

Building Community-Based Solutions To Address Public Health Crises

A Guidance Document and Action Plan to Create the Technology-Enabled *Health Emergency Linkages and Preparedness (HELP) Model*



Healthcare Information and Management Systems Society
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“By failing to prepare, you are preparing to fail.”

— Benjamin Franklin



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. Thousands of volunteers work with HIMSS to improve the quality, cost-effectiveness, access and value of healthcare through IT. Major initiatives within HIMSS North America include the [HIMSS Annual Conference & Exhibition](#), [National Health IT Week](#), [HIMSS Innovation Center](#), [HIMSS Interoperability Showcases™](#), [HIMSS Health IT Value Suite](#) and [ConCert by HIMSS™](#).



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. We believe utilizing information-sharing, interoperability and the Social Determinants of Health and Well-Being is the key to achieving enduring progress – especially for the most underserved, vulnerable and at-risk populations of our country, for whom the broad range of HHS-related services remain out of reach.

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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. Health-related emergencies, whether caused by nature (e.g., Hurricanes Irma and Katrina or the Zika virus) or by people (e.g., the nation's opioid/heroin epidemic or the water crisis in Flint, MI), clearly fit that description.

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 five of the primary domains that operate across the spectrum of care to address health emergencies in our country. What this report seeks to accomplish that we believe has not previously been done is to examine the workings of each of the five domains; identify and analyze their successes, problems, commonalities and intersections; and then, based on that learning and additional research (see Methodology), devise recommendations on how they might work more cooperatively and interoperatively to deal with public health crises.

The five domains are: public health; public safety; human and social services; emergency services; and health information technology, which has a different infrastructure than the other four domains but is included because it is critical to their operations. The mission and work of each domain are summarized in Section III of this Guidance Document and Action Plan, 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 (see Acknowledgements), to whom we are very grateful for the knowledge and guidance they contributed.

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Methodology

HIMSS and SOCi conducted several types of research for approximately six months over the past year for the preparation of this Guidance Document. Our activities included:

- Convened symposia and roundtables in Washington, DC; Lansing, MI; and Orlando, FL, to obtain experts' knowledge and insights, as well as to help shape recommendations. Also conducted separate, individual interviews with subject matter experts around the country. In all, we received input from more than 100 public health and policy specialists, legislators, providers, patient advocates, researchers, practitioners and community leaders.

- Conducted an environmental scan of projects/initiatives across the U.S. that utilize interoperability and information-sharing in innovative ways to assess applicability to the subject of this report.
- Utilized case studies (e.g., opioid/heroin epidemic, natural disasters, and water crises in the United States) to focus on problem identification and solution generation.
- Conducted an extensive literature review, encompassing more than 80 sources relating to both health crises and information-sharing.
- Reviewed other national, state and local roadmaps, white papers, presentations, news stories and relevant documents relating to interoperability and information-sharing, with a specific focus on addressing health-related crises.
- Examined five principal domains that operate across the spectrum of care to address health-related emergencies in the U.S., with the intent of identifying commonalities to expand interoperability among them.

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The objective of this report is to highlight realistic steps that can be taken, starting *at the community level*, to optimize the effectiveness of these five domains in dealing with health emergencies by advancing the secure, responsible exchange of *specific information that is identified as most-relevant/beneficial for addressing crises such as the opioid epidemic*. In other words, we are not looking to revamp entire infrastructures but, instead, are suggesting a sharp focus on “the tip of the spear” – i.e., accelerating the sharing of data and use of interoperability (and of other tools that each domain has developed over time) that would contribute most to near-term progress on defined, particular problems.

To accomplish that goal, we offer several actionable recommendations in Section VI below, all intended to build on the considerable work that already has been done; to incorporate the extensive knowledge that is already available; and, most pointedly, to better-utilize interoperability and information-sharing to “connect the dots” among the many systems that already exist but do not yet routinely exchange specific information most useful for addressing particular problems (as described in the previous paragraph). This report also delineates specific actions SOCI and its collaborators are planning or are already taking – with the support of HIMSS, the Kresge Foundation, and other state and national partners – to implement our recommendations.

It is important to state from the outset that numerous initiatives and technologies (described throughout this report) have contributed to considerable progress in preventing, detecting, surveilling and responding to public health-related crises, in particular since the national catastrophe on 9/11 led to the creation of the Information Sharing Environment (ISE, Department of Homeland Security) *in the public safety domain* and of the Assistant Secretary for Preparedness and Response (ASPR, Department of

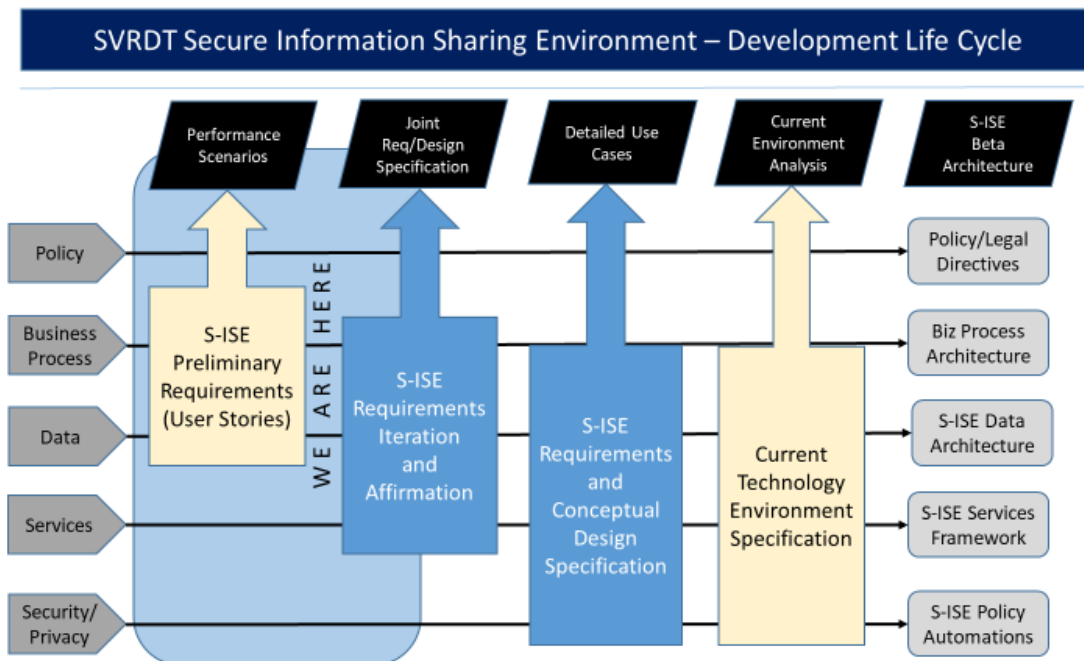
Health and Human Services) *in the public health domain*, among others. More information about these two important but less-well-known initiatives is provided later in this paper, and our recommendations include bolstering existing efforts such as ISE's and ASPR's.

ISE has not only been highly successful in advancing interoperability and information-sharing among its "mission-partners" – federal agencies and state, local, tribal and private sector entities dealing with public safety – it also has developed guidelines and instructions for applying its approach, governance and architecture in other arenas. Indeed, the leaders of ISE have clearly indicated that their work can be applicable to efforts to expand interoperability and information-sharing within HHS.

For example, in April 2015, then-ISE Program Manager Kshemendra Paul provided input on the Nationwide Interoperability Roadmap drafted by the Office of the National Coordinator (ONC), which is part of the U.S. Department of Health and Human Services. In his comments to then-National Coordinator Karen DeSalvo, Paul wrote:

" . . . we were struck by how many similarities and equivalencies there were in your roadmap and our implementation plans and programs. For each mission and area of responsibility that you face in HHS and we face in dealing with national security and public safety, we find many of the same challenges to interoperability and information sharing. Furthermore, the solutions we separately seek to address are also remarkably similar."

A good example of how the ISE model can be utilized outside of public safety is playing out in California, where the Silicon Valley Regional Data Trust (SVRDT) is creating an integrated data system that encompasses the public schools and health, human services and juvenile justice agencies in Silicon Valley's three counties: Santa Clara, San Mateo and Santa Cruz. SVRDT named this effort the Secure Information Sharing Environment (SISE). Its goals are to enable data-sharing for integrated case management; policy development of new and better practices and services; and research in partnership with the University of California, Santa Cruz. SVRDT is making substantial progress in bringing its partners together to develop a uniform set of data and information elements to benefit all parties and, thereby, the populations they serve.



Based on the work Stewards of Change is currently doing with SVRDT on this project, as well as on the research conducted with HIMSS over the past year, one of the primary recommendations in this report is to adapt the ISE approach/architecture to more-effectively address major public health problems. The means we suggest for achieving that objective is to create and test a community-based Health Emergency Linkages and Preparedness Information Sharing Environment (HELP-ISE), which would bring together and enable greater information-sharing and interoperability among our own “mission partners” – that is, the five domains delineated at the beginning of this report. More information about building HELP-ISE is in Section V of this report.

We propose the creation of HELP-ISE, along with our other recommendations, because it is clear from our research – including examinations of public health emergencies such as the Flint water crisis and the national opioid epidemic, as well as extensive interviews with experts nationwide – that despite significant progress, some systems still operate in silos or are not fully connected with others that could improve their efficacy. The result is that prevention, early detection, mitigation, surveillance and intervention are too often impeded, while procedural, medical and related responses are sometimes similarly slowed. The consequences can include frustration for responders, higher costs and, most pointedly, greater potential for harm for longer periods to individuals and communities. Our recommendations are aimed at facilitating further progress, abetting existing efforts and, ultimately, improving outcomes.

Toward those ends, this report has these primary objectives:

- To examine the uses of interoperability and information-sharing in addressing health-related emergencies such as the Flint water crisis and the opioid epidemic
- To examine the practices of and intersections among the five domains that deal with health-related emergencies
- To offer concrete, actionable recommendations based on those examinations, as well as on a review of relevant literature, interviews with experts and other research
- To provide direction for addressing health-related crises based on our synthesis and analysis of the information accumulated for this report
- To encourage a greater emphasis on preventing disasters and, when that's not possible, improving detection and early response to mitigate impact.

It is also important to acknowledge that there already are numerous “roadmaps,” white papers and other evidence-based reports that thoughtfully discuss the use of interoperability, information-sharing, “open data,” and related approaches/technologies to improve processes and results in various domains related to the subject of this Guidance Document (e.g., the ONC report referenced above and the National Academies’ Institute of Medicine’s “Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risks”).

Similarly, we know and respect that there has been considerable progress in numerous areas relating to public health. At the same time, many organizations have examined how specific health-related crises have been and are being addressed, and have offered recommendations for making further improvements (e.g., the Markle Foundation’s “Lessons from KatrinaHealth” and the National Governors Association’s “Finding Solutions to the Prescription Opioid and Heroin Crisis”). In the wake of Hurricanes Harvey, Irma, Jose and Katia – as well as the wildfires raging in the Northwest U.S. and the earthquakes in Mexico – the U.S. National Library of Sciences also recently updated the resources of its online Disaster Information Management Research Center with the admonition: “Disasters don’t plan ahead. You can.”

This Guidance Document and Action plan seeks to build on the work that already has been done – and the progress that has been made – by focusing on ways to: 1). integrate the use of interoperability and information-sharing not just within one or even among a few domains, but across the multiple systems that come into play before, during and after public health crises; and 2). address not just one particular type of health emergency, but the broad spectrum of such crises irrespective of their scale or whether they are created by people or nature.

At the bottom line, we are stipulating that institutionalizing better communication and collaboration among the five domains identified in this report (public health, health IT, public safety, social and human services, and emergency services) would yield more-effective processes and better results. Again, we are not envisioning any major restructuring to accomplish this aim but, instead, suggest a focused approach of

“connecting the dots” so that explicitly identified data can be shared that will be of most use to address specific problems like the opioid epidemic.

We recognize that coordinating and harmonizing guidance around interoperability, standards development and utilization, as well as privacy, confidentiality and security concerns, will require support from federal agencies through existing mechanisms (e.g., DHHS Standards Coordinating Council) and new structures that are empowered to cut across domains to support greater collaboration and data-sharing.

Problem Statement and Strategic Needs Assessment

While many efforts are underway to bring a more-systematic, interoperable approach to dealing with health-related crises, interviews with experts indicated that many of these efforts do not yet include inventories of their relevant information technology (IT) systems or collaboration to optimally leverage those systems to meet public and population health needs. Instead, they typically address the complex issues involved within specific arenas such as health record access, patient location or other factors needed for immediate delivery of medical services – and there is considerable variability in the ways they do so.

This Guidance Document and Action Plan suggests that work begin on building such a model, which would contribute to moving from the current, mainly tactical approach to dealing with public health emergencies to one that is genuinely strategic. The objective is to more-effectively put into place flexible/adaptable structures and capabilities that will enable communities to systemically deal more successfully – whether measured by cost, detection, surveillance, response or outcomes – with all types of health-related crises.

“Public health (primarily a local, state and federal governmental function) is concerned with addressing population health goals across all segments of society (local communities, state-wide and nationally). The aims are primarily to support efforts that prevent and control chronic and both communicable and non-communicable disease. The term ‘population health’ has mainly been applied to sub-populations within discrete health systems. But the ultimate goal is to improve overall health outcomes, improve quality of care, and lower costs to the health system and patient costs.”

– Regina M. Benjamin, MD, MBA, Former US Surgeon General

Many existing information technology (IT) systems, electronic data and exchange capabilities within communities could be brought to bear to prevent, detect and effectively respond to public health emergencies. Many communities have not inventoried their existing legacy health-related IT systems, however, nor have they launched collaborative efforts to leverage those systems to optimally carry out their day-to-day or long-term public and population health responsibilities. Our assessment of the strategic needs that should be addressed, based on expert input and our literature review, leads to conclusions including:

- There are fundamental health IT challenges relating to the effective detection of and response to public health, human services and environmental emergencies.
- Communities would greatly benefit from updated, interoperating IT infrastructures that could ensure connectivity across the spectrum of behavioral and clinical care.
- Existing mobile and telehealth technologies are not being sufficiently utilized, particularly to serve those that might benefit most from them (e.g., rural communities).
- Decision-making is hampered by a lack of cross-system governance and execution for IT security, interoperability, and clinical and business intelligence.

Section II: Guiding Principles and Acknowledgements

This report is not intended as a detailed, how-to instruction manual. Rather, it is an initial step on a longer path; that is, it provides a focused overview of what is, what could be and how to get there. In the course of creating this report, SOCI and HIMSS developed the following guiding principles; they constitute the foundation on which our recommendations are built:

- Information-sharing and interoperability across sectors are vital components for achieving progress relating to health crises (and to numerous other problems).
- The Social Determinants of Health and Well-Being play a central role in everyone's lives, so they must be integrated into any holistic approach to deal with health crises.
- A robust, connected public health system is vital not only during emergencies, but every day, in order to broadly protect and improve people's health and well-being.
- The HELP-ISE model should be initially developed by facilitating the utilization/leveraging of existing systems and standards in innovative, connected ways to accelerate implementation and minimize costs.
- Any suggested solutions need to be based on an understanding of all the key parts of the problems being addressed, pointedly including their root causes.
- Making concrete plans and preparing systems in advance, rather than reacting once an emergency emerges, is vital to early identification, prevention and response.
- The model created to address public health emergencies should include metrics (such as the longitudinal impact of the problem on population health).
- The model should be viewed as a work-in-progress, since it will necessarily be adapted after testing in varying locales and from learning after each successive crisis. The beneficiaries will be the real people who suffer the consequences of health-related crises, so patient/client/community input and participation should be integral throughout, from creating a viable model to ensuring optimal use.

Acknowledgements

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Section III: Understanding the Five Domains . . . to Connect the Dots

Every domain that plays a vital role in addressing public health emergencies 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 domain has a full complement of daily and long-term mission responsibilities beyond dealing with health crises. It is therefore unrealistic to think they can find a way to broadly exchange data anytime soon, even if the scope were limited to the subject of this report.

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 such as 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 emergency has occurred. 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: a). What information currently is being shared? b). What connections have already been made relating to this issue? And c). 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 five domains, including a review of its fundamental functions and structures; its key challenges; and its pragmatic opportunities for taking short-term action. The aim is to provide context for Section IV, which discusses the HELP-ISE model and outlines the key issues for conceiving, building and utilizing it. The common threads for improving information-sharing and interoperability among these five domains are incorporated into our recommendations and suggested action steps.

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.

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 the majority 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 of Health (SDOH), 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 anything else for that matter). 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 but rather state, local and tribal laws 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 Trusted Exchange Framework and Common Agreement is the latest effort 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 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; 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

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

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 (SOA³). 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 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 an even greater potential for enabling the sharing of services and capabilities in the larger healthcare ecosystem.

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 certainly some strong examples of state HIEs that are thriving – in DE, IN, MI, NY and VT, to name a few. The ONC 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 Alliance⁴), and private national organizations providing health information exchange services (like the Sequoia Project⁵ and its CareQuality⁶ collaborative).

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-SOA-Spring2010.pdf>>

⁴ <http://www.commonwellalliance.org/>

⁵ <http://sequoiaproject.org/>

⁶ <http://sequoiaproject.org/carequality/>

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 Public Health 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 Taskforce 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

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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 Rachel N. 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 Rachel N. Avchen

Public Safety

Mission: The U.S. public safety system includes the 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 to ensure readiness to prevent and respond to natural or man-made disasters and 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 hazards, including natural and man-made emergencies. 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 Intelligence: The Program Manager for the Information Sharing Environment (ISE) was positioned in ODNI in response to the congressional mandate (contained in § 1016 of the Intelligence Reform and Terrorism Prevention Act (IRTPA) of 2004, as amended) to the President 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.

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 information. 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 information-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, 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 the FirstNet program, and this mobile, wireless, broadband capability will stimulate improvements just by its existence. New applications are needed and 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 collaborative activities. We should rethink our collective response to emergencies 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>

Human and Social Services

Mission: The provision of human and social services in the United States involves a vast number and variety of agencies, programs, organizations and processes that are legislatively authorized and funded largely by the federal government and implemented by states, localities, nonprofits and for-profit businesses. The “safety net,” as it is commonly called, has three basic components: 1). Social Security and Medicare for the elderly; 2). unemployment insurance and workers compensation; and 3). anti-poverty and means-tested welfare or social services programs.

We are focusing largely on the third component because it is most relevant to the subject of this report. 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 variety 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 behavior 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.⁷

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.⁸ 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 other domains, such as healthcare, public health, public safety and emergency response.

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 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 I not impossible.

Infrastructure: Human services assistance/programs are delivered and run by a wide variety of 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

⁷ Schroeder, SA. (2007). We Can Do Better – Improving the Health of the American People. NEJM. 357:1221-8.

⁸ <https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/Value-Based-Programs.html>

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:

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 workgroup, 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 architectural 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 APIs, systems can exchange 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 are headed by single parents.⁹

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.¹⁰

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

⁹ 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.

¹⁰ https://www.acf.hhs.gov/sites/default/files/assets/acf_toolkit_july_2012_final.pdf

FY 2015 shows 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 Assistance for Needy Families (TANF).¹¹

A key challenge for these programs is that they are authorized by different federal statutes and enacted at different times, 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 programs so 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.

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. Finally, there were simply fewer services available, so fewer systems were needed to facilitate coordination and communication. And, of course, there was less technology, so the work had to be done person to person.

Since the 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

¹¹ 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.

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 for 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>

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 service 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, whether man-made or natural, and others that may vary by community but have a role in protecting the public during such crises. 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 Safety 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 of federal grant 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.

Funding for programs, services and educational resources is supported in part by the **Centers for Disease Control** 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 among dispatch, ambulance, clinics and hospitals, as well as with public safety agencies and information systems, is vital.

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, and social and human services. 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

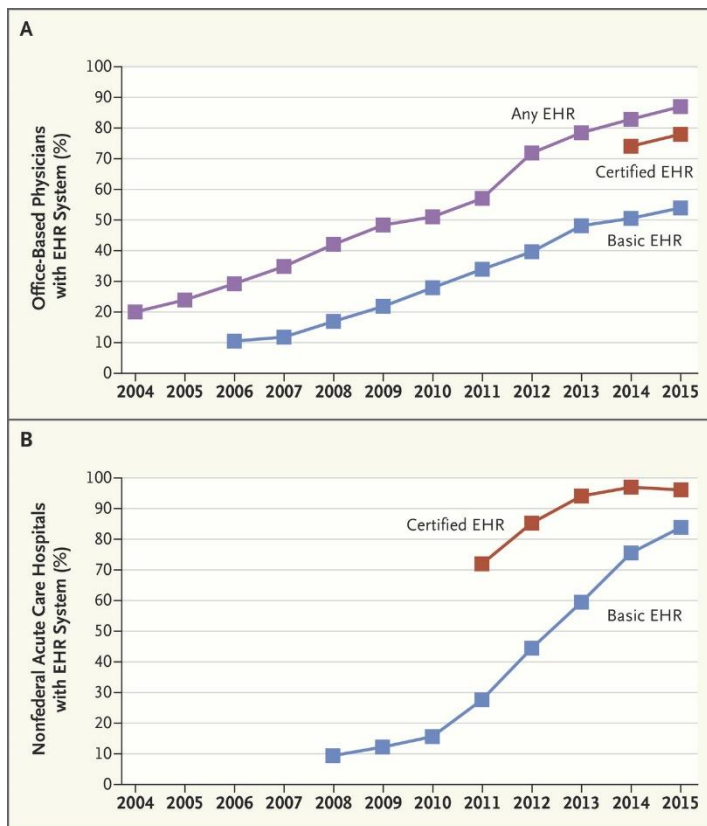
www.ems.gov/OEMhistory.html

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: 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.

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 threatened repeal of 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.

Challenges¹²: 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,¹³ there are many more working definitions in use in healthcare. Even if a definition is widely accepted, there is no real agreement on the scope of 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”

¹² 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>

¹³ <http://docs.house.gov/billsthisweek/20161128/CPRT-114-HPRT-RU00-SAHR34.pdf> (p.351)

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 we are dealing 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 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.

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 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-interest and conflicts of interest in check.

Potential Improvements: There is no single answer to this set of challenges, but consider this advice from a recent article which proposed that we begin by:¹⁴

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 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/>

¹⁴ See *The Interoperability of Things* cited elsewhere, p. 8.

Bringing Together the Domains and the Research

As noted earlier, in addition to our examination of the five domains described above, preparation for this report included extensive interviews, a literature review, group discussions with numerous experts and an appraisal of relevant, innovative efforts around the U.S. This work during the past year yielded considerable information about specific initiatives and innovations, successful (and not-so-successful) methods and approaches, and insights that provided both content and context for this document.



In addition, and very importantly, it became clear that there were numerous common threads across various domains, projects, interviews and documents. Few if any of them were surprising; rather, they provided consistent, strong evidence to support the “sense” that has grown in and pervaded the HHS world (and many others) for many years – i.e., that sharing information, collaborating across siloes and breaking them down are key to making, sustaining and institutionalizing progress. Among the commonalities/findings we identified under that headline were:

1. Incorporating the Social Determinants of Health and Well-Being is vital to both fully understanding and resolving problems, including health-related emergencies such as the opioid crisis. This understanding, by definition, entails bringing together and crossing silos of all sorts.
2. Establishing a governance structure and working relationships among all partners/stakeholders is critical and should be done in advance of a crisis; this step is vital to being prepared to respond.
3. Identifying the precise problem, and obtaining agreement from all partners/stakeholders as to the problem statement, are key to pursuing solutions.
4. Establishing specific and evidence-based metrics is essential to any information-sharing and interoperability initiative, both to ensure its efficacy and its worthiness/ability to be brought to scale. As with the above bullet on Social Determinants, this report recommends embedding measurements as an integral part of creating and testing the HELP-ISE model.
5. Utilizing common data-exchange standards is key to bridging the communications gap among domains, as well as among programs within an existing domain or even agency.

6. Addressing responsible information-sharing methods to “Get to Yes” can be expedited by clearly defining all state and federal laws pertaining to confidentiality and privacy.
7. Building technology with agility and modularity is crucial, so that successful solutions can be adapted and reused quickly and cost-effectively.
8. Promoting enhanced, cross-sector communications, as well as learning about new methods and approaches, is fundamental to success. Serious consideration of the organizational change management impact is crucial.

Section IV: Building the HELP-ISE Model

Greater interoperability and information-sharing among the five domains examined in this paper (public health, public safety, health information technology, human and social services, and emergency medical services) clearly would contribute to better effectiveness, efficiency and outcomes in many respects. The primary purpose of our holistic examination of those domains, their functions and their commonalities – as well as our other research for this report – was to gain insights and shape recommendations relating to progress that could be made in one specific area: health-related emergencies.

The need to increase interoperability and cooperation across domains came into sharp focus in the aftermath of 9/11. Indeed, one of the major problems that tragedy exposed was the hurdles that siloed government agencies faced in sharing critical information and coordinating efforts. To address that potential risk to U.S. national security, Congress voted to establish the Information Sharing Environment, the responsibility of which is to promote interoperable efforts at the local, state and federal levels. For over a decade, ISE has successfully demonstrated that sensitive information can be responsibly exchanged, privacy concerns can be effectively addressed, and agencies with histories of not communicating with each other can efficiently collaborate.

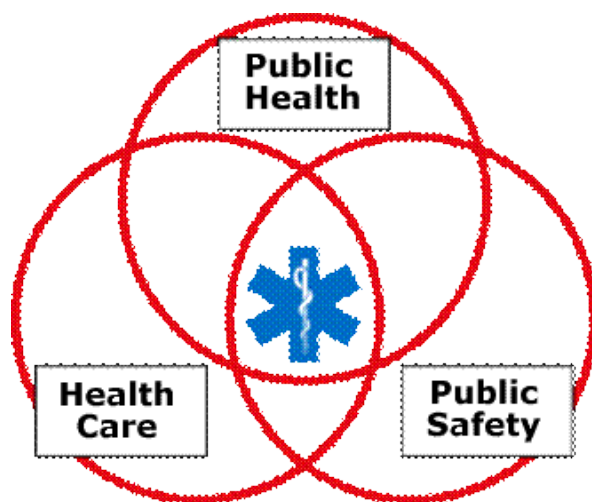
Today, the need for state, local and federal officials to enhance their communications is evident in addressing crises such as the nation’s opioid/heroin epidemic. This and other health-related emergencies – most recently, the series of hurricanes that struck Texas, Florida, Puerto Rico and elsewhere in the Caribbean, but also threats such as contaminated water, among others – regularly arise and persist in communities around our country, affecting millions of people’s health (through environmental impacts such as lead poisoning and medical impacts such as the spread of infectious diseases), and their very lives. Indeed, various types of improved cross-sector data-sharing and coordination are among the recommendations in the recent preliminary report by the President’s Commission on Combatting Drug Addiction and the Opioid Crisis.

Our goal in recommending the creation of the Health Emergency Linkages and Preparedness Information Sharing Environment (HELP-ISE) is to do what the federal ISE is successfully doing at the federal and state levels, and what SVRDT in Silicon Valley is

being built to do: enable and support existing agencies, organizations and other entities – in our case, the five domains that deal with health emergencies – to conduct their work more effectively and efficiently through improved information-sharing and interoperability.

Two elements of ISE offer particularly on-point and valuable insights, guidelines and even specific steps that can be applied to the development of HELP. Those are its [Project Interoperability](#), which provides tools and resources specifically targeted for improving information-sharing and interoperability to improve performance, reduce duplication and cut costs; and its [Information Interoperability Framework](#), which details the governance models, architecture, standards, technical specifications and other key components for creating an environment that facilitates information-sharing and interoperability. Excerpts of both documents, with links to their full versions, are in Appendix I of this report.

While HELP-ISE is envisioned as a hybrid that both learns from and enhances the work of all five domains, we propose that it initially be formulated by emulating and adapting the ISE – with one significant addition. Because there are service-provision elements of the work that needs to be done before, during and after health-related emergencies, we suggest that HELP-ISE also incorporate some ideas from the nation's EMS system, which obviously has long experience operating at the intersection of various domains:

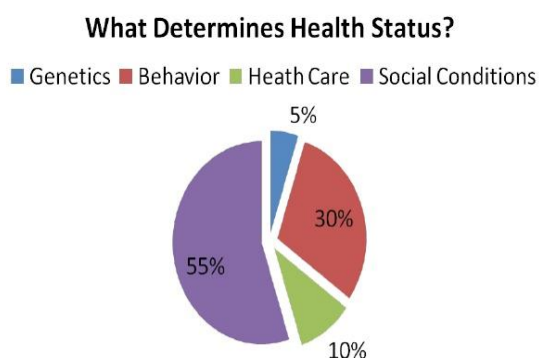


The strength of the EMS system lies in the components of the time-tested model that it employs to deliver services nationwide in a standardized, reliable and interoperable manner. While we are not prescribing precisely how to build the HELP-ISE – which should be done in collaboration with the five domains it aims to serve and the initial demonstration sites – we believe the EMS service-delivery model is highly instructive for application at the community level to create organizational structures, problem identification, communications, interoperability, local responsiveness and evaluative feedback.

Components of HELP-ISE Model	Implementation Steps and Functions
Governance and Leadership: Central control of key resources in each locale	Create a governance structure with defined leadership for each locale - Identify roles and reporting relationships for all resources - Create funding mechanisms - Create communication channels - Identify data sharing agreements - Document policies and procedures - Build collaboration channels in advance of a crisis: - Build relationships in advance (engage BEFORE any crisis) and institutionalize of these so that they persist - Include non-traditional partners, anticipating every possibility (i.e., Public Health and Safety, Environmental Health, Interfaith, Infrastructure & engineering, Government)
Identification of the Problem	Systematically monitor and prevent man-made and naturally caused health crises - Leverage existing Public, Environmental Health and syndromic surveillance functions to identify and monitor for health risks - Identify significant Key Indicators and monitoring levels and monitor over time - Convene the Key Resources (governance structure) to define and agree upon the problem to be addressed
ISE Information Interoperability Framework	Systems architecture, standards, technical specifications and other key components for creating an environment that facilitates information sharing and interoperability - Set up systems to interoperate in advance, based on the Key Indicators - Adopt technical standards and monitoring systems - Adopt interoperability among HIEs - Identify data and measurement systems and have them in place - Tools and resources from Project Interoperability - Data visualization to make it “consumable”
Communication Systems	Education and Communication Transparency - Develop IN ADVANCE the methods to reach all sectors of the community, across socioeconomic barriers - Build mechanisms from the start with key stakeholders - Develop a national repository of each local Community Preparedness System, its location, components and progress
Identification of Issues and Channels to Resolve	Issue Identification during the acute or chronic crisis - Monitor for new issues as they arise - Convene governance body to address new issues - Data choice supports the identification of the problems and contingencies (feedback loop from monitoring)
Regulation and Policy for Response and Resolution	Laws, policies, regulations, procedures in place and in use by governing body - Clarify who is in charge - Specify where the crisis is managed - What is the infrastructure needed to support the resolution - Data-sharing agreements already in place - Privacy issue addressed in advance
Practice Implementation	Practice drill of all components every 1-2 years in each locale
Evaluation: Learning Health System	- Install a quality-assurance and improvement feedback loop - Transition to long-term, ongoing support and longitudinal analysis

	c. Create feedback loop for continuous learning and improvement d. Populate the Communication Repository
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Another example of information that can be leveraged to build HELP-ISE is the Kresge Foundation’s comprehensive “Blueprint for a Healthier America 2016,” which contains highly relevant information, analysis and recommendations. A section of the report titled “Modernizing to Real-Time Interoperable Disease Surveillance,” for instance, points out that most of the hundreds of federally supported U.S. health surveillance systems “are often disjointed and out-of-date ... [and] are often overburdened with redundant, siloed disease reporting systems.” It continues: “Health information technology is transforming the way healthcare is delivered, and public health must adapt just as quickly to take advantage of these advancements. ... New data systems and sources, electronic health records, electronic laboratory reporting, mapping systems, cloud-based disease reporting stems and relational and non-relational databases have the ability to significantly improve the dissemination of real-time, interoperable and interactive information across public health, healthcare providers and other systems.”



Source: World Health Organization, *Report of the Commission on the Social Determinants of Health*, 2008.
See also Robert Wood Johnson Foundation Report, *Beyond Health Care: New Directions to a Healthier America* and CDC, *Healthy People 2020*.

BERNALILLO COUNTY PLACE MATTERS TEAM - - - - HEALTH EQUITY ASSESSMENT TOOL

The Robert Wood Johnson Foundation, as part of its ambitious “Building a Culture of Health” Initiative, has elevated and broadened the national conversation about another key, essential component relevant for the HELP approach: The Social Determinants of Health and Well-Being. Colloquially, these translate into the environments in which all of us live, work, go to school and play, which are understood to be responsible for a huge majority of people’s health-related outcomes. In other words,

even if systems and organizations relating to medicine, health and healthcare were to be successfully linked, they could not accomplish their ultimate goals unless they also shared information and interoperated with schools, criminal justice, child welfare, support services, and other cultural, employment-related and economic elements of society.

Again, a great deal of the information, analysis and recommendations that RWJF provides is on-target for building and advancing HELP-ISE. Furthermore, all the Action Areas outlined by the Foundation as steps to fulfill its vision would both complement and accelerate the work that this Guidance Document is suggesting.



Section V: Shaping Strategic, Community-Based Solutions

Clearly, serious efforts have been (and are being) made to deal more effectively with individual health-related emergencies and, in many cases – notably through efforts by federal programs such as ASPR and ISE – in increasingly systemic ways. Based on the input we received during scores of HIMSS-organized discussions and interviews around the country, however, it became evident that experts on the ground widely believe that there is still insufficient information-sharing, interoperability and collaboration, and that enhancing those activities across domains *in strategic ways* will both mitigate current hurdles to progress and improve crisis-related processes and outcomes prospectively.

With that understanding as backdrop, we are proposing to aggregate, disseminate and coordinate the best of what’s already being done; to “connect the dots” among existing programs/projects to improve communications and efficacy; and, with a long-term view, to accelerate the development of systems and processes that can be used to both enhance current efforts and future ones to improve early detection, surveillance, response and outcomes for public health-related crises across the board.

While the long-term objective is clearly to affect change nationally, our work on this report consistently found that the most realistic and effective way to reach the desired destination is to begin at the community level; that was the strong consensus among the professionals we interviewed. Healthcare delivery, human services, public health and public safety are all implemented locally, as we saw repeatedly when examining a broad variety of innovative projects around the country (a sampling of which are described later in this report).

That said, the prospects for a successful initiative presumably would be optimized if every tier of government were to fully participate, since it presumably would be in the interest of every state and the country as a whole to help this ambitious effort. Such support could come in many forms, from strengthening existing laws, policies and regulations; to providing additional funding and/or other resources; to greater engagement in planning, information-sharing and other aspects of the work itself.

The certainty that there will continue to be natural disasters in our country, along with the breadth, scope and consequences of current health-related problems – most notably the opioid crisis – warrant the kind of focused, coordinated initiative outlined in this report.

For example, public health officials agree the opioid/heroin epidemic is the worst drug-related emergency in U.S. history, ravaging residents in all 50 states; accumulating costs of \$100 billion by some estimates; and taking an increasing number of lives each year (e.g., 33,000 people in 2015 and 59,000 in 2016). The long-term human, social and financial impact of this public health disaster are harder to quantify.

The same is true for other emergencies, such as the Flint water crisis. Officials believe it eventually could cost that low-income city \$400 million and the nation as much as \$300 billion, but those numbers don't include the many other municipalities around the U.S. dealing with less-chronicled water and lead crises – nor can they account for the repercussions for all the people, especially children, who will suffer the potentially lifelong developmental, economic and health effects of consuming contaminated water.

Beyond the significant human, societal and financial tolls of these man-made public health crises is the reality that they have been treated too often as singular events, addressed in largely siloed responses by organizations carrying out their individual missions. The same has largely been true for natural disasters such as Hurricane Katrina, which cost almost 1,000 people their lives, displaced more than 1 million residents and caused about \$135 billion in damages. And, of course, the series of hurricanes that struck the U.S. mainland and beyond in September 2017 took and disrupted even more lives, and will cost governments at all levels hundreds of billions of dollars for years to come.

It is the hope of HIMSS and SOCI that this Guidance Document and Action Plan will be used to: 1). stimulate a broad conversation about the need to alter our current tactical approach; and 2). generate concrete actions that move the U.S. toward a more-holistic strategy, with interoperability and information-sharing at its core.

The experts interviewed during our research – listed in Appendix II – offered numerous suggestions for a multi-tiered, interoperability-based model for addressing health-related crises. This mirrors the approach taken to form, operate and grow the Information Sharing Environment – which, as stated earlier, is the primary system (with EMS) from which we are drawing to mold the HELP model. ISE's stated metrics provide valuable content for thinking about appropriate performance and outcome measures for the work outlined in this report. Kshemendra M. Paul, then the PM-ISE, wrote in April 2015: "The metrics we have developed to measure our progress include the extent to which we collectively are able to: 1). productize, align, and gain mainstream adoption, and therefore reduce barriers to use and encourage adoption of the various (open) tools, processes, and methodologies that we and our various partners champion; 2). support our partners to increase capacity to transform and collaborate; 3). demonstrate reasonable implementation of priority

objectives; and 4). show causal linkage to partner program outcomes from planned and managed use of our tools, processes, and initiatives.”

Mr. Paul laid out those metrics as part of his response to an early draft of “Connecting Health and Care for the Nation: A Shared Nationwide Interoperability Roadmap,” published by Office of the National Coordinator for Health Information Technology in October 2015. The goal of that ambitious, 10-year plan is to use interoperability to help “build a strong foundation of health IT in our healthcare system, equipping every person with a long-term, digital picture of their health over their lifespan.”

While that objective does not directly address public health emergencies, improving and utilizing better electronic health records and related technologies clearly will enhance the ability of public health professionals – as well as patients – to make more-informed judgments relating to a host of questions, such as who might be most susceptible to an epidemic and what solutions might be targeted for which segments of the population.

The ONC vision in its report also views interoperability as necessary to develop a “learning health system” in which “health information flows seamlessly and is available to the right people, at the right place, at the right time.” That is a goal we share with ONC,

“At the heart of the LHS vision is a fundamental question: How do we catalyze, sustain and continually advance a massive socio-technical transformation of a system touching everyone’s life and health, and encompassing over one-sixth of a nation’s economy when such a transformation will take years or decades, likely requires the participation – or at least affects – stakeholders inside and outside of healthcare and is urgently needed?”

“Addressing this challenge requires stakeholders with seemingly divergent interests to work together. It involves knowledge and skills from many disciplines to come together and be able to effectively and efficiently communicate and collaborate with one another. It requires technology and people, and it affects physical systems, information systems and social systems.”

– Joshua Rubin, JD, MBA, MPP, MPH, LHS Initiatives Program Officer

and we also suggest the implementation of a Learning Health System, albeit focused on dealing with health-related emergencies. The good news – as evidenced by the ONC roadmap and numerous other, comparable documents – is that no one involved in shaping our newly envisioned HELP-ISE initiative will need to reinvent the wheel, either to get started or to make progress along the way.

Indeed, just as the ISE and EMS operations are already firmly in place, health-related infrastructures, models and systems that already exist in every city and town – encompassing all five domains discussed in this report – should be the primary vehicles for initiating development of HELP-ISE. The process could start with an environmental scan and result in a white paper/overview explaining current command structures and other critical elements, as well as pointing out where the best near-term opportunities exist for collaboration and information-sharing across relevant domains. The scan and white paper would also include the many existing ideas, initiatives, recommendations, case studies, resource documents and research reports relating to interoperability in the HHS realm that could be adopted, adapted and utilized at every stage of development.

One example is a medical history portal, called the Patient Unified Lookup System for Emergencies, or PULSE, which grew out of a 2014 joint directive from the ONC and ASPR to evaluate how HIEs could be used to provide safer, more-effective care to people affected by disasters. It would allow disaster workers to find and view documents such as prescriptions and test results for any patient who went to an emergency room, field hospital, or evacuation shelter. The first major test of PULSE, which could become an important tool during and after crises such as this year's devastating hurricanes, was successfully concluded in California in June 2017.

Among the case studies that are highly relevant to informing the creation of HELP-ISE, as well as the new National Interoperability Collaborative, is one that SOCI developed for its 2016 National Symposium and continues to build upon. By telling the real-life story of a 47-year-old single mother of five, this use case provides a clear window into the profoundly personal impact and systems-level complexity of our nation's opioid/heroin epidemic. Local and state jurisdictions can learn and extrapolate from this type of use case scenario to apply to their own circumstances.

In sum, Kerry (not her real name) became addicted to the oxycodone that was prescribed for her pain after a car accident, and events quickly spiraled downward from there; within months, she was hooked on heroin and lost her job, the bank foreclosed on her house, and her family was living in a homeless shelter. There's much more to her story, which is told in the full version of the SOCI case study in Appendix III.

Most pointedly, even as it illustrates the devastating human toll of a historic public health emergency, Kerry's journey vividly demonstrates that any genuinely effective, patient-centered approach to dealing with such crises needs to include interoperability and information-sharing. Here's why: During the course of her decline, Kerry and her children interacted with numerous medical professionals, who provided her with everything from treatment and prescriptions after her accident to rehabilitation services for her addiction; an array of law enforcement and court personnel, who dealt with her on various legal matters throughout her journey; assorted education and child welfare employees, who came into the picture because of issues relating to her children's schooling and her legal custody of them; and several housing/homelessness personnel, for obvious reasons. In

addition to intersecting with all those systems, and others, Kerry also applied for and was granted TANF, Medicaid and Food Stamps for herself and her three minor children.

It is clear that a successful response would have required the multidisciplinary, cross-sector sharing of information to prevent or mitigate the problems experienced by this family. The organizational cultures, processes and technologies needed for a holistic approach could be advanced by using HELP-ISE to facilitate linkages among all the players who interacted with Kelly and her family: public health, public safety, health information technology, social and human services and emergency services.

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Michigan Interviews & Workshop, HIMSS 2017 Roundtable

Over 100 professionals in the health, human services and emergency response fields shared their experience and knowledge for our research, largely during or in connection with events organized by HIMSS. The consensus among them regarding health-related crises – whether acute or chronic in nature – was that an interoperative, multi-sector system needs to be in place before a crisis event in order to be able to respond in timely and effective ways. The experts' input repeatedly emphasized the need for a collaborative information-sharing system to:

1. Break down organizational and professional silos; invest in building relationships to create public/private partnerships
2. Overcome cultural barriers to exchanging relevant health information
3. Put in place bidirectional information exchange; EHRs and registries
4. Connect to environmental health monitoring
5. Link in laboratory systems for population health reporting
6. Link in case-management systems for surveillance
7. Create solutions for matching patient records
8. Provide education at the community level and across the digital divide
9. Identify healthcare crisis problems early and obtain cross-organization buy-in to the precise definition of that problem
10. Prepare systems to track health longitudinally

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Addressing Individual and Community Needs

The central focus of implementation for health crises response is that the model be individual-centered, population-focused, community-based and technology-enabled. These criteria should be built into the Health Emergency Linkages and Preparedness Information Sharing Environment. The following considerations for this approach stem from the research we conducted with numerous stakeholders:

- Create a national data infrastructure over time; start by leveraging existing solutions in specific jurisdictions to spur near-term progress; include/support robust predictive analytics, risk assessment, surveillance, and electronic case and lab reporting.
- Focus on providing timely response, care management and coordination, and mitigation for individuals and communities harmed or threatened by environmental hazards and/or emerging pathogens.
- Deliver care management, coordination and other support mechanisms through secure, multi-dimensional, community-based longitudinal records.
 - Leverage existing policy and funding to expand surveillance, environmental health monitoring and reporting
 - Provide a central repository/record-locator service for first responders
- Utilize trusted mechanisms to collect, analyze and report cross-functional data (clinical, administrative, socio-economic and community-based) to monitor patients and address the impact of crises.
- Develop a localized, community-driven communications strategy to ensure that the public receives up-to-date information and resources in a timely fashion during and after health emergencies.
- Institute blended and braided funding approaches across local and state systems to help eliminate and/or transcend siloes.
- Focus on approaches that break down cultural and policy barriers to health information exchange – including confidentiality, privacy and security considerations.
- Build robust linkages among case management, surveillance systems, registries, lab systems and other population health data captured by public and private health systems (clinical and non-clinical).

Since communities are the primary focus of the work outlined in this report, HIMSS has developed a series of overarching “themes” that would serve their needs, while also accomplishing the broad, long-term objectives of our initiative. They include:

- Creating a national data infrastructure, based on a health-in-all-policies framework and supporting robust predictive analytics, risk assessment, surveillance, etc.
- Providing timely response, care management, care coordination and mitigation to populations threatened or affected by environmental hazards and/or pathogens
- Producing a secure, multi-dimensional, community-based longitudinal record, so residents can receive proper care management, coordination and other support
- Employing a localized, community-driven communications strategy to ensure that the public has up-to-date information and resources during health emergencies

Environmental Scan: Innovations and Insights

As part of our research, we examined innovative initiatives around the country that are utilizing interoperability and information-sharing in ways that could be relevant to the focus of this report. The following are examples of the projects, programs and approaches we reviewed over the past year; cumulatively, these and additional efforts contributed to shaping our understandings and recommendations. We are highlighting the ones below because (among many others that could also have been included) they provide a glimpse of the ingenuity, innovation and cross-sector thinking that is currently being attempted – and that can be learned from, emulated and scaled. For more details about each, please click on the links embedded in its name. SOCI and HIMSS express their sincere gratitude to the leaders of these initiatives, as well as to the scores of other people and organizations that enabled us to produce this Guidance Document and Action Plan.

Fusion Centers. These 79 facilities are operating in major urban areas and in every state around the country, operating in partnership with ISE and working closely with the federal Department of Homeland Security, but owned and run by states and localities. While the objective for all of them is to enhance national security by promoting information-sharing, various centers carry out their work in differing ways. For instance, the one in New Jersey is described as taking a novel approach that focuses on cybersecurity, spending its first year building technical and analytical capacity in order to share information in real-time with the private sector; here is a news account about [the NJ fusion center](#).

“Jersey is working to build an information sharing environment for public safety that links their state, county, and local law enforcement agencies. We believe these efforts could serve as a model for other states throughout the country.”

- From a blog on ISE website, New Jersey: A Model for State ISES

The fusion centers also offer a possible model for advancing efficacy through collaboration and information-sharing between/among organizations with common goals. For instance, in addition to their interactivity with ISE, the centers work with the federal High Intensity Drug Trafficking Areas (HIDTA) Program, including by sharing information, analysis and threat assessments relating to the nation’s opioid/heroin epidemic; for more details on this joint effort, see Appendix IV.

Digital Bridge. The aim of this RWJF initiative is to improve health through better information exchange between public health and healthcare. It plans to do that, in part, by identifying a consistent, sustainable, nationwide approach to using Electronic Health Records to improve public health surveillance. Its first project is to design and pilot a multi-jurisdictional approach to electronic case reporting (eCR). Digital Bridge is in the process of implementing a trial at sites in several U.S. cities, where testing will take place on the technical aspects and viability of eCR for public health and healthcare.

AquaHacking. This unique initiative aims to solve pollution and other freshwater problems by bringing technology into the mix. The idea of staging annual “hackathons” to find solutions was hatched in Canada in response to issues faced by the St. Lawrence River, and is now being applied to the Great Lakes in the United States. The winners of last year’s competition developed a mobile app that acts as an early warning system, tracking the risk of microbiological contamination to predict health risks for swimmers. This approach could be leveraged broadly to greatly increase resources at the community level among technologically savvy and committed individuals who are vested in their locality’s health and wellness, as well as in other areas of need.

CMMI Accountable Health Communities. This five-year pilot program essentially seeks to bring the Social Determinants of Health and Well-Being into the healthcare equation. It is based on emerging evidence that better health outcomes and lower costs can be achieved by improving linkages between clinical settings and community services that address health-related social needs such as housing instability, food insecurity, utility necessities, interpersonal violence and transportation. The 44 funded sites should provide evidence and insights from an array of demonstration projects about effective means for sharing information at the community level.

Telehealth. This is a term that describes a growing array of technologies, initiatives and approaches for bringing healthcare to the consumer, rather than the other way around; its uses are particularly promising, for example, in rural areas where doctors and hospitals may not be nearby. It exemplifies innovative interoperability that bridges a geographic and socioeconomic gap. Examples include a program at Partners Healthcare in Boston, where 3,000 patients with congestive heart failure used at-home monitoring devices to transmit medical information (ex., blood pressure) to medical personnel, who then identified whether and which interventions were needed. Partners estimates the program ultimately cut re-admissions by 44 percent and saved \$10 million.

Additional Initiatives. Other projects and approaches examined for this report include utilization of applications by local health providers to engage the public in tracking health status. For instance, Boston Child’s Health uses an app called Flu Near You, which combines an active and passive consumer approach to awareness. This project demonstrates the potential value of leveraging remote technologies to gather data cost effectively and provide near-real-time surveillance for urgent public health and safety programs. This is a promising example of interoperability that brings current data to populations to stimulate pro-active healthcare awareness and responsiveness.

A local health effort in part of rural Mississippi has deployed smartphones to monitor patients with diabetes and track daily interventions to form a feedback loop for patients about their choices of intake and effects on their disease. This type of behavioral health surveillance can also impact other chronic diseases. Some of these are short-term feedback loops; others are long-term (e.g., opioid overuse, heart disease) and require sustained awareness and more face-to-face interaction. Again, using existing systems in

a more interoperative manner between providers and patients yields improved community-level health.

A promising approach to bridging many of the health record gaps noted above comes from the Centers for Disease Prevention special topic report titled “A Community Health Record: Improving Health Through Multi-Sector Collaboration, Information Sharing, and Technology.” It presents a framework for developing a cross-sector community health record tool (CHR). There are also successful examples of tracking data and using it for analysis across states, such as the centers for health informatics in state organizations in Washington and Minnesota, among others. This approach improves population health through increased interoperability.

An emerging success story involving Flint is Michigan’s Statewide Public Health Crisis Service. Led by Tim Pletcher, DHA, Executive Director of the Michigan Health Information Network Shared Services (MiHIN), the system is among the first of its kind to capture data on individuals exposed to toxic substances. This registry links consumers to their care providers, and delivers communications for all parties through an Active Care Relationship Service. This type of registry, which advances interoperability, supports provider awareness and assists the state in surveillance for toxic exposures. The system leverages the state’s existing data warehouse, a customer relationship data service and a Trusted Data Sharing Organization. It enables Michigan to identify anyone who has been exposed to toxic substances and might need more attention.

In Flint, as is now well-chronicled, the problem was a water supply that was not safe to drink. Among the impediments to identifying the impact was the fact that individual patient blood levels of lead were not widely tracked or reportable to any central surveillance team. There was no reporting mechanism, nor were there guidelines as to what blood levels should be reported. How to find people who are impacted by any crisis can be a huge initial barrier to resolving it. Communities facing this problem must learn what information needs to be collected, how to collect it, how to identify affected individuals, and how to connect their information to known medical interventions.

One positive initiative coming out of Hurricane Katrina in Louisiana resulted from an early finding that evacuees’ healthcare records were not readily available. A successful effort was launched to collect records from providers and pharmacies in order to supply medical professionals with data to provide continuity of care.

Example of SUCCESS: Hurricane Katrina hit Louisiana in 2005; a multi-sector approach to access as many health records as possible had positive results:

“Within the first 60 days, KatrinaHealth had fielded nearly 5,000 queries from doctors (17 percent of total queries) and pharmacists (83 percent). Patient specific results were successfully obtained for 1,500 of the inquiries. Approximately 1,100 of the successful searches were from the community pharmacy (SureScripts) database, 250 were from RxHub, and 160 were from the LA Medicaid data. Improving patient identity matching could have had a somewhat positive boost on the number of queries that produced results. ... KatrinaHealth – the project – was more than just “a triumph of good will,” as one participant said, it also demonstrated a feasible, pragmatic strategy for gathering personal healthcare information from multiple sources quickly and (relatively) easily, without creating a massive centralized database. In this regard, it was a poster child for the concept of interoperability.”

– Lessons from KatrinaHealth, Markle Foundation

Section VI: Recommendations and Action Steps

The ongoing, potentially life-threatening nature of health-related challenges – in particular the burgeoning opioid/heroin epidemic – underscores the urgency of better-utilizing interoperability and data-sharing, and pointedly, of promoting policies that further that aim. The opioid crisis also offers a very accessible case study that concretely articulates the crucial need for better information-sharing and interoperability. And it presents opportunities to advance the work of all five domains discussed in this report, for example by leveraging or rechanneling existing funding streams, while making it easier to utilize current systems that share data (or enabling them to be more useful) through legal, regulatory and/or policy changes.

This document provides guidance for updating such policies, as well as for creating appropriate infrastructures in communities and states so they can develop beyond current operational silos. In addition, it addresses ways to collaborate better to support innovative initiatives that advance improvements toward more-coordinated surveillance, detection and response to health emergencies, as well as to support relevant longitudinal research. In this regard as in others, ISE offers a model from the public safety domain that could be adapted, because it has demonstrated that facilitating and furthering such collaboration at scale is indeed possible.

The following are our Recommendations and Action Steps, including activities that SOCI and HIMSS – along with other partners – have begun or are planning to undertake:

1. Develop and pilot HELP-ISE to facilitate a community-based, population-focused, individual-centered approach for addressing public health crises. This model, work on which SOCI and HIMSS plan to begin in early- to mid-2018, would leverage existing technical infrastructure, with enhanced interoperability, to “connect the dots” among current communications and data-sharing efforts by relevant organizations and systems to enhance surveillance, prevention, detection and response. Conducting demonstration/pilot projects to assess and improve efficacy will be vitally important. Action steps to accomplish this objective should include:
 - a. Approach the leadership of the Department of Health and Human Services to champion the development of an Opioid ISE, building on the recommendations of the Presidential Commission on Opioids (whose report explicitly addresses the need for better information-sharing and prevention activities). SOCI, with partners, has already begun this outreach process.
 - b. Convene major players to help plan proof of concept, strategies and tactics – including identification of barriers, policies and metrics. SOCI and HIMSS plan to hold such a convening, with additional partners, in mid-2018.
 - c. Develop a consensus on the impediments to information-sharing and their mitigation, using the challenges relating to health emergencies as a prism to better understand the broader cultural, policy, process and technology issues.
 - d. Select targeted and significant problems, including but not necessarily limited to the opioid/heroin crisis, that require multi-agency, multi-disciplinary responses.
 - e. Design and implement demonstration projects to test, validate and refine strategies for establishing information-sharing and interoperability as fundamental elements of responding to health-related emergencies.
 - f. Create and execute a communications plan to generate public and political support for evidence-based practices – focusing on the HELP model – to improve the “climate” for expending this work.
 - g. Incorporate systemic monitoring and evaluation to ensure efficacy and to provide evidence for ongoing improvements and, eventually, scaling.
 - h. Support and advocate for longitudinal health records; research and write a Policy Brief on the subject; provide education on social media, at conferences, etc.
 - i. Develop and provide training and certification through SOCI’s InterOptimability Training and Certification Curriculum (see www.stewardsofchange.org).
2. Build on the cross-domain approach of this report by conducting a deeper environmental scan of key organizations, systems and projects/initiatives *across the five domains* to identify which data sets, processes and linkages could be advanced most expeditiously to make the biggest short-term impact on specific public health emergencies, starting with the opioid/heroin epidemic. The scan would also include relevant work by ISE and ASPR, among others who are focused on or would be of consequential benefit to more-effectively addressing health crises. Produce a white

paper or best practices guide containing this information and additional research, disseminate the document, conduct a campaign to build greater awareness, and use the contained knowledge to advocate for better policies and practices.

3. Develop and regularly update a checklist of concrete, readily achievable actions that communities can take even before a comprehensive initiative such as HELP-ISE is fully in place – and that can continue to be updated as the model is developed and implemented. Such a checklist, created by the communities themselves, would enable them to make immediate progress relating to interoperability and information-sharing for prevention and response to health-related emergencies; furthermore, it would prepare them to better take advantage of any other broad initiative that might be launched, whether by the federal government or one like HELP. These actions should be shaped by the communities themselves to address their specific needs and realities; their action steps could include activities such as:
 - a. Negotiate data-sharing agreements between/among the key stakeholder organizations identified as necessary for efficient, effective efforts before, during and after health emergencies of the type encountered by the specific community. These should be across disciplines, including but not limited to law enforcement and schools, and not only EMS and other crisis-specific organizations.
 - b. Discuss and formalize roles, tasks and responsibilities of the various parties that deal with health emergencies so there is no confusion or misunderstanding about who does what and when, and so that collaboration and coordination are optimized. It is obviously difficult to make such decisions in the midst of a crisis.
 - c. Even before such agreements are achieved, and ongoing afterward, build community coalitions and hold regular meetings among the key stakeholders – as explained in the recommendation above – both for planning purposes and to build trusting relationships in which a culture of responsible, reliable collaboration and information-sharing can be advanced.
 - d. Move as much information as possible into the cloud so that it is less vulnerable to being degraded or wiped out by a natural disaster like a hurricane, and so that the data are as readily and broadly accessible as possible during the emergency. Create a secure system by which stakeholders can access that data, as needed.
 - e. Focus more attention on prevention and mitigation. These actions will differ greatly by community and type of crisis; for example, there is high variability in the extent to which localities have provided training of first responders on the use of naloxone or on building awareness about state prescription drug monitoring programs.
4. Research, write and disseminate a series of two-page “action” documents to further the aims of this report and its recommendations. SOCI and HIMSS plan to seek funding to oversee production of these documents throughout 2018. Their content and emphasis likely will evolve as various other activities take place and in response to needs in the field, but these two-pagers would focus on specific actions for:

- a. Motivating ongoing education and advocacy on key issues (e.g., regarding the Social Determinants and longitudinal health records).
 - b. Pursuing collaboration opportunities to leverage the 21st Century Cures Act to advance information-sharing and interoperability for this work.
 - c. Devising and implementing a cross-disciplinary community of practice, including by building a business case for infrastructure grants.
 - d. Launching a national campaign for a more-robust public health, environmental, long-term care and human services health IT infrastructure.
 - e. Championing infrastructure grants to communities for robust public healthcare and human services, public safety, environmental health, and emergency response.
5. Aggregate and consolidate past research and learning from all five domains about the impediments to cross-domain interoperability and information-sharing related to health-related emergencies, and develop a consensus on minimizing or ending them. Incorporate key factors such as laws, regulations, culture, policy, process and technology, and formulate concepts for mitigation that deal with issues including privacy, identity and privilege management, cybersecurity and a scalable model to improve interoperability. Action steps to accomplish this goal should include:
 - a. Publish/disseminate a white paper or guidance document to promote awareness, advocacy and progress. Utilize the developed knowledge in building HELP-ISE.
 - b. Promote a health-focused policy framework in all budget decisions to mitigate the prospect of repeating preventable emergencies like the Flint water crisis.
 6. Provide communities with information, resources and guidance to inventory their health IT and related/relevant systems. Start by enabling this process in at least two identified communities, then disseminate the learning and scale the resulting model. Work with the community to facilitate collaborative efforts that optimally leverage those systems to meet public and population health needs.
 7. Work as a partner of the National Interoperability Collaborative (NIC, see <http://stewardsofchange.com>) to facilitate the execution of appropriate recommendations in this report. A relationship with NIC will be particularly useful to further the work by learning from existing programs and systems, and then by utilizing NIC for dissemination and scaling. (NIC is a “community of networks” that is being built by SOCI and AcademyHealth, with seed funding from the Kresge Foundation.)
 8. Develop learning communities and build human capital for sustainable inclusion of information-sharing and interoperability in addressing health-related crises. SOCI, in partnership with AcademyHealth and others, has begun this process through NIC. Action steps to accomplish these objectives should include:

- a. Make available a set of methodologies and tools that support standards-based interoperability and information-sharing to facilitate adoption as a basic component of strategic planning for addressing health emergencies.
 - b. Develop an extensive training and education program (SOCl's ITCC), which includes certification, to create a national force of human talent to deploy standards and methodologies that are evidence-based.
 - c. Assess and incorporate proven practices (e.g., Learning Health Systems), as appropriate, from other domains and the demonstration projects suggested above.
 - d. Adopt and implement interoperability standards. This could be an activity guided by a collaboration of NIC and state agencies.
9. Advance the state of the art in the use of analytics that contribute to improving health-crisis detection, prevention, surveillance and response. Action steps to accomplish this objective should include:
- a. Document and assess the utility of advanced analytics in health emergencies, particularly exploring the potential of scientific and technological innovations, including concepts found in precision medicine, cognitive computing, natural language processing, and other forms of artificial intelligence that may expedite and contribute to detection and response to health emergencies.
 - b. Seek support for demonstration projects that provide evidence of the value of technologies to deal with health crises. Increase practitioners' knowledge of the available evidence and scalability of proven practices and methodologies.

Conclusion

While many efforts are underway to bring a more-systematic, interoperable approach to dealing with health-related crises, a concerted initiative to “connect the dots” among them – and across the five domains that deal with such emergencies – could stimulate greater near-term progress, pointedly starting with the nation's opioid/heroin epidemic. Such an approach could also contribute to making existing systems increasingly interoperative, cohesive and collaborative, and thereby presumably more effective, into the future.

This Guidance Document and Action Plan envisions such an approach and offers recommendations on how to achieve it by moving from current, largely tactical efforts to ones like the HELP-ISE that are genuinely strategic. The objective is not to more-effectively address any one type of emergency, but to facilitate and support the advancement of flexible/adaptable structures and capabilities that will enable communities to systemically deal more successfully – whether measured by cost, detection, surveillance, response or outcomes – with all types of health-related crises.

Appendix I

ISE: Information Interoperability Framework and Project Interoperability

The [Information Sharing Framework](#) is the Information Sharing Environment's implementation plan for responsibly sharing information across multiple levels of government and non-government entities. Its approach links information across jurisdictional boundaries and creates a distributed, protected, trusted environment for sharing information. It provides mechanisms to permit partner agencies at the Federal, state, local, tribal, and territorial levels (e.g., fusion centers) to share similar data based on common standards and practices.

The Information Sharing Framework exploits existing information architectures, suggesting standards, tools and methodologies to link existing systems as well as specifying the development of common artifacts that will enable disparate departments and agencies' architectures to make the full framework operational. It was developed so that ISE participants could better respond to complex policy challenges and improve the delivery of services and information to protect U.S. citizens.

The ISE's [Project Interoperability](#) is an information interoperability start-up guide that makes tools and resources available to government and the private sector for improving information interoperability. The goal of Project Interoperability is to establish a baseline of terms, tools and techniques as a foundation for greater information sharing. A draft of the guide, which includes tools and use cases, is [located here](#).

Appendix II

Professionals Who Provided Information in Interviews and Roundtables

Roundtable Participant/Interviewee	Title/Affiliation
Ranjit Alyagari	
Alexandra Albers	
Holt Anderson	North Carolina HIMSS Chapter, NCHCIA
Laura Appel	Senior VP and Michigan Health & Hospital Association
Stephanie Arnston	
Dara Barrera	Practice Manager, Michigan State Medical Society
Christopher Beal	CMIO, St John's Internal Medicine, P.C.
Dan Blum	National Capitol Area HIMSS Chapter, State Advisory Roundtable
Dan Boyle	
Brandi Briones	
Kevin Brooks	Director HIT/HIE, Michigan State University Institute for Health Policy
Kristy Brown	
Jim Brule	Solutions Director, Allscripts
Melissa Cassity	
Marcus Cheatham	Health Officer, Mid-Michigan District Health Department
Lauren Choi	Senior Advisor & Director, Officer of National Coordinator for Health IT
Denise Chrysler	Director, Network for Public Health Law – Mid-States Region

Chad Cockran	Healthcare IT Consultant
Jim Collins	Director, Communicable Disease, MI Dept. of Health and Human Services
Jeff Coughlin	Senior Director, Federal & State Affairs, HIMSS
Wendy Couturier	Director of IT Project Management, United Physicians
Kelly Cronin	Healthcare Reform Coordinator, HHS, OS, ONC
Rebecca Cunningham	Co-Director, Healthy Flint Research Coordinating Council
Katie Deems	Strategic Account Manager, More Direct
Stephanie Denvir	
Karen DeSalvo	Asst. Secretary and National Coordinator, HHS
Doug Dietzman	Executive Director, Great Lakes Health Connect
Jim Douglas	(VT. – State Advisory Roundtable)
Tim Dubois	IT Manager, Southwest Michigan Behavioral Health
Kathleen Falk	Regional Director, US Dept. of Health and Human Services
Mary Anne Ford	Principal, Mary Anne Ford Consulting
Gregory Forzley	System Ambulatory CMIO, Trinity Health
Esteban Gershanik	Chief Information Officer, Louisiana department of Health and Hospitals
Jim Geringer	Former Governor of Wyoming
George Gooch	Texas Human Services Agency
Katie Goulette	Business Analyst – BI/HIE, Ascension-Genesis
Cynthia Green-Edwards	Director, Support Services, MI Dept. Health and Human Services
Diana Hadzibegovic	Project Analyst – Recovery, Dept. Health and Human Services
Gayle Harrel	State Representative, Florida
Nancy Hartley	Clinical Informatics Transformational Leader, St. Joseph Mercy Health System
Robin Hepfinger	Outreach Coordinator, Michigan Public Health Institute
Megan Herbst	
Ben Hiatt	Regional VP, ICG
Helen Hill	MI HIMSS Director of Public Policy, HIE Liaison, FHIMSS
Therese Hoyle	
Evilia Jankowski	Coordinator School Health Services, Genesee Intermediate School District
Ashwini Jarrel	(LHS)
Maureen John	Onboarding Coordinator, Michigan HIN
Rick Keller	
Mike Kelly	
Mike Judd	IT Manager, Medical Network One
Jessica Kahn	Director, Data and Systems Group, Centers for Medicare and Medicaid Services
Sharon Kim	Healthcare Analyst, BCBSM
Raja Krishnamoorthy	VP – Innovation and Research, Infomagnetics Technology Corporation
Phillip Kurdunowicz	Department Analyst, MI Dept. of Health and Human Services
Mark Lazar	Director of Corporate Affairs, MedNetOne HS
Thomas Leary	Vice President, Government Affairs, HIMSS
Jim Lee	VP Data Policy, MHA
Christina Leininger	Marcomm Intern, Michigan HIN
Jeff Livesay	
David Livesay	
Lucy Mancini Newell	
Erica Mann	
Brian Manning	Head of Growth, Patient Planning
Tom Mason	Chief Medical Officer, OS/ONC
Ewa Matuszewsk	CEO, Medical Network One
Lisa McHuan	NACCHO

Lynda McMillin	Manager, Blue Cross Blue Shield of Michigan
Scott Monteith	Population Behavioral Health, Trinity Health
Susan Moran	Deputy Director, Population Health, MI Dept. of Health and Human Services
Jerry Morin	Account Executive, MoreDirect
Neil Newton	
Thomas Novak	U.S. Health and Human Services
John Paganini	HIMSS Innovation Center
Tanya Patino	Director, IS Clinical Technology, Spectrum Health
Ksmendra Paul	Deputy Director for Mission and Strategy, Information Sharing and Services Office, Department of Homeland Security
Esmerelda Pereira	Director for Recovery Coordination and ASPR Lead, HHS/ASPR/OEM
Jodyn Platt	Assistant Professor, University of Michigan School of Public Health
Tim Pletcher	Michigan HIN
Lawrence Reynolds	President/CEO, Mott Children's Health Center
Valerie Rogers	Director, State Government Affairs, HIMSS North America
Jacqueline Rosenblatt	Interim President/CEO MPRO
Hank Sanberg	CIO, Catholic Healthcare; President of Louisiana HIMSS Chapter
Jim Schephorn	Henry Ford Health System
Tina Scott	
Mark Scrimshire	
Brian Seggie	
Jeff Shaw	
Vik Shetty	Edifecs
Tom Simmer	SVP & CMO, Blue Cross Blue Shield Michigan
Ned Simpson	Executive VP, NJ Associates
Sallie Sims	
Carla Smith	Executive Vice President, HIMSS
Scott Southard	Technical Writer, MIHIN
Brian Stubbs	Cleveland Water Alliance
Gary Strelecki	Vice President, Cordea Consulting
Bob Swanson	
Matthew Swain	Special Assistant to National Coordinator for Health IT, ONC
Falyaz Syed	Associate Director of Clinical Services, Michigan Primary Care Association
Clare Tanner	Program Director, Center for Data Management, Michigan Public Health Institute
Denice Toby	Director of Clinical Systems, Ascension - Genesys
Kassandra Tousignant	
Angela Vanker	Director, Quality Initiatives, MPRO
John Vismara	President, Ingenium
Claire Wang	Fellow, HHS/OS/OASH
Ellen Ward	Manager, Blue Cross Blue Shield Michigan
John Waters	President, Complete Eye Care
Mike Wilkening	Undersecretary, California Health and Human Services Agency
Rick Wilkening	
Marty Woodruff	
Laura Wotruba	Director of Public Affairs, Michigan Health and Hospital Association

Appendix III

Opioid/Heroin Case Study, Stewards of Change Institute

Kerry is a 47-year-old mother with one adult son and three minor children – a daughter who is 16, another daughter who is 6, and a son who is 4. The two younger children are from different relationships. For 13 years, Kerry was a manager at a shipping warehouse, and she was up for a promotion to be a district area manager.

In 2013, while driving home from work, Kerry was in a car accident that resulted in her requiring spine surgery. Her surgeon prescribed two non-abuse-deterrent pain relieving opioids, one short-term and one longer-acting, and staff kept her pain very well controlled while she was in the hospital. When she was discharged, Kerry received a prescription for 60 extended-release, long-acting opioids (a 30-day supply) and 120 of the short-acting opioids to use for “breakthrough pain as needed.”

Kerry remained on both medications for several months. When her surgeon began to taper Kerry from the opiates, she continued to report pain that interfered with her sleep and work. Her surgeon told her that due to the nature of her injury, complete relief was unlikely and she should see her family doctor for ongoing pain management. Kerry’s family doctor was sympathetic and prescribed the same opioids she’d been taking, but after she requested early refills several months in a row, he refused further prescriptions.

Kerry had to have the medications to get through the day. On days when she ran out, she felt too debilitated to go to work, and many days when she went to work, she left early. She never revealed her medication use to her employer, nor did she take advantage of her Employer Assistance Program (EAP) benefits. Finding sources who would prescribe the opiates to stay on top of her growing need for pain medicine became a priority. Several doctors and pharmacies refused to write prescriptions or fill them for her. A few noticed via the prescription drug-monitoring program that she was seeing more than one doctor at a time and frequenting several pharmacies. Also during this period, Kerry enrolled in two different detoxification programs, but once discharged, she could not remain abstinent and she returned to opioids shortly after each one.

Eventually Kerry was arrested for speeding in her car and she failed a sobriety test. She was arrested and her children were temporarily placed into foster care. Because she was able to prove that the opioids she was on were prescribed for her, she pled guilty to a misdemeanor and was placed on probation. Her children were returned, with the child welfare system providing in-home supervisory services pursuant to a family service plan.

Unfortunately, because she missed so much time at work, Kerry lost her job and could not find other work. She then lost her house because she fell behind in her mortgage. For two weeks, the family lived in the one-bedroom apartment of her adult son until the landlord threatened to evict him, so they moved to a family shelter. At the shelter, Kerry applied for and was granted TANF, Medicaid and Food Stamps for herself and her three minor children. As a requirement for receiving these federal public benefits, Kerry also

completed the interviews necessary to file for child support from her former husband (the father of her 16-year-old daughter) and from the fathers of her two younger children.

At this point, Kerry was addicted to opiates; as her access to prescribed medications dwindled and then ended, she sought relief through alternative means. She began to purchase pills on the street, but the price continued to rise and she became aware that heroin was much less expensive. Her 22 year old son told her that heroin could address her pain. Reluctantly, she asked her son to obtain some for her, which he did. She became addicted to heroin and spiraled down into addiction. She would often stay out all night. Because she was violating the shelter rules, she and her children were evicted. The shelter notified the child welfare services and the 3 children were placed into foster care, each in a different home.

A week later, Kerry lost control of the car she was driving and hit a traffic light pole. When the police arrived and searched the car, they found seven “Big Bags” of heroin in the pocket of a coat that was in the back seat. Kerry was arrested on charges of felony drug possession, intent to distribute heroin and impaired driving. She was also charged with a probation violation. Kerry was placed in the county jail because she could not make bail.

At the arraignment hearing, a public defender explained that Kerry was going through heroin withdrawal because of her opiate addictions, and the judge transferred her to the jurisdiction of a specialized drug court. There, the judge approved her request to participate in another detox program. The drug court's pre-trial services worker contacted the behavioral health system, which sent a case manager to the courthouse to assess Kerry; the recommended treatment was a specialized 30-day detox program for women who had previously been in treatment and relapsed quickly thereafter. A vacancy in this program was expected in three days. Following the assessment, Kerry was taken back to the county jail, and her case manager made arrangements for her to be transported from there to the treatment facility once a bed became available.

During her stay at the detox program, Kerry was concerned about how she was going to maintain her sobriety, so she called the behavioral health office case manager for help. Kerry also told the case manager that she was worried that, once she left the treatment facility, she would have no place to live where her children could visit and eventually be returned to her custody. Kerry asked the case manager to arrange for a visit with her children while she was in rehab. The case manager tried several times to reach the child welfare social worker, but they never connected.

Appendix IV

Interoperability in Action: Fusion Centers and HIDTAs

Fusion centers have been helping to protect America in the aftermath of Sept. 11, 2001, when the nation recognized the dire need for improved federal, state, local, tribal and territorial government and private-sector partner threat-related data-sharing and analysis. In partnership with the Information Sharing Environment (ISE), which was created in

response to 9/11, the 79 facilities across the country comprising the National Network of Fusion Centers have become key components of the homeland security information sharing environment. Fusion centers incorporate a multi-disciplinary approach for identification of major threats, major crimes and major hazards that includes collaboration with partners from the public safety, public health, and private sector communities.

The High Intensity Drug Trafficking Areas (HIDTA) program, created by Congress with the Anti-Drug Abuse Act of 1988, provides assistance to Federal, state, local, and tribal law enforcement agencies operating in areas determined to be critical drug-trafficking regions of the United States.

The purpose of the program is to reduce drug trafficking and production in the United States by facilitating cooperation among law enforcement agencies to share information and implement coordinated enforcement activities, enhancing law enforcement intelligence, and supporting coordinated law enforcement strategies.

As part of ONDCP's Heroin Response Plan the Washington/Baltimore HIDTA has developed the Overdose Detection Mapping Application Program (ODMAP). ODMAP uses a web service accessible through a smart phone or computer to allow first responders to report fatal and non-fatal overdose incidents.

Together, the HIDTAs and Fusion Centers can leverage their resources to coordinate narcotics data collection, analysis and information sharing across the United States and three territories. They are a powerful resource that should be at the heart of any planned strategies to combat the opioid epidemic our country is currently facing.

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