



# Partnerships, Programs, and Platforms:

Addressing Social Determinants of Health through Multi-Sector Data Sharing

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# EXECUTIVE SUMMARY

**Background.** The National Interoperability Collaborative (NIC) is a “community of networks” co-launched in 2017 by Stewards of Change Institute and AcademyHealth. NIC was founded to help promote technology strategies and best practices for collaborative and integrative multi-sector work among health and human services organizations to address social determinants of health and well-being (SDoH). Seed funding was provided by the Kresge Foundation (<https://kresge.org/integration-of-health-and-human-services>), which supports the creation of more seamless systems that provide greater opportunities for social and economic mobility (SEM) as well as better health outcomes.

NIC is based on the premise that individual health outcomes and community health disparities are influenced by far more than access to health care. Just think about asthmatic children who live near a bus station, an elderly widow who lives alone and needs a ride to a clinic appointment, a veteran with a traumatic brain injury (TBI) who needs a place to live, families drinking contaminated water in Flint, or a single mother who was just laid off and cannot afford to feed her children or pay rent. In all of these examples, a variety of community-based groups and public agencies may offer individual and family services, supports, and interventions that make a significant difference in quality of life and well-being.

Interest in addressing these social, environmental, and other non-medical determinants of health and well-being has accelerated rapidly in recent years. Across the country, health and human services policy-makers, service providers, researchers, advocates, and data scientists are looking for better, faster, and more efficient ways to connect people with the services and resources they need to lead healthier, more productive and self-sufficient lives. There is a significant increase in support for a health equity perspective, which uses actionable information collected at the individual and community levels to intentionally reduce and eliminate health disparities.

While the idea of integrating health and human services has been around for decades, coordinating community-based human services organizations with health care systems has proven to be a huge challenge. NIC is particularly interested in the ways that technology can help to connect people and promote the flow of information to improve care and services and to promote self-determination.

Once human needs are addressed in a more coordinated way, and people and organizations are connected through relationships and digital information-sharing, it becomes possible - even desirable - to aggregate, analyze, and visualize the available information so it can be better understood by policy-makers and the public. Data sharing allows us to gain a deeper understanding of trends and patterns and to take actionable steps to address issues directly at the community level.

Over time, by improving health outcomes for individuals and families, data about their experiences can be aggregated and mapped to better predict what services will be needed at the community level in the future, while protecting their individual privacy. And individual success stories grouped together at the community level contribute to overall community health improvements.

**About this Report.** This overview of the technology behind emerging multi-sector initiatives is geared toward those who are beginning social determinants work, preparing to scale up existing programs, or looking for new partners. We will highlight some of the leading initiatives that use technology to provide better care and services by connecting health care systems with human services organizations. Some of these initiatives also involve connections with public health agencies at the state and local levels. While there are many other kinds of services that play vital roles (e.g., housing, transportation, food pantries), this report will focus on intersections among health, human services, and public health initiatives and organizations.

The report reflects a broad synthesis of information from published, peer-reviewed articles as well as web sites, blogs, conference presentations, and interviews with a variety of experts on social determinants of health and health equity. It is intended to describe exemplary work in progress and is by no means exhaustive, because new initiatives and resources emerge constantly.

**Summary and Recommendations.** We find that the organizations seeking to connect people with the right care and services, and to ensure that all service providers have complete information available when and where they need it, are transforming the way social determinants are addressed at the community level. Their leaders share a sense of urgency about



solving community-based problems, and they view data sharing and collaborative systems not as a technical challenge, but as the lifeblood for successful, coordinated and strategic actions that promote health equity at the community level.

For example, coordination of information systems is greatly improved through integrated eligibility and enrollment systems for Medicaid, Temporary Assistance for Needy Families (TANF), and the Supplemental Nutrition Assistance Program (SNAP), and is supported by CMS 90/10 funding. Systems integration can help to improve efficiencies and reduce eligibility and enrollment costs to individual administrative programs, while also reducing the burden and stress for families.

An integrated approach does not mean that human services and public health will be “medicalized” or brought “under” the healthcare system. Rather, it reflects the realities that:

1. There is a significant and longstanding imbalance of resources between health care and the public health and human services sectors;
2. Low-income individuals are disproportionately more likely to experience social and environmental risks that publicly funded systems have a mandate to address; and
3. Current collaboration models are generated predominantly from health care systems reaching out to other sectors, and they are far from comprehensive.

The figure shows how these different components might be viewed from a perspective that integrates health and human services along with public health and other sectors. The availability and focus of these components vary in different communities, and there are other sectors (e.g., personal safety) that are not represented graphically here because of space limitations but that may have an impact on health and well-being.

We recommend the following steps for stakeholders interested in addressing social determinants:

**Build stronger collaborations at the intersections of health, human services, and public health.**

**Make a commitment to technology integration for better coordination of services and data about services.**

**Leverage available resources within existing systems to facilitate information exchange.**

**Align professional incentives, jobs, and training to systems thinking and strategic management that leads to collaborative technology integration.**

**View multi-sector collaboration through an equity lens.**

Our recommendations reflect a sense of urgency about addressing social needs in a comprehensive way, based on evidence of what works. Over time, the most successful collaborations will integrate health and human services approaches with public health systems in new ways, leveraging the work of programs in other sectors focusing on social and economic mobility for individuals and families.

We are encouraged by the emerging body of work and growing evidence that the strategic coordination of resources and flow of information across organizations - based on relationships, shared goals, and trust - can make a major difference in the lives of the public. When those success stories are summarized and brought together, we believe they will show a return on upstream investments that will ultimately reduce disparities, improve health and social outcomes at the population level, and promote equity.

# BACKGROUND AND CONTEXT

The National Interoperability Collaborative (NIC), a “community of networks” funded by the Kresge Foundation and co-led by Stewards of Change Institute and AcademyHealth, aims to identify and promote technology strategies and best practices for collaborative multi-sector work among health and human services agencies and organizations. We have defined interoperability as “the ability to collect, review, share, and use information seamlessly across organizations and systems” (Edmunds, Johnson, Kang, 2018) (<https://www.academyhealth.org/publications/2018-07/life-isnt-lived-siloes-and-our-data-shouldnt-either>).

NIC focuses on sharing information and promoting best practices among a variety of initiatives, organizations, and projects that address risk factors in the places where we are born, live, study, work, play, and age. These risk factors have both immediate and

long-term impacts on our health, our families’ health, and on the opportunities for health equity at all levels. The most frequently used umbrella term for these conditions is “social determinants of health” (SDoH) (see CDC, 2016; DeSalvo et al., 2016; *Healthy People 2020*, 2018; Stout, 2017; WHO, 2018) (see Figure 1).

This report provides an overview of the technology behind multi-sector initiatives that are working to address the social determinants of health. Its intent is to describe exemplary work in progress and is by no means exhaustive, because new initiatives and resources emerge constantly. The report reflects a synthesis of information from published, peer-reviewed articles as well as web sites, blogs, conference presentations, and interviews with a variety of experts on social determinants of health and health equity.

**Figure 1: A Framework for Social Determinants of Health (SDoH)**

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

**Health Outcomes**  
 Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations

Our intended audience is broad, including those who are beginning to work on social determinants of health, preparing to scale up existing programs, or looking for new partners. While there are many other kinds of services that play vital roles (e.g., housing, transportation, food pantries), we will focus on intersections among health, human services, and public health initiatives and organizations.

### What's in a Name?

People use a variety of terms to describe and measure social and environmental conditions that influence health. The Centers for Medicare and Medicaid Services (CMS) refer to “health-related social needs” (HRSN) (<https://innovation.cms.gov/initiatives/ahcm/>), which is sometimes shortened to “social needs” (Gottlieb, Wing, & Adler, 2017). In the United Kingdom, the term “health and social care” is often used to describe what has been called “the safety net” in the United States and Canada (Glasby, 2018).

The U.S. separates health and social spending programs. It spends more on healthcare than any other industrialized nation, but the U.S. population as a whole is less healthy than other industrialized nations on several key global health indicators used by the World Health Organization and Organization for Economic Cooperation and Development. Studies done by Elizabeth Bradley and Lauren Taylor have shown that larger investments in social programs lead to better health outcomes than healthcare investments alone, both at the national level and across the states (Bradley et al., 2011; 2016).

In most U.S. communities, human services agencies and organizations provide a broad range of assistance for individuals and families to meet basic human needs and to promote quality of life and self-sufficiency. The types of available services and supports vary geographically, reflect local differences in resources and preferences, and are maintained through many different funding streams. There is no single standard vocabulary or framework, so many social and human services organizations refer broadly to “service integration” without specifying the types of services. However, most are chronically and seriously under-resourced and under-funded compared to local levels of need and are facing severe budget threats (<https://chronicleofsocialchange.org/child-welfare-2/trump-budget-for-family-and-youth-services-2020/34274>).

The County Health Rankings Report (<http://www.countyhealthrankings.org/>) talks about “social & economic factors” that can be used to drive improvement reflected by key measures such as length of life and quality of life. The American Academy of Family Physicians refers to “community vital signs” (Bazemore et al., 2015), suggesting that publicly available information on community health can be integrated with personal health records.

The Robert Wood Johnson Foundation (2018) uses the term “culture of health” to refer to a broad, multi-faceted equity approach in which “everyone has the opportunity to live a healthier life” (<https://www.rwjf.org/en/how-we-work/building-a-culture-of-health.html>).

The term “upstream determinants of health” seeks to capture the importance of addressing conditions before they cascade “downstream” to cause specific disease states and poor health. It also focuses on factors such as income, education, employment, neighborhood and broader physical environments, and social support networks, as well as many other environmental, economic, cultural, and social factors that reflect exposure to systemic racism and discrimination (Bharmal, Derosé, Felician, Weden 2015; RWJF, 2013 link: <https://www.rwjf.org/en/library/articles-and-news/2013/08/putting-social-determinants-data-to-work-for-patients-and-provid.html>).

The catchphrase “your zip code is a better predictor of your health than your genetic code,” coined by the researcher Melody Goodman (Roeder, 2014; KFF, 2018), sums up the complexities quite well. For example, babies born a few subway stops apart in Chicago can face up to a 16-year difference in life expectancy (<https://societyhealth.vcu.edu/work/the-projects/mapschicago.html>) (see Figure 2).

**Figure 2: Short Distances to Large Gaps in Health: Chicago, Illinois**



Public Health 3.0 is a national model launched in 2016 by the US Department of Health and Human Services to promote multi-sector partnerships and to leverage data to address social determinants (DeSalvo, Wang, Harris, Auerbach, Koo, & O'Carroll, 2017). The model envisions the role of a Chief Health Strategist at the community level for bringing together partners to collaboratively address the upstream determinants of health.

We will use a variety of phrases in this document to describe the social needs challenges, reflecting the diverse sectors and stakeholders working in this area. Figure 3 shows how we visualize the opportunities for cross-sector collaborations.

We will focus on collaborations in the health and human services ecosystem, which frequently also engage with public health agencies whose mission and core functions include setting up systems and infrastructure for information-sharing (Edmunds et al., 2014; DeSalvo et al., 2017; Braveman & Gottlieb, 2014; Gamache, Kharrazi, & Weiner, 2018; Gold et al., 2017).

### Why Now?

Some view addressing social needs as a social movement or a moral imperative. Others see the current interest in social risk reduction as a natural reaction to policy incentives to manage costs by moving from fee-for-service payment to value-based policy initiatives. These include alternative payment models, system redesign (e.g., team-based care, telehealth), and transformation through increased and reciprocal engagement with care recipients, consumers, and caregivers.

For a variety of reasons, a growing number of initiatives are making and measuring SDoH connections within and across health and human services (H/HS) and public health sectors. Here are some of the main accelerators affecting the groundswell of interest and investment in addressing SDoH:

**1. Evidence shows that social spending improves health outcomes.** The U.S. spends more on health care than any other industrialized nation, but ranks lower than other countries on key indicators of health status. Evidence shows that addressing social and other non-medical needs can reduce health care costs and services needs while improving outcomes and promoting health equity (Bradley, Elkins, Herrin, Eibel, 2011; Bradley, Canavan, Rogan et al. 2016; Udow-Phillips et al., 2018).

**2. Payment models are shifting to value-based care.** Based in part on evidence that high U.S. spending on health care was not yielding results in terms of the health of the population, alternative payment models have been replacing traditional fee-for-service payments and changing the focus away from procedural transactions. New payment models take a systems approach to outcomes, expect documentation of return on investment (ROI), and recognize ecosystem and upstream influences on cost reductions (Shrank et al., 2018). As a condition of payment, Medicare and Medicaid programs may now require health plans to coordinate with community-based human services and other providers. This approach not only helps to reduce expensive emergency room use but also helps to connect people with the right levels of care to address their needs. Emerging evidence on ROI for SDoH shows that these interventions to improve health outcomes and reduce inappropriate health care utilization may eventually produce cost savings (Lee, Majerol & Burke, 2019).

**3. Equity models are gaining support.** Addressing social determinants is not only important for improving health, and potentially reducing or preventing unnecessary expenditures, but also for reducing the disparities that are often caused by systemic, intergenerational poverty and other social and economic disadvantages (KFF.org, 2018). Calls for health equity are supported by an extensive body of evidence that documents health disparities over several decades, with an increasingly clear understanding of how various combinations of risk factors affect different groups and communities (Bharmal et al., 2015; Braveman & Gottlieb, 2014; Hernandez-Cancio et al., 2019). It is clear that achieving the goal of better health for all will require addressing long-term, systemic disparities in community investments and health outcomes.

**4. Adverse Childhood Experiences (ACEs) influence responses to other risk factors.** Traumatic or stressful events experienced or witnessed during childhood, such as abuse, neglect, divorce, violence, or addiction can result in long-term negative effects on a person's health, learning, and coping. A "toxic stress" response to these adverse experiences can lead to physiological changes, including permanent changes in brain development. Trauma-informed approaches to programs that address social determinants and equity are critical to addressing both the impact of childhood trauma and improving health outcomes (American Academy of Pediatrics, 2014; Administration on Children & Families, n.d.; Center on the Developing Child, n.d.).

**Figure 3. How Communities Address Equity and Social Determinants**



As these examples show, the complexities of human experience cross both organizational and geographic boundaries. There are limits to what any one sector can achieve on its own.

For example, the solutions to health issues go beyond medical treatment and require healthcare providers to engage and work collaboratively with community connections to improve the health and vitality of people and their communities. Conversely, clients of human services agencies may need health care in order to return to work and for self-determination and economic viability. Eliminating an environmental risk such as contaminated drinking water at a school may require coordination among

public health and educational agencies as well as working with private clinicians to treat and remediate illnesses or exposures to toxins.

This cross-sector approach does not mean that all services need to be medicalized: rather, it means that the sectors need to focus on and share the same end goal; identify synergies and mutual interests along the way; and share the responsibility – and the resources. Putting the well-being of an individual or family at the center of programs and systems, and acting intentionally in their best interest, is the most unifying end goal in the long run.

# OUR APPROACH TO THIS REPORT

There is rich and seemingly endless variation in services provided in different geographic areas across the country, reflecting local preferences, history, and availability of resources. Funders and providers support and perform similar kinds of work to address social needs, and they often use different terms to describe it, depending on the sector, its mission, its professional scope of practice, and many other factors.

We have focused on multi-sector data sharing as an indicator of successful collaboration. From our previous work, we knew that the number of organizations who are actually sharing data is far smaller than the number of organizations who aspire to do so.

Most data-sharing initiatives take a significant amount of time and effort to launch and implement: develop a strategic plan, hire and train staff, build technical capacity, negotiate and develop shared governance, and engage in infrastructure-building and implementation before data can be shared.

These challenges may be discussed at conferences, webinars, and other convenings, as well as among members of online communities of practice, but they are not typically written about. To approach this review, we re-engaged experts from our previous NIC scan on interoperability, *From Siloes to Solutions* (Edmunds, Johnson, Kang, 2018.) (<https://www.academyhealth.org/publications/2018-07/life-isnt-lived-siloes-and-our-data-shouldnt-either>), other recent AcademyHealth reports (Brodt, Kang, & Rein 2017; Hunter et al., 2018), as well as presenters and participants at the NIC New England Symposium in Avon, Connecticut in November 2018 (<https://hub.nic-us.org/events/new-england-symposium>).

Because of the overwhelming amount of activity to address various aspects of SDoH, we decided to focus our review on publicly available information about the tools and platforms being used to help make collaboration happen. We started with nearly 30 programs that we had reviewed in our previous scan on interoperability in nine sectors and added others suggested through our professional networks. We synthesized information from formal interviews and informal conversations with leaders and program

managers directly involved in national and regional SDoH policy initiatives and programs involving data sharing and reviews of their formal program descriptions and online presentations.

We then applied the following inclusion criteria:

- Nationally applicable or replicable;
- Multiple sectors collaborating to address SDoH;
- Grantmaking program, portfolio of projects, or technology platform that supports data sharing;
- Active within the last seven years (2012 to 2019);
- Freely available online (i.e., not behind a paid firewall); and
- Based in the United States.

The review includes a variety of sources of information, including peer-reviewed publications, online and print issue briefs, white papers, blog posts, and reports published by well-known and reputable sources (as defined by a consensus of our team and reviewers). New resources become available and/or are updated all the time, so our examples are exemplary but not exhaustive.

Given the rapid pace of this work, we view this scan as a snapshot of the field as of early 2019. We hope our review will help to raise awareness and make these resources available to a broad audience that seeks to understand the scope, breadth, and challenges of the work and learn more about emerging successes.

# WHAT WE FOUND

Many kinds of health care and service organizations are now bridging medical and non-medical needs by using screening, information and referral, and navigation services to help people with food and income insecurity, housing, utility payments, and transportation. Funding for many of these efforts comes through federal and state delivery and payment reform initiatives that connect Medicare, Medicaid, and Children's Health Insurance Program (CHIP) beneficiaries to available services near where they live. A growing number also support telehealth services when providers and consumers are in different physical locations (Tuckson, Edmunds, Hodgkins, 2017).

## Federal and State Initiatives

The following delivery system and payment reform initiatives initiated within the Medicare and Medicaid programs have expanded the range of services to address social needs.

- **Accountable Care Organizations (ACOs)** (<https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/ACO/>) are groups of doctors, hospitals, and other health care providers who collaborate to give coordinated high quality care to Medicare and Medicaid patients. Medicaid ACOs have been launched in 12 states (see <https://www.chcs.org/resource/medicaid-aco-state-update/>), and some states require ACOs to implement social needs interventions. For example, New York State has a menu of social interventions including a Housing First program to address homelessness or mold abatement (<https://www.chcs.org/addressing-social-determinants-health-medicare-accountable-care-organizations/>), and also encourages partnerships with food banks to help address food insecurity. Massachusetts, Rhode Island, and Colorado require establishing relationships with community-based organizations to help coordinate services to meet social needs. Hospitals and health systems are beginning to focus on social needs in Medicaid and Medicare, including Medicare Advantage plans (<https://www.aha.org/guidesreports/2019-01-09-social-determinants-medicare-and-medicare-white-papers>).
- **Accountable Health Communities** (<https://innovation.cms.gov/initiatives/ahcm/>) will connect Medicare and Medicaid beneficiaries with community services through screening, referral, and community navigation services. In 2017, CMMI provided funding to 32 organizations to test the model over a 5-year period: 12 will be providing community navigation services and the others will focus on community partnerships. For example, the Baltimore City Health Department received \$4.3 million to work with hospital and community health center partners and social services partners to provide comprehensive screening and referral for Medicare and Medicaid participants (<https://health.baltimorecity.gov/baltimore-accountable-health-community>). Some Medicare Advantage plans are expanding beyond traditional Medicare benefits to cover more social needs among defined populations, and CMS is providing guidance on what can be included (<https://khn.org/news/medicare-advantage-plans-cleared-to-go-beyond-medical-coverage-even-groceries/>). Early findings suggest that these models may help improve access to medical care, help to reduce health care costs, and improve health outcomes by addressing social needs (Shrank, Keyser & Lovelace, 2018).
- **Community Health Needs Assessment (CHNA):** The Affordable Care Act requires tax-exempt hospitals to identify unmet community needs and to implement strategies that benefit their communities (ASTHO 2014; Heath, 2018). Some health systems have partnered at the local level to share the funding and design of CHNAs and then to develop collaborative community health improvement strategies that leverage local resources and build a larger audience to help support local health issues. For example, the CHNA effort in Montgomery County, Maryland, led to Nexus Montgomery Regional Partnership, a collaborative effort of six hospitals and a network of community-based organizations that are making creative investments in behavioral health, food security, respite beds for homeless people, and other initiatives. The partnership was funded by the Maryland Health Services Cost Review Commission (HSCRC), which used \$7.6 million in re-appropriated DSH (Disproportionate Share Hospitals) payments (see <http://www.healthymontgomery.org/index.php?module=Tiles&controller=index&action=display&id=46187274561166799> and <https://nexusmontgomery.org/montgomery-county-hospitals-announce-funding-of-nexus-montgomery-regional-partnership-state-awards-7-6-million-to-implement-population-health-measures/>).

■ **Delivery System Reform Incentive Payment (DSRIP):**

Beginning in 2010, the DSRIP program approved Medicaid waivers to set up new types of care delivery, including new approaches to screening for social needs. For example, the New York waiver allows provider systems to seek supportive housing for Medicaid patients (Artiga & Hinton, 2017). The DSRIP program has provided \$40 billion over seven years in 12 states (California, Texas, Massachusetts, New Mexico, New Jersey, Kansas, New York, Oregon, New Hampshire, Rhode Island, Washington, Arizona) (see <https://www.macpac.gov/wp-content/uploads/2018/03/Exploration-of-the-Evolving-Promise-of-DSRIP-and-Similar-Programs.pdf>).

- **Medicaid Managed Care** plans have defined populations and financial incentives to address social needs and thereby improve care and treatment outcomes. Many states are using 1115 (Medicaid and CHIP) and 1915 waivers (Home and Community Based Services, or HCBS) to expand their work on social determinants within the Medicaid program. For example, North Carolina is using waivers to expand the range of social services (e.g., housing, food insecurity, intimate partner violence, behavioral health) and may eventually implement statewide (see <https://www.commonwealthfund.org/publications/issue-briefs/2017/nov/addressing-social-determinants-health-through-medicaid-managed>; also Center for Health Care Strategies, <https://www.chcs.org/resource/addressing-social-determinants-of-health-via-medicaid-managed-care-contracts-and-%C2%A7-1115-demonstrations/>).

- **SIM (State Innovation Models)** (<https://innovation.cms.gov/initiatives/state-innovations-round-two/>) are state-led, multi-payer health care payment and delivery models designed to improve health outcomes and test state policy and regulatory approaches to accelerate health care transformation (<https://www.rti.org/impact/evaluating-state-innovation-models-sim-initiative>). Six states (Arkansas, Maine, Massachusetts, Minnesota, Oregon, and Vermont) were funded by CMMI in 2013, and an addition 11 states were funded in 2015 (Colorado, Connecticut, Delaware, Idaho, Iowa, Michigan, New York, Ohio, Rhode Island, Tennessee, and Washington). States are pursuing a variety of approaches to address social needs and population health.

This flexibility in funding is helping to accelerate system transformation, but it is challenging to evaluate and difficult to make generalizations across the board. Interested readers are referred to other resources, such as the Center for Healthcare Strategies (2018b), The Commonwealth Fund (2018), and RTI (2019) for more detailed assessments.

**Implementation Assistance: Federal Resources**

While CMS drives payment through Medicare and Medicaid, implementation guidance and support for the data infrastructure is being provided by other agencies.

- **Administration for Children and Families** (ACF), U.S. Department of Health and Human Services. Interoperability Action Plan (IAP) and Toolkit (<https://www.acf.hhs.gov/about/interoperability>): developed to coordinate and guide data improvement activities across ACF and all human services at HHS; coordinates with CMS and the Office of the National Coordinator for Health IT (ONC) to support coordinated case management and data-informed decision making.
- **Centers for Disease Control and Prevention (CDC) Resources on SDoH** (<https://www.cdc.gov/socialdeterminants/index.htm>): Website provides links to SDoH data, maps, tables, graphics, programs, policy resources, guidance documents, and research on SDoH at state and city levels of intervention. CDC has also identified policy interventions at the state and community level that address broad social and economic conditions, in their Health Impact in 5 Years (Hi-5) Initiative, <https://www.cdc.gov/policy/hst/hi5/index.html>. Another CDC resource is the Community Health Improvement Navigator (<https://www.cdc.gov/chinav/index.html>), which includes a variety of tools and resources, including a database of successful interventions with steps for planning, communications, and public reporting.
- **MITA (Medicaid Information Technology Architecture), Centers for Medicare and Medicaid Services** (<https://www.medicare.gov/medicaid/data-and-systems/mita/index.html>): Provides a process and toolkit for states to share/exchange standardized data. Maintains a bimonthly Medicaid Enterprise Systems newsletter to share information. MITA includes a Reuse Repository for states to share documents/products others might reuse and adapt; a MITA Maturity Model; a Health Information Sharing Maturity Model (HISMM); and other resources.
- **NIEM (National Information Exchange Model) Domains for Human Services** (<https://www.niem.gov/communities/human-services>): NIEM provides a common vocabulary and standardized exchange development process with active user communities at the federal, state, and local levels. It began as the Global Justice Information Sharing Initiative in 2003 and was developed by Federal CIOs of DHS and DOJ; HHS was added in 2010. All 50 states and many federal agencies use the data model, which features flexible formats, (XML, UML, and JSON) (<https://www.niem.gov/about-niem/strategic-initiatives>). Grant support is available to states to improve information exchange and interoperability using the NIEM model.

- **ONC (Office of the National Coordinator for Health IT, Office of the Secretary of U.S. Department of Health and Human Services):** released a toolkit for states to guide their IT infrastructure planning to support Medicaid 1115 waivers and other delivery system reforms ([https://www.healthit.gov/sites/default/files/1115HealthITToolkit\\_LE\\_2017\\_01\\_13\\_ASN.pdf](https://www.healthit.gov/sites/default/files/1115HealthITToolkit_LE_2017_01_13_ASN.pdf)) ONC also provided a resource center for SIM states to build an information infrastructure to support the transition to value-based payment systems.

## Private Sector Funding Sources to Address Social Determinants of Health

Several national foundations, notably Aetna, de Beaumont, W. K. Kellogg, Kresge, and The Robert Wood Johnson Foundation (RWJF) have focused on bridging health and non-health sectors to coordinate services, promote equity, and support individual health and self-sufficiency as well as community planning. In many cases, these initiatives build on local resources and public funding through Medicare and Medicaid, as well as investments from health plans, hospitals, and anchor institutions (Nichols & Taylor, 2018; Ragin, Jr. & Palandjian, 2013).

The rationale for these investments varies from cost savings through efficiencies to reduce overutilization through value-based purchasing to a moral and ethical imperative. From a purely pragmatic perspective, however, it seems clear that services need to be coordinated and integrated to be successful.

- **All In Online Community: Data for Community Health** (<http://www.allindata.org/about-us/>): Peer-to-peer learning network that helps 100+ communities build multi-sector data sharing collaboratives to address SDoH. Funded by the Robert Wood Johnson Foundation (RWJF), All In seeks to improve understanding of data-sharing strategies across community-based and public programs and to disseminate evidence on what works so that effective policies and programs can be implemented. It includes a community collaboration platform (<http://allin.healthdoers.org>) and was co-founded by the Illinois Public Health Institute, AcademyHealth, and other partners.
- **The BUILD Health Challenge: BUILD 1.0 and 2.0 Communities** (<https://buildhealthchallenge.org/our-communities/>): supported by multiple foundations, including deBeaumont, W. K. Kellogg, Kresge, & RWJF. Promotes systems change through partnerships and a shared commitment to move resources, attention, and action upstream. National awards program promotes collaborations among community-based organizations, hospitals and health systems, local health departments, and others to address SDoH through education, housing, transportation, the built environment, employment, and other multi-sector projects. See the report on Data Sharing within Cross-Sector Collaborations on the Box Platform <https://buildhealthchallenge.app.box.com/s/emzj4uqbd84z4hgzye0ti2vd171300yi>
- **The California Endowment** (<https://www.calendow.org/>): Beginning in 2010, the Building Healthy Communities Initiative has been providing \$1 billion over ten years for 14 California communities to use a Framework for Health Equity to address social determinants of health.
- **Data Across Sectors for Health (DASH)** ([http://dashconnect.org](http://dashconnect.org/)): funded by RWJF and co-led by Illinois Public Health Institute and Michigan Public Health Institute. National network of local learning communities that are testing multi-sector partnerships to connect information systems and share data. Builds local capacity to foster multi-sector data and information sharing to improve community health.
- **de Beaumont Foundation** (<https://www.debeaumont.org/our-approach/>): invests in tools, partnerships, policies, and the public health workforce to promote community health. Supports BUILD Health Challenge (<https://buildhealthchallenge.org/our-communities/>), Practical Playbook (<https://www.debeaumont.org/practical-playbook/>), and CityHealth (<https://www.cityhealth.org/>).
- **Kresge Foundation** ([https://kresge.org](https://kresge.org/)): provides grants that promote healthy communities through integration of health and human services and build equity-focused systems of health through cross-sector collaboration. Supports the National Interoperability Collaborative, BUILD Health Challenge and Place-Based Opportunity Ecosystems (advancing social and economic mobility) <https://kresge.org/programs/human-services/building-place-based-opportunity-ecosystems-0>. Also see Nine Lessons For Leaders Of Health And Human Services Integration Initiatives (And For The Grantmakers That Want Them To Succeed), Health Affairs Blog, July 10, 2018. DOI: 10.1377/hblog20180709.359520)
- **The Robert Wood Johnson Foundation** (<https://www.rwjf.org/>): The largest health philanthropy in the country funds leadership, health systems, healthy communities, and related initiatives that promote a culture of health in which social determinants are addressed from a health equity perspective.



- **National Interoperability Collaborative (NIC)** (<https://nic-us.org> and <https://nic-us.org/nic-collaboration-hub/>): funded by Kresge Foundation to develop a community of practice for sharing SDoH data among health and human services agencies and organizations.
- **National Collaborative’s Analytics Committee, APHSA (American Public Human Services Association)** ([https://aphsa.org/NC/NC/Guidance\\_and\\_Resources\\_Sub/data\\_sharing\\_analytics.aspx](https://aphsa.org/NC/NC/Guidance_and_Resources_Sub/data_sharing_analytics.aspx)): produced a guide to Data Management, Privacy & Confidentiality, and Predictive Analytics to help county H/HS directors, Health IT coordinators, analysts, and CIOs in state and county H/HS departments, researchers, and industry partners to improve cross-sector systems of care.
- **SIREN (Social Interventions Research and Evaluation Network)**: based at University of California, San Francisco, with support from RWJF, Kaiser Permanente, and other sources. Founded to catalyze and disseminate high quality research to advance addressing social risks in healthcare settings. Maintains

a comprehensive Evidence Library (<https://sirenetwork.ucsf.edu/tools/evidence-library>) that includes a comparison of social health screening tools.

At the non-technical end, traditional screening and referral services – especially in community-based organizations - may include homegrown directories of local services developed by single institutions and departments, which are time-consuming to maintain and update. There has been an explosion of interest in using standardized online tools and toolkits such as PRAPARE (Protocol for Responding to and Assessing Patients’ Assets, Risks, and Experiences) ([http://www.nachc.org/wp-content/uploads/2018/05/PRAPARE\\_One\\_Pager\\_Sept\\_2016.pdf](http://www.nachc.org/wp-content/uploads/2018/05/PRAPARE_One_Pager_Sept_2016.pdf)); the Health Leads social needs screening toolkit (<https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/>); and the CMMI Accountable Health Communities screening tool to identify health-related social needs (<https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf>).

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## February 2019 Research Round Up

Thursday, February 28, 2019



Below we highlight recent literature on screening for and/or addressing social needs in clinical settings. To receive the Research Round-Up in your email, [sign up for our monthly newsletter](#).

Find these articles and many more in our searchable [Evidence Library](#).

### RECENT NEWS

**February 2019 Research Round Up**  
Thu, 02-28-2019

**January 2019 Research Round-Up**  
Thu, 01-31-2019

**December 2018 Research Round-Up**  
Wed, 01-02-2019 | SIREN Staff

**November 2018 Research Round-Up**  
Thu, 11-15-2018 | SIREN Staff

**October 2018 Research Round-Up**  
Wed, 10-17-2018 | SIREN Staff

Another innovative approach to streamlining care coordination is led by the Community Information Exchange (CIE) powered by 2-1-1 San Diego (<https://ciesandiego.org/what-is-cie/>). The CIE provides enhanced, technology-based, community-driven care coordination to individuals; generates a longitudinal record that helps service navigators provide long-term support to clients; and collects social determinants of health data that can highlight community and population-level needs to inform community planning.

### Implementation Assistance: National Non-Profit Organizations

National non-profit organizations also provide technical assistance, capacity-building, and other supports for implementation with support from a variety of public and private sources.

- **ASTHO (Association of State + Territorial Health Officials)** (<http://www.astho.org/Programs/Health-Equity/>): has several initiatives addressing public health practice funded by CDC,

OMH, states, and other cross-sector partnerships. ASTHO's Center for Population Health Strategies advances population health improvement through three pillars: Health Equity and SDoH; Clinical to Community Connections; and Data Analytics and Public Health Informatics.

- **HealthDoers Network** (<https://healthdoers.org/>): launched by the Network for Regional Healthcare Improvement (NRHI) and funded by RWJF, the online platform provides opportunities for tailored collaboration and shared learning and offers community management, a resource library, and technical assistance to several collaboratives.
- **Illinois Public Health Institute** (<http://iphionline.org/2018/12/iph-2018-impact/>): supported by foundations and project partners, IPHI Provides consultation, technical assistance and advocacy; public education; and policy and systems research. Co-leads DASH National Program Office. Co-founded All In: Data for Community Health and helps to maintain collaboration platform using the HealthDoers platform.

- **Institute for HealthCare Improvement (IHI): SCALE I and II** (Spreading Community Accelerators through Learning and Evaluation) ([https://www.100mlives.org/wp-content/uploads/2017/07/Overview-of-SCALE-Community-of-Solutions-7.7.17\\_final.pdf](https://www.100mlives.org/wp-content/uploads/2017/07/Overview-of-SCALE-Community-of-Solutions-7.7.17_final.pdf)) are funded by RWJF. SCALE I involves forming regional networks with 4-6 neighboring communities. SCALE II involves bringing about change in community-wide practices and key anchor institutions. IHI uses an online platform (<http://connect.100mlives.org>) for several projects including Community of Solutions, a model of community transformation that leads to sustainable improvement in health, wellbeing, and equity.
- **National Human Services Data Consortium (NHSDC)** (<https://nhcdc.org>): Works to develop effective leadership for the best use of information technology to manage human services through information-sharing, convening, training, peer-to-peer consultations, and networking.
- **Public Health Institute** (<http://www.phi.org/about-phi/funders/>): Funded by federal and state government agencies, foundations, and universities to improve research, partnerships and programs, and advance sound health policies. Multi-sector, online professional information-sharing community facilitated through Web platform Dialogue4health <http://dialogue4health.org>
- **Public Health National Center for Innovations** (<https://phnci.org>): PHNCI coordinates public health practice innovations and shares innovative ideas as local communities transform to improve health outcomes. Housed at the Public Health Accreditation Board (PHAB), with funding from The Robert Wood Johnson Foundation (RWJF).
- **ReThink Health** (<https://www.rethinkhealth.org>): With funding from the Rippel Foundation, develops tools for leadership and change management to improve the health ecosystem. Conducts research, develops tools, and provides assistance to innovators to help them navigate change. Tools include Rethink Health simulation model to stimulate multi-sector strategy design <https://forio.com/app/rippel/rethink-health/login.html>.

# WHO IS SHARING DATA?

Health and human services (H/HS) organizations around the country are looking for ways to share data so they can provide more coordinated approaches to individual, family, and community health and well-being.

In the human services sector, the Administration on Children and Families (ACF), part of the U.S. Department of Health and Human Services, is leading the initiative to standardize the exchange of information through providing a common architecture and data model (<https://www.acf.hhs.gov/about/interoperability>). The American Public Human Services Association (APHSA) has provided several toolkits to promote horizontal integration of H/HS, develop strategies for data sharing and analytics, and address data management, privacy, and confidentiality ([https://aphsa.org/NC/NC/Guidance\\_and\\_Resources\\_Sub/guidance\\_and\\_tools.aspx](https://aphsa.org/NC/NC/Guidance_and_Resources_Sub/guidance_and_tools.aspx)).

In the public health sector, data within certain core functions related to health assessments – e.g., immunization registries, emergency alerting systems – already tend to be standardized and shareable, but they tend to be disease-specific or defined geographically by a jurisdiction. Standardization of public health data is usually driven by the funding source, typically the Centers for Disease Control and Prevention (CDC), making it a condition of funding. National public health partner organizations then lead a consensus-based process to agree on the data structure and format.

The health care sector information infrastructure for data sharing on social determinants is complex, fragmented, and highly variable. No single definition or framework fully captures all dimensions of the conditions that impact the social determinants of health, and there are many approaches to defining the sectors that are currently involved in multi-sector collaboration.

Current SDoH initiatives vary significantly in terms of:

- Funding sources, amounts, and eligibility restrictions;
- Goals, purposes, and objectives;
- Stakeholders involved;
- Leadership and governance structures;
- Types of individuals or populations engaged;

- Types of agencies/organizations engaging with those individuals or populations;
- Sources of data;
- Strategies for data sharing and capacity for integration;
- Reporting requirements;
- Degree of evaluation; and
- Public documentation of strategies, methods, and progress.

Given such a complex, compelling set of perspectives and challenges, it is not surprising that there are multiple sources of unconnected data in different formats running on whatever applications and systems are native to specific organizations. To establish and maintain a flow of information among organizations and even between different parts of one organization, a multi-stakeholder team approach is essential to bring together the executive management, information technology, research/analytics, program management teams, and communications and public affairs. Ideally, team members bring together multiple areas of technical and programmatic expertise, work with collaborative leadership, and leverage available resources to address data integration challenges in carefully planned phases.

No single source of information or guidance can fully address all stakeholders' interests or fully assess similarities and differences in approaches and applications across sectors. Within the time and resources we had available for this report, we hope to provide useful descriptive information that synthesizes different experiences our partners have had; highlights key findings that seem consistent across sectors; and describes best practices in information sharing that can affect outcomes at the community, program, and individual levels.

## Step by Step

In our experience, the typical first – and often the longest - step for building, expanding, or upgrading information systems that will integrate different sources of data is to spend time on visioning what the system will need to accomplish. This includes determining how it will be led and organized (i.e., governance), making the case for building and investing in a new system, and securing the funding. Only then can an implementation plan be developed and launched.

The most challenging parts of the planning process are identifying the right entities to engage and developing the rules of engagement, or governance structure. With such a broad range of potential partners, it is vitally important to come to agreement on purpose, goals, means of achieving those goals, as well as technical and legal requirements for sharing information, including data structure and standards and other business operations. The Healthcare Information and Management Systems Society (HIMSS) Alternative Payment Model Governance Toolkit (<https://www.himss.org/library/governance-toolkit>) is one example of a guidance document that can help to delineate concrete activities and provide guidance on how to proceed in building a collaboration for the purposes of data sharing.

As part of the governance and planning process, it is important to clearly define the enterprise business proposition for data integration from both a program and policy lens. The technology is a tool to facilitate integration, which will improve efficiencies and eliminate duplication of effort, but the technology alone does not define the integration. The program stakeholders need to designate qualified and competent staff with direct lines to program leadership in order to maintain the integrity of the programmatic vision.

With financing and governance in place, the leadership team identifies technology experts, usually outside consultants, who will do a basic requirements analysis and advise program leaders on whether to buy new software, build on top of existing systems, or some combination of the two. The designated lead program and technical staffers and other end-users of the current and future need to be involved at every step of the decision-making process.

Next, the consultants choose a platform (with varying degrees of consultation with clients); develop a plan; and make a timeline known to the organization, providing reasonable updates on the development process as it proceeds. Most experienced jurisdictions pick an existing platform and hire a consultant to do the data integration, rather than starting from scratch.

Similarly, a transparent implementation plan is essential. After the initial launch, there is a period of training and support while program staff learn to use the platform. The usual business model for external consultants is to contract to provide ongoing technical support and plan for upgrades after the initial installation and implementation, and transition maintenance to an internal IT team whenever possible to maintain an interface with the organizational users.

The plan for sharing data (e.g., claims, encounters, clinical information) with external organizations for oversight or research is usually an entirely separate process, unless it is built into the regular contracting and workflow by leaders who oversee both workstreams. Because of the need to protect sensitive personal information, data use agreements must be negotiated in order to ensure legal and regulatory compliance and security of the information from breaches and hacking.

We are aware of circumstances where separate legal contracts were drawn up for every data sharing partner, which is time-consuming and expensive. Fortunately, there are other models that rely on a common infrastructure. One is the Health Information Exchange (HIE), where a third-party organization provides technical services in a secure multi-stakeholder environment in exchange for user fees (<https://www.healthit.gov/topic/health-it-and-health-information-exchange-basics/what-hie>). The Strategic Health Information Exchange Collaborative (SHIEC) <https://strategichie.com>) represents community, regional, and statewide HIEs that are interested in sharing best practices and working toward interoperability across the country.

Another emerging model in the non-profit sector is to include information technology and informatics experts with good management, analytics, and communications skills as part of the core executive team, so that program information drives the collection, management, curation, and sharing of information rather than being primarily responsive to billing or reporting requirements. Many of NIC's members work in high-functioning teams that reflect this kind of cross-sector expertise. Fortunately, there is a rapid acceleration in the number of programs that offer training in data science and strategic management to address the shortage of personnel who meet these core competencies.

In the broadest sense, the technology needs of most helping organizations include the following functions, in order of complexity:

- Messaging
- Scheduling appointments
- Providing information and making referrals
- Prescription ordering and management
- Care management and coordination
- Feedback on completed referrals and patient/client outcomes
- Analytics



# Community Information Exchange

Navigating the intersection of health and social services through information sharing and coordinated care.

What is CIE?

While there are still paper and home-grown systems for all of these functions, a growing number of affordable software systems and plug-and-play modules are coming on the market.

Still in development are procedures and protocols to enhance consumer/client access to their own personal information and decision support tools that provide filtered or curated electronic information that helps in making choices about options for treatment or service decisions (e.g., <https://www.healthit.gov/topic/safety/clinical-decision-support>).

Some early adopters and innovators are driven by the priorities and availability of funding from national sources (e.g., foundations) with organizing frameworks (e.g., culture of health, social and economic mobility). Some local and regional programs and initiatives are able to use a single source of funding to accomplish several decidedly different goals; while others are use multiple sources of funding to accomplish a common initiative to coordinate different sets of services for different populations: this is known as blending and braiding (Cabello & Ballard, 2018; TFAH, 2018).

The collective impact model ([https://ssir.org/articles/entry/collective\\_impact](https://ssir.org/articles/entry/collective_impact)) is being widely used as a cross-sector organizing and implementation framework for community-based groups and multi-sector organizations alike. The collective impact model has five elements:

- Common agenda
- Shared measurement
- Mutually reinforcing activities
- Continuous communication; and
- Backbone support.

From our perspective in this review, the collective impact model's emphasis on having backbone support - where an independent, dedicated staff or organization provides infrastructure support and maintains the operational continuity of an initiative ([https://ssir.org/articles/entry/understanding\\_the\\_value\\_of\\_backbone\\_organizations\\_in\\_collective\\_impact\\_4#](https://ssir.org/articles/entry/understanding_the_value_of_backbone_organizations_in_collective_impact_4#)) - is often where the information sharing and curation function is managed. There are numerous examples of this model's use among our featured examples such as 2-1-1 San Diego, DASH, and others (also see

e.g., Community Tool Box, Kansas University <https://ctb.ku.edu/en/get-started>), and CDC Community Health Improvement Navigator <https://www.cdc.gov/CHInav/database/>).

## How Partners Use Collaboration Platforms

Even when following a common model such as collective impact, there is no one-size-fits all approach to building and sustaining multi-sector partnerships. Numerous sources recommended the following platforms and tools as being successful in multi-sector data sharing.

- **2-1-1 San Diego Community Information Exchange Platform (CIE)** (<https://ciesandiego.org>): A network of health and social service providers that use a shared language, a resource database, and an integrated technology platform to deliver enhanced community care planning. Connects people with community, health, and disaster services through a free 24/7 phone line. Uses a cloud-based Salesforce platform. Uses AIRS standards (Alliance of information and Referral Systems).
- **AIMS (Association of Public Health Laboratories Informatics Messaging Services Platform)** ([https://www.aphl.org/programs/informatics/Documents/AIMS\\_OnePager.pdf](https://www.aphl.org/programs/informatics/Documents/AIMS_OnePager.pdf)): a secure, cloud-based environment that enables secure and efficient messaging and information exchange among diverse partners, including federal, state, and local government agencies; commercial laboratories; hospitals; and state health information exchanges (HIEs).
- **Aunt Bertha** (<https://company.auntbertha.com>): A public benefit corporation that helps users to find and make referrals for free and reduced cost human services. Uses a zip code locator to search hundreds of programs across the country. Basic use is free, and additional services are available for a fee (HITEQ, 2018; Glaser & Gupta, 2017).
- **Digital Bridge** (<https://digitalbridge.us/infoex>): An initiative supported by the Robert Wood Johnson Foundation, de Beaumont Foundation, and CDC with the Public Health Informatics Institute and Deloitte serving as a program office. Public health, health care, and Health IT representatives are working to accelerate exchange of electronic health record (EHR) data for public health surveillance and action, beginning with electronic reporting of notifiable disease cases.
- **Health Leads** (<https://healthleadsusa.org>): A not-for-profit organization supported by the Chan Zuckerberg Initiative, Commonwealth Fund, Robert Wood Johnson Foundation, and Skoll Foundation. Partners with communities and health systems to address systemic causes of inequity and disease through workforce development, technology and data partnerships, and learning collaboratives. Social Needs Screening Toolkit is available through Creative Commons license at <https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/>.

- **Healthify** (<https://www.healthify.us/platform>): A for-profit organization that offers products and services to find community and social services and government benefits; provides analytics and consulting services, including database, EHR integration, and assessment tools.
- **HealthLandscape** (<https://www.healthlandscape.org/about.cfm>): An interactive web mapping platform provided by the American Academy of Family Physicians (AAFP) and Robert Graham Center (RGC). Web-based application suite includes asset mapping, community data portals, workforce distribution, local rea needs, quick geocodes, and others at <https://www.healthlandscape.org/Programs.cfm>.
- **NowPow** (<https://www.nowpow.com/>): A for-profit organization in the South Side of Chicago that spun off a Center for Medicare and Medicaid Innovation (CMMI) innovation grant to the University of Chicago. NowPow offers a community resource directory and a secure messaging platform to help coordinate referrals.
- **SHIEC (Strategic Health Information Exchange Collaborative)** (<https://strategichie.com/initiatives/pcdh/>): Triggering episode alerts notify providers that a patient is receiving care outside of the patient's "Home" HIE; all clinical data is centered around the patient and is part of a comprehensive longitudinal patient record in the HIE where the patient resides, also known as the Patient-Centered Data Home.

## Integrating Social Needs Information with Electronic Health Records (EHRs)

Industry observers agree that there is an emerging IT market for data on social determinants of health (KPMG Government Institute, 2018; Landi, 2018; Lee et al., 2019; Zieger, 2018). A complete market analysis is beyond the scope of this review, but some key features, functions, and challenges are worth noting in terms of integration of health and human services data.

For example, as described above, Health Leads and Healthify have developed customized, HIPAA-compliant technology for collecting and sharing social and health data. Health Leads has a customized case management and resource system and uses a Salesforce cloud-based solution for data base management and search. Healthify similarly has customized technology to support screening and referrals, including a system for patient and provider ratings of service providers (DeMillo & Nakashian, 2016).

The challenge for both platforms is that they are not interoperable with EHRs. There is no immediate way for a clinician to know whether a patient needs help with food, housing, or transportation.

On the health care side, several commercial and nonprofit EHR vendors have been working on creating IT interfaces that facilitate sharing of health and SDoH information with human services and public health agencies and organizations. The SIREN project (Social Interventions and Evaluation Research Network) at UCSF curates a comprehensive Evidence Library that are relevant to health and human service integration (<https://sirennetwork.ucsf.edu/tools/evidence-library>).

Some of the most widely-used SDoH screening tools include the following (also see <https://sirennetwork.ucsf.edu/tools-resources/screening-tools>):

- **The Accountable Health Communities Health-Related Social Needs Screening Tool** (<https://innovation.cms.gov/Files/work-sheets/ahcm-screeningtool.pdf>): originally developed in 2017 and updated in 2018 by the Centers for Medicare and Medicaid Services (CMS). Screening tool for health plans to identify non-health risks in five domains: housing instability, food insecurity, transportation, utilities, and interpersonal safety. Additional domains were added in 2018.
- **American Academy of Family Physicians (AAFP) EveryONE Project Toolkit** (<https://www.aafp.org/patient-care/social-determinants-of-health/everyone-project/eop-tools.html>): provides resources to learn about communities and social influences and helps clinicians to adopt a practice-wide approach to improve health equity.
- **HealthBegins** (<https://www.healthbegins.org>) developed a free Upstream Risk Screening Tool with questions on education, employment, social support, immigration, financial strain, housing insecurity and quality, food insecurity, transportation, violence exposure, stress, and civic engagement (<https://healthbegins.wufoo.com/forms/upstream-risk-screening-tool-2015/>).
- **PRAPARE** (Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences <http://www.nachc.org/research-and-data/prapare/>) was first released in 2016 as a collaboration among the National Association of Community Health Centers, OCHIN, AAPCHO, and other organizations. It emphasizes standardized collection of information about actionable measures and EHR templates are freely available for eClinicalWorks, Epic, GE Centricity, and NextGen.

Evidence shows that standardized data collection and presentation in Epic EHR systems in community health centers can help to improve patient outcomes (Gold et al., 2017 [www.jabfm.org/content/30/4/428;full](http://www.jabfm.org/content/30/4/428;full)); Monica, 2017). Cerner Corporation also provides a PRAPARE-based tool for capturing SDoH data in its products ([http://www.nachc.org/wp-content/uploads/2018/10/Cerner-Corporation\\_PRAPARE-Tool\\_NACHC-.pdf](http://www.nachc.org/wp-content/uploads/2018/10/Cerner-Corporation_PRAPARE-Tool_NACHC-.pdf)).

Also underway is a Social Determinants of Health Coding Collaborative (SDHCC), recently launched by SIREN and EMI Advisors with funding from the Robert Wood Johnson Foundation. The Collaborative is using a consensus approach to develop use cases that will guide the harmonization of different coding and messaging protocols for SDoH through a standards-based process, with guidance from a Steering Committee of experts from industry, government, and non-profit organizations.

In the human services sector, the American Public Human Services Association (APHSA) along with the Alliance for Strong Families and Communities (Alliance) have been working on common language and national standards for human services (<https://alliance1.org/web/community/strengthen-human-services/web/community/national-imperative-joining-forces-strengthen-human-services-america.aspxhe>).

The National Human Services Interoperability Architecture (NHSIA) proposes a framework to improve information sharing, improve service delivery, and improve outcomes. It was developed by the Administration for Children and Families to foster greater interoperability and integration (<https://www.acf.hhs.gov/national-human-services-interoperability-architecture-nhsia>). By incorporating the NHSIA framework, it is hoped that systems will be more client-friendly, costs will be lower, and ultimately children and families will experience better outcomes.

### Approaches to Analytics

A Guide to Data Management, Privacy & Confidentiality, and Predictive Analytics has been produced by APHSA in collaboration with state and local stakeholders. The Guide includes state and county use cases, case studies, and other resources designed to help improve system capacity and readiness to support cross-sector systems of care ([https://aphsa.org/NC/Guidance\\_and\\_Resources\\_Sub/data\\_sharing\\_analytics.aspx?WebsiteKey=ac5e6746-8ef3-4324-b887-4a59e094f0ab](https://aphsa.org/NC/Guidance_and_Resources_Sub/data_sharing_analytics.aspx?WebsiteKey=ac5e6746-8ef3-4324-b887-4a59e094f0ab)). The guide also includes “living documents” that can be frequently updated by members of its community of practice.

PROMIS (Patient-Reported Outcomes Measurement Information System) is a set of person-centered measures that evaluates and monitors physical, mental, and social health in adults and children. It can be used for research with the general population and with individuals living with chronic conditions. ([www.healthmeasures.net/explore-measurement-systems/promis](http://www.healthmeasures.net/explore-measurement-systems/promis)). Having a standardized set of measures is helpful in producing comparable information across projects.

As managed care organizations (MCOs) enter the population health management market through Medicaid contracting, states may require them to move beyond risk management and assist with social concerns that affect their health status (Shrank et al., 2018).

Electronic records can facilitate data sharing for clinical purposes to improve care coordination and tracking of outcomes. Electronic clinical data can be aggregated and reused for predictive analytics in quality improvement, targeting services where they are most needed, and improving patient and client engagement (e.g., Walker & Fishman, 2015).

Predictive analytics are also being promoted to industry clients as a way to improve care and reimbursement levels (Harris, 2018), although incorporating social determinants information does not necessarily improve the accuracy of analytics over purely clinical data (Bresnick, 2019; Kent, 2018). We expect that providers and payers will continue to refine their analytic models as the structure and accuracy of social determinants data continue to evolve.

# DISCUSSION

## Challenges and Opportunities for Sharing Data

The aspirational goal for the social determinants information community might be described as setting up systems with direct electronic connections among partners so they can share standardized, structured, and meaningful information that helps to provide better care and services in real time. The individual clinical and service information can be aggregated and reused to inform quality improvement, do clinical and community outcomes research, and use data analytics to identify gaps and future needs. In this scenario, care and services are streamlined, improving the client and patient experience and often reducing costs by providing the appropriate levels of care and services.

This work is not easy, but it can be highly rewarding. In our experiences with the NIC, we have seen that the most successful data sharing endeavors are based on shared values and goals, mutual respect, transparent and shared governance, and often on the basis of strong interpersonal relationships among leaders at their core.

In our July 2018 report, *From Siloes to Solutions: Getting to Interoperability in Health and Human Services* ([https://www.academyhealth.org/sites/default/files/siloes\\_to\\_solutions\\_july2018\\_2.pdf](https://www.academyhealth.org/sites/default/files/siloes_to_solutions_july2018_2.pdf)), we concluded that data sharing across organizations and settings brings organizational and cultural challenges, not just legal and technical ones. We noted several barriers to data sharing, including:

- **A need for technology literacy and systems thinking among decision-makers**, to more readily integrate technology solutions with programs and services. We also noted a need for deeper understanding of change management processes, with a tendency to underestimate the amount of time it takes for workflow changes, upgrades, and systems implementation.
- **A need to come to agreement on use of standards for structuring and exchanging data.** With multiple providers, there is an urgent need to quickly match up data for the same individual from different sources to construct a single record. When providers use different messaging and data standards and frameworks, significant time delays and disconnects are a problem.

- **A need for more convincing incentives to share data.** Organizational fears about breaches and confusion about legal and regulatory issues are significant barriers, primarily related to the Health Insurance Portability and Accountability Act (HIPAA) and the Family Educational Rights and Privacy Act of 1974 (FERPA). Privacy and security concerns often result in significant delays in negotiating data use agreements or refusals to make data available, even in a crisis or an ongoing relationship where care and services should be coordinated.

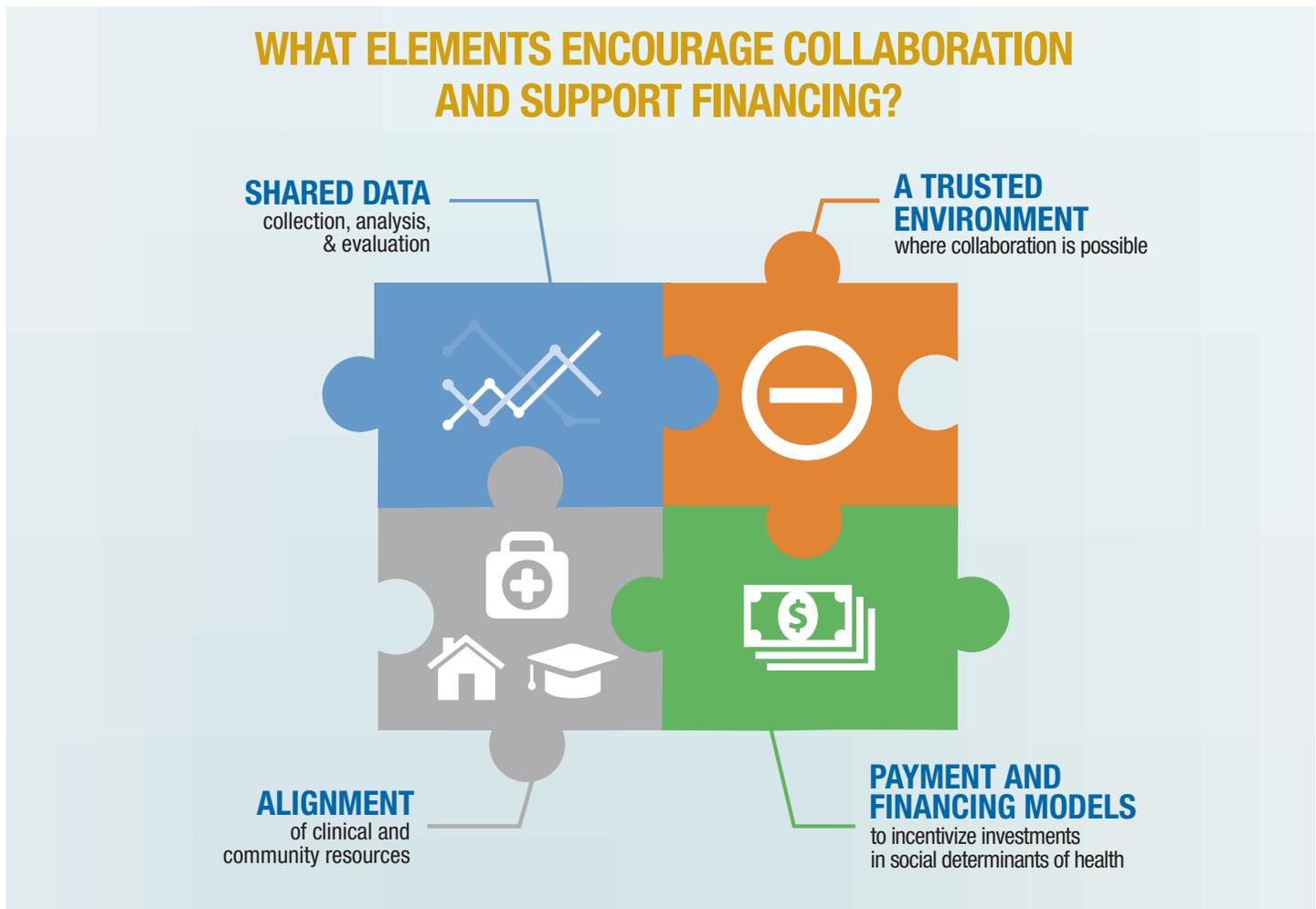
We are excited about a new Public Interest Technology University Network that has been forming with the goal of collaboratively training the next generation of software engineers, policy makers, community leaders, and social justice advocates to develop, regulate, and use technology for the public good (Singer, 2019; <https://www.nytimes.com/2019/03/11/technology/universities-public-interest-technology.html>). Over the long term, this kind of cross-sector training in teams will help to create a more collaborative management ecosystem and train more informatics and data science experts to support cross-sector analytics work.

## The Search for a Common Framework

In preparing this report, we have found multi-sector collaboratives that are successfully sharing health, human services, and public health information. In general, the successful collaborations see themselves as working in the public interest at local and community levels, whether their funding sources are public, private, or a combination of the two. We are encouraged by what we have learned, but we recognize that systems integration is not always a feasible or even desirable goal.

The goal of coordinating responses to environmental and social factors that influence health is not a new one. Yet each of the approaches to social and health integration that we have described brings its own set of data management strategies; uses different data platforms, data structures, and formats; develops its own exchange and curation protocols; and presents different data privacy and security challenges.

**Figure 4: Four Elements that Influence Payment Reform for Population Health**



Source: AcademyHealth, Payment Reform for Population Health. <https://www.academyhealth.org/publications/2017-12/four-elements-influence-payment-reform-population-health>

A recent AcademyHealth study of payment for population health developed an infographic that describes the ecosystem (see Figure 4). This is a useful way to view the elements that promote collaboration.

In recent months, there have been new efforts to develop a common framework or approach to social determinants. The Funders Forum on Accountable Health has brought together public and private funders of accountable community for health (ACH) models that includes several foundations, including Kresge, W. K. Kellogg, RWJF, the Episcopal Health Foundation, the California Endowment, and Blue Shield of California Foundation. The Forum, housed at The George Washington University, has developed an assessment framework that will be used with innovations in more than 100 communities. The framework focuses on three overarching categories: readiness, common elements, and outcomes (Levi et al., 2018).

The National Alliance to Impact the Social Determinants of Health (NASDOH), led by Governor Mike Leavitt and former Assistant HHS Secretary for Health Karen DeSalvo, is a new group of payers, health and social care providers, and non-profit organizations seeking to promote innovation, information sharing and a supportive policy environment to address social needs in evidence-based and sustainable ways (NASDOH, 2018). NASDOH recently outlined its principles of screening for social risks, discussed challenges in implementing screening, provided an overview of screening efforts, and made recommendations for improvements in how we address social determinants of health (see <http://www.nasdoh.org/wp-content/uploads/2019/01/NASDOH-Social-Risks-Issue-Brief.pdf>).

A noteworthy influence on multi-sector collaborative models is the collective impact approach, in which a group of leaders from different sectors develop a common agenda to solve a specific problem through “mutually reinforcing activities” (Kania &

Kramer, 2011). These collaborations need a “backbone support organization” to coordinate and manage their efforts and these organizations often also provide the valuable service of promoting best practices among stakeholders and more broadly to the public and policy-makers. Building and sharing the evidence base of “what works” is a common activity for several of the initiatives we profiled here, including SIREN, 2-1-1 San Diego, and DASH.

### **Summary and Recommendations: Data Moves at the Speed of Trust**

Reflecting the NIC’s mission, our focus for this scan has been on the information infrastructure that supports multi-sector collaboration to address social needs, with an emphasis on the health, public health, and human services sectors and emerging ecosystem. We chose to focus on data sharing as an outcome of successful collaboration that reflects partners having successfully negotiated the key ingredients of collaboration: shared values, governance, funding, leadership, and trust.

As a group, these initiatives are helping to create new collaborations across organizations and sectors and are generating new sources of data, which may then require updated or new information systems and infrastructure to securely maintain personal health information while making it available to different providers and organizations at the point of care. They also are increasing the demand for data scientists and data analytics experts to curate data, keep data secure, and create dashboards for management and the public to learn more about local needs and to monitor progress.

Given the recent national investment of \$38 billion in provider adoption of electronic health records (EHRs), the imbalance of financial and technical resources in healthcare and human services is striking. Resource and power differences between health care and human services organizations are significant in dollar terms but leverage is shifting as social determinants data and services become more highly valued.

We have described tools that help partners to share and aggregate electronic information to address health, social, and public health risks. This sharing of information is not merely a series of technical problem to be solved. Collaboration around information-sharing also helps organizations focus outside of themselves, making it less likely that their patients and clients will need to keep giving their same information over and over again to different providers, creating unnecessary delays and frustration, and sometimes forcing them to re-experience traumas and discomfort. Instead, we foresee a future in which direct electronic connections can help information flow and be used in real time to address social and environmental needs.

Our report has focused on national initiatives because they are funded well enough to provide information that is easily accessible online. We are also aware that there is tremendous activity at the local government/community level where the trust quotient tends to be highest, and we have pointed to San Diego County, California, and Montgomery County, Maryland, as national examples.

We are aware of a tremendous amount of talent and commitment in public sector information technology and informatics leadership that is quietly “doing more with less” and creating architectures and promoting application programming interfaces (APIs) that will accelerate sharing among older, legacy systems.

While we do not anticipate anything like a “HITECH for human services,” we do see some advantages for some of the newer multi-sector data sharing platforms, like 2-1-1 San Diego’s CIE, that can build customized, user-friendly, accessible, secure, and standards-based systems that will promote broader sharing. We encourage them to be well-documented so they can be easily replicated by other stakeholders.

In general, technology-based approaches are proliferating, but they are geographically diverse, fragmented, and lacking a common framework or data model. Some organizing efforts are underway, notably All In, SIREN, and NIC, but there is an overwhelming amount of activity that is challenging to track.

Having done a deeper dive into the data sharing experiences of several partners, we believe a coordinated national investment in cross-sector collaboration will be essential to address social, economic, and environmental risks in the future from a systems perspective. Even when there is a shared commitment and values about coordination and integration, we have found that the volume of data being generated from these public and private organizations and initiatives is staggering.

There is a lot of variation and very little standardization in how information is collected, resulting in inefficiencies, errors, information gaps, and duplication of effort. Streamlining and securing the information infrastructure presents challenges for all organizations, but existing resources such as the Medicaid 90/10 match for information systems are being used to build integrated eligibility and enrollment systems for SNAP and TANF programs (<https://www.healthcareitnews.com/news/cms-9010-ruling-increasing-funds-medicaid-it>). This approach improves administrative efficiency while reducing the enrollment burden for families.

We call on individuals and organizations working on social determinants of health to do the following:

**Build stronger collaborations at the intersections of health, human services, and public health.**

**Make a commitment to technology integration for better coordination of services and data about services.**

**Leverage available resources within existing systems to facilitate information exchange.**

**Align professional incentives, jobs, and training to systems thinking and strategic management that leads to collaborative technology integration.**

**View multi-sector collaboration through an equity lens.**

In closing, multi-sector collaboratives that are successfully sharing health and social information are working in the public interest, whether their funding sources are public, private, or a combination of the two. They view data sharing as the foundation for successful collaborative actions that promote health equity at the community level and bring a return on upstream investments that improve health outcomes for everyone.

In sum, we are encouraged by what we found and are optimistic about the future of data sharing to address SDoH. We hope that the technology solutions, sense of shared values, and leadership approaches will continue to evolve.

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