher expectations about accessing data, especially with the rapid growth of technology. This reality underscores the importance of developing common infrastructures and other elements that will enable and accelerate greater interoperability and information-sharing.

Potential Improvements: An array of changes are needed to drive progress on data-sharing and interoperability. Some of the key ones include:

Increase education, dissemination and action to integrate the Social Determinants of Health and Well-Being. Pursuing this goal is integral to achieving a comprehensive approach to treating clients and patients. Having a common view and model of how to serve people and families will provide a shared vision of what the interplay of systems could accomplish.

Implement standard data-sharing protocols and architectures. Taking this step will mean new systems could be built, ready to exchange information with other programs or services that adopt the same standards and exchange protocols.

Develop a universal enterprise data-sharing agreement template. The purpose is to encourage responsible information-sharing through a common understanding of the legal requirements for doing so. Some laws created in the 1960s should also be updated to reflect the social and technological changes that have taken place, including tools to protect privacy/confidentiality.

Increase collaboration and information-sharing among communities. In particular, create new means – and utilize existing ones – to showcase successful (and unsuccessful) efforts, so that jurisdictions can learn from each other and avoid repeating each other's mistakes.

Leverage advances in analytics and augmented intelligence. Effectively utilizing the best modern technologies will require more national leadership from all sectors. It is important to do so in order to more-effectively use the vast stores of information we already have, as well as to educate workers about effective practices and assist them with tasks ranging from mundane scheduling and logistics to complex case planning and interventions.

Key Resources fo More Information

National Human Services Interoperability Architecture: https://www.acf.hhs.gov/nhsia- definition

Human Services NIEM Domain: https://www.niem.gov/ https:/www.acf.hhs.gov/about/interoperability#chapter-3

Confidentiality and Privacy Toolkits: https://www.acf.hhs.gov/sites/default/files/assets/acf_ confidentiality_ toolkit_final_08_12_2014.pdf

http://stewardsofchange.com/what-we-do/Pages/confidentiality.html

National Interoperability Collaborative: http://kresge.org/news/new-national-initiative- seeks-increase-impact-data-sharing-health-and-human-services

www.stewardsofchange.com

Augmented Intelligence applications to Child Welfare: http://stewardsofchange.org/wp- content/uploads/2016/06/Child-Welfare-and-Cognitive-Computing-White-Paper.pdf

Social Determinants of Health and Well-Being: http://itcc.stewardsofchange.org/resources/SDOH%20Learning%20Report- external%20FINAL%205-24-16.pdf

Public Health

Mission: The U.S. public health system has been defined as the network of public, private, and voluntary organizations that contribute to the health of the population as a whole in a geographic jurisdiction (see https://www.cdc.gov/nphpsp/essentialservices.html). Public health partners include state and local governmental health agencies, healthcare providers, public safety agencies, human services organizations, environmental organizations, and others that may vary by community. By law, governmental public health agencies have the responsibility to monitor health status, diagnose and investigate health hazards, mobilize community partnerships, develop policies and plans to support personal and community health, enforce laws and regulations, and conduct research to ensure and maintain community health.

Infrastructure: The federal government sets health goals for the nation and provides funding for programs, services, and educational efforts. Federal agencies with lead public health responsibilities include:

Centers for Disease Control and Prevention (CDC). Part of the US Department of Health and Human Services, the CDC works to increase health security through scientific research (advanced computing and lab analysis), investigation of outbreaks, provision of information about health risks and hazards, and response to health crises (see https://www.cdc.gov/about/organization/mission.htm).

Assistant Secretary for Preparedness and Response (ASPR). After the devastation caused by Hurricane Katrina, Congress passed the Pandemic and All Hazards Preparedness Act (PAHPA) and created ASPR to coordinate preparedness planning and response, build federal emergency medical operational capacity, fund hospital preparedness activities and infrastructure, and develop a national system to reinforce state and local capacity in an emergency or disaster.

In some states, public health responsibilities and funding are focused at the state level, while in others the local health agencies are in the lead. By law, the governmental public health agency has the chief responsibility for the essential services described above, and can engage the private sector to carry out the services and programs.

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Because of the variability across the country and across jurisdictions in how public health is organized, national professional organizations play a major role in advising on policy development, sharing information on best practices, and professional development for the workforce. The leading public health organizations at the national level are the Association of State and Territorial Health Officials (ASTHO) and the National Association of County and City Health Officials (NACCHO).

Sources of Funding: The majority of public health funding is at the state level, with most coming from pass-through federal funds from HHS, EPA, USDA, and DHS and additional support from state general funds (NORC, 2014). Private foundations such as the Robert Wood Johnson Foundation and the DeBeaumont Foundation also provide funding to state and local health agencies for demonstration projects.

Workforce: Approximately 300,000 people are estimated to be employed at federal, state, and local health agencies (Beck et al., 2014). There are numerous vacancies for skilled professionals such as epidemiologists and informatics experts.

Partners for Information Exchange: Because public health is responsible for monitoring, forecasting, and analytics around community health, its information infrastructure comprises information and communication technologies (ICT) including hardware, software, services and devices; broadband infrastructure; and a workforce skilled in "public health informatics" (Edmunds et al, 2014). Every health agency is organized differently, but generally a person, team, or department is responsible for making health data flow to the state and to other public partners in the jurisdiction.

Private healthcare providers and laboratories are required to notify health departments when they see a case of a reportable disease (e.g., Zika, measles), but healthcare delivery systems rarely share clinical data that is not mandated by law. With the growing interest in tracking and incorporating the Social Determinants, some communities are beginning to exchange health information more readily among private and public sector agencies and organizations.

Challenges to Public Health Data-Sharing: Public health has encountered some specific challenges to making interoperability and information-sharing effective, including:

Diversity and Decentralization. There are more than 2,500 public health agencies in the U.S. at the federal, state, local, territorial, and tribal levels. One result of this expansiveness is great diversity, but another is that public health cannot and does not speak with one voice about interoperability issues (or much else). This reality makes it difficult for some stakeholders to engage public health consistently or to implement solutions that can be used more uniformly, and therefore more effectively, across public health.

Legal Framework. There is no federal public health law; rather, there are state, local, and tribal statutes and regulations. The result is that the legal framework is specific to a jurisdiction, which means discussion about interoperability and implementation can be inhibited. This is best exemplified by public health's collective

inability to reconcile data-sharing and consent laws across jurisdictions in the U.S., though not for want of trying. The 2017 effort to address the 21st Century Cures Act's Trusted Exchange Framework and Common Agreement is the latest attempt to address this issue.[1]

Funding and Policy Mismatch. Most public health activities are federally funded by the CDC, the Center for Medicare and Medicaid Services (CMS), and others. Even though the legal framework for public health is state/local/territorial/tribal, there are strong financial incentives for agencies at all levels to comply with the guidelines and requirements that federal funders often stipulate in their grants, contracts, and cooperative agreements. While this may sound like a unifying force, it produces tension in some jurisdictions, which feel internal pressure not to comply or which result in federal guidelines that permit substantial variability.

"Stovepipe" Funding. The CDC primarily funds public health program by program, usually due to stipulations from Congress or the reality of federal appropriations. State, local, territorial and tribal public health agencies similarly organize their programs in this "stovepipe" fashion, so the information systems they create are often hostage to the individual programs they support. There are often barriers to creating common, shared, or leveraged systems that can be used by multiple programs, and jurisdictions that have been able to implement more-integrated systems have usually done so with their own funds.

Increasing Centralization of Technical Resources. Technical infrastructure at public health agencies is becoming increasingly centralized, especially at the state level. The result is that individual programs are less in control of their system infrastructure and less able to make their own decisions about which systems to deploy and how. The primary motivation for this centralization is cost containment, as well as technical risk-reduction through more-rigorous information-security practices, but interoperability can encounter new challenges – especially outside the agency. In many agencies, for instance, simple installation of a digital certificate may require months of negotiation and delay with internal service providers.

Potential Improvements: Public health is an active player in healthcare interoperability, with numerous needs and opportunities for internal systems integration as well as external interoperability. The CMS EHR Incentive Programs have pushed a good number of these activities to the forefront, but many of their clinical reporting requirements were pre-existing and often legally mandated. Here are a few suggestions about what public health agencies could do:

Embrace Standards. Move wherever possible to more-standardized versions of both transport and messaging standards, with as little local variation as possible. For example, the American Immunization Registry Association has developed an Aggregate Analysis Reporting Tool to help Immunization Information System projects assess their compliance with national interoperability standards.[2]

Move Toward Service-Oriented Architectures (SOA[3]). SOA, which involves modularization of software into smaller, reusable components, is one approach to making interoperability practical. It allows for increased scalability, lower cost through re-use of software components, increased flexibility in software implementation, and less lock-in to a specific hardware or software platform. SOA is being used increasingly within public health systems to reduce costs and keep more up-to-date, and it has even greater potential for enabling the sharing of services and capabilities in the larger healthcare ecosystem.

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[1] https://www.healthit.gov/21st-century-cures-act-trusted-exchange-and-common-agreement-tfca-kick- meeting-1

[2] http://www.immregistries.org/initiatives/assessment

[3] See Arzt, Noam H. "Service-Oriented Architecture in Public Health: Interoperability Case Studies," Journal of Healthcare Information Management, 24(2), Spring 2010. <https://www.hln.com/noam/JHIM- SOASpring2010pdf>

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Partner with Health Information Exchanges (HIEs). Public health should continue to work with state-based or community HIEs where they exist, as they make good partners for interoperability and can promote standard approaches within the jurisdiction. There are strong examples of state HIEs that are thriving – in DE, IN, MI, NY, and VT to name a few. The Office of the National Coordinator recently released a report, "Connecting Public Health Information Systems and Health Information Exchange organizations," that includes best practices and lessons learned in the use of HIEs to mediate connections to public health information systems. Public health should also consider participating in new organizations that are working aggressively to promote health exchange, but which have had very little formal public health participation to date, including vendor associations (like the CommonWell Health Alliance[4]), and private national organizations providing health information exchange services (like the Sequoia Project[5] and its CareQuality[6] collaborative).

Strengthen National Organizations. Public health should continue to work with and strengthen its own professional organizations to promote its interests in interoperability. Many of these organizations – such as the American Immunization Registry Association, the Association of PublicHealth Laboratories, the Council of State and Territorial Epidemiologists, and the International Society for Disease Surveillance – work in specific domain areas to promote standards, represent public health in the broader healthcare ecosystem, and even support interoperability operationally. Additionally, public health should continue to advocate with the CDC and other government agencies for public health funding to promote and implement standards-based solutions for interoperability. The Joint Public Health Informatics Task Force is a key convening organization that brings together major public health organizations, industry organizations, and government to discuss major informatics issues facing public health today.

Key Resources for More Information

Arzt, Noam H. "The Interoperability of Things," Journal of Healthcare Information Management, 29(4), Fall 2015. https://www.hln.com/wp-content/uploads/2016/03/JHIM- InteroperabilityOfThings-Fall-2015.pdf

Office of the National Coordinator for Health Information Technology, "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap version 1.0," October 2015. https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide- interoperability-roadmap-final-version-1.0.pdf

Office of the National Coordinator for Health Information Technology, "Connecting Public Health Information Systems and Health Information Exchange Organizations: Lessons from the Field. September 2017. https://www.healthit.gov/sites/default/files/FINAL_ONC_PH_HIE_090122017.pdf

ASPR Public Health Emergency. http://www.phe.gov/

Beck A, Boulton ML, Coronado F. Enumeration of the governmental public health workforce, 2014. American Journal of Preventive Medicine, 47(5):S306-S313.

[4] http://www.commonwellalliance.org/
[5] http://sequoiaproject.org/
[6] http://sequoiaproject.org/carequality/

Edmunds M, Thorpe L, Sepulveda M, Bezold C, and Ross, DA. The future of public health informatics; Alternative scenarios and recommended strategies. (2014). eGEMs 2(4):1156. https://www.ncbi.nlm.nih.gov/pubmed/25848630

HIE Toolkit for Public Health. HIMSS and NACCHO. http://www.himss.org/public-health- hie-toolkit

NORC (2014). An examination of public health financing in the United States. http://www.norc.org/PDFs/PH%20Financing%20Report%20-%20Final.pdf

From the American Journal of Public Health, Supplement 2, 2017, Vo. 107, No.S2:

From Anthrax to Zika: Fifteen Years of Public Health Emergency Preparedness
Rachel Nonkin Avchen, Tanya Telfair LeBlanc, and Christine Kosmos

Public Health Disasters: Be Prepared Robert James Kim-Farley

Science in Emergency Response at CDC: Structure and Functions
John Iskander, Dale A. Rose, and Neelam D. Ghiya

The Evolution of Public Health Emergency Management as a Field of Practice
Dale A. Rose, Shivani Murthy, Jennifer Brooks, and Jeffrey Bryant

A Child's Health Is the Public's Health: Progress and Gaps in Addressing Pediatric Needs in Public Health Emergencies Eric J. Dziuban, Georgina Peacock, and Michael Frogel

Project Public Health Ready: History and Evolution of a Best Practice for Public Health Preparedness Planning Sarah K. Summers and Madison J. Ferraro

Applying the 15 Public Health Emergency Preparedness Capabilities to Support Large- Scale Tuberculosis Investigations in Complex Congregate Settings Alison Jaffe Levy,
Katelynne Gardner Toren, Carina Elsenboss, and Masahiro Narita

Funding Public Health Emergency Preparedness in the United States
Rebecca Katz, Aurelia Attal-Juncqua, and Julie E. Fischer

Public Health Preparedness Funding: Key Programs and Trends From 2001 to 2017
Crystal R. Watson, Matthew Watson, and Tara Kirk Sell

Progress in Public Health Emergency Preparedness—United States, 2001–2016 Bhavini Patel Murthy, Noelle-Angelique M. Molinari, Tanya T. LeBlanc, Sara J. Vagi, and RachelN. Avchen

Community Assessment for Public Health Emergency Response (CASPER): An Innovative Emergency Management Tool in the United States. Amy Schnall, Nicole Nakata, Todd Talbert, Tesfaye Bayleyegn, DeAndrea Martinez and Amy Wolkin

Public Health System Research in Public Health Emergency Preparedness in the United States (2009–2015): Actionable Knowledge. Public Health System Base. Elena Savoia, Leesa Lin, Dottie Bernard, Noah Klein, Lyndon P. James, and Stefano Guicciardi

Improvements in State and Local Planning for Mass Dispensing of Medical Countermeasures: The Technical Assistance Review Program, United States, 2007– 2014
Paul G. Renard, Sara J. Vagi, Chris M. Reinold, Brenda L. Silverman, and RachelN. Avchen

Public Education

Mission: Public elementary and secondary education in the U.S. serves children in grades K-12, mainly through schools that are open to all children regardless of immigration status, income, ethnicity, disability status, religion, sexual orientation, or other factors. Broadly speaking, the mission of public education is to prepare students with the necessary skills to fully participate in society and the workforce.[1] The accountability requirements established in the 2001 No Child Left Behind law spurred an unprecedented focus on accountability and standardized testing at the state level that precipitated a decades-long emphasis on data collection, reporting, and quality.[2]

Traditionally, states have been responsible for setting standards and systems of accountability for public education. In 2007, however, with support from the federal government, state leaders began working together with national convening organizations to develop a shared set of standards for math and English language arts known as the *Common Core State Standards*, which were adopted by 42 states as of 2015 (http://www.corestandards.org). These in turn spurred development of new standardized tests and data-collection strategies.[3] In 2010, 26 states began the process of jointly revising science standards, resulting in the *Next Generation Science Standards* (https://www.nextgenscience.org/developing-standards/developing-standards), which were adopted by 20 states as of 2017 (http://ngss.nsta.org/About.aspx).

In 2015, then-President Obama signed into law the Every Student Succeeds Act (https://www.ed.gov/essa?src=ft). Among other goals, it establishes annual statewide assessments to be provided to educators, families, students, and communities; it also maintains accountability to improve the lowest-performing schools, while at the same time devolving flexibility and accountability back to the state level.

Infrastructure: Public education is governed by laws and regulations at the federal, state, and local levels, with oversight from both appointed and elected leaders. The U.S. Department of Education oversees federal law and funding, and state education agencies oversee their own state approaches to standards, curriculum, accountability and funding. States differ on the extent of local control offered to counties and school districts.

U.S. Department of Education. Its mission is to "promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access" (https://www2.ed.gov/about/overview/mission/mission.html). Established by Congress in 1980, the department's goals are to: (1) strengthen the federal commitment to access to equal educational opportunity for every individual; (2) supplement and complement the efforts of states and local school systems to improve quality of education; (3) encourage involvement of the public, parents, and students in federal education programs; (4) promote improvements in the quality and usefulness of education through research, evaluation, and sharing of information; (5) improve the coordination of federal education programs; (6) improve the management of federal education activities; and (7) increase accountability of federal education programs to the President, the Congress, and the public.

State Education Agencies. Each state has an agency that oversees elementary and secondary education and is led by an elected or appointed chief education officer, superintendent, or secretary. Its roles include funding and funding oversight, data-collection systems and federal reporting, accountability systems, teacher credentials, assessments, and many other obligations. ets.aspeninstitute.org/content/uploads/2015/12/Aspen-SEA-Roles-Nov24-final.pdf).

[1] Jobin-Leads (2012).
[2] U.S. Department of Education (2006).
[3] Gewertz (2017)

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State Boards of Education. These are bodies overseeing state education; they are made up of leaders appointed by the governor or legislature, or elected by constituents, depending on the state. While their oversight is generally "big picture," state boards are charged with a number of activities, including setting statewide curriculum standards; establishing high school graduation requirements; determining qualifications for professional education personnel; establishing state accountability and assessment programs; and developing rules and regulations for the administration of state programs (http://www.nasbe.org/about-us/state-boards-of-education/).

School Districts. Public schools are organized into school districts, led by an official appointed by the district's governing body, the school board. In most states, districts are local governing bodies with powers including taxation. School districts oversee all aspects of curricula and instruction. They also manage data-collection systems and mandatory reporting. In some states, they also have control over funds allocation.

Local School Boards. Local school boards oversee school districts and are usually composed of elected officials who represent the diversity of their communities. In compliance with state and federal laws, they establish policies and regulations by which their local schools are governed. They are responsible for: employing and overseeing the superintendent; developing and adopting policies, curriculum, and the budget;overseeing facilities issues; and adopting collective bargaining agreements (http://www.nsba.org/ABOUT-US/FREQUENTLY-ASKED-QUESTIONS).

Sources of Funding: Most public education funding comes from state and local coffers; in 2012-13, 45 percent came from states, 45 percent from local sources (including property taxes), and 9 percent from the federal government.[4] The federal funds are typically allocated for two types of students: those who are socioeconomically disadvantaged and those who are in special education programs.

Workforce: A total of 7.7 million people were employed in public education at the federal, state, and local levels in 2012, with 99 percent of them employed locally.[5]

Partners for Information Exchange: With its organizing infrastructure, local education agencies retain control over data systems for gathering and storing information on student, teacher, and school performance. Information is generally not shared between local school districts or states, although most states have aggregate statistics by school or district available to the public; the federal government also reports state and local education statistics, in aggregate.

The Statewide Longitudinal Data Systems program was authorized by the Educational Technical Assistance Act of 2002. It provides grant funds to states to establish data systems that securely follow students from early education through the workforce and facilitate the disaggregation, reporting, and analyses of longitudinal data. These data systems are intended to "help States, districts, schools, and teachers make data-driven decisions to improve student learning, as well as facilitate research to increase student achievement and close achievement gaps" (https://nces.ed.gov/programs/slds/faq_grant_program.asp). As of 2016, 16 states plus Washington, DC, had fully established P-20W (pre-school to college to workforce) data systems and 37 states plus DC had the ability to link across at least some of their education agencies' data.[6] They have the ability to follow students within states and across educational systems, but not across states or into other types of systems that serve children and youth (e.g., child welfare).

Challenges to Education Data-Sharing: Education data are highly informative when integrated with data from other systems that serve children and youth. These cross-agency collaborations are still somewhat rare, however. Key challenges to education data-sharing both within education and across different sectors include the following:

> **Legal Frameworks**. The data privacy law that governs education data is the Federal Education Right and Privacy Act (FERPA). In general, FERPA states that schools are required to allow students and their parents access to educational records, but are prohibited from sharing those records with third parties without prior written consent. There are several key exceptions, including: to school officials at the current or a future school, in connection with financial aid, to organizations conducting studies for or on behalf of the educational entity, or to comply with a judicial order or a lawfully issued subpoena (https://www2.ed.gov/policy/gen/guid/fpco/ferpa/students.html). Data-sharing across agencies is an allowable activity and there is a solid legal framework for cross-tegration.[7] In ted FERPA rule made more explicit the kinds of agencies that can serve as agents of K-12 entities for data-sharing purposes, which allowed for more flexibility (https://studentprivacy.ed.gov/training/data-sharing-under-ferpa-regulations-january-2012). A subsequent 2017 clarification by the U.S. Department of Education's Privacy Technical Assistance Center outlines how education data can be legally included in third-party integrated data systems (https://studentprivacy.ed.gov/sites/default/files/resource_document/file/IDS-Final_0.pdf).

[4] https://nces.ed.gov/programs/digest/d15/tables/dt15_235.10.asp?current=yes
[5] https://www2.census.gov/govs/apes/2012_summary_report.pdf
[6] Perez(2016)
[7] Petrila, Cohn, Pritchett et al (2017).

The Children's Online Privacy Protection Act (COPPA) also governs data collection in schools, specifically as it pertains to operators of websites or online services directed to children under 13 years of age, including vendors providing educational technology services in schools (https://www.ftc.gov/enforcement/rules/rulemaking-regulatory-reform-proceedings/childrens-online-privacy-protection-rule).

Systems Integration. Each locality has the authority to determine which data system it invests in. Tracking across systems can be thwarted when they do not align or when there are not common identifiers to track students. Educational data pertaining to students' pre-school experiences, K-12 education, higher education, alternative education, career technical education, and workforce development experiences reside in different systems governed by different agencies, which may or may not come together for the purposes of sharing information.[8] There are technical and institutional barriers for sharing data across these domains. The U.S. Department of Education Common Education Data Standards (CEDS) initiative aims to streamline the understanding of data and data items within and across State Longitudinal Data Systems, including information specifically for practitioners, policymakers, researchers, IT specialists, and others (https://ceds.ed.gov/Default.aspx).

Limitations of Education Data for Research Purposes. Information about non-school factors is critically important for understanding students' educational outcomes, as roughly 70 percent of variance in K-12 student achievement is attributable to non-school factors (Coleman et al., 1966). These are principally the negative impacts of poverty (Jones & Schneider, 2009). Currently, data are not systematically available for the integration of in-school and out-of-school experiences and their roles in student achievement. Other limitations include a lack of geographic breadth, with data often drawn from one classroom, one school, or one school district, though students at greatest risk for poor academic performance have the highest transiency rates (Sampson et al., 2009; Schafft, 2006); and a lack of temporal breadth, drawing from just one or a few years, but not tracking students lon itudinally from K-12.

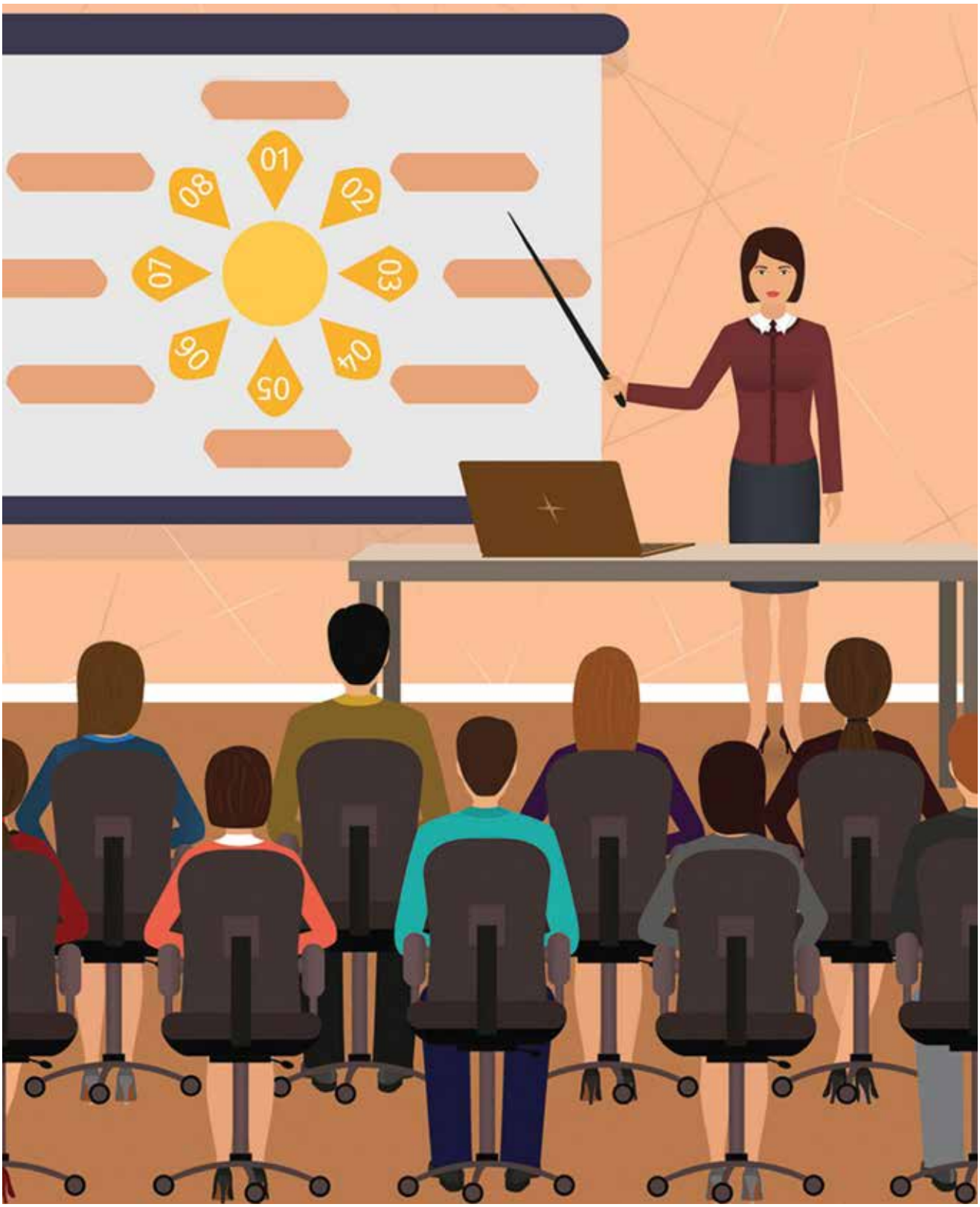
Potential Improvements: Public education is the sector that serves the most children and youth nationwide. It is nearly universal in its coverage of children from different racial and ethnic, socioeconomic, immigrant, cultural, and linguistic backgrounds. Harnessing the power of these data – and using them to better serve children and youth – is a key means of improving individual lives, as well as bolstering the U.S. economy and reducing income inequality. The following are a few suggestions about what public education agencies could do to better share data and better use data for improving programs and practice:

Increase education, dissemination and action to integrate the social determinants of educational outcomes. Pursuing this goal is integral to achieving a more-comprehensive approach to understanding and improving educational outcomes for the most-disadvantaged students. Recognizing that a large portion of students' in-school outcomes can be attributed to factors that are outside the school walls is an important first step. Integrating those factors into curricula, service approaches, and data-driven decision-making is essential.

Implement standard data-sharing protocols and architectures. Taking this step will mean new systems could be built, ready to exchange data with other educational programs or student-focused services that adopt the same standards and protocols.

More clearly define and promote integrated data systems. Educating policy-makers and funders on the availability of integrated data would spur progress, as would providing proof-of-concept examples of how they support better outcomes for students, as well as cost savings for government agencies. Collaborating with related initiatives and funding sources – such as Social Innovation Fund's administrative data grants, collective impact, and social impact financing – could leverage existing resources.

[8] London and Gurantz (2010).



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Create legal frameworks to support responsible integrated data systems. The many overlapping state and federal privacy laws governing the collection, use, and disclosure of administrative data pose a significant challenge to data-sharing initiatives. In the face of this ambiguity, agency legal counsels take approaches that minimize risk to their individual agencies by adopting the most-prohibitive interpretation of relevant privacy statutes. Legal advocacy to help integrated data systems negotiate data- sharing agreements is necessary to form a more-collective rather than individualized governance structure.

Increase collaboration and information-sharing among communities. In particular, create new means – and utilize existing ones – to showcase successful (and unsuccessful) efforts, so that jurisdictions can learn from each other and avoid repeating each other's mistakes.

Resources for More Information

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Public Safety

Mission: The U.S. public safety system includes law enforcement, fire and rescue services, and the emergency medical service (EMS) network of public, private, and voluntary organizations that contribute to the safety of the public in a geographic jurisdiction. Public safety partners include agencies that respond to emergencies, whether man-made or natural, and others that may vary by community but have a role in protecting the public and dealing with health and safety crises. By law, governmental public safety agencies have the responsibility to monitor safety status, develop policies and plans to support personal and community safety, enforce laws and regulations, and conduct research to ensure and maintain community safety.

Infrastructure: Public safety is generally regarded as a community responsibility. While agencies exist at the state and federal levels that play supportive roles in some cases, the bulk of public safety exists at the local (city, county, tribal) level, with no element of state or federal direct control over operations. The federal government works to provide consensual standards and to conduct research in public safety methods and processes and provides funding for programs, services and educational efforts. Federal agencies with lead public safety responsibilities include:

> **Department of Homeland Security**: DHS provides the coordinated, comprehensive federal response in the event of a terrorist attack, natural disaster or other large-scale emergency, while working with federal, state, local, and private sector partners to ensure a swift and effective recovery effort. DHS provides funding for state and local emergency operations centers, as well as for public safety agencies

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to ensure readiness to prevent and respond to situations such as natural or man-made emergencies that particularly require multiple responding agencies. DHS has been instrumental in designing and funding projects related to emergency response and communications issues, including interoperability initiatives to enhance communications among agencies and jurisdictional levels. DHS also conducts scientific research related to emergency management and communications interoperability (see https://www.dhs.gov).

Department of Justice: After the tragic events of 9/11, DOJ invested fully in assisting state, local, and tribal agencies to prepare for preventing and responding to all relevant situations/crises. While DOJ focuses on law enforcement aspects of public safety, it has been an influential leader in information-sharing across all agencies and in the formulation of the National Information Exchange Model (NIEM), which is a framework for standardizing exchanges such as those that help facilitate information-sharing in the event of an emergency. Through its Office of Justice Programs, DOJ funds state and local governments for technology and training, and conducts research through the

National Institute of Justice to develop improved processes and technologies for public safety. The Bureau of Justice Assistance in the Office of Justice Programs was heavily involved in funding and technical assistance related to 9/11, Katrina and pandemic preparations

Office of the Director of National Intelligence: (ODNI): The Program Manager for the Information Sharing Environment (ISE) was positioned in ODNI in response to a congressional mandate to the President (contained in the Intelligence Reform and Terrorism Prevention Act of 2004, as amended); the mandate was to build an ISE across the federal government, with respect to state and local governments, in order to share information to support counter-terrorism initiatives. This office pioneered many of the architectures, concepts, and frameworks that have been adopted by the Department of Homeland Security, the Department of Defense, DOJ, and other federal agencies to improve information-sharing across multiple domains. The ISE framework is documented and used by federal, state, local, territorial, tribal, and international partners to foster better information-sharing and interoperability in support of improving government operations (see https://www.ise.gov).

States generally provide a coordination and planning role for public safety, with associated funding varying widely across the nation. All states have some sort of state-level version of homeland security, with varying degrees of capability, generally reporting to their governors. States also generally have fire marshals who coordinate the work of fire services and standards. Emergency management operations often exist at the state as well as the local level. States are the conduits for significant amounts of federal grant dollars, distributed to them via block grant programs.

Because of the autonomy of local public safety agencies, national professional organizations play a major role in advising on policy development, sharing information on best practices, and professional workforce development. The leading public safety organizations at the national level are the International Association of Chiefs of Police, the International Association of Fire Chiefs, the National Emergency Management Association, and the Association of Public Safety Communications Officials.Because of the autonomy of local public safety agencies, national professional organizations play a major role in advising on policy development, sharing information on best practices, and professional workforce development. The leading public safety organizations at the national level are the International Association of Chiefs of Police, the International Association of Fire Chiefs, the National Emergency Management Association, and the Association of Public Safety Communications Officials.

Sources of Funding: Public safety funding comes primarily from tax revenues at the local level, augmented to a small extent with federal funds from DHS, DOJ and additional, limited support from state general funds. Private foundations such as the Robert Wood Johnson Foundation and Arnold Foundation also provide funding to state and local safety agencies for research and demonstration projects.

Workforce: About 850,000 people are estimated to be employed in law enforcement activities at all levels. In addition, as of 2014, there were 1,134,400 firefighters in the U.S. (not including those who work for the state or federal governments or in private fire departments). Of these, 346,150 (31%) were career and 788,250 (69%) were volunteer. As of 2014, there were also 241,000 emergency medical technicians (EMTs) in our country. There are numerous vacancies nationwide, particularly in law enforcement.

Partners for Information Exchange: Information-sharing among public safety agencies in the normal course of their work has always been of critical importance to practitioners. When police, fire and Emergency Medical Services (EMS) personnel are responding to a major emergency, interoperability among their communications and information systems is vital. But public safety agencies also have urgent needs to exchange information with other domains, including public health, hospitals and other healthcare and transportation service providers. Because of the long history of recognizing this need, a number of critical national networks have been established to support interoperability.

The FBI provides the national Crime Information Center, which allows for 40,000 separately identified agencies to seek data on crime, criminals, and other subjects. The Homeland Security Information Network was established precisely to enable public safety agencies to create an information-exchange capability to share situational awareness prevention and response information across multiple users and domains. The National Law Enforcement Telecommunications System links all law enforcement agencies across the country through state control points to share information on all matters pertaining to law enforcement and public safety. Common situational awareness is provided in many consolidated communications centers, which dispatch police, fire, and emergency medical resources when warranted.

Because public safety is constantly in motion and mostly mobile, its information infrastructure encompasses information and communication technologies, including both fixed and mobile hardware, software, services and devices; broadband infrastructure; and a workforce skilled in public safety communications and technology. Field-based personnel are equipped with mobile radios, computers, smart phones, and/or tablets to enable data-sharing and situational awareness. Public safety personnel are trained to use mobile technology to communicate and share critical data with each other and with external systems, such as an EMT communicating with a hospital before arrival.

One of the most striking advances in decades is envisioned by the creation of the First Responder Network Authority, which was authorized by Congress in 2012 and operates independently within the Department of Commerce. FirstNet, which is scheduled to begin implementation in spring 2018, will provide nationwide broadband wireless capability for interoperability, information-sharing, and communications across all of public safety.

Challenges to Information-Sharing in Public Safety: Because of the autonomous and distributed nature of public safety, local agencies have both tactical and strategic information-sharing challenges. The events of 9/11 revealed a serious lack of interoperability in the field environment using mobile communications technology due to a lack of common standards, frequency of sharing problems, and proprietary technologies that pervade this field. It also became clear in assessments of the challenges to public safety during 9/11 that information exchanges using computer technology were not easily managed. The 9/11 Commission report and others led to a major investment in improving communications interoperability and, to some extent, to moving forward with digital data standards that have ameliorated this problem.

Within a specific community, the public safety agencies are well aware of the need to communicate and share information in responding to an emergency involving all public safety services, and there is no contention about this need at the service-provider level. There is less consensus about the needs and means to share information with other agencies, particularly state and federal supporting organizations.

Creating a multi-agency, multi-jurisdictional interoperability situation requires common standards for operational procedures, as well as technology, and there has been progress in operational agreements over the past several decades. The standards of the National Incident Management System are widely supported in the public safety community.

Given the status of much of the nation's public safety communications systems, the older technology is not conducive to effectively integrating with a smart phone-equipped public, so it is still true in most parts of the nation that citizens cannot send texts or images to the 911 dispatch centers that could inform responding units. The response to this challenge has been the introduction of NextGen 911, which is focused on introducing an IP-based technology to solve this incompatibility.

As we more fully recognize the need for collaboration between public safety and public health, and indeed between public safety and the health and human services broader community (including additional domains), we also realize that common approaches and standards are lacking.

Potential Improvements: The reliance on mobile phones in society today has accelerated the need to convert all public safety agencies to the NextGen 911 model. This move is progressing, but not rapidly. There will be significant opportunities to expand and improve interoperability with the implementation of FirstNet, and this mobile, wireless, broadband capability will stimulate improvements. New applications will be developed as this infrastructure is implemented.

Public safety has an opportunity to improve the exchange of information about specific emergencies through the development of information-exchange standards, building on the work previously done using NIEM methodologies. More work is needed to develop and gain full acceptance of the standards for specific exchanges within public safety, but also for exchanges between public safety and other entities, for example among police, fire, and EMS units with hospitals covering pre-arrival information.

Public safety can also play a role in detecting the start of emergencies such as pandemics. Calls for service come most immediately to public safety dispatch or 911 centers, and the early warning of expanding illnesses is mostly available in the data captured by the call centers in public safety. While some research has been done and pilot projects have been tried to take advantage of this potential, there is no nationally recognized set of best practices for doing so.

One of the potential improvements that deserves considerable attention is the reinvention of collaboration principles to govern interoperability in response to an emergency. Agencies must re-examine what collaboration means in all levels of pre- and post-event activities, and integrate information-sharing as a fundamental principle in designing collaboration. We should rethink our collective responses from the knowledge gained, particularly over the past 17 years, in dealing with major emergencies; strive to design truly integrated responses that overcome the constraints imposed by jurisdictional boundaries or non-interoperable technology; and then derive standards and processes that will lead to more-streamlined approaches and practices.

Key Resources for More Information

Why can't we talk? National Task Force on Interoperability, https://www.ncjrs.gov/pdffiles1/nij/204348.pdf

Public Safety and Democracy, Paul Romer and William Bratton, https://www.city- journal.org/html/public-safety-and-democracy-11277.html

Unlocking interoperability, Emerging Management Magazine, http://www.govtech.com/em/next-gen-911/Unlocking-Interoperability-What-It-Means-for-Next-Generation-Public-Safety-Communications.html

First Responder Network Authority, https://www.firstnet.gov Critical Decisions in Data Sharing, IJIS Institute,

http://c.ymcdn.com/sites/www.ijis.org/resource/collection/93F7DF36-8973-4B78-A190-

0E786D87F74F/IPSTSC_Critical_Decision_Criteria_for_Data_Sharing_20130710.pdf

National Information Exchange Model, PM-ISE, https://www.ise.gov/mission- partners/national-information-exchange-model-niem

Next Generation 911, https://www.911.gov/911-issues/standards.html

Emergency Medical Services

Mission: In 1966, a report entitled "Accidental Death and Disability" was released by the National Academies of Sciences, bringing to light the "neglected epidemic" of accidental injury. This report, along with passage of the 1966 Highway Safety Act, provided impetus for increased national attention to victims of motor vehicle trauma. The federal government was given a leadership role in reducing the number of injuries and deaths on America's highways. As a result, the National Highway Safety Bureau (the predecessor of the National Highway Transportation Safety Administration) was created. A part of this new agency, the Division of Emergency Treatment and Transfer of the Injured was dedicated to Emergency Medical Services (EMS).

The EMS system has grown to become the best-known public-response system for individual medical crises in the U.S. EMS includes the public safety answering points (PSAPs), emergency medical dispatchers (EMDs), Emergency Medical Responders (EMRs), Technicians (EMTs), Advanced EMTs (AEMTs), Paramedics, and designated Medical Directors. EMS is part of a tiered response system that dispatches law enforcement, fire services, and/or ambulances, as dictated by the nature of the emergency (also see the Public Safety section above). These resources are deployed in specific geographic locations as part of a larger network of services organized by each state.

Medical services partners include agencies that respond to emergencies, and others that may vary by community but have a role in protecting the public. Emergency services contact, diagnose, triage, and transport patients under the direction of a locally authorized Medical Director. The service may be delivered in home, ambulance, local clinic, or hospital (if the patient is transported). It may be a general hospital or one of the following types of specialty facilities: trauma center, pediatric center, burn center, cardiovascular care, or stroke center.

Governmental emergency medical services are governed by state laws, regulations, policies, and procedures. These include a requirement to provide leadership to local jurisdictions. Each state must also have a system in place to evaluate and improve the quality of its EMS system. EMS operates at the intersection of Public Health, Public Safety, and healthcare

Infrastructure: Under the Department of Transportation (DOT), the National Highway Traffic Sa fety Administration (NHTSA) developed the framework for, and leads, EMS systems in the United States. Every state has legislation that authorizes the EMS system within its borders, as well as the authorities that oversee service delivery and resource training. National EMS standards are determined by DOT and are modified by each state's Department of EMS (usually under its Department of Health); they are also altered by Regional Medical Advisory Committees (usually in rural areas), by other committees, or even by individual EMS providers.

States generally provide coordination and planning roles for EMS, with associated funding varying greatly across the nation. Emergency management operations for medical and safety issues exist at the state as well as the local levels. States are the conduits for significant amounts o f f ederal g rant dollars, distributed to them via block grant programs. Federal partners and their roles with EMS include:

Department of Defense. Provides criteria, guidance and instructions to inform delivery of services.

Department of Health and Human Services. Provides technical assistance, subject matter expertise, and direct program services to states, tribes, territories, and local communities to prepare for and respond to disasters and emergencies.

Department of Homeland Security. Provides coordination for federal response to terrorist attacks and natural disasters.

Federal Communications Commission. Through the Public Safety and Homeland Security Bureau, works to ensure that first responders have access to reliable, interoperable equipment.

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Funding for programs, services, and educational resources is supported in part by the CDC and the Assistant Secretary for Preparedness and Response as a part of other efforts covered by these federal agencies. EMS systems, however, are practical examples of the minute-by-minute emergency response mechanism for individuals in crisis. The organizational model that has tested out so well to deliver this response, in coordination with public safety and medical agencies, applies just as well to community and regional health responses.

Sources of Funding: Public emergency services funding derives primarily from tax revenues at the state and local levels, augmented to a small extent by federal funds. The services themselves may be provided by a local government or may be the responsibility of the regional or state government. Municipality-operated services may be funded by service fees and be supplemented by property taxes.

Workforce: As of 2014, there were approximately 241,000 emergency medical technicians in the United States. There are numerous other support personnel, such as emergency medical responders and paramedics, throughout the country. In addition, there are private agencies that provide emergency medical services and that are not part of the public network.

Partners for Information Exchange: Information-sharing among public medical agencies in the normal course of their work has always been of critical importance to practitioners. When EMS personnel are responding to a major emergency, interoperability is vital among dispatch, ambulance, clinics, hospitals, and public safety agencies and information systems.

Emergency medical services are constantly in motion and mostly mobile; information infrastructure includes information and communication technologies, including both fixed and mobile hardware, software, services and devices; and broadband infrastructure. Personnel are equipped with mobile radios, computers, smart phones, and/or tablets to enable information-sharing and situational awareness. EMS personnel are trained to use mobile technology to communicate and share critical information with each other and with external systems, such as Emergency Medical Technicians or paramedics on the way to a hospital, communicating with a Medical Director.

Potential Improvements: A potential improvement over the existing EMS system would be a further integration with public health, public safety, environmental health, social and human services, and education in some circumstances. This integration could play an important role in detecting the start of emergencies, such as the Flint water crisis or other comparable events, as well as the national opioid epidemic. Once these groups are coordinated across their individual vertical towers of care, earlier detection could be accomplished through public and environmental health systems, and further services could be coordinated with social and human services systems.

Calls for service come most immediately to public safety dispatch or 911 centers; medical services are dispatched along with safety professionals, and the early warning of expanding illness is mostly available in the data captured by the call centers in public safety, or downstream in the EMS reporting.

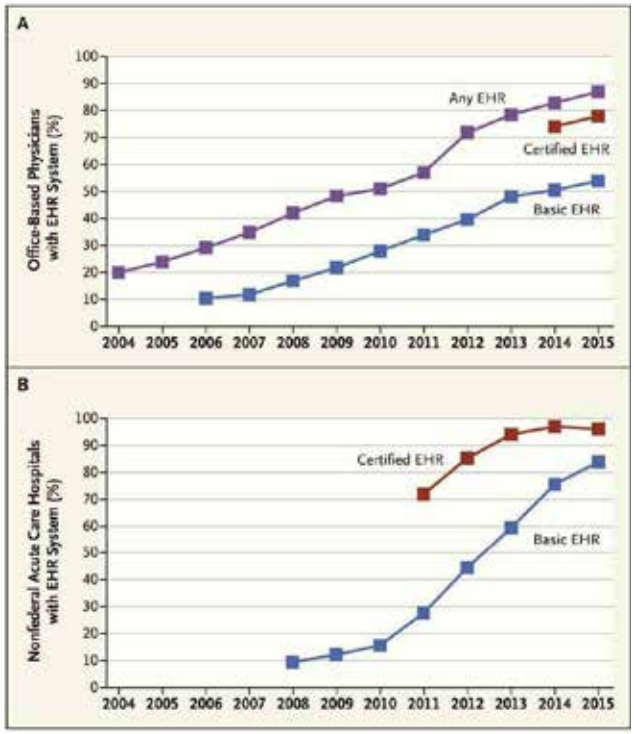
Key Resources for More Information

www.ems.gov/OEMhistory.html_
www.ems.gov/partners.html

Health Information Technology

Mission: While a strong business case and appropriate policy are necessary for interoperability to flourish, at the end of the day it's the available information technology (IT) that makes data flow. Because of the distributed nature of healthcare in the U.S., the IT resources, decision-making, and infrastructure are equally decentralized. And a competitive marketplace on the one hand leads to great innovation, while on the other hand often limits effective cooperation. Rapid advancements in technology have also led to implementation stratification on the part of health organizations, so users can rarely keep pace equally in all technical areas. This leads to conflicting pressure to implement new technology as it becomes available, and to allow existing technologies and approaches to become more widely implemented.

Infrastructure: Infrastructure: Health information technology (HIT) encompasses many components. The following are the most crucial relating to Interoperability:



Commoditization of Computing Equipment. Unlike in the past, today almost all types of computing equipment – from the largest virtual servers to the smallest hand-held devices – are essentially commodity purchases, with little to differentiate the hardware or basic operating system functionality. Cloud computing has simplified the deployment of scalable servers, and even Apple- and Windows-based desktops and laptops are all but interchangeable. Most application development has moved to the web anyway, reducing dependence on user hardware choices. Furthermore, prices continue to drop as speed, screen pixel count and storage capacity increase. Users need these devices to interact with data in the healthcare ecosystem.

Clinical Systems. These support a wide range of activities, from direct patient care, to population health management, to more- specialized functions like radiology,laboratory information and pharmacy management. Clinical systems often look a little different at ambulatory versus hospital- based environments. At the center of these systems are Electronic Health Records, the adoption of which has been spurred financially by the CMS EHR Incentive Programs, which were part of the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009; they continue to be revised as CMS advances its overall payment models. Additional systems also contain clinical data, often fed from EHRs and other clinical systems, including various public health registries and other surveillance systems.

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Administrative Systems. While these are more transparent to many in the healthcare ecosystem, they drive the payment for healthcare services that, at the end of the day, drive most spending in healthcare organizations. The advent of payment reform, uncertainty in insurance markets spurred by recent changes in the Affordable Care Act (ACA), and new data-coding standards that impose additional data-entry burdens on users raise additional challenges for the ongoing survival of these systems.

The Internet. Fundamental to interoperability is the internet itself, fed by local networks within organizations that provide connectivity between computers and other devices. Advances in telecommunications have turned computing into an "anytime, anywhere" activity. The nation's backbone network continues to improve in resilience and speed. Ubiquitous access to high-speed communications is an essential requirement for almost all activities. While the cable TV industry has largely supplanted the telephone carriers in providing network connectivity to the home, cell providers have enabled mobile computing at increasing access speeds.

Mobile Computing. While this term once referred to the "lucky ones" who had a laptop, mobile computing has exploded to include a wide variety of devices – conventional and unconventional – now referred to as the Internet of Things. Laptops have been supplemented (and in time may be supplanted) by cell phones big and small, tablet computers big and small, and "wearable" devices, all of which have found a place in the clinic as well as the home. Through this transformation, we have all but taken multimedia for granted as faster networks and central processors in our devices no longer constrain the types of information we can view.

Sources of Funding: Infrastructure certainly has its costs, but information technology is moving into our society as a core capability of our work, family, and social lives. Different industries spend different amounts on IT in general. While commoditization of hardware has reduced cost, increased demand for more and more capacity continues to drive spending, which competes with other organizational priorities for investment. The CMS EHR Incentive Programs have spurred investment in EHRs, but payment reform continues to introduce uncertainty into the future availability of funds for investment in Health IT.

Workforce: Approximately 188,600 people are estimated to work as medical records and health information technicians (Bureau of Labor Statistics, 2014). Demand for health IT workers continues to grow steadily, as does the need for clinical staff trained and experienced in healthcare informatics. As the labor market for skilled IT in the U.S. tightens, and sometimes shifts overseas, organizations may find it increasingly difficult to advance their health IT projects successfully.

Partners for Information Exchange: There was a time when healthcare professionals assumed they only needed to talk to each other. Those days are long gone, however, as patient access to healthcare data is not just "nice to have" but a clear expectation of both government ("view/download/transmit" requirements for EHRs in the CMS EHR Incentive Programs) and patients themselves. As we think of the healthcare ecosystem as a Learning Health System, all participants – patients, clinicians, researchers, payers, government – have more expectations about access to data. We are coming to realize the growing interdependency among all these individuals and the importance of partnerships supported by common infrastructure and purpose to enable interoperability.

The Office of National Coordinator's (ONC) work implementing the 21st Century Cures Act and its focus on trusted exchange is an important step toward advancing the creation of a national interoperable health system.

In January 2018, ONC published a draft Trusted Exchange Framework and Common Agreement (TEFCA) for public comment. The draft is meant to build on and recognize the industry's significant work over the last few years to broaden the exchange of data to meet the needs of patients and the providers who serve them. It aims to improve the flow of information among healthcare stakeholders and expand patient access to their health data, while allowing for a competitive marketplace that fosters innovation and development of new technologies

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to improve care coordination, population health management, and patient outcomes. Its goal is to help scale interoperability efforts for health nationwide and ensure that patients, providers across the care continuum, community and social services, and many more stakeholders can effectively and efficiently participate in interoperability efforts.

The single on-ramp described by ONC seeks to enable access by existing Health Information Networks (HINs) to electronic health information regardless of what health IT developer they use, health information exchange or network they contract with, or how far across the country the patients' records are located. Moreover, the on-ramp would provide opportunities for HINs to innovate and build out additional use cases and services that would provide value to their participants and support their long-term sustainability.

While implementation of TEFCA will not begin until 2019 or later, it is important to recognize the potential to create national approaches and standards to achieve interoperability in health, and potentially in related fields such as human and social services.

Challenges: [1] Healthcare is complex. Challenges to working together abound, including:

Lack of agreement on definitions, scope, and priorities. While the 21st Century Cures Act provides a definition of interoperability [2] there are many more definitions in use in healthcare. Even if a definition is widely accepted, there is no real agreement on the scope pf interoperability that we should focus on – clinical data, administrative, medical devices, all of the above? – nor on what the appropriate "world view" really is. Despite broad discussion of "patient-centered" healthcare,the U.S. system remains largely provider-centered, and this core difference affects how we view and implement interoperability.

Ambiguity over the role of HIEs and state government. A national strategy around HIEs has not been developed, including not on a "hub and spoke" scheme that seems natural to many given the size and complexity being dealt with. State-level HIEs are strong in some places, non-existent in others. In the absence of a strategy, the private sector has moved to fill the gap with vendor-based HIEs, collaboratives such as the Commonwell Health Alliance, the Sequoia Project and CareQuality. The Strategic Health Information Exchange Collaborative (SHIEC) is working to link independent community and state-level HIEs together, especially through its Patient Centered Data Home project.

Lack of agreement over timelines and pace of change. We observe other sectors of the economy where market disruptors have caused real, leap-frogging change: iPhone, clever apps like Waze, smaller and smaller microprocessors. But it appears we've been waiting for a decade or more for healthcare IT's transformative moment. Healthcare is very complex, however, and different organizations view change and the pace of change differently. So the road toward a singular, transformative moment could be a long and hard one.

Inconsistent Laws and Regulations. U.S. laws related to health IT, especially regarding privacy and patient consent for sharing, are a patchwork of federal, state, local, and tribal statute and regulations that often conflict or are ambiguous. From HIPAA to FERPA to 42 CFR Part 2 to various state laws regarding the sharing of mental health or adolescent health data, it is difficult for participants (let alone their automated systems) to navigate this world within their jurisdiction. The introduction of cross-jurisdictional sharing makes the navigation even more difficult.

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[1] London and Gurantz (2010). Based in part on Arzt, Noam H. "The Interoperability of Things," Journal of Healthcare Information Management, 29(4),
Fall 2015. https://www.hln.com/wp-content/uploads/2016/03/JHIM- InteroperabilityOfThings-Fall-2015.pdf

[2] London and Gurantz (2010). http://docs.house.gov/billsthisweek/20161128/CPRT-114-HPRT-RU00-SAHR34.pdf (p.351)

Standards. We have been working on interoperability standards for nearly 20 years, and it feels like great progress and little progress have been made at the same time. Some participants maintain that the implementation of standards needs to continue to evolve as healthcare evolves. Others ask for patience because of how long it takes to implement a particular version of a standard consistently among a set of data-sharing partners. There is no consensus on which approach might be best.

Semantics. Even if data flowed freely and unimpeded from one organization to another, the use of that data would be suspect at best (and harmful at worst) without consistent and shared meaning. Medicine is a complicated business, and its knowledge base is constantly changing and evolving. If nothing else were done over the next few years other than to ensure that data in various systems use standard terminologies and code sets, there would be far greater progress for interoperability and information-sharing.

Governance. A shared governance experience helps us make tough decisions to address some of the challenges described above. Some argue that only government can bring all the stakeholders to the table and convene the conversation. Many observe that this has not happened in the past few years, and the sector continues to flounder. While some private initiatives have tried to fill the void, participation is self-selected, technical architectures sometimes seem arbitrary, and it is even more challenging to keep self-interests and conflicts of interest in check.

Potential Improvements: Here is no single answer to this set of challenges, but consider this advice from a recent article which proposed that we begin by:[3]

Be skeptical of the notion of "consensus." The best strategy might not be the most popular one. Some problems are, in fact, intractable. One critical role of leadership is to provide direction when the best choice is not obvious.

Leverage the past with an eye to the future. Broad experience and knowledge are available about the successes and failures of past initiatives. At this inflection point, we must consider everything that has occurred before we charge ahead.

Recognize this is more about the pace than the substance of change. The healthcare ecosystem is too large, complex, and fragmented to move in lock-step. So a broad vision is needed for early adopters, mainstream implementers, and laggards to all see a path forward. Details should be tailored to each phase of implementation.

Key Resources for More Information

Arzt, Noam H. "The Interoperability of Things," *Journal of Healthcare Information Management,* 29(4), Fall 2015. https://www.hln.com/wp-content/uploads/2016/03/JHIM- InteroperabilityOfThings-Fall-2015.pdf

Office of the National Coordinator for Health Information Technology, "Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap version 1.0," October 2015. https://www.healthit.gov/sites/default/files/hie-interoperability/nationwide- interoperability-roadmap-final-version-1.0.pdf

Interoperability Standards, https://www.hln.com/knowledge/interoperability-standards/

By providing this unique, explicit look at the six primary domains that operate across the spectrum of care, NIC's goal is to engage the broader interoperability community in identifying and analyzing the common and divergent factors among them in order to accelerate information-sharing and collaboration. One of our near-term goals is to compare these domains – through crowd-sourcing on the new NIC Collaboration Portal to gain deeper insights about them and to stimulate cross-sector communication/dialogue. Each of the domains are examined more fully in the expanded version of this document at www.stewardsofchange.org/NIC.

This document was written by **Adam Pertman**, a Senior Consultant for SOCI and the National Coordinator and Communications Director for NIC; **Juli Baker**, a Senior Consultant for SOCI and a Project Site Leader for NIC; and **Daniel Stein**, President of SOCI and Co-Principal Investigator for NIC. We sincerely thank the contributors and reviewers who provided the research, writing, and other input that made this document possible. They included:

Noam H. Arzt, PhD, President, HLN Consulting

Margo Edmunds, PhD, Vice President for Evidence Generation and Translation, AcademyHealth

Rebecca Freeman, PhD, RN, PMP, Chief Nursing Officer, Office of the National Coordinator for Health IT

Nedra Garrett, MS, Senior Advisor for Informatics, Center for Surveillance, Epidemiology and Laboratory Services, Office of Public Health Scientific Services, Centers for Disease Control and Prevention

Chris Kingsly, Senior Associate for Data Initiatives, Annie E. Casey Foundation

Rebecca London, Assistant Professor of Sociology, University of California, Santa Cruz

Susan Moran, Deputy Director, Population Health Administration, Michigan Department of Health and Human Services

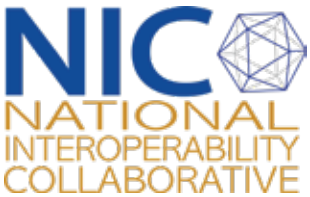
Kshemendra Paul, Deputy Director for Mission and Strategy, Information Sharing and Services Office, Department of Homeland Security

Valerie Rogers, Director, State Government Affairs, HIMSS North America

Joshua Rubin, JD, MBA, MPP, MPH, Program Officer, Learning Health Systems Initiative

Daniel Stein, President, Stewards of Change Institute

Paul Wormeli, Wormeli Consultants; Executive Director Emeritus, Integrated Justice Systems Institute; member, SOCI Board of Directors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