



C O D E

Leveraging Data on the Social Determinants of Health

Roundtable Report
December 2019

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Foreword

HHS Assistant Secretary for Health Admiral Brett Giroir

America yearns for a new approach to healthcare, and addressing the social determinants of health must be a foundational principle of that approach. America's healthcare spending is unprecedented and unequalled, accounting for almost 18 percent of our Gross National Product (GNP), potentially topping \$6 trillion by 2027. But sadly, we are not getting our money's worth for those expenditures - no matter how you look at the data. Of our 36 peer high-income OECD nations, the United States is 28th in life expectancy, and our life expectancy decreased even more in 2015 and 2017. If this trend continues, my two-year-old granddaughter will live a shorter life and with less quality than my generation. None of us believe that's acceptable.

While sophisticated immunotherapies and genetic manipulations are always welcomed by those already suffering, the key to our successes is much less esoteric – but equally challenging. Our nation must transform our “sick care system” into a “health promoting system.” And the key to that transformation is meaningfully and sustainably addressing the social determinants of health. Social determinants impact every aspect of disease risk – nutrition, exercise, stress, and the environment; access to primary healthcare and early detection; and adequacy of treatment and recovery support. A few examples based on current HHS priorities are as follows:

The drug overdose crisis. This is the most complex and daunting public health issue of our time, with almost 70,000 Americans dying a year, often at the prime of their lives. The underlying factors are frequently found in social determinants, including unemployment and lack of economic opportunity; housing insecurity; arduous labor that predisposes to traumatic injury and chronic pain; lack of access to treatment or alternatives; and the significant impact, especially on risk of methamphetamine abuse, of adverse childhood experiences, including sexual or physical abuse.

Infant mortality. A recent study by researchers at the National Center for Health Statistics documented the high rate of infant mortality in the poorest regions of our country, the Mississippi Delta and Appalachia.ⁱ Obesity, teenage pregnancy, smoking, and malnutrition all contribute to infant mortality in these areas. We will never solve infant mortality or maternal mortality if we don't work on these socially related problems.

The obesity epidemic. A 2017 study of trends among today's two-year-olds projected that nearly 60 percent of them will be clinically obese by the time they're 35.ⁱⁱ We're already seeing that three-quarters of our 17-to-24 year-olds would not qualify for the military if they tried to join, many of them because of obesity. For obesity, social determinants are everywhere: food deserts and food insecurity; lack of access to safe sidewalks and parks; lack of affordable youth sports; and lack of access to preventative and treatment services. From my former work in Texas, in the border counties, people generally knew what they should eat and how they should change their lifestyle, but were prevented from doing so by social, economic, and demographic roadblocks.

ⁱ Thakrar, Ashish P., Alexandra D. Forrest, Mitchell G. Maltenfort, and Christopher B. Forrest. "Child Mortality In The US And 19 OECD Comparator Nations: A 50-Year Time-Trend Analysis." *Health Affairs* 37, no. 1 (January 2018): 140–49. <https://doi.org/10.1377/hlthaff.2017.0767>.

ⁱⁱ ScienceDaily. "More than Half of US Children Will Have Obesity as Adults If Current Trends Continue." Accessed November 25, 2019. <https://www.sciencedaily.com/releases/2017/11/171130085733.htm>.

Dementia. Social engagement and cognitive activities can decrease the risk of Alzheimer's and other diseases, but isolation and loneliness are rampant in our society. Together with proper nutrition and exercise – themselves dependent on social determinants – we have a real opportunity to impact the upcoming "silver tsunami."

HIV/AIDS. Despite the "medical miracle" of modern anti-retroviral therapy and pre-exposure prophylaxis, there are still approximately 40,000 new HIV cases a year in America. We believe, and programs such as Ryan White have proven, that the social determinants are inexorably linked to new infections – beginning with social stigma preventing early diagnosis and linkage to care. But even then, lack of transportation, housing, adequate food, or a home, the expense and time associated with getting medical therapy, often keeps treatment out of reach.

Truly, in America, your ZIP code is still more important than your genetic code. And as a society, we must "change the map" and finally address health disparities stagnant for generations. While the emphasis on access to clinical care and the quality of that care is important, they account for only about 20 percent of health outcomes. Everything else is wrapped up in air and water, housing and transit, faith, family and social support, community and safety. We will never solve our healthcare spending addiction, or our progressive degradation of health, unless we focus on what causes 80 percent of the poor health outcomes in this country.

Value-based care means meeting patients where they are, and freeing up doctors and nurses and pharmacists and health systems to attack the core of the problem. That could translate into temporary housing, or transportation, or medically tailored meals. Or it could be an exercise coach, or sponsored farmers' markets, or just extra love and attention by a visiting paraprofessional. Value-based transformation means that social determinants are no longer an afterthought, but for many people are truly the "main event."

Our office emphasized in Healthy People 2020 that the social determinants are an essential ingredient for a healthful nation. But we can only focus on social determinants that we can reliably and accurately measure – so much foundational work still needs to be accomplished. As we begin work on Healthy People 2030, we have reliable data on employment, college enrollment, poverty, and housing insecurity, among other indicators. We need more indicators, and ones which more closely correlate with the health outcomes we desire; by 2025, it is my hope that we have new levers to pull, and more tools in our social determinants toolbox.

Our office is dedicated to catalyzing a health-promoting culture, moving people from treatment towards prevention, with a focus on integrating social determinants into sustainable healthcare systems and platforms. And by doing that, we will decrease costs, and increase longevity and quality of life – not for some, or most, but all.

Admiral Brett Giroir
Assistant Secretary for Health
U.S. Department of Health and Human Services

Executive Summary

The independent nonprofit Center for Open Data Enterprise (CODE) and the Office of the Chief Technology Officer (CTO) at the U.S. Department of Health and Human Services (HHS) have co-hosted a series of three Roundtables to find ways to improve how health data is shared and utilized for the public good.

As the third event in this series, CODE and the HHS Office of the CTO convened a Roundtable on *Leveraging Data on the Social Determinants of Health*. The social determinants of health (SDOH) are defined as the “conditions in which people are born, grow, live, work and age that shape health.”¹ This Roundtable brought together about 80 expert stakeholders from industry, academia, federal, state and local government, healthcare, and civil society to help HHS catalyze the use of SDOH data to improve health outcomes. Participants discussed current SDOH data use cases, reviewed high-priority data elements and scenarios, and shared actionable opportunities for HHS to support individual-level and population-level approaches to addressing the social determinants of health.

This report, written by CODE, includes a number of recommendations from CODE based on the input of Roundtable participants and CODE’s additional research. (These recommendations do not represent a consensus of Roundtable attendees, and do not represent the views of HHS or any other government agency.) CODE’s overall recommendation is that **HHS develop an SDOH data strategy** that comprehensively maps the space and helps coordinate action among different stakeholders. That strategy can include action plans to achieve three critical goals:

- **Define and Standardize SDOH Data.** This can include improving and aligning open-source assessment tools, adopting data standards and definitions, and developing a data governance body.
- **Create a Sustainable SDOH Data Infrastructure.** This can include improving financial alignment for payers, providers, and community-based organizations (CBOs) and strengthening CBO data capacity.
- **Support Local and State-based Decision-makers.** This can include developing hyper-local snapshots of communities and creating state-level SDOH strategy toolkits.

This Report summarizes the findings of the Roundtable in the following sections:

Introduction: An overview of the Roundtable’s purpose, format, and major findings of the Roundtable.

SDOH Data Landscape and User Ecosystem: This section describes high-priority SDOH data, key stakeholders for the data, the decisions they seek to make, and high-value examples of how they are using SDOH data.

Addressing SDOH Data Along the Care Continuum: This section describes what’s working and what can be improved to increase the proper and effective use of SDOH data along the care continuum.

Actionable Opportunities: Based on the challenges identified in the Roundtable, this section describes high-priority opportunities for HHS to leverage SDOH data and presents CODE’s recommendations.

Conclusion: The report concludes with perspective from Dr. Karen DeSalvo, the former Assistant Secretary for Health and Co-Convenor of the National Alliance to Impact the Social Determinants of Health.

Introduction

Health disparities in the United States are often related to factors that exist outside the four walls of the doctor's office. The social determinants of health (SDOH) represent a growing area of focus in the healthcare industry, and a major tool for addressing healthcare inequalities. SDOH are defined as the "conditions in which people are born, grow, live, work and age that shape health."² Doctors and researchers increasingly recognize how profoundly SDOH data can influence health risks and treatment outcomes. As some experts have put it, a person's ZIP Code can be at least as important as his or her genetic code in predicting health risks.

Health-focused organizations across the private sector and civil society are now realizing the potential of SDOH data. Healthcare providers and payers are using the data to better understand and address their patients' needs. Health management companies are applying the social determinants of health to predict health risks like opioid overdose and target preventive interventions. Other companies are serving as SDOH data providers, creating platforms of SDOH data for research and healthcare applications. Civil society groups are serving as conveners for a variety of stakeholders and seeking to increase coordination to improve patient care. They are demonstrating how SDOH data can provide a holistic understanding of factors that affect an individual's risk of disease and response to treatment, including measures as diverse as the air quality of a person's neighborhood or their proximity to a grocery store.

The Roundtable on *Leveraging Data on the Social Determinants of Health* brought together health and data experts from HHS, other federal and state government agencies, industry, healthcare provider organizations, and patient-advocacy groups to identify ways to realize the power of SDOH data. Opening remarks from Mona Siddiqui, Chief Data Officer in the HHS Office of the Chief Technology Officer (CTO), and HHS CTO Ed Simcox underscored the Department's commitment to harnessing data on social determinants of health to tackle health and social problems.

The Roundtable then featured lightning talks on innovative applications of data to address the social determinants of health. Speakers from Humana, the Mount Sinai Health System, the Robert Wood Johnson Foundation, Unite Us, and Lyft all highlighted unique uses of SDOH data to address comprehensive needs of the populations they serve. Many of the use cases from these lightning talks are described in this report.

Throughout the day, participants engaged in a series of discussions and facilitated breakout sessions that covered a wide variety of topics. The day kicked off with a discussion on SDOH use cases and opportunities and led into an afternoon session on identifying and prioritizing data elements for HHS's SDOH strategy. Additional breakout sessions focused on challenges and actionable opportunities for individual and population-level SDOH data.

As policymakers work to apply SDOH data, this report can contribute to the conversation in two ways. First, it provides a user-focused view of SDOH data by describing several innovative examples and the policy and healthcare issues they address. Second, this report describes the challenges of applying SDOH data along the continuum of care and ways that the use of this data use can be improved. This Report, written by the staff of CODE, summarizes insights and recommendations from individual Roundtable participants as well as expert input before and after the Roundtable. It is not meant to represent a consensus of the participants, and does not represent the views and opinions of HHS or its leadership or staff. CODE hopes this report will be of value to all stakeholders, inside and outside of government, as they address these important issues.

The Ecosystem of SDOH Data

In today's healthcare sector, clinicians, researchers, and policymakers recognize that conditions outside of the doctor's office have a disproportionate impact on a patient's health. While a person may spend 15 minutes in a doctor's office, they reside in communities with varying levels of access to nutritious food, safe housing, reliable transportation, and other critical needs. The rise of interest in the social determinants of health has been complemented by increasing access to health data. Healthcare companies are relying on growing amounts of consumer-generated, genomic, and survey-based public health data to produce more sophisticated algorithms to model patient risk profiles.³ The same kinds of data can be used to develop public health strategies, support health research, and target social services. This data can be produced by the government, collected by the private sector, gathered from consumers, or aggregated and shared through third parties like research and civil society organizations. This section describes the distinction between individual and population-level data, the primary categories of social determinants of health, and the work that HHS is carrying out to prioritize high-level SDOH data. In this report, CODE has used the following definitions of these key terms:

- **Social Determinants of Health:** The conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems that shape the conditions of daily life. These conditions impact everyone, and may have either positive or negative effects.
- **Social Needs:** An individual's immediate non-medical needs such as food, housing, or transportation.
- **Social Risk Factors:** Specific adverse social conditions that are associated with poor outcomes. These risk factors are distinct from social needs since a person may have social risk factors, such as food insecurity or housing instability, but may not have immediate needs for food, housing, or other essentials. Social risk factors can also include factors like high crime or lack of recreational facilities that impact the community as a whole and its residents' health.

Individual-Level SDOH Data

A large amount of SDOH data is collected directly from individuals and is captured in their health records, where it can be analyzed. Medicaid recipients, for example, may have individual-level data collected by their physicians or through clinical trials. This data may be collected through health networks, schools, and Community-based Organizations (CBOs). Individual-level data is often the focus for the Centers for Medicare & Medicaid Services (CMS), the Gravity Project launched by the Social Interventions Research and Evaluation Network (SIREN), and other initiatives that are improving precision medicine. While this data can be extremely useful in tailoring interventions for the individual, much work remains to be done to standardize data elements, data collection, and data sharing, as well as resolve important ethical issues identified below. Better systems are needed to enable consumers to give permission for their data to be used before it can be widely applied.

Population-Level SDOH Data

Many federal, state, and local government agencies and civil society organizations openly publish SDOH data on factors such as income, education, and other factors at the community level. This data may be available at the county, city, ZIP Code, or Census tract level, and can be analyzed together with individual-level health data to better predict individual and population risk. Population-level SDOH data can come both from HHS and from other federal agencies such as the Census Bureau, the Department of Labor, the Department of Transportation, and the Department of Education. This data is increasingly generated at the local level and

can be aggregated by private sector companies, researchers, and nonprofits to create visualizations that help understand risk and prioritize underserved communities.

Overview of SDOH Data Categories

Many national groups are working to define categories of SDOH data. Among these, the Kaiser Family Foundation has produced an accessible and widely used framework to describe the high-level categories of SDOH data. (The Gravity Project and Healthy People 2020, described below, also provide important frameworks.) The Kaiser Family Foundation matrix, shown in the table below, provides an excellent starting point for reviewing key categories behind the social determinants of health. This section describes some of the important factors in the first four of these categories: economic stability, neighborhood and physical environment, education, and food. These categories may draw on important data sources that are not restricted to health and healthcare institutions. The fifth category, community and social context, appears to have fewer data sources readily available, and data on the sixth category, healthcare system, is found within health and healthcare organizations.

Figure 1: Kaiser Family Foundations Social Determinants of Health⁴

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

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

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Economic Stability: A person's ability to pay bills on time, create longer term budgets, and stay out of debt are functions of their economic stability. More at-risk communities may experience challenges due to part-time work at low-paying jobs, a lack of access to stable financial institutions, and financial hurdles in paying for insurance to protect their assets. The literature on unemployment, for example, has repeatedly demonstrated that long-term unemployment has adverse health outcomes.⁵

Neighborhood and Physical Environment: Even when patients have access to healthcare, they may face challenges in getting to and from their doctors' offices. Moreover, they may not feel comfortable leaving their homes due to safety issues or may lack access to public green spaces. A person's neighborhood may also impact his or her health outcomes because of subpar housing, the threat of crime, environmental hazards, and poor walkability. A body of evidence has emerged that a person's neighborhood directly impacts the amount of walking and cycling they can do, which impacts overall health.⁶

Education: People who have limited educational opportunities or attend poor schools may fall behind and generally receive less support as they progress through the system. These educational disadvantages can impact an individual's health literacy by limiting comprehension of important clinical recommendations or making it difficult to understand diagnoses. They also may lead to poorer economic outcomes as individuals must accept low-wage positions or work in environments with higher risk factors. A 2013 Report notes that the mortality rate for white women who have not completed high school is four times higher than it is for white women with 16 or more years of education.⁷

Food: Access to healthy foods and subsidy programs like SNAP and WIC are indicators that can provide important insights into nutrition and health. Individuals who consume high amounts of fatty or sugary foods are more likely to develop obesity, hypertension, and other chronic conditions. In addition, the literature has demonstrated that cheaper foods often have fewer nutrients, causing more micronutrient deficiencies and impacting obesity.⁸ Moreover, children with poor access to nutritious foods or milk may face developmental challenges from poor nutrition.

Climate and Environment Data. This category is a suggested addition to the categories in the Kaiser matrix. While SDOH data within a neighborhood is important, additional factors that are not confined to neighborhood borders also have a major impact on an individual's health. These include climate, weather, and air and water quality.

Figure 2: Social Determinants Categories and Sample Public Data Sources

| Category | Sample Determinants | Sample Public Data Source |
|---------------------------------------|--|--|
| Economic Stability | <ul style="list-style-type: none">● Access to employment● Hourly wages● Level of personal debt | <ul style="list-style-type: none">● Department of Labor Unemployment Statistics● Internal Revenue Service Income Tax Rates |
| Neighborhood and Physical Environment | <ul style="list-style-type: none">● Housing● Access to transportation● Public parks● Safety● General geography | <ul style="list-style-type: none">● Zillow's walkability and home ownership rates● DOT's data on proximity to public transportation● National Parks Service data on parks and recreational areas |
| Education | <ul style="list-style-type: none">● Literacy rates● Vocational training opportunities● Early childhood education● Rates of higher education | <ul style="list-style-type: none">● Department of Education high school dropout rates● Head Start early childhood education enrollment figures |

| | | |
|--------------------------------|---|---|
| Food | <ul style="list-style-type: none"> Access to fresh fruits and vegetables Number of grocery stores in a neighborhood Number of residents who access food pantries | <ul style="list-style-type: none"> WIC and SNAP rates by neighborhoodⁱⁱⁱ Proximity to a grocery store Access to a food pantry or other emergency food service |
| Climate and Environmental Data | <ul style="list-style-type: none"> Air and water quality Access to clean water Exposure to power plant emissions | <ul style="list-style-type: none"> U.S. Environmental Protection Agency (EPA) air quality and toxic waste data U.S. Department of Energy (DOE) data on power plants. |

SDOH Projects and Initiatives

There are several nationwide initiatives that seek to better categorize data elements and produce a comprehensive information repository. Healthy People 2020, led by HHS, has sought to promote a shared understanding of the social determinants of health. Additional projects have been led by civil society, such as the Gravity Project and the National Alliance to Impact the Social Determinants of Health, which have helped build multi-sectoral collaboration around data standards and the value of addressing social needs.

Healthy People 2020. Healthy People 2020 provides a broad-based strategy for health promotion and disease prevention based on a wide range of stakeholder feedback. It is also the primary framework that the U.S. federal government uses to promote and leverage data on SDOH. Healthy People 2020 uses a place-based organizing framework to address SDOH. This framework focuses on five areas and is designed to identify ways to create social and physical environments that promote good health for all.⁹ Healthy People 2020 defines the SDOH as the conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. HHS is currently developing a Healthy People 2030 initiative to build on this work.

The Gravity Project: Establishing SDOH Data Standards. The Gravity Project is a public multi-stakeholder initiative that is seeking to standardize key data elements necessary for documenting clinical and other activities related to the social determinants of health, in order to improve interoperability, exchange, and use of SDOH data across the health and human services sectors.¹⁰ Started by the Social Interventions Research & Evaluation Network (SIREN) at the University of California, San Francisco, the Gravity Project convenes a broad range of public and private stakeholders including healthcare providers, payers, civil society, government, and others, and has focused its work initially on transportation, food insecurity, and housing instability and quality. The consensus-based project will study use cases to identify common data elements and set guidelines compatible with the Fast Health Interoperability Resources (FHIR) Specification, an emerging standard for exchanging healthcare information electronically. The Gravity Project will also articulate a set of standard data elements and recommended medical codes needed for faster data exchange and wider use in clinical settings.

ⁱⁱⁱ WIC stands for “The Special Supplemental Nutrition Program for Women, Infants, and Children” and SNAP stands for Supplemental Nutrition Assistance Program.

National Alliance to Impact the Social Determinants of Health (NASDOH). NASDOH is a cross-collaborative group of stakeholders that is seeking to build a common understanding around the importance of addressing the social determinants of health.¹¹ The Alliance brings together this wide range of policymakers, healthcare practitioners, civil society members, and technology companies to identify best practices in emerging applications of the social determinants. These best practices often feature case studies by sector, and also demonstrates the value that technology can play in enhancing the use of the social determinants of health. Moreover, NASDOH provides a suite of resources and tools for groups hoping to leverage new technologies, screening assessments, and data metrics to better evaluate patients for their social needs.

SDOH Data Stakeholders

Individual and population-level data on the environmental and social contexts of health forms the foundation of SDOH, and stakeholders leverage this data to improve patient care, increase the ecosystem of available information, and improve preventive strategies. The ecosystem of SDOH data providers and users is comprised of both non-governmental and government stakeholders. These stakeholders utilize and contribute to the SDOH data ecosystem in a variety of ways that are outlined below.

Throughout this section and those that follow, we have included a number of examples in boxes, taken from talks at the Roundtable and other sources, that show how SDOH data is now being applied.

Non-Government Stakeholders

The private sector, healthcare groups, and civil society have developed different initiatives and approaches to collect, analyze, and use SDOH data at the local level.

Civil Society Alliances and Groups

Civil society groups develop local coalitions, task forces, and working groups to better share data and provide resources to their clients. Groups like Aligning for Health are diverse coalitions of stakeholders that focus on improving coordination of care or increasing the use of SDOH data to advance research on treatment and outcomes. Other civil society groups, like the Urban Institute and Kaiser Family Foundation, publish research-driven white papers and host conferences like the Next50 Changemaker Forum. These groups serve as support systems for larger data-sharing coalitions and provide research and recommendations to improve SDOH data sharing and usage. They develop advocacy strategies and identify underserved demographic groups. The Alliance for Better Health, for example, is a diverse coalition of stakeholders who work across medical and community sectors to address the health needs of Medicaid members and uninsured individuals, and relies on a combination of data from different providers. Other groups like the National Alliance to Impact the Social Determinants of Health (NASDOH) aim to build multi-sectoral coalitions to articulate the value of addressing the social determinants of health.

Robert Wood Johnson Foundation's City Dashboards and Indicators

The Robert Wood Johnson Foundation (RWJF) has been a strong proponent of increased action on the social determinants of health and helped develop the Culture of Health Action framework to improve overall population health. This framework seeks to make a culture of health a shared value, increase collaboration across sectors, and strengthen the integration of health services and systems. RWJF has chosen to build on the work of the county health rankings to more granular approaches to SDOH data through cities and small area estimates. These metrics can allow researchers to compare major indicators like food access, housing costs, violent crime, walkability, and other metrics across cities. RWJF has now partnered with the National Association for Public Health Statistics and Information Systems (NAPHSIS) to create a U.S. Small-area Life Expectancy Estimate that will be based on a combination of observed data and predictive values.¹²

Patients and Patient Advocates

An individual's health status is heavily influenced by social needs and social risk factors. Patients are the primary recipients of the benefits of utilizing SDOH data and are increasingly interested in learning about risks and resources in the communities where they reside. They may seek support in accessing healthcare, from individual-level transportation assistance to connecting with community-led remote clinics. Inside a clinical setting, patients often have three key interests: being screened for social needs, being referred to social services, and feeling that the screening is appropriate and protects their privacy.

Patients can provide additional information to their physicians through health screening assessments or basic questionnaires. They may feel more comfortable sharing this information if they also are recommended services and interventions to address these social needs. For example, the American Academy of Family Physicians 2017 Social Determinants of Health Survey found that over half of these physicians failed to collect social needs data because they could not refer patients to these services.¹³ However, other studies have found that many patients and caregivers still feel that it is appropriate for clinicians to gather information about a patient's social determinants and social risk factors, regardless of the personal benefit to the patient.¹⁴ Outside of the clinical setting, patients can also access community information through provider portals or through commercial sources like Zillow walkability scores.

Sisters Working It Out

Sisters Working It Out (SWIO) is a Chicago-based patient advocacy organization that has trained over 40 educators to help educate thousands of women about breast cancer and other health-related issues.¹⁵ SWIO aims to reduce disparities in breast cancer mortality for African American women on the South Side of Chicago and gathers data, builds initiatives based on this data, and hosts community events to increase awareness. Their outreach program "Sisters Thriving Together" helps fellow patients navigate screening services and identify any barriers to access that may come from social risk factors.

Technology Companies

Companies are using SDOH data to better comprehend their consumers and clients. They often work with this data at the local level to make sense of consumer needs and the environments they operate in. Technology companies often use software solutions to provide granular SDOH data, analytics, and care coordination for healthcare companies that are seeking to understand their patients. These companies draw on a combination of commercial and publicly available data sources that can include clinical, financial, and social data. Companies like Healthify and Socially Determined provide sweeping approaches to the social determinants, while other groups focus on specific areas. (For example, Kaizen Health looks specifically at transportation services.) Still other companies such as Unite Us provide comprehensive technology solutions that seek to offer decision support, electronic referral management, care plan management for CBOs receiving referrals, and outcomes measurement.¹⁶ Other companies have leveraged data on the social determinants to better support their own customers.

Lyft Providing Free and Limitless Rides to Seniors

Lyft is an on-demand transportation service that is accessed through a ridesharing mobile application. Lyft entered the healthcare space because it can offer low-cost, high-quality transportation to underserved communities. Lyft noted that approximately 3.6 million missed healthcare visits in the United States are due to transportation barriers. Transportation challenges, such as long waits for public buses, can increase healthcare costs and lower the quality of care. Lyft partnered with the University of Southern California's Center for Body Computing to provide unlimited free rides to 150 seniors over the period of three months.¹⁷ Although doctors' visits accounted for approximately 31 percent of rides, seniors used the remaining rides to get to fitness, social and leisure activities, and generally reported a significant increase in their quality of life. Lyft is now exploring the second phase of its project: Working with healthcare payers to have companies pay for the cost of these rides based on their demonstrable impact on quality of care.

Healthcare Payers

Healthcare payers and insurance companies often drive innovation and experimentation in using data on the SDOH. As insurance companies manage increasing numbers of underserved members through the Medicaid and Medicare Advantage programs, they are identifying strategies to better understand the conditions that impact patient utilization of care. To gain better snapshots of their patients, healthcare payers are partnering with technology companies to identify particularly vulnerable communities and developing risk profiles of certain communities using population-level data. They are also working with these platforms to develop resource directories for individuals that need additional care. Kaiser Permanente, for example, has partnered with Unite Us to develop its Thrive Local Network and pinpoint services and resources for members with housing and transportation issues.¹⁸ Given the expansion in referrals to CBOs, other groups are providing additional funds and grants to social services and community resources. Last year, for example, UnitedHealth provided a \$1.95 million grant to Feeding Wisconsin to expand their supply of healthy and nutritious foods for vulnerable populations.¹⁹

Humana's Loneliness Prediction Model

Humana has been a pioneer in the healthcare space and has attempted to address the key social risks of its patient community through its Bold Goal program. The Bold Goal is a population health strategy that aims to improve the health of its members by 20 percent by co-creating solutions that address all of its members' needs.²⁰ As part of the Bold Goal, Humana identified loneliness and social isolation as a key challenge for its Medicare Advantage members. In response, Humana has screened thousands of its members and created a predictive model that combines commercial and claims data to profile its members for loneliness and social isolation. The predictive model found that approximately 28 percent of their Medicare Advantage members experience loneliness and that these individuals have 24.4 unhealthy days a year. Humana used this information to partner with Papa, an on-demand matching service, to help connect lonely seniors to college students who provide assistance with transportation, house chores, and companionship.²¹

Community-based Organizations and Service Providers

CBOs and service providers are critical actors in the SDOH data ecosystem since they administer services to address the social risk factors. CBOs often work directly with healthcare providers through established partnerships or build relationships through technology platforms. Hundreds of CBOs across the United States now work closely with healthcare payers to deliver services to members, ranging from healthy bags of produce to housing services. Many CBOs are part of larger networks of vetted organizations and share critical data about members with the organizations that make the referrals. As healthcare providers increase the amount of work they do with CBOs, CBOs are increasingly reviewing their governance and data gathering capacity to meet the demand.

DC Central Kitchen's Workforce Development Program

DC Central Kitchen has served the Washington D.C. community since 1989 and combats hunger and poverty through job training and workforce development, with a specific focus on former inmates. Their program model seeks to reduce hunger through culinary training, community meals, healthy school foods, healthy corners, and the Campus Kitchens project.²² Its healthy corners program seeks to increase food access in D.C.'s food deserts by delivering healthy produce to D.C.'s corner stores. Moreover, DC Central Kitchen serves hundreds of its clients by creating sustainable livelihoods and addressing core measures that drive food insecurity.

Healthcare Providers

Healthcare providers often interact with patients in clinical care settings and can generate individual-level data from these clinical encounters. A 2017 report published by the Deloitte Center for Health Solutions found that when they surveyed 300 hospitals and health systems, approximately 80 percent of respondents claimed that leadership had committed resources and operational processes to better address the social needs of clinical care.²³ Healthcare providers often aim to collect data on SDOH through Electronic Health Records (HER) and employ screening tools to gain a better understanding of the contextual and social conditions affecting their patients. For example, as part of its Moving Healthcare Upstream project, the New York Presbyterian Hospital (NYP) has focused on identifying the psychological and social determinants of health for children ages 0-5 living in Harlem, New York.²⁴

Other healthcare systems are striving to move towards value-based care, the concept that healthcare organizations should be compensated based on patient outcomes and the objective measures of the quality of the care they deliver. Many payers and providers hope that value-based care will realign incentives, partnerships, and data-gathering activities to include addressing health quality and social care needs. As Medicare moves towards value-based reimbursement, providers are now exploring new ways to measure results from their initiatives and identify which interventions are producing the best health outcomes.

Mount Sinai Health System's Value-Based Care

The Mount Sinai Health System has developed a value-based care approach that has attempted to better predict and prescribe interventions to its patients. Mount Sinai has maximized its patient touchpoints to increase data collection and create a data-driven culture. Mount Sinai has partnered with Epic Healthy Planets to leverage claims and commercial data for predictive analytics and machine learning programs to estimate their patients' needs. Mount Sinai, similarly to other providers, has also sought to expand its network of CBOs and is working with these organizations to increase their data gathering capacities. As it advances its population health strategy, Mount Sinai aims to gather more data to measure the return on its investments and create better feedback loops for its referrals to social services.

Government SDOH Data Stakeholders

Federal and state-level government stakeholders are major users and providers of SDOH data through their administration of federally funded programs and initiatives. As users, government stakeholders draw on data sources from surveys, programs, and reports to develop a better understanding of their performance and any resource gaps in those communities. As providers, larger government stakeholders can provide, organize, and curate granular geographic data at the city or county levels. Smaller stakeholders, such as local public health agencies, also need access to well-curated and presented data.

State and City Public Health Departments

Public health departments often function as clearinghouses of local information and visualizations of SDOH data from both their departments and other entities. Many local and state-level departments actively collect information about local populations or work closely with Medicaid recipients and other underserved populations that may benefit from access to services. Public health departments can partner with other research institutions and private sector companies to better visualize key socioeconomic data and draw upon datasets from civil society groups to better comprehend major resource gaps. For example, the Baltimore City Health Department manages statistics and indicators on the social determinants and makes data available to different stakeholders. The city then created a map using a visualization tool to display the various social determinants of health in Baltimore's 55 different Community Statistical Areas (CSAs). Public Health departments are often at the front lines of local data collection and can provide a rich understanding of neighborhood and county metrics than federal stakeholders.

Pennsylvania Department of Health's Office of Health Equity

The Pennsylvania Department of Health's Office of Health Equity aims to address major disparities and outcomes in vulnerable populations by providing leadership and offering targeted, collaborative programs. The Office of Health Equity has focused on developing a Public Health 3.0 framework and has produced recommendations that include advancing common leadership on health equity, expanding the range of partnerships in the community, and investing in the collection and storage capacity of local data.²⁵ Currently, the Pennsylvania Department of Health draws on county-level and district-level data that comes from sources such as the Enterprise Data Dissemination Informatics Exchange (EDDIE), which allows policymakers to download data on vital statistics, disease tracking, demographics, and environmental public health.

U.S. Department of Health and Human Services

HHS has sought to promote the use of SDOH data by enabling cross-cutting initiatives to set standards, definitions, and priorities for SDOH data, expanding its technological infrastructure for standardized SDOH data, and creating new programs that pilot the use of SDOH at the local level, often through Medicaid and Medicare Advantage.

- **Standards and Priorities:** As described above, Healthy People 2020 is the primary framework that HHS has developed to advance major categories of SDOH data, including economic mobility, education, social and built environment, community context, and other health metrics. The Healthy People 2020 initiative also includes metrics for these categories and a list of possible datasets from sources such as the Census Bureau, Department of Labor, and the Department of Justice. HHS has worked to develop broader SDOH standards policies that have resulted in initiatives like the Argonaut Project and the CARIN Alliance. These policies have also created cross-sector collaborations such as the Gravity Project, described above, which aims to improve interoperability for SDOH definitions in HER screening tools. Moreover, HHS can help set the rules and specifications for International Classification of Diseases (ICD) 10 Codes which is used in billing and reimbursement in Medicare and Medicaid.
- **Technological Infrastructure and Tools:** The Health Information Technology Advisory Committee (HITAC) has been a critical actor in developing tools and technological infrastructure. For example, the Office of the National Coordinator for Health Information Technology (ONC), under the auspices of the 21st Century Cures Act, was tasked with developing a trusted exchange framework for secure health data exchange and to create an application programming interface (API) that can connect third party apps to health IT systems.²⁶ Moreover, HHS has started to provide free assessment tools to encourage the collection and use of SDOH data at the clinical level.
- **Local Programs:** The Center for Medicare and Medicaid Innovation (CMMI) has spearheaded a series of programs that work at the local level. HHS also can support initiatives that partner with local agencies to support the collection of SDOH data and provide special data use agreements to release program data. Programs like the Maternal Opioid Misuse (MOM) Model and the Integrated Care for Kids Model (InCK) are developing new approaches and interventions to address mental health issues and social risk factors for opioid abuse. These initiatives aim to create alternative payment models, support local and community health providers with better integration of care, and spread accountability across providers.

The CMMI Accountable Health Communities Model

The Accountable Health Communities Model (AHC) works to reduce costs through better care management by connecting eligible Medicaid recipients with “navigators” who help connect them with services. AHC supports 30 local agencies around the country who screen Medicaid recipients for socioeconomic indicators in an effort to connect them with services that are responsive to their needs. Thus far, these agencies have screened and gathered data from thousands of Medicaid recipients and plans to release this data to the public as part of the first phase of its evaluation in early 2020. The model works both on the assistance track, which helps high-risk beneficiaries receive services, and the alignment track, which ensures that those services are relevant and responsive to the needs of beneficiaries. Partner bridge organizations serve as community resource hubs.

Other Federal Government Efforts

The Federal Government has taken broad steps to collect and store the diverse types of data that constitute SDOH data, and also work to coordinate the sharing of that data across its many programs. Entities like the U.S. Census Bureau, the U.S. Department of Housing and Urban Development (HUD) and the U.S. Department of Agriculture (USDA) collect and publish data that can provide population-level insights to both the private sector and civil society. These datasets can include unemployment rates, SNAP and CHIP utilization rates, and the ethnic makeup of a specific neighborhood, and are often available on websites like data.gov. Moreover, as mentioned above, the HITAC coordinates efforts between 20 different agencies to enhance health information exchange and coordinate services.²⁷ These services range from developing interoperability standards to identifying when health information has been improperly blocked.²⁸ As the federal government develops a more integrated and cross-sectoral approach to the social determinants of health, newer datasets may be centralized or improved for use.

The VA’s Million Veterans Program

The Million Veterans Program (MVP) is a precision medicine program that has now gathered individual-level data from over 750,000 veterans to learn how genes, lifestyle, and military exposure affect health and wellness. The MVP survey asks specific questions related to veteran lifestyles, including obesity, tobacco use, alcohol consumption, and other factors that may influence a person’s health. The survey also includes measures of environmental exposures, exercise habits, and overall well-being. While the program has made immense strides in developing predictive profiles of diseases such as cancer and diabetes based on genetic backgrounds, the program is also seeking to better understand the environmental and lifestyle determinants of veterans’ health.

The SDOH Continuum of Care: Data Gaps and Successes

“Continuum of care” is a framework for an integrated system of care that spans different interventions and services to provide an individual with comprehensive healthcare delivery. This type of framework is used to address population health issues and establish accountable care organizations, which seek to improve care coordination between local healthcare providers and hospitals.²⁹ Healthcare providers and treatment groups now use several such frameworks, especially to address behavioral health challenges or substance abuse. For example, the New Hampshire Center for Excellence has developed a comprehensive healthcare framework to address substance abuse through health promotion and prevention, risk identification, treatment, and recovery supports.³⁰

This section begins by identifying a series of high-level data challenges that impact every stage of care, which include ethical data issues, a lack of standardization, and issues with incomplete data.^{iv} It then describes a proposed SDOH Care Continuum framework, reviews data needs for each phase of that continuum, and highlights both successes and areas for improvement.

General SDOH Data Issues

Several generalized concerns about data cut across all dimensions of care. These include ethical and privacy considerations, lack of standards, and gaps in data and data sharing.

Figure 3: Overview of General SDOH Data Issues

| Cross-Cutting Data Issues in SDOH | |
|---|--|
| Ethical Data Gathering and Privacy Challenges | |
| Developing social risk profiles could result in community redlining and individual stereotyping. Privacy concerns become a significant issue as a growing number of stakeholders are using individual-level commercial data that may be vulnerable to re-identification. | |
| Lack of Data Standards and Interoperability | |
| The growing interest in SDOH data has produced more and more measures of different health risk factors and indicators. Their lack of data standardization impedes interoperability and may create confusion among the wide variety of tools and resources available to providers. | |
| Incomplete Data | |
| There are data gaps at each phase of the data collection lifecycle which hinder new technological applications such as machine learning and the development of impactful interventions. | |
| Lack of Financial Alignment | |
| Throughout the entire SDOH care continuum, stakeholders have confronted hurdles in leveraging the power of the social determinants of health without the proper financial incentives. | |

^{iv} This continuum of care is specific to clinical settings and does not include non-clinical continuums of care, such as the ONC’s Community Health Peer Learning Program that ran from 2015 to 2017. The ONC initiative gathered data from 10 communities on housing, education, social services, criminal justice, and other factors and produced short community profiles that outlined best practices in data gathering strategies and sharing them with clinicians.

Ethical Issues of Data Gathering and Privacy

Providers and payers are increasingly leveraging SDOH data to better understand the risk profiles of the communities they serve. As this use increases, it's possible that these same companies could engage in health care "redlining" and exclude or profile communities that they identify as high-risk areas.³¹ Additionally, individuals may be directly profiled for residing in a high-risk ZIP Code, which could affect the quality of their treatment. These generalized assumptions could exacerbate the unequal distribution of care and limit some groups' medical options.

Moreover, there are emerging privacy concerns around data that may be collected without explicit patient consent. Some companies are leveraging de-identified patient data from commercial sources, but could combine this data with other tools to re-identify the patient data. For example, TransUnion provides localized individual data for 95 percent of the American population that includes information about a person's socioeconomic risk from credit scores to medical eligibility.³² These data sources often inform artificial intelligence (AI) and machine learning programs that may not be transparent about their algorithms. As these data sources become more widely used, companies may combine commercial data with other sources and potentially re-identify a person. While some of this information may be protected under the safeguards of the Health Insurance Portability and Accountability Act (HIPAA), the level of protection is not always clear. This lack of clarity and consent could result in risks to patient privacy as well as consumer backlash.³³

Lack of Standardization in Data Collection

The growth in the use of SDOH data has yielded a diverse array of definitions and terms for the various categories and metrics of SDOH data. The differences in how providers collect housing data, for example, can include different definitions, metadata, and measurement. Moreover, a wide variety of screening tools are currently used in clinical settings to capture data about the social determinants of health. These screening tools range from privately held screening questionnaires that can be added to EHRs to the open source measures developed by the North Carolina Department of Public Health. Several Roundtable participants pointed out that the AHC screening tool, for example, has not been widely adopted by healthcare payers and key stakeholders. Without a standardized and widely adopted screening tool, SDOH data lacks an interoperable set of fields and may face challenges in data sharing and linkage.

Poor Data Sharing and Completeness

Data completeness is necessary in population health where comprehensive surveillance data enables better machine learning and other advanced applications. There are data gaps at each phase of the data collection lifecycle, from population level data that does not include key SDOH variables, to a CBO that cannot report the outputs and impact of a key social intervention. All stakeholders face major challenges in accessing rich, complete data to build out deeper applications and interventions to address the social determinants of health. This lack of complete data may skew the causal attribution for different risk factors and provide an inaccurate snapshot of a community.

Lack of Financial Alignment

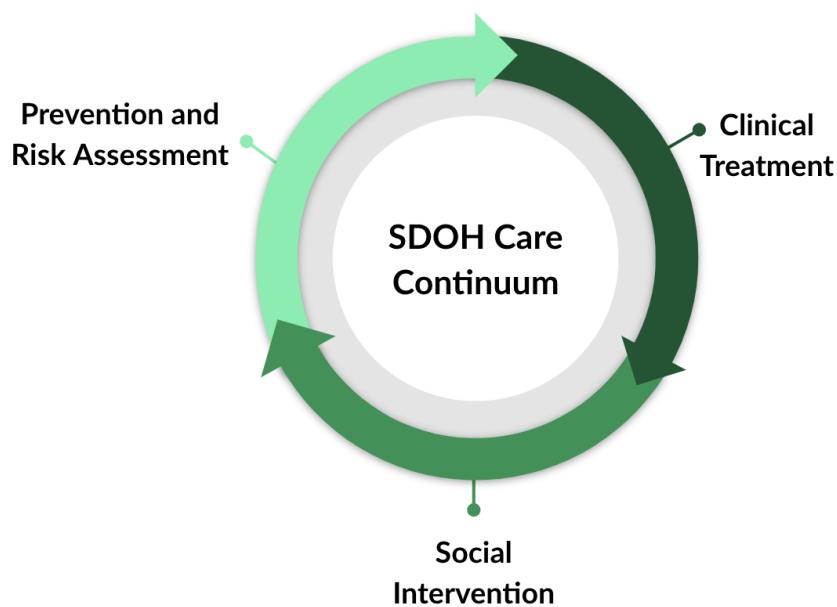
Despite the growth and ability to gather data about the social needs and risk factors of patients, there is still little financial alignment across the healthcare sector. While some SDOH data may be included in a patient's

EHR, much of this data is not included due to inconsistencies around medical billing codes, payer models, and the lack of follow-up with CBOs. The growth of value-based care has been a promising start to increase the use of SDOH data, but there is still much more needed to incentivize SDOH data across the entire healthcare sector. Several studies have demonstrated that the use of hybrid payment models with state Medicaid, that would “blend” or “braid” funding, is a promising avenue to increase funding for localized SDOH models.³⁴

The SDOH Care Continuum

A continuum of care model focused on SDOH could help stakeholders think strategically about how to employ SDOH and other data to deliver better healthcare. This paper proposes an SDOH Care Continuum for clinical settings that draws from existing models. It excludes the health promotion phase and utilizes three stages: prevention and risk assessment, clinical treatment, and social intervention and referrals.

Figure 4: The SDOH Care Continuum



| Prevention and Risk Assessment | Clinical Treatment | Social Intervention |
|---|--|--|
| Risk assessment and prevention leverages predictive analytics and risk mapping to identify patient populations that are at greater risk than other populations for developing certain diseases or chronic conditions based on their social needs. | Patients in clinical settings can be screened for social needs. These screenings determine key risk factors and recommend treatment based on conditions. | Social interventions include referrals or treatments that aim to address a key social need such as food insecurity or housing instability. These interventions usually are with social services organizations. |

Prevention and Risk Assessment

Prevention and risk assessment are the most upstream stage of the continuum of care for SDOH and enable health providers, CBOs, and other stakeholders to better pinpoint risk hotspots and allocate resources appropriately. A variety of private sector businesses, healthcare payers, and technology companies are working to identify high-risk patients and prevent the onset of disease. Despite these advances, challenges in collecting representative population-level data, restrictive access to public files, and a lack of clarity on data priorities create barriers to improved prevention and risk assessment.

What's Working. Health payers and providers are advancing the study of SDOH by contracting with private technology firms that incorporate SDOH data into complex models for risk assessment and prevention.

- Expanding Population-Level Data and Resources: Federal statutes have increased population-level data from the Census Bureau, the U.S. Environmental Protection Agency (EPA), and the Internal Revenue Service (IRS). For example, the Centers for Disease Control and Prevention (CDC) is cataloguing and documenting public data resources for researchers, healthcare providers, and other groups to use.³⁵
- Growing Market for Commercial Risk Platforms: A wide variety of companies have entered the market to provide better social risk tools that seek to flag high risk neighborhoods. Technology platforms that seek to better understand the social determinants have leveraged diverse commercial, social, and public data sources to produce visualizations and social risk maps.

What Needs Improvement. Risk assessment has advanced but unfortunately still suffers from a lack of complete information, poor alignment of incentives around preventive care, and the lack of consensus around high priority data elements.

- Accessing Open and Available Data Sources: Many of the platforms advancing health risk assessment have paid, tiered access models that can be restrictive for researchers or groups striving to investigate SDOH trends among vulnerable populations. For example, one Roundtable participant noted that the HHS Health Services and Resource Administration (HRSA) has restricted access to their Area Health Resources Files (AHRF). These files provide comprehensive data on population characteristics, economics, hospital utilization, hospital expenditures, and environment at the county, state and national levels, from over 50 data sources.³⁶
- Using Timely and Representative Data: Survey-based, public health surveillance data and population-level data are not collected with the same frequency or granularity as data collected in a clinical setting. Risk profiles may rely on overly large geographic units, such as county-level data, which may not provide an accurate snapshot of the smaller communities within those areas. Many datasets may not be relevant or available for healthcare providers. Moreover, a lack of timely and regularly updated data may lead healthcare providers and payers to wrongly assess social risk factors like poverty, housing, and transportation issues in certain neighborhoods. This problem can be solved through application program interfaces (APIs) that provide automated updates of datasets, but many sources of SDOH data don't use APIs. Timely data is especially important for programs that leverage machine learning for risk prediction.
- Lacking Consensus Around High Priority Data Elements: Despite the growth in the use of SDOH data to identify patient risk, there is less research that captures how different data elements impact one another and which data elements may have the most causal impact on patient health.

The Chicago Health Atlas

The Chicago Health Atlas is widely recognized as a model for providing SDOH data at a detailed geographic level that is very useful for public health analysis and planning. The Atlas is a comprehensive tool developed by the City Tech Collaborative and the Chicago Public Health Department to help monitor the progress of Healthy Chicago 2.0, a citywide plan to enhance health equity.³⁷ The project enables Chicagoans to compare neighborhood indicators on SDOH and generally identify opportunities for intervention and support. The site includes a comprehensive index of indicators that include social and economic factors, morbidity, mortality, and physical factors. The Atlas also presents user-friendly dashboards that rank Chicago's 77 community areas and denote high risk and hardship zones through comprehensive data. The interactive maps continue to be updated with new information such as grocery store density and available affordable housing units.³⁸

Clinical Care and Treatment

For populations expected to be at risk, providers may carry out clinical screenings to better understand the key conditions that the person is facing. In the world of SDOH data, many providers and payers have developed robust social screening assessments and are increasingly gathering individual-level data to inform treatment. Regardless of these advances, issues with data for care coordination, a lack of standards, and issues with patient access to data have created major obstacles to improved SDOH data use.

What's Working. The proliferation of screening questionnaires and improved health information technology in the workplace, such as Natural Language Processing (NLP), have increased the ability of physicians to gather social needs data.

- Increased Use of Social Screening Assessments: Additional plugins and the growth of modern EHR have allowed physicians to gather more detailed data about the patients they serve. More and more practices are integrating open source social screening tools, such as the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE)³⁹, and the North Carolina Department of Health and Human Services (NCDHHS) screening questionnaire⁴⁰, to better understand the social risk factors of their patients.
- Ability to Gather Individual-Level Data: The use of these social screening assessments and technologies like NLP have increased the volume of granular, individual-level data about a person's social environment. Programs like the AHC model and the Integrated Care for Kids model are producing individual-level data on Medicaid and Medicare beneficiaries. This data allows for increasing insights on key social risk factors, and can likely enable greater research around the SDOH.

What Needs Improvement. Despite the ability to better gather data in clinical care settings, the lack of standardized assessment tools and poor patient access to SDOH data have limited physician and patient trust when it comes to gathering this data.

- Poor Data on Care Coordination: As care coordination and accountable health screenings are increasingly seen as the best approach to value-based care, clinicians face technology and process challenges in gathering data from parties responsible for administering care to a patient. While improved EHRs and healthcare data sharing has increased care coordination, many hospitals and

providers continue to face challenges in seamlessly sharing and gathering important data about patients' social needs.

- Lack of Incentives to Gather SDOH Data from Patients: The growth in Health IT in the clinical care setting has increased physician data workloads and burdens. Reports have shown that more and more time in front of a computer screen leads to greater physician burnout.⁴¹ In addition, many physicians report that their inability to provide patient referrals after identifying a social need as a barrier to collecting this data.⁴² Many patients are also less inclined to share this data if the answers to screening questions are not tied to outcomes.
- No Standardized Screening Assessments: Although the growth of different screening assessment tools is encouraging, the multitude of EHR plugins has produced a variety of data entry fields, definitions, and data collection points. In some cases, healthcare providers themselves may provide multiple tools at different care sites around the country. Moreover, SDOH data is not often coded to align with payer codes or a person's EHR. This lack of unified patient screening often leaves patients unable to transfer personal data on social needs from one provider to another.
- Patient Access to Clinical Data: While there is an expansion of data collection taking place in the clinical setting, many patients do not have access to the detailed personal data that is gathered by their physicians. Access to this data would potentially enable patients to make better decisions and understand strategies to improve healthy behaviors. For example, the VA and Apple announced in November 2019 that veterans' medical records would be accessible on their smartphones.⁴³ Moreover, doctors lack access to the social risk factors that may determine much of a patient's health.

The North Carolina Clinical Assessment Tool

The Roundtable featured an announcement introducing the first open source, FHIR-enabled SDOH screening questionnaire.⁴⁴ FHIR is a respected interoperable web-based technology that has gained support from Amazon, Apple, Google, and Microsoft for its ability to enable standardization of health data. It is also the standard expected in EHRs and other clinical spaces. Developed by the North Carolina Department of Health and Human Services (NCDHHS) Healthy Opportunities program, the questionnaire can be used by any provider with an FHIR-enabled server. The screening questions include a series of questions that ask patients about food access, housing and utilities, transportation, and interpersonal safety. The answers to these questions can be delivered to health providers to better help address those needs.

Social Interventions and Referrals

Social interventions represent a continuation of treatment and a form of prevention that extends outside a clinical setting and are a critical portion of the care continuum. Social intervention data is an essential part of assessing the impact of SDOH on health, and more of this data is becoming available as partnerships and networks of CBOs and providers grow in size and scope. Despite the prospect of greater data impact, there still are major hurdles with outcomes data, CBO data capacity, and the broader data infrastructure necessary to measure impact.

What's Working. The increasing networks of CBOs that serve referred patients have demonstrated that many patients are advancing from prevention to screening to referrals. The growth of comprehensive referral platforms and the availability of hyper-local CBO data are two of the more promising uses of SDOH data.

- **Comprehensive Referral Platforms:** In addition to the growth in platforms that effectively predict risk, there is a growing suite of platforms that refer patients to services after clinicians build out a patient's care plan. These comprehensive referral platforms often enable health providers to conduct a CBO analysis of their communities, identify those organizations that will best serve their patients, and create a shared platform for referral sharing. For example, Healthify, a comprehensive referral platform, aims to provide end-to-end services and improve accountability between CBOs and healthcare providers.⁴⁵ These platforms, however, can add additional strain to CBOs.
- **Advancing Data-Driven Partnerships:** Accountable care organizations, accountable communities for health, and the federally-driven CMMI AHC model (mentioned above) are all emerging examples of data-driven partnerships between health providers and CBOs. A July 2017 national request for information (RFI) survey, carried out by the Scripps Gerontology Center at Miami University, discovered that nearly half of the 593 responding CBOs already have or are pursuing partnerships with healthcare providers.⁴⁶ Many of these partnerships have established some form of data sharing that enables the CBO to share data about client referrals with the health provider.⁴⁷ For example, a Washington accountable care organization is receiving data through dashboards hosted as part of the state's Analytics, Research and Measurement (ARM) strategy.⁴⁸

What Needs Improvement. Despite the prevalence of platforms and partnerships between CBOs and providers, there are continued gaps in available data to measure patient impact, CBO data capacity, and broader data infrastructure to capitalize on this growing amount of information.

- **Poor Quality Measures for Intervention Outcomes and Impact:** Numerous healthcare payers and providers have noted that there is still a significant gap in the available data capturing the effectiveness of recommended interventions. While companies like Unite Us and Healthify are striving to create better outcome measures, there is still no unified system of impact measurements or quality measures to determine if the intervention can be credited with improving patient health.
- **CBO Data Capacity:** As more and more patients secure referrals to CBOs, the volume of data generated from these interactions will expand significantly. While many larger CBOs have sophisticated databases and intake forms, smaller and less equipped CBOs will face challenges in gathering data from their clients. The increase in accountable care and care coordination will necessitate more data gathering capabilities. The Center for Healthcare Strategies notes that philanthropists and funders can be one set of actors to help bridge this important gap by supporting data capacity.⁴⁹
- **Broader Data Infrastructure:** The growth of referral platforms and CBO partnerships has taken place in many states at the local level without federal or state support. As these partnerships and interventions generate more data, there is an increasing need for better data infrastructure and systems to ensure that data remains accessible by researchers, civil society, and other key stakeholders.

The Unite Us Platform

Unite Us began as a technology platform to connect veterans with key social services after they returned from duty. The platform has since expanded to become a full suite of services that seeks to provide patients with the best referrals to social services and track them through the course of that intervention. Unite Us works closely with community service providers, state and local governments, behavioral health organizations, and general healthcare providers. The platform provides patient screening with decision support, electronic referral management, care plan management for the organizations receiving referrals, and tracking of outcomes. The platform also provides support services and in-product communication for social service agencies that receive referrals.

Figure 5: Data Successes and Challenges on the SDOH Continuum of Care

| SDOH Continuum of Care | | |
|--------------------------------|---|--|
| Continuum of Care Stage | Successes | Challenges |
| Prevention and Risk Assessment | <ul style="list-style-type: none">● Expansion of population-level data● Increased use of commercial platforms | <ul style="list-style-type: none">● Difficulty accessing open and available data sources● Difficulty finding timely and representative data● Poor understanding of high-priority data elements |
| Clinical Treatment and Care | <ul style="list-style-type: none">● Wide availability of social screening assessments● Ability to gather individual-level data | <ul style="list-style-type: none">● Poor data on care coordination● No standardized screening assessments● Lack of incentives to gather data● Opaque rules about patient ownership of data and privacy concerns |
| Interventions and Referrals | <ul style="list-style-type: none">● Comprehensive referral platforms● Growth in data-driven partnerships | <ul style="list-style-type: none">● Lack of CBO data capacity● Need for broader data infrastructure● Poor data measuring patient outcomes and impact |

Recommendations and Solutions

As SDOH data becomes more widely adopted along each stage of the continuum of care, HHS and its partners can play an increasingly important role in coordinating this work to maximize healthy outcomes for patients. To address these issues, this report recommends defining and standardizing data, building out a sustainable infrastructure along the data management lifecycle, and empowering local and state decision makers. CODE has based these recommendations on input from individual Roundtable participants and CODE's additional research. They do not represent a consensus of Roundtable attendees, and do not represent the views of HHS or any other government agency.

Based on the input of many Roundtable participants and CODE's additional research, this report recommends that **HHS develop an SDOH Data Strategy** that comprehensively maps the space and helps coordinate action among different stakeholders. Such a comprehensive strategy could improve interoperability and data access, address privacy concerns, and broadly set the agenda for improved use of SDOH data. Each of the following sections includes recommendations that could be a part of that broader SDOH Data Strategy.

Define and Standardize SDOH Data

Data standards and commonly agreed upon definitions serve as the foundation for data interoperability, privacy and protection, and ethical data use, including the principle of data minimization.^v As more and more data is gathered about financial, housing, environmental, and contextual indicators, Roundtable participants proposed a series of recommendations to ensure that SDOH data is standardized and streamlined for use.

Improve and Align Open Source Assessment Tools

The Problem: Many of the emerging SDOH screening assessment tools and predictive analytics platforms are commercial products that are not financially accessible to CBOs, smaller health clinics, and other key stakeholders. While open source screening tools like PRAPARE have been adopted, little coordination exists between the different providers who use open source screening assessments.

| | |
|-------------------------|---|
| Solution | Develop a centralized repository of open source assessment tools and social screening platforms to identify best practices and build consensus. |
| Impact | Enable centralized use of key screening tools and promote coordinated open source development in the SDOH data space. |
| Resources Needed | Dedicated funds to review existing platforms, staff resources, technology expertise to develop integrated tools, and federal oversight. |
| Stakeholders | Commercial SDOH vendors, patient advocacy groups, CMMI, healthcare providers and payers, state governments, federal government, civil society, CBOs |
| Policy Changes | Updates to the forthcoming CMS and ONC rules on APIs and interoperability and patient access. ⁵⁰ |

^v The data minimization principle emphasizes that data collection and the amount of data used for any particular project is only what is necessary to accomplish the needed tasks. This reduces the possibility of unnecessarily gathering potentially sensitive information about an individual.

| | |
|--------------------------|---|
| Immediate Actions | <ul style="list-style-type: none"> ● Develop a working group to identify the variety of open source SDOH screening tools (potentially work with the Gravity Project). ● Create comprehensive inventory of existing tools, similar to the Gravity Project, and the wider work of SIREN, which oversees Gravity.⁵¹ ● Aggregate open source assessment tools into a single repository to be hosted on HHS website. |
| Long-Term Goals | Develop a single, customizable SDOH screening assessment that can be adopted across healthcare settings and accessed by patients. |

Adopt Data Standards and Definitions

The Problem: The lack of data standards and definitions for SDOH data has led to challenges in data sharing, interoperability, and improved coordination of care. As stakeholders expand population health interventions and programs, increasing amounts of data will need to be shared and integrated across platforms to gain greater insights from this data.

| | |
|--------------------------|---|
| Solution | Increase funding and support from federal and state governments to bolster national initiatives, such as the Gravity Project, to expand, accelerate, and align work around SDOH data standards. |
| Impact | Develop a national consensus around SDOH Data standards and definitions for better alignment and interoperability. |
| Resources Needed | Additional government funding for standards collaboratives, staff resources to oversee collaboratives, and incentives for adoption. |
| Stakeholders | Healthcare payers, providers, CBOs, federal government |
| Policy Changes | Updating the CMS health interoperability rules and adjusting the ICD Codes. |
| Immediate Actions | <ul style="list-style-type: none"> ● Review successes and hurdles faced by the Gravity Project to develop new working group models. ● Review the capabilities of developing a health data standards collaborative. ● Develop a small working group of private and public stakeholders to pilot updated definitions in clinical settings. |
| Long-Term Goals | Promote the use of standardized definitions of SDOH data and realign the healthcare space towards addressing holistic care. |

Develop A Data Governance Body

The Problem: SDOH data is generated and used by a wide array of stakeholders both within and outside the healthcare sector. This multitude of actors can range from smaller community food banks that are distributing nutritious goods to clients to a larger healthcare payer that is tracking value-based care for its members across different states. This can pose a challenge to coordinating policy, data sharing, and new programs.

| | |
|--------------------------|---|
| Solution | Develop a data governance body to help coordinate working groups and standards development, and to set policy, around SDOH data. |
| Impact | Better align SDOH data work to prevent the duplication of efforts and increase consistency of SDOH data development in the United States. |
| Resources Needed | HHS guidance and leadership for data governance body, funding for dedicated team to oversee governance, funding for sustainability. |
| Stakeholders | Federal government, state and local health officials, healthcare payers and providers, patients and community members, ethicists, CBOs, existing SDOH Data working groups |
| Policy Changes | Potential development of a national SDOH Data Strategy and adjustments to the Trusted Exchange Framework and Common Agreement (TEFCA). ^{vi} |
| Immediate Actions | <ul style="list-style-type: none"> ● Complete initial ecosystem and stakeholder analysis of ongoing efforts in the SDOH data space. ● Convene a working group that can coordinate efforts among these various bodies. |
| Long-Term Goals | Create a long-term SDOH Data Strategy that will provide guidance on standards, definitions, privacy, financial alignment, and policy development across sectors. |

Create a Sustainable Infrastructure for SDOH Data

As value-based care and population health are implemented across the healthcare system, more and more stakeholders will engage in the collection, aggregation, and sharing of SDOH data. This will require increasing access to data infrastructure, such as online data storage, the integration of SDOH data into EHRs, and the ability for small and larger stakeholders alike to streamline data collection.

Improve Financial Alignment for Payers, Providers, and CBOs

The Problem: The clinical setting represents the primary forum to gather individual-level data on social risk factors and other environmental conditions. Despite the importance of gathering these metrics, many clinicians lack access to the plugins to support this data collection and have poor financial incentives to work more closely with CBOs and other service providers to track the outcomes of these interventions.

| | |
|-------------------------|--|
| Solution | Realign the payment structure across providers and CBOs to improve financial alignment and adoption of SDOH data in a clinical setting. |
| Impact | Transform healthcare by advancing from responsive cures to preventive treatment. |
| Resources Needed | Better infrastructure, increased monetary resources, involvement from the National Committee for Quality Assurance (NCQA) and National Quality Forum (NQF) |

^{vi} TEFCA is a common set of principles, terms, and conditions to support a wider agreement that would enable nationwide exchange of healthcare information. The framework's details, developed by ONC, can be found in its entirety here: <https://www.healthit.gov/sites/default/files/page/2019-04/FINALTEFCAQTF41719508version.pdf>

| | |
|--------------------------|--|
| Stakeholders | CMS, hospitals, physicians, plans, CBOs, employers, patients |
| Policy Changes | Improving payment alignment to facilitate the sharing of information across providers, payers, and CBOs. Also, adjusting the quality measures in the CMS Measure Management System and providing more implementation support for the Federal Health IT Strategic Plan. |
| Immediate Actions | <ul style="list-style-type: none"> ● Create a national task force to establish SDOH outcome measures. ● Update and increase ICD-10 Codes and Z Codes for entering patient conditions.^{vii} ● Achieve EHR certification for SDOH data. ● Leverage braided funding models at the state level to increase local adoption |
| Long-Term Goals | Influence behavior by tying payment to SDOH outcomes and payment. |

Empower and Strengthen CBO Data Capacity

The Problem: CBOs are critical providers of SDOH data and document key services that are administered to growing numbers of patients. However, many CBOs lack the measurement capacity or storage infrastructure to oversee the influx of new clients. Important information such as numbers of bags of food distributed or the level of temporary homelessness helps healthcare providers better track outcomes and close the feedback loop for care coordination.

| | |
|--------------------------|--|
| Solution | Provide additional resources and technical support for CBOs to help expand their data gathering capacity. |
| Impact | Create a sustainable infrastructure to scale the use of SDOH in healthcare. |
| Resources Needed | Foundation and philanthropic funding to CBOs, staff resources and training materials for CBO staff, online toolkits |
| Stakeholders | Healthcare providers, private sector companies, foundations, CBOs, data scientists. |
| Policy Changes | Including language around community data capacity in the Federal HIT Strategic Plan. ^{viii} |
| Immediate Actions | <ul style="list-style-type: none"> ● Identify sponsoring philanthropies to lead strategy for CBO Data Capacity. ● Develop an RFP to release to CBOs to expand data capacity. ● Identify foundations and groups to provide small-scale grants. ● Potentially pilot program with CMMI-led AHC zones. |
| Long-Term Goals | Increase the capacity of CBOs to better collect, store, and share data about patients they're serving. |

^{vii} Z-Codes are factors “influencing health status and contact with health services.” For more information: https://www.cdc.gov/nchs/data/icd/10cmguidelines_2016_final.pdf

^{viii} The Federal HIT Strategic Plan “explains how the federal government intends to apply the effective use of information and technology to help the nation achieve high-quality care, lower costs, a healthy population, and engaged individuals.” For more information: <https://dashboard.healthit.gov/strategic-plan/federal-health-it-strategic-plan-exec-summary.php>

Support Local and State-based Decision-makers

A large portion of healthcare delivery takes place at the local level through health clinics, small providers, and community health centers. HHS can play a unique role in expanding the resources and representative data available to state policymakers and practitioners to enhance policy decisions and funding allocations. This is best achieved by developing granular, representative snapshots of communities and creating toolkits for state officials seeking to improve their SDOH strategies.

Develop Hyper-Local Snapshots of Communities

The Problem: Many healthcare providers and private sector companies face challenges in gathering geographically granular and representative data for the communities they serve. Many providers cannot administer better value-based care without access to ZIP Code level data, such as housing, transportation, or food indicators, or could improve decisions with access to county-level federal funding overviews.

| | |
|--------------------------|---|
| Solution | Create hyper-local, small area SDOH estimates at the ZIP Code level. |
| Impact | Enable better distribution of resources and improved understanding and trust among local communities. |
| Resources Needed | Increased data collection abilities through APIs and better data integration, funding for cloud-based platform, and staff resources to oversee the data collection. |
| Stakeholders | U.S. Census Bureau, CBOs, Healthcare Providers, HHS CTO Office, State health agencies. |
| Policy Changes | Update Federal Health IT Strategy; adjust HIPAA privacy and security rule for SDOH data gathering abilities. |
| Immediate Actions | <ul style="list-style-type: none">● Aggregate all available open data at the ZIP Code level.● Work with larger CBOs using digital tools to collect key information about their neighborhoods and communities.● Potentially aggregate federal funds into county or ZIP Code level. |
| Long-Term Goals | Enhance decision-making for local stakeholders and improve interoperability for hyper-local data. |

Create State-Level SDOH Strategy Toolkits

The Problem: States often face difficulties in implementing and distributing funding from the federal government to carry out comprehensive SDOH strategies. Without the proper resources and support from the federal government, HHS and the healthcare sector will face challenges in scaling and coordinating data collection strategies across the country.

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|--------------------------|--|
| Solution | Create state-level toolkits and resources to enable state agencies to implement comprehensive SDOH data strategies. |
| Impact | Scale and streamline standardized data collection across states. |
| Resources Needed | Funding to gather information about state-wide best practices, funding for pilot models, staff resources to coordinate toolkits. |
| Stakeholders | Public health agencies, state health departments, patients and patient advocates, CMMI, health insurers and providers, private SDOH data platforms (Unite Us, Healthify, etc.) |
| Policy Changes | State-level Medicaid Plan Amendments on an as-needed basis to reflect changes to Medicaid administration. |
| Immediate Actions | <ul style="list-style-type: none"> ● Identify best practices from existing state initiatives ● Create small technical documents and state-based case studies for guidance ● Develop online portal to host these resources ● Pilot toolkits with select states already developing SDOH strategies |
| Long-Term Goals | Ensure that states are effectively aligning SDOH strategies with national guidance. |

Conclusion

The social determinants of health hold great potential to address prevention and care alike. The SDOH are becoming the bedrock for value-based care, the current effort to tie reimbursement for healthcare services to patient outcomes. SDOH factors have to be considered in assessing the success of care, since different individuals and groups have different levels of risk and vulnerability depending on their social context. Moreover, addressing SDOH concerns as part of a continuum of care – such as ensuring access to a food pantry as part of a patient’s care plan - can improve a patient’s outcomes and quality of life cost-effectively.

Health care practitioners and policymakers today are expanding their use of SDOH Data at all stages of care to address both individual-level needs and community-wide interventions. The use of this data will require a broader governance strategy that should inform the necessary infrastructure, data standardization, and local supports for state and local policymakers.

In a keynote address at the Roundtable Dr. Karen DeSalvo, former Assistant Secretary for Health and Co-Convener of the National Alliance to Impact the Social Determinants of Health, described the solitary push to build a robust SDOH data ecosystem as a Sisyphean task. In collaboration, however, Dr. DeSalvo noted that healthcare providers could overcome these hurdles. She also provided five important principles for moving towards value-based care and a more preventive, upstream model of health care.

- 1. Begin with The End in Mind:** As data collection increases in scope, practitioners should always remember why they’re gathering the data and what outcomes they hope to achieve. These outcomes may relate to SDOH profiles, payment models, or identifying better public policies that solve issues of transportation, housing, or other social needs.
- 2. Develop Open Ecosystems:** An open SDOH data ecosystem allows for health care providers to compete on what they do with the data, not on access to the data itself. Through open technologies like FHIR-based APIs, data should be used to develop more comprehensive longitudinal health care records that individuals can access.
- 3. Work in Partnership:** SDOH Data is bigger than a single sector and will require ongoing collaboration between the public and private sectors. It will also require the involvement of CBOs that have access to different, more granular data sources and have their own goals for data use.
- 4. Do No Harm:** Providers shouldn’t only understand SDOH data through a medical lens nor use it to cherry-pick select patients based on their conditions. Patient and community data should be used carefully. It should not be used to profile individuals negatively or to stigmatize entire communities, but should be used in ways that build trust between the health system and those they serve.
- 5. Engage Strategically:** HHS should lead work on an SDOH Data Strategy, that includes a Data strategy, to provide guidance on the use of this data and insight into what works and what doesn’t. The private and public sectors should work together to develop this broad national strategy.

Many stakeholders in SDOH data are already working to identify data uses, build open data ecosystems, focus on avoiding potential harms, and engage with each other at a strategic level. The work of groups like the Gravity Project, the FHIR Open Questionnaire, and other projects described in this report are important steps in the right direction. New partnerships between healthcare providers and CBOs, and collaborative efforts to provide health to rural communities, are also showing new ways that stakeholders can work together. CODE hopes that this report will be a valuable resource for everyone working to create this emerging, data-driven, social model of healthcare.

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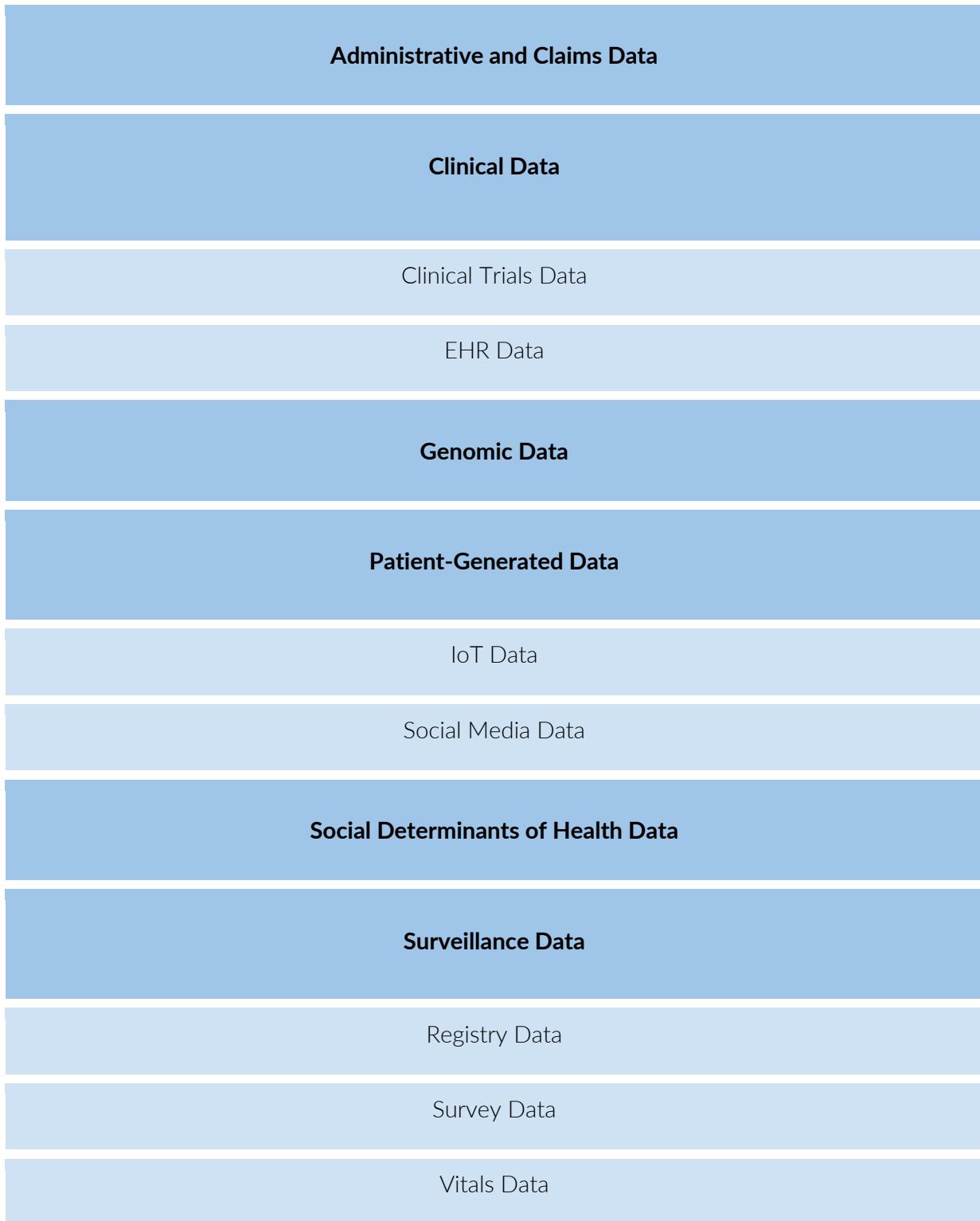
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The following resources are included as appendices to this report:

- High-Value Data Types
- Health Data Elements and Scenarios Handout
- List of Participating Organizations
- Roundtable Agenda

Appendices

High-Value Data Types for Health



Administrative and Claims Data generally comes from federal, state, and local government agencies as well as healthcare providers and insurers. This can range from hospital discharge summaries to payment records between insured patients and the healthcare system.⁵²

Clinical Data is a broad term that encompasses different kinds of data generated “in a clinical setting and controlled by a clinician, as opposed to a patient or caregiver.”⁵³

- **Clinical Trials Data** includes registries and results from publicly and privately funded clinical studies. Large amounts of data, including sensitive information about participants, are generated over the course of a clinical trial. Researchers must obtain regulatory approval to collect and use this data.
- **EHR Data** is focused on individual patients, and can include information on routine checkups, prescriptions, and medical procedures. Physicians can draw upon EHR data to develop individual treatment plans and diagnose conditions. This data can also be combined with social determinants of health to develop rich longitudinal profiles of individual patients and populations.

Genomic Data can include many different characteristics, ranging from full DNA sequences to individual DNA variants.⁵⁴ Recent advances have made it possible to analyze and store data on a person's entire genome sequence. According to the National Institutes of Health, “Genome-based research is already enabling medical researchers to develop improved diagnostics, more effective therapeutic strategies, evidence-based approaches for demonstrating clinical efficacy, and better decision-making tools for patients and providers.”⁵⁵ Genomic data is considered highly sensitive and must be shared and used under carefully controlled conditions.

Patient-Generated Data includes “health-related data created and recorded by or from patients outside of the clinical setting to help address a health concern.”⁵⁶ This data type is becoming increasingly prevalent through the creation of mobile health applications and wearable health devices.

- **IoT Data** includes data from mobile software applications, voice assistants, and wearable devices such as smart watches. These technologies are part of the “internet of things,” or IoT, which refers to the growing system of machines and devices connected to the internet. This data is generally collected under “terms of service” agreements and has the potential to provide important information on a variety of critical health indicators, such as heart rate, sleep cycles, and diet.
- **Social Media Data** includes interactions on social media platforms such as Facebook and Twitter. Researchers have noted that “Social media may offer insight into the relationship between an individual's health and their everyday life, as well as attitudes towards health and the perceived quality of healthcare services,” among other opportunities.⁵⁷ Like IoT data, social media data is collected under “terms of service” agreements.

Social Determinants of Health Data represent “conditions in the environments in which people are born, live, learn, [and] work...that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”⁵⁸ Examples of these social determinants include access to transportation, education, and job opportunities as well as the availability of food and housing options. Social determinants of health data can come from many sources inside and outside of government, and can be used to better understand population health.

Surveillance Data is a broad term that encompasses the “ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice.”⁵⁹

- **Registry Data** includes data shared voluntarily by individuals that is generally focused around a specific diagnosis or condition such as cancer or cystic fibrosis. This data can be used to track trends and better understand conditions over time. According to the NIH, this data “belongs to the sponsor of the registry and...may be shared with the participants and their families, and approved health care professionals and researchers. However, personal, identifying information is kept private.”⁶⁰
- **Survey Data** includes the results of surveys and studies conducted to assess population health. This data can help stakeholders monitor the spread of disease, track health insurance coverage across regions, and assess trends in nutrition and exercise, among other uses.⁶¹
- **Vitals Data** is generally collected and exchanged between local jurisdictions and the federal government. This data represents “vital events,” such as births, deaths, marriages, divorces, and fetal deaths.⁶²

Data Elements and Scenario Handout

This handout was developed by Sandeep Patel and the HHS Office of the CTO for distribution at the Roundtable. The handout was used for Breakout Session 1: Identifying and Prioritizing SDOH Data Sources.

Data Elements by County Level Targeted for Integration

| Category | Specific Data Element |
|--------------------|---|
| Clinical | <ul style="list-style-type: none">● Medicaid eligibility and enrollment● % of Medicare beneficiaries that are dual-eligible for Medicaid, and reason for dual-eligibility (low-income, disabled)● % Medicare beneficiaries eligible for MSP and/or Part D LIS (if not fully dual eligible)● % uninsured● Healthcare access● prevalence of overweight |
| Education | <ul style="list-style-type: none">● Education measures such as high school graduation rates● % school lunch eligible● % reading at grade level● % kindergarten readiness |
| Financial/Economic | <ul style="list-style-type: none">● TANF eligibility and enrollment● unemployment rate● underemployment rate● LIHEAP eligibility and enrollment● Poverty rate |
| Food | <ul style="list-style-type: none">● SNAP eligibility and enrollment● WIC eligibility and enrollment● Meals on Wheels eligibility and enrollment● USDA on household food insecurity, access to a grocery store, etc. |

| | |
|----------------|--|
| Housing | <ul style="list-style-type: none"> ● % unaffordable housing (HUD defines as >30% of income going to housing, HP2020 defines as >30% for all households, <200% FPL and >30%; >50% for all households; and renters that spend >50%) ● homelessness rate (HUD collects through an annual survey; can be broken down to provide a separate rate for homeless families) |
| Transportation | <ul style="list-style-type: none"> ● Access to transportation (% eligible for some type of transport assistance? DoT data?) |
| Contextual | <ul style="list-style-type: none"> ● Demographic data ● % of children in foster care or juvenile justice system ● Social engagement measures such as: % registered to vote, % registered and voted in last election; % reporting having a person in their life they can trust/sufficient social/emotional support ● Safety/built environment: % of people with personal experience with and/or community exposure to violence/physical assault ● Air quality ● Urban/rural |

Additional Options:

- life expectancy at birth
- Premature death
- Low birthweight
- Adult smoking rates
- USDA's food environment index
- Teen births
- Availability of mental health providers
- High school graduation rate
- Children in single-parent households
- Air pollution
- Blood lead levels
- Access to exercise opportunities

Use Cases/Decisions Better Informed by Quality SDOH Data

1. In **designing a new federal funding program**, I'd like to know how best to target funds and customized services to people in counties with the most need. I'd like to know what federal funds are already being utilized in those counties for similar purposes, so I'm not duplicating efforts but adding unique value. Does that County Health Rankings already allow me to do this? What's missing?
2. As a **federal or state program officer**, I'm interested in understanding how much impact the interventions I funded had on my stated goals, and how much might be attributable to other dynamics.
3. As a **large hospital organization**, I'm looking to expand my footprint to new regions, and I'd like to know how I can best predict hospital utilization, revenue, including how many people are experiencing food insecurity or lack of access to transportation for health care visits. I'd also like to know what proportion of people are on SNAP, and what proportion of children are reading at grade level so I can best design services for the hospital.
4. As a **state health program officer**, I have a federal grant to distribute across the state to improve health outcomes, and I don't know how best to target these funds and for what purposes. Is there a way I can understand where the most critical gaps lie? I'd also like to understand how upstream factors are interacting with one another to impact community members and their health?
5. I'm a **population health researcher** trying to understand and tease apart a variety of confounding factors all contributing positively and negatively towards the health outcomes of interest for me. I don't have enough detailed information on all inputs and outputs, which forces me to make more assumptions than I'd like to make strong conclusions on comparative effectiveness.
6. I'm a **food retailer** looking to expand operations across the state, and I'm targeting locations and delivery services for which I'd like to know if recent federal funding efforts, SNAP enrollment, and other factors are working to address upstream factors that might create a larger customer base for me in the near future.
7. I operate a set of small community health centers funded in part by the govt, and I know many of my patients have difficulty making appointments because of public transportation issues. I'd like to know who I can partner with or whether are any available grants for others to seek creative solutions, since I don't have time or expertise to deal with it.
8. I've created a new service within my community to provide healthier food options to people. I know what I'm doing, but I'm not sure what goals should I be setting for my intervention/are the goals I selected ones it's possible for me to make an impact on? Can someone do a study to show that what I do works and helps people?

Some additional questions:

1. Do you utilize resources like County Health Rankings already? If yes, in what ways are resources like that helpful/not helpful? If no, why not?
2. What resources, other than Country Health Rankings, do you use to identify needs in your community? What are the pros/cons/barriers to using those resources?
3. To what extent are you already able to answer the above questions using those types of resources? What gaps are there in the data provided by those resources that federal data might help address?
4. Do you agree these are potential use cases/would these uses be helpful to you? What other use cases specific to adding federal data do you see as being helpful to your organization and community?

Participating Organizations

Leveraging Data on the Social Determinants of Health

PARTICIPATING ORGANIZATIONS

Civil Society, Philanthropy, and Advocacy Groups

ACT | The App Association represents more than 5,000 app companies and information technology firms across the mobile economy. ACT advocates for an environment that inspires and rewards innovation, while providing the necessary resources to help its members leverage their intellectual assets to raise capital and create jobs.

Alliance for Better Health engages medical and social service providers in developing innovative solutions to promote people's health, with a goal of transforming the care delivery system into one that incentivizes health and prevention.

Aligning for Health is a membership association which will bring a team of federal and state administration experts to address the issues that challenge the common purpose of its members – the need for efficient, integrated and coordinated programs to better improve health outcomes for Americans.

American Hospital Association is the national organization that represents and serves all types of hospitals, health care networks, and their patients and communities. Through representation and advocacy activities, it seeks to ensure that members' perspectives and needs are addressed in national health policy development, legislative and regulatory debates, and judicial matters.

American Public Human Services Association (APHSA) is a bipartisan, nonprofit membership organization representing state and local health and human service agencies through their top-level leadership. Through its member network and national Collaborative Centers, APHSA seeks to influence modern policies and practices that support the health and well-being of all children and families and that lead to stronger communities.

Beeck Center for Social Impact and Innovation was launched in 2014 at the Georgetown University to provide students with new ways to impact society, in a cross disciplinary, hands-on experiential way.

Benefits Data Trust uses private-sector strategies to reduce poverty by using data, targeted outreach, policy change, and new technologies to proactively connect people to benefits and services.

Center for Digital Health Innovation at the University of California, San Francisco supports the discovery, innovation and implementation of digital health technologies by providing developmental resources and leveraging external partnerships. CDHI focuses on data science, product management, software development, EHR integration, and project management.

Center for Open Data Enterprise (CODE) is an independent nonprofit organization based in Washington, D.C. whose mission is to maximize the value of open government data for the public good.

Data Across Sectors for Health was launched by the Robert Wood Johnson Foundation and aims to identify barriers, opportunities, promising practices and indicators of progress for multi-sector collaborations to connect information systems and share data for community health improvement.

DC Central Kitchen develops and operates social ventures targeting the cycle of hunger and poverty by training jobless adults for culinary careers and then hiring dozens of their own graduates to prepare the 3 million meals we provide for homeless shelters, schools, and nonprofits each year.

Michigan Public Health Institute is a Michigan-based and nationally engaged, non-profit public health institute. Their mission is to advance population health through public health innovation and collaboration.

National Quality Forum is a not-for-profit, nonpartisan, membership-based organization that works to catalyze improvements in healthcare. NQF measures and standards serve as an important foundation for initiatives to enhance healthcare value, make patient care safer, and achieve better outcomes.

OCHIN is a non-profit health care innovation center designed to provide knowledge solutions that promote quality and affordable health care for all. It works to bring electronic health records and sophisticated health care IT solutions to public health clinics that are serving the underserved.

Robert Wood Johnson Foundation (RWJF) is the nation's largest philanthropy dedicated solely to health. RWJF supports research and programs targeting some of America's most pressing health issues—from substance abuse to improving access to quality health care.

Sage Bionetworks is a nonprofit biomedical research and technology development organization that was founded in Seattle in 2009. Its focus is to develop and apply open practices to data-driven research for the advancement of human health. Sage believes open practices can help improve the role of data in biomedicine.

Stanford University's Clinical Excellence Research Center generates robust scientific evidence demonstrating how lower cost, high quality care delivery can be achieved, while driving its national adoption through training, strategic partnerships, and quantitatively evaluating its value to U.S health care systems, patients, and society.

Trust for America's Health is a non-profit, non-partisan organization dedicated to saving lives by protecting the health of every community and working to make disease prevention a national priority. It reports on and recommends evidence-based programs and policies that make prevention and health equity foundational to health and community systems.

Urban Institute is a non-profit organization dedicated to elevating the debate on social and economic policy. Its scholars have conducted research and offered evidence-based solutions that improve lives and strengthen communities across a rapidly urbanizing world.

Government

The U.S. Department of Health and Human Services (HHS) is a cabinet-level department of the U.S. federal government with the goal of protecting the health of all Americans and providing essential human services.

Administration for Children and Families is a division of the HHS that promotes the economic and social well-being of families, children, individuals and communities with funding, strategic partnerships, guidance, training and technical assistance.

Agency for Healthcare Research and Quality (AHRQ) seeks to produce evidence to make health care safer, higher quality, more accessible, equitable, and affordable, and to work within the U.S. Department of Health and Human Services and with other partners to make sure that the evidence is understood and used.

The Centers for Disease Control and Prevention Center (CDC) works to protect America from health, safety and security threats, both foreign and in the U.S. Whether diseases start at home or

abroad, are chronic or acute, curable or preventable, human error or deliberate attack, CDC fights disease and supports communities and citizens to do the same.

The National Center for Health Statistics (NCHS), part of the CDC, compiles statistical information to help guide policies to improve the health of Americans. Holds a biennial data user conference; consult the NCHS website for date and location. NCHS disseminates data and statistics online and in print.

Center for Medicare and Medicaid Services (CMS) administers the Medicare program and works in partnership with state governments to administer Medicaid, the Children's Health Insurance Program (CHIP), and health insurance portability standards.

Center for Medicare and Medicaid Innovation, or the Innovation Center, was established under the Affordable Care Act. The Innovation Center allows the Medicare and Medicaid programs to test models that improve care, lower costs, and better align payment systems to support patient-centered practices.

The Immediate Office of the Secretary (IOS) is responsible for operations and coordination of the work of the Secretary.

The National Institutes of Health (NIH) seeks fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.

The Office of the Assistant Secretary for Preparedness and Response leads the nation's medical and public health preparedness for, response to, and recovery from disasters and public health emergencies.

The Office of the Chief Technology Officer (CTO) provides leadership and direction on data, technology, innovation and strategy across the HHS. Areas of focus include promoting open data and its use to create value, driving more efficient operations through technology utilization, and coordinating innovation strategy across the Department to improve the lives of the American people and the performance of the Department.

The Office of Minority Health was created in 1986 and is dedicated to improving the health of racial and ethnic minority populations through the development of health policies and programs that will help eliminate health disparities.

The Office of the National Coordinator for Health Information Technology (ONC) works to improve the health and well-being of individuals and communities through the use of technology and health information that is accessible when and where it matters most.

US. Department of Housing and Urban Development is a cabinet-level department of the U.S. federal government that seeks to provide housing and community development assistance and to make sure everyone has access to "fair and equal" housing.

U.S. Department of Veterans Affairs seeks to provide veterans the world-class benefits and services they have earned - and to do so by adhering to the highest standards of compassion, commitment, excellence, professionalism, integrity, accountability, and stewardship.

State and Local Government:

New York eHealth Collaborative is a non-profit organization, working in partnership with the New York State Department of Health to improve healthcare by collaboratively leading, connecting, and integrating health information exchange across the state.

Pennsylvania Department of Health is responsible for planning and coordinating health resources throughout the Commonwealth. It licenses and regulates a variety of health facilities, such as hospitals, nursing homes, ambulatory surgical facilities and other in-patient and out-patient facilities. I

Healthcare Insurers:

America's Health Insurance Plans is the national association whose members provide coverage for health care and related services. They are committed to market-based solutions and public-private partnerships that improve affordability, value, access and well-being for consumers.

Amerigroup is part of the Anthem Inc. Government Business Division (GBD). Through its GBD, Anthem serves 7.9 million seniors, people with disabilities, low-income families, other state and federally sponsored beneficiaries, and National Government Services and Federal Employee Program beneficiaries in 26 states.

Amerihealth Caritas is a mission-driven organization operating in 12 states and the District of Columbia and with a history of serving low-income and chronically ill populations. It serves more than 5 million Medicaid, Medicare, and Children's Health Insurance Program members.

Anthem is a health insurance provider and was formed in 2004 by the merger of WellPoint (based in California) and Anthem (based in Indianapolis). It has approximately 40 million people enrolled in its family of health plans.

Blue Cross Blue Shield of North Carolina is an insurer that serves more than 3.89 million customers in North Carolina. It seeks to offer its customers high quality health insurance at a competitive price.

CareSource Management Group is one of the country's largest Medicaid managed care plans. It is headquartered in Dayton, Ohio and has a diverse offering of insurance plans in addition to Medicaid coverage.

Commonwealth Care Alliance is a community-based healthcare organization dedicated to improving care for individuals who are dually eligible for MassHealth (Medicaid) and Medicare with complex medical, behavioral health and social needs, including those with disabilities.

CVS Health/ Aetna was founded in Hartford, CT and is committed to providing individuals, employers, health care professionals, producers and others with innovative benefits, products and services. It is a subsidiary company of CVS Health Corporation.

Humana is a healthcare insurer headquartered in Louisville, Kentucky. As of 2018, It has approximately 17 million members in its medical benefit plans, as well as approximately 6 million members in its specialty product.

SCAN Health Plan was founded in Long Beach, CA in 1977 by a group of senior activists committed to improving access to the care and services they needed as they aged. SCAN is a recognized leader in senior care.

UCare is an independent, nonprofit health plan providing health coverage and services across Minnesota and western Wisconsin. It serves individuals and families choosing health coverage through MNsure, Medicare-eligible individuals, those enrolled in Minnesota Health Care Programs, and adults with disabilities.

Wellcare Health Plans, headquartered in Tampa, Florida and focuses primarily on providing government-sponsored managed care services to families, children, seniors and individuals with complex medical needs primarily through Medicaid, Medicare Advantage and Medicare Prescription Drug Plans.

Healthcare Providers

America's Essential Hospital is an industry trade association representing 325 members. It supports its members through advocacy, policy development, research, and education. It operates research and quality activities through the Essential Hospitals Institute. The Institute supports hospitals in providing high-quality, equitable, and affordable care to communities.

City of Hope Medical Center was founded in 1913 and is one of 49 comprehensive cancer centers in the nation, as designated by the National Cancer Institute. Their mission is to transform the future of healthcare by turning science into a practical benefit, hope into reality

Kaiser Permanente was founded in 1945 and serves 12.2 million members in 8 states and the District of Columbia. It aims to provide high-quality, affordable health care services and to improve the health of the members and the communities it serves.

Mount Sinai Health System is an integrated healthcare delivery system with seven hospitals, one medical school, and more than 300 locations. It is also one of the oldest and largest teaching hospitals in the US.

Patient Advocacy

National Patient Advocate Foundation (NPAF), the advocacy affiliate of the Patient Advocate Foundation, represents the patient voice, both the powerful stories of individuals and the collective needs of the community. The NPAF's primary objective is to prioritize the patient voice in health system delivery reform to achieve person-centered care.

Patient-Centered Outcomes Research Institute (PCORI) helps people make informed healthcare decisions, and improves healthcare delivery and outcomes, by producing and promoting high-integrity, evidence-based information that comes from research guided by patients, caregivers, and the broader healthcare community.

PatientsLikeMe is the world's largest personalized health network. 650,000+ people living with 2,900 conditions have generated more than 43 million data points, creating an unprecedented source of real-world evidence and opportunities for continuous learning. Everything members have shared empowers the community with personal agency, establishing PatientsLikeMe as a clinically robust resource that has published more than 100 research studies.

Private Sector

Allscripts is a leader in healthcare information technology solutions that advances clinical, financial and operational results. Its solutions connect people, places and data across an Open, Connected Community of Health.

Booz Allen Hamilton provides management and technology consulting and engineering services to leading Fortune 500 corporations, governments, and not-for-profits across the globe. Booz Allen partners with public and private sector clients to solve their most difficult challenges through a combination of consulting, analytics, mission operations, technology, systems delivery, cybersecurity, engineering, and innovation expertise.

CareJourney was founded in 2014 under the belief that the nation's transition to value-based care is an important one, but without an "operating manual" that can reliably deliver on the promise of better quality at lower cost. CareJourney provides a variety of tools to achieve its mission, including a population health insights platform.

Google is a multinational technology company that specializes in Internet-related services and products, which include online advertising technologies, search engine, cloud computing, software, and hardware.

Healthify is a platform that manages the social determinants of health for vulnerable populations. It helps healthcare and government organizations search for community services, track referrals, and coordinate with community partners.

Healthsperien, LLC is a Washington, D.C.-based consulting firm focused on strategic issues operating at the intersection of public policy, business strategy, and government affairs. Their clients reflect a range of health care stakeholders across a broad cross-section of health care.

Kaizen Health is a logistics platform that enables patients from the low-income, aging, disabled and veteran communities to maintain independent living by increasing access to healthcare through connecting them with the transportation that they need to get to and from their medical appointments.

Leavitt Partners is a healthcare intelligence business that delivers collaborative, high-value intelligence that helps clients transition to new models of care.

LifePoint Health provides healthcare services in growing regions, rural communities and small towns. It was established in 1999 operates 89 hospital campuses in 30 states. LifePoint also operates a Health Support Center to bring resources to bear across the continuum of care, from before a patient accesses healthcare services to after they are sent home.

Lyft is a transportation network company based in San Francisco and operating in the United States and Canada.¹ It operates the Lyft mobile app, offering car rides, scooters, and a bicycle-sharing system.

Mathematica Policy Research is dedicated to improving public well-being by bringing the highest standards of quality, objectivity, and excellence to bear on public policy. It advances its mission through objective, evidence-based standards, superior data, and collaboration.

Microsoft is an American multinational technology company with headquarters in Redmond, Washington. It develops, manufactures, licenses, supports and sells computer software, consumer electronics, personal computers, and related services.

Omada Health is an innovative program designed to help individuals lose weight and brings together the individualized attention of professional health coaches with a researched curriculum and manageable but powerful goals.

Signify Health is the largest network of mobile clinicians and uses a sophisticated technology platform to work with healthcare delivery organizations and healthcare payers. Signify Health's continuum of care delivers health risk evaluations and complex care management in the home and other settings.

Socially Determined is a healthcare analytics company based in Washington, DC. It measures the impact of social determinants of health through platforms like SocialScape.

Unite Us is an outcome-focused technology company that builds coordinated care networks to connect health and social service providers together. It aims to connect providers around each patient through a seamless integration of the social determinants of health into care delivery.

Welltower provides healthcare infrastructure to the world's leading health and senior care providers to develop the health care infrastructure necessary to keep people well.

ZeOmega's mission is to deliver proven population health management software solutions that enable our clients to enhance the value of healthcare and bend the cost curve. We deliver integrated informatics and business process management solutions so actionable information can be delivered in real-time, at the right time, and to all stakeholders in the care management continuum.

Roundtable Agenda

Roundtable on Leveraging Data on the Social Determinants of Health

U.S. Department of Health and Human Services | Thursday, October 3, 2019

Purpose: Help HHS catalyze the use of data on the social determinants of health at the federal, state, local, and individual levels to improve health outcomes.

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| 9:30 | Registration and Networking (<i>Coffee and light refreshments will be provided</i>) |
| 10:20 | Welcome Mona Siddiqui, Chief Data Officer, U.S. Department of Health and Human Services (HHS) |
| 10:25 | Opening Remarks Ed Simcox, Chief Technology Officer, HHS |
| 10:30 | Structure of the Day Joel Gurin, President, Center for Open Data Enterprise (CODE) |
| 10:35 | Lightning Talks: Innovative Applications of SDOH Data at the Local Level Robert Fields, SVP, Chief Medical Officer Population Health, Mount Sinai Health System Angela Hagan, Associate Director - Population Health Insights, Humana Taylor Justice, Co-Founder and President, Unite Us Oktawia Wójcik, Senior Program Officer, Robert Wood Johnson Foundation Omar Nagji, Head of Healthcare Partnerships, Lyft |
| 11:00 | Special Presentation: Katherine Verlander, The Centers for Medicare and Medicaid Services |
| 11:05 | Keynote Speaker Aneesh Chopra, President, CareJourney |
| 11:20 | Introductory Discussion: SDOH Use Cases and Opportunities |
| 12:00 | Special Remarks Admiral Brett P. Giroir, M.D., Assistant Secretary for Health, HHS Karen DeSalvo, M.D., MPH, Professor, Dell Medical School |
| 12:25 | Lunch Break (<i>Lunch will be provided</i>) |
| 1:15 | Breakout Session 1: Identifying and Prioritizing SDOH Data Sources |
| 2:15 | Networking Break |
| 2:25 | Breakout Session 2: Collecting and Using Individual SDOH Data: Challenges and Solutions |

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| 3:05 | Networking Break |
| 3:15 | Breakout Session 3: Applying Population-Level SDOH Data: Challenges and Solutions |
| 4:00 | Presentation of Highlights |
| 4:20 | Closing Remarks & Next Steps Mona Siddiqui, Chief Data Officer, HHS Joel Gurin, President, CODE |
| 4:30 | Adjourn for Reception |

*To ensure openness of discussion, the Roundtable will be held under the Chatham House Rule:
Any participant is free to use information from the day but is not allowed to reveal who made any comment.*

This Roundtable is co-hosted by



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