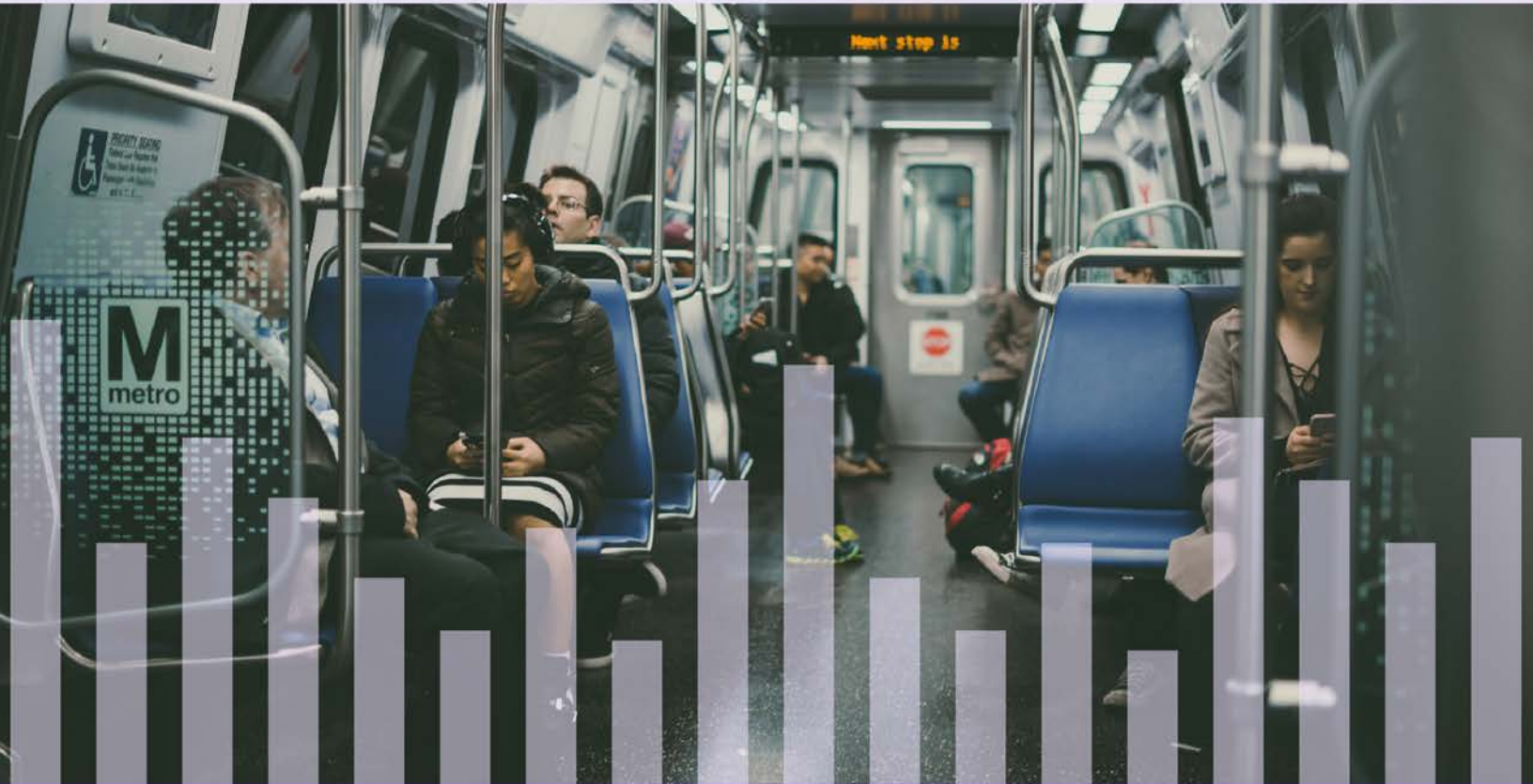




CODE



BRIEFING PAPER

Leveraging Data on the Social Determinants of Health

September 2019

Table of Contents

- Introduction1**
- What frameworks are helpful for understanding the Social Determinants of Health? 2**
 - Theoretical Frameworks 2
 - Policy Frameworks 3
- Why do the Social Determinants of Health matter? 4**
- How is data on SDOH collected? 5**
 - Individual-Level Health Data 5
 - Population-Level Health Data 5
- What are the types of SDOH Data? 6**
- How are stakeholders using SDOH Data at the local level? 9**
 - Civil Society Alliances and Organizations 9
 - Local Departments of Public Health 9
 - Technology and Private Sector Companies 10
 - Healthcare Providers and Payers 10
- How does the government promote and use SDOH Data?12**
 - The Accountable Health Communities Model 12
 - The Maternal Opioid Misuse (MOM) Model 12
 - Integrated Care for Kids Model (InCK) 12
 - The 500 Cities Project: Local Data for Better Health Partnership 13
- Risks and Challenges when using SDOH Data14**
 - Data Availability, Quality, and Use Considerations 14
 - Policy Considerations 14
- Next Steps and Questions16**

INTRODUCTION

Large health disparities in the United States are often related to factors that go 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 social inequity. They are defined as the “conditions in which people are born, grow, live, work and age that shape health.”¹ Doctors and researchers increasingly recognize how profoundly SDOH influence health risks and treatment outcomes. There is increasing recognition that a person's ZIP Code is at least as important as his or her genetic code in predicting health risks.²

Health-focused organizations across the private sector and civil society are now realizing the potential value of SDOH data. Healthcare providers and payers are beginning to use SDOH data to better understand and address patients' needs. Companies working in population health management are applying the social determinants of health to predict health risks like opioid overdose and help target preventive interventions. Other organizations are serving as SDOH data providers, making platforms of highly granular social determinants data available 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, and can include measures as diverse as the air quality of a patient's neighborhood or their proximity to a grocery store.

In the federal government, the U.S. Department of Health and Human Services (HHS) Secretary Alex Azar has emphasized that the social determinants of health are central to the mission of HHS. In a recent speech, Secretary Azar noted that the “social determinants would be important to HHS even if all we did was healthcare services...but in our very name and structure, we are set up to think about all the needs of vulnerable Americans, not just their healthcare needs.”³

This briefing paper has been prepared as background for a Roundtable on Leveraging Data on the Social Determinants of Health to be co-hosted by the Center for Open Data Enterprise (CODE) and the HHS Office of the Chief Technology Officer (CTO) on October 3, 2019. It describes innovative applications of SDOH data across the United States and how government can support these efforts. The paper provides an overview of the value of data on SDOH, the categories that define these emerging types of data, their current applications in both private-sector and government contexts, and key considerations and challenges in using data on SDOH, especially in the context of health equity. It concludes with a set of questions that will inform discussions at the Roundtable.

¹ Artiga, Samantha, and Elizabeth Hinton. “Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity.” Issue Brief. San Francisco, California: Kaiser Family Foundation, May 2018. <https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>.

² Roeder, Amy. “Zip Code Better Predictor of Health than Genetic Code.” Harvard T.H.Chan School of Public Health (blog), August 4, 2014. <https://www.hsph.harvard.edu/news/features/zip-code-better-predictor-of-health-than-genetic-code/>.

³ “The Root of the Problem: America's Social Determinants of Health.” Text. HHS.gov, November 14, 2018. <https://www.hhs.gov/about/leadership/secretary/speeches/2018-speeches/the-root-of-the-problem-americas-social-determinants-of-health.html>.

WHAT FRAMEWORKS ARE HELPFUL FOR UNDERSTANDING THE SOCIAL DETERMINANTS OF HEALTH?

Over the past two decades, work on the Social Determinants of Health (SDOH) has grown in scope and is now considered necessary to achieve health equity and better health outcomes for all Americans. While SDOH are generally defined as the “conditions where people live, work, and play”, there are also a variety of frameworks to understand their impact on health.⁴ This section reviews the most prominent theoretical and policy frameworks for the use of SDOH data and why they are important to different stakeholders.

Theoretical Frameworks

Several leading organizations, such as the RAND Corporation and the National Academies of Science, Engineering, and Medicine, have developed key theoretical frameworks to address SDOH and understand how they impact long-term health outcomes.

Social Disadvantage Approach. The social disadvantage approach studies how lower socioeconomic status can impact health. Low-income communities lack the resources to protect and improve health.⁵ Research has also demonstrated that social disadvantages in education, neighborhood environment, and living and working conditions can increase risk factors for disease and adverse health outcomes.

Life Outcomes Approach. This framework takes into account critical or sensitive periods in exposure to risk, and also focuses on the cumulative effects of being exposed to risk.⁶ The life outcomes approach includes three different models. The first model focuses on a latency period where early childhood experiences may affect later life outcomes. The second model is a life course model that studies the cumulative effect when each life stage affects the subsequent life stage.⁷ The third model for the life outcomes approach, called “social trajectory”, argues that early exposure to SDOH factors may create opportunities or challenges later in life.

⁴ “Social Determinants of Health | CDC,” April 9, 2019. <https://www.cdc.gov/socialdeterminants/index.htm>.

⁵ Bharmal, Nazleen, Kathryn Pitkin Derose, Melissa Felician, and Margaret Weden. “Understanding the Upstream Social Determinants of Health.” Working Paper. RAND Health, May 2015. https://www.rand.org/content/dam/rand/pubs/working_papers/WR1000/WR1096/RAND_WR1096.pdf.

⁶ Bharmal, Nazleen, Kathryn Pitkin Derose, Melissa Felician, and Margaret Weden. “Understanding the Upstream Social Determinants of Health.” Working Paper. RAND Health, May 2015. https://www.rand.org/content/dam/rand/pubs/working_papers/WR1000/WR1096/RAND_WR1096.pdf.

⁷ “Life Course and Social Determinants.” MCH Evidence. Accessed September 11, 2019. <https://www.mchlibrary.org/professionals/lifecourse.php>.

Health Equity Approach. The health equity approach addresses health inequities by focusing on the institutions that perpetuate disparities in communities. This framework often informs “health in all” policies where policymakers are encouraged to incorporate health considerations into the policies they draft. This approach assumes that policies implemented by corporations, nonprofits, schools, and other institutions can have a profound impact on health outcomes.

Policy Frameworks

These theoretical frameworks have influenced some of today’s leading policy approaches. Two prominent examples come from the World Health Organization (WHO) and HHS.

WHO Commission on Social Determinants of Health. The 2008 Commission on the Social Determinants of Health took a “health equity approach” that aimed to reduce health inequities in and between countries by addressing the structural determinants and conditions of life. The WHO Commission asserted that addressing inequities in structural conditions is a matter of social justice and proposed three principles of action to address this issue, including improving the conditions of life, tackling the inequitable distribution of power, and identifying the technical approaches that are needed to address the SDOH.⁸

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 focused on five areas and was 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.

⁸ Weltgesundheitsorganisation, ed. Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health ; Final Report. Geneva: WHO, 2008.

⁹ <https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health>

WHY DO THE SOCIAL DETERMINANTS OF HEALTH MATTER?

The Social Determinants of Health are some of the most important factors in determining our day-to-day health and improving health outcomes. By addressing the SDOH, health stakeholders can reduce health inequities, help at-risk communities, and reduce healthcare costs.

Addressing Health Inequities. SDOH data enables policymakers to analyze healthcare disparities across communities and understand health inequities. Through appropriate interventions and advocacy healthcare professionals can reduce disparities across the US health system. For example, children in environments with higher risk factors such as exposed garbage, substandard housing, and a lack of access to neighborhood playgrounds have an increased risk of obesity. An awareness of these risk factors can help policymakers target diet and exercise programs to these children.¹⁰ For example, the Shape Up Somerville initiative in Massachusetts implemented community-wide interventions for obesity that focused on improved infrastructure, walk to school campaigns, and new school play equipment. The initiative had a documented impact on reducing childhood obesity in comparison to other cities.¹¹

Targeting High-Risk Communities. As the rise of precision medicine and predictive analytics reshapes the U.S. healthcare system, SDOH data can support these approaches through improved location-based data about at-risk communities. Companies and state and local governments across the U.S. healthcare system understand that they can draw on SDOH data to combat localized health epidemics and help the most at-risk communities. For example, a 2016 paper published by the Brookings Institution noted that social and economic factors have shaped the modern opioid epidemic since they affect access to important social support systems that impact drug adherence and treatment plans for recovery.¹²

Reducing Costs. Payers and healthcare providers recognize the limitations of clinical care in treating their patients and the steep costs associated with excessive care utilization. As providers increasingly focus on connecting patients with social services and encourage prevention, they can reduce the costs of clinical procedures and interventions. A 2016 Robert Wood Johnson Foundation study found that Aligning For Health, a coalition of payers and providers dedicated to using the social determinants, realized a 17 percent reduction in emergency room use, a 26 percent reduction in emergency spending, and a 53 percent decrease in inpatient spending.¹³

¹⁰ Singh, Gopal K., Mohammad Siahpush, and Michael D. Kogan. "Neighborhood Socioeconomic Conditions, Built Environments, And Childhood Obesity." *Health Affairs* 29, no. 3 (March 2010): 503–12. <https://doi.org/10.1377/hlthaff.2009.0730>.

¹¹ Sallis, James F., Myron F. Floyd, Daniel A. Rodríguez, and Brian E. Saelens. "Role of Built Environments in Physical Activity, Obesity, and Cardiovascular Disease." *Circulation* 125, no. 5 (February 7, 2012): 729–37. <https://doi.org/10.1161/CIRCULATIONAHA.110.969022>.

¹² Matthew, Dayna Bowen. "Un-Burying the Lead: Public Health Tools Are the Key to Beating the Opioid Epidemic." *Brookings (blog)*, January 23, 2018. <https://www.brookings.edu/research/un-burying-the-lead-public-health-tools-are-the-key-to-beating-the-opioid-epidemic/>.

¹³ HealthPayerIntelligence. "Payers Form Coalition to Address Social Determinants of Health." *HealthPayerIntelligence*, March 28, 2018. <https://healthpayerintelligence.com/news/payers-form-coalition-to-address-social-determinants-of-health>.

HOW IS DATA ON SDOH COLLECTED?

There are two primary methods for collecting and using SDOH data. The first is collecting *individual-level* SDOH data directly from patients in a clinical setting, and storing or combining this with information from individual electronic health records (EHRs) to better characterize the health risks people face. The second is gathering and using *population-level* SDOH data from a wide range of sources to develop an understanding of risks shared by groups of individuals in the same community or who share other characteristics. This Roundtable will discuss both methods for collecting SDOH data and their applications to improve health outcomes.

Individual-Level Health Data

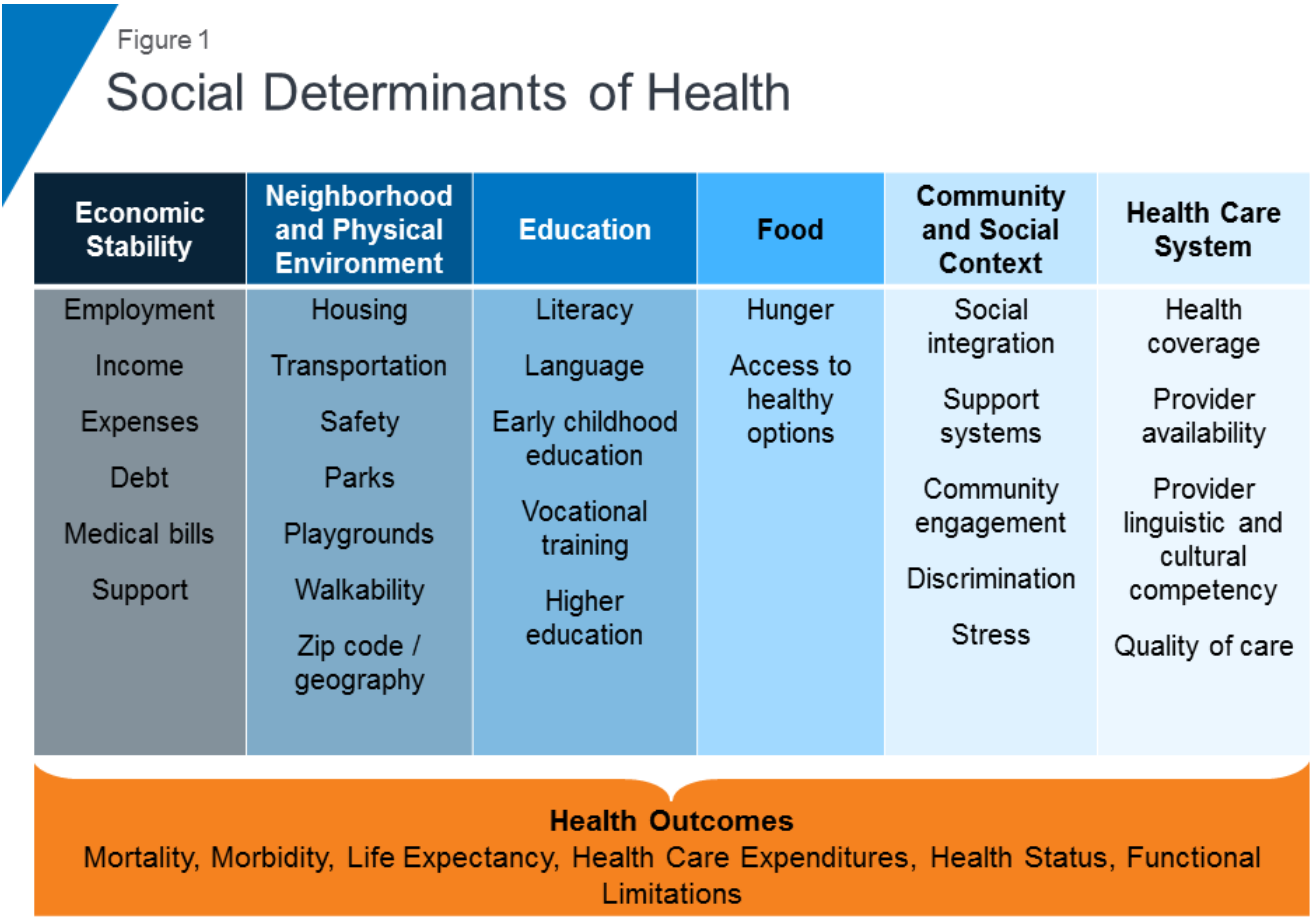
A large amount of SDOH data is collected directly from individuals and is integrated and analyzed as part of their health records. Medicaid recipients and other groups may have individual-level data collected from their physicians or may have their data collected through clinical trials. This is the focus for the Centers for Medicare and Medicaid Services (CMS) and the Gravity Project launched by the Social Interventions Research and Evaluation and other initiatives that are improving precision medicine.

Population-Level Health Data

Many federal, state, and local government agencies provide SDOH data to private companies, government policymakers, and other stakeholders under certain conditions to understand a population's income, education, and other factors. This data also 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 Census, the Department of Labor, the Department of Transportation, and the Department of Education. Private companies like Socially Determined or Healthify, for example, use artificial intelligence to develop better risk-prediction models or provide quick snapshots of high-risk neighborhoods. Many federal and state agencies are striving to improve the sharing of population-level data and how population data can be linked to individual records for analysis.

WHAT ARE THE TYPES OF SDOH DATA?

In an influential study, the Kaiser Family Foundation identified six high-level categories of SDOH, shown in the table below, that are now being widely used.¹⁴ This section describes aspects of the first four of these categories: economic stability, neighborhood and physical environment, education, and food. These are categories that may draw on data sources from outside the healthcare system. (The fifth category, community and social context, appears to have fewer data sources readily available, while the sixth category describes healthcare access that are directly affected by the previous five categories.) This section also lists examples of publicly available sources of data for these categories.



¹⁴ Artiga, Samantha, and Elizabeth Hinton. "Beyond Health Care: The Role of Social Determinants in Promoting Health and Health Equity." Issue Brief. San Francisco, California: Kaiser Family Foundation, May 2018. <https://www.kff.org/disparities-policy/issue-brief/beyond-health-care-the-role-of-social-determinants-in-promoting-health-and-health-equity/>.

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 and lack of access to stable financial institutions. The literature on unemployment, for example, has repeatedly demonstrated that long-term unemployment has adverse health outcomes.¹⁵ These determinants consist of a person's employment access, hourly wages, level of personal debt, and other key factors that impact their economic status.

Sample Data Sources:

- Department of Labor Unemployment Statistics
- Internal Revenue Service Income Tax Rates

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, 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.¹⁶ This area of social determinants includes housing, access to transportation, parks, safety, and a general geography.

Sample Data Sources:

- 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: 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 reduce comprehension of important clinical recommendations or generally create confusion about 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 Population Bulletin report notes that the mortality rate for white women who have not completed high school is four times higher than it is for women with 16 or more years of education.¹⁷ The educational social determinants include literacy rates, vocational training opportunities, early childhood education, and higher education rates.

Sample Data Sources:

- Department of Education high school dropout rates
- Headstart early childhood education enrollment figures

¹⁵ Mathers, Colin D, and Deborah J Schofield. "The Health Consequences of Unemployment: The Evidence." *Medical Journal of Australia* 168, no. 4 (February 1998): 178–82. <https://doi.org/10.5694/j.1326-5377.1998.tb126776.x>.

¹⁶ Mathers, Colin D, and Deborah J Schofield. "The Health Consequences of Unemployment: The Evidence." *Medical Journal of Australia* 168, no. 4 (February 1998): 178–82. <https://doi.org/10.5694/j.1326-5377.1998.tb126776.x>.

¹⁷ Robert A. Hummer and Elaine M. Hernandez, "The Effect of Educational Attainment on Adult Mortality in the United States," *Population Bulletin* 68, no. 1 (2013).

Food: Access to healthy foods and subsidy programs like the Supplementary Nutrition Assistance Program (SNAP) and Women, Infants, Children (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.¹⁸ Moreover, mothers with poor access to nutritious foods or milk may find that their children are experiencing developmental challenges.

Sample Data Sources:

- WIC and SNAP enrollment rates by neighborhood
- Proximity to a grocery store
- Access to a food pantry or other emergency food service

Additional Data Categories

Climate and Environment Data. While SDOH data within a neighborhood is important, additional factors that are less confined to neighborhood borders also have a major impact on an individual's health. These environmental factors can include poor air and water quality, water access, and proximity to power plants, toxic waste, and superfund sites.

Sample Data Sources:

- U.S. Environmental Protection Agency (EPA) air quality and toxic waste data
- U.S. Department of Energy (DOE) data on power plants.

¹⁸ Cook, John T., and Deborah A. Frank. "Food Security, Poverty, and Human Development in the United States." *Annals of the New York Academy of Sciences* 1136, no. 1 (July 25, 2008): 193–209. <https://doi.org/10.1196/annals.1425.001>.

HOW ARE STAKEHOLDERS USING SDOH DATA AT THE LOCAL LEVEL?

The private sector, healthcare groups, and civil society have developed different initiatives and approaches to employing SDOH data. This section reviews how different stakeholder groups have worked to collect, analyze, and use SDOH data at the local level. It highlights specific use cases and examples where groups have used SDOH data to address core health issues for their stakeholders.

Civil Society Alliances and Organizations

Some civil society groups develop local coalitions, task forces, and working groups to improve sharing of data and resources with constituents and thereby improve the coordination of care. Research institutions and philanthropies, like the Urban Institute and Kaiser Family Foundation, publish research-driven white papers and host conferences like the [Next50 Changemaker Forum](#). These groups do everything from developing advocacy strategies to identifying underserved groups that should be included in discussions about health outcomes.

Example: Alliance for Better Health

The Alliance for Better Health is a diverse coalition of stakeholders who work across medical and community sectors to address the health needs of Medicaid members and uninsured individuals. The Alliance for Better Health works as a convener of different stakeholders but also deploys a Solutions Management Team that uses platforms like its Health Together initiative, which refers individuals from medical providers to service providers including food banks, homeless shelters, and senior services.¹⁹

Local Departments of Public Health

Public health departments often function as key resource hubs that can provide information and visualizations of key SDOH data. Local health departments also 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 SDOH data.

¹⁹ "What We're Doing – Alliance for Better Health." Accessed August 22, 2019. <https://abhealth.us/what-were-doing/>.

Example: Baltimore City Health Department Displaying SDOH Data

The Baltimore City Health Department manages statistics and indicators on the social determinants and makes data available to different stakeholders. The Department created an **ArcGIS powered map** to display the various social determinants of health in Baltimore's 55 different Community Statistical Areas (CSA). The map includes statistics such as housing affordability rates and the percentage of students expelled within each CSA. Moreover, Baltimore has leveraged this data to create Neighborhood Health Profiles that include data on health outcomes and granular information on possible neighborhood risks.

Technology and Private Sector Companies

Companies are using SDOH data to better comprehend their consumers and clients and often work with this data at the local level to make more sense of consumer needs and the environments they operate in. Technology companies often provide software solutions that can provide granular SDOH data, analytics, and care coordination for healthcare and related companies that seek to understand their patients.

Example: HeyTutor's Stress Index

HeyTutor analyzed data from the U.S. Census Bureau's American Community Survey and the CDC's 500 Cities Project to develop a composite Stress index related to health, lifestyle, and the economy.²⁰ HeyTutor discovered that with a few exceptions, most indicators are getting worse, including housing costs, commute time, inequality, and mental health. This impacts HeyTutor's services in those cities that scored higher on their stress index.

Healthcare Providers and Payers

Healthcare providers are finding new and important ways to connect their patients with resources and assistance outside of a clinical setting. Payers are building capacity for local groups that are addressing health challenges by providing grants to programs carrying out innovative work, and establishing

²⁰ "The Most and Least Stressed out Cities in America." Ladders | Business News & Career Advice. Accessed August 21, 2019. <https://www.theladders.com/career-advice/the-most-and-least-stressed-out-cities-in-america>.

partnerships with groups that have access to valuable SDOH data. Lastly, many healthcare providers and payers now have dedicated groups or offices that specifically focus on building capacity and relationships in their local communities.

Example: New York Presbyterian Hospital

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.²¹ This work specifically entails providing psycho-social screens for children during visits and then helping stratify these children based on risk profiles. NYP works with community partners such as the Northern Manhattan Prenatal Partnership (NMPP) which provides over twenty services and programs including comprehensive case management and education for pregnant and parenting women.²²

²¹ “New York-Presbyterian Hospital.” Moving Health Care Upstream. Accessed September 12, 2019. <https://www.movinghealthcareupstream.org/new-york-presbyterian-hospital/>.

²² New York-Presbyterian Hospital.” Moving Health Care Upstream. Accessed September 12, 2019. <https://www.movinghealthcareupstream.org/new-york-presbyterian-hospital/>.

HOW DOES THE GOVERNMENT PROMOTE AND USE SDOH DATA?

The federal government has sought to promote the use of SDOH data through a variety of initiatives that have been spearheaded by the Center for Medicare and Medicaid Innovation (CMMI) and other government agencies, as well as the public-private collaborative the Gravity Project. Healthy People 2020, mentioned earlier, is a prime example of a holistic approach to address SDOH. These entities often partner with local agencies to support the collection of SDOH data and work with other civil society groups to ensure that data is available. This section provides a brief overview of some of the most prominent programs.

The 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 includes 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. 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 and will conduct systematic social needs screenings in clinical settings and link beneficiaries to key community services that address those needs.

The Maternal Opioid Misuse (MOM) Model

The opioid crisis has caused substance abuse to become the leading cause of death for new mothers. Drug abuse can lead to “preterm labor and complications related to delivery; problems frequently exacerbated by malnourishment, interpersonal violence, and other health-related social needs.”²³ The Maternal Opioid Misuse (MOM) Model is part of CMMI’s broader strategy to combat the opioid crisis. The program supports pregnant women with substance abuse issues and integrates other services such as services for health, wellbeing, and recovery. The MOM model also provides critical wrap-around services such as nutrition and housing referrals.

Integrated Care for Kids Model (InCK)

Unhealthy behaviors in children and youth, including substance abuse, can raise the risk of morbidity, health care utilization, and premature death.²⁴ As part of their effort to fight the opioid crisis, CMMI

²³ “Maternal Opioid Misuse (MOM) Model” Accessed September 13, 2019. <https://innovation.cms.gov/initiatives/maternal-opioid-misuse-model/>.

²⁴ “Integrated Care for Kids (InCK) Model | CMS.” Accessed September 13, 2019. <https://www.cms.gov/newsroom/fact-sheets/integrated-care-kids-inck-model>.

and the Children's Health Insurance Program (CHIP) are providing better screening for behavioral and mental health conditions as a preventive approach to substance abuse through the Integrated Care for Kids (InCK) Model. InCK aims to create alternative payment models, support local and community health providers with better integration of care, and spread accountability across providers. The integration of care for children will coordinate different children's services such as food and nutrition, schools, housing, and other agencies that can address other social determinants. Similar to AHC, the model deploys lead organizations to convene community partners and state Medicaid agencies to support local implementation.

The 500 Cities Project: Local Data for Better Health Partnership

A collaboration between the Robert Wood Johnson Foundation and the Centers for Disease Control and Prevention, the 500 Cities Project seeks to provide 27 chronic disease indicators and risk factors, such as smoking, obesity, and binge drinking, at the census tract level for the 500 largest cities in the United States.²⁵ This constitutes approximately one-third of the U.S. population. This project specifically aims to complement existing surveillance data and help local and state health departments fully comprehend the population health of a given area. The 500 Cities project includes downloadable interactive maps, and is unique in its collaboration with HHS, civil society, and the U.S. Census Bureau.

²⁵ "500 Cities | About the Project," April 16, 2019. <https://www.cdc.gov/500cities/about.htm>.

RISKS AND CHALLENGES WHEN USING SDOH DATA

The increasing use of SDOH data to inform healthcare decisions and local-level policy has brought greater attention to limitations of using this data and the possibility of unforeseen risks in local communities. Specifically, there are issues around data availability, quality, and use, as well as policy considerations around potential discrimination and a reliance on individual insights.

Data Availability, Quality, and Use Considerations

Significant challenges exist for stakeholders looking to find and use SDOH data. The most relevant challenges are limited data availability for certain SDOH categories, data quality concerns, and issues with timeliness of the data. There is an abundance of publicly available SDOH data online, but this data can be hard to find at the appropriate level of geographic focus. For example, food data is difficult to find at the ZIP Code level, and there are also similar issues with crime and safety data. Many SDOH datasets are too outdated to be useful: the most recent data available is often five to seven years old.

Another challenge in using SDOH data is the translation of census tract and longitude/latitude level data to ZIP Code-level. Census tract and longitude/latitude level data is most commonly available, for example through the 500 Cities Project. However, ZIP Code-level data makes it easier to link SDOH data to clinical records, claims data and other individual level sources of information. Luckily, this is not an insurmountable problem as processes exist to convert across different geographic data types.

Lastly, there are not common standards and definitions for many key SDOH categories. Philanthropic organizations like the Kaiser Family Foundation and government agencies like the CDC broadly define SDOH, but do not clearly define specific SDOH datasets or resources which prevents proper standardization for broad use. The lack of definitions has prompted policymakers and providers to draw on a disparate set of geographically disaggregated datasets and rely on a wide spectrum of social screening tools that collect different aspects of a patient's social needs.

Policy Considerations

As policymakers seek to leverage SDOH data, care is needed to ensure that this data is not misused or deployed in ways that could harm communities and individuals.

Possibility for Redlining and Discrimination

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 healthcare “redlining” and exclude or profile communities that they identify as high-risk areas.²⁶ Alternatively, 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.

Individual Insights Masking Community Challenges

As individual-level SDOH data is gathered in a clinical setting, the reverse effect may also pose a risk to broader healthcare policy. The risk is that individual diagnoses may not properly inform policymakers about the macro-level issues affecting that person’s community. A clinician may prescribe a certain set of activities to address a person’s personal health, but without broader policy to affect the persistent conditions of that individual’s environment, that person and his or her community may continue facing local level challenges.

Data Use Without Patient Consent Leading to Privacy Concerns and Backlash

SDOH data is collected and used in a variety of ways by a variety of organizations. Some collect data directly from patients with their explicit consent. Others analyze data about individuals collected from other sources - both public and private - without explicit consent from patients. These data often inform Artificial Intelligence and Machine Learning programs that are not always transparent about their algorithms. 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.²⁷

²⁶ Gottlieb, Laura M., and Hugh Alderwick. “Integrating Social and Medical Care: Could It Worsen Health and Increase Inequity?” *The Annals of Family Medicine* 17, no. 1 (January 2019): 77–81.

²⁷ <https://catalyst.nejm.org/big-data-analytics-social-determinants-privacy/>

NEXT STEPS AND QUESTIONS

The October 3, 2019 Roundtable on Leveraging Data on the Social Determinants of Health seeks to identify how HHS can support advances in the use of SDOH data and also address some of the challenges in their broader adoption. Roundtable participants will be invited to address questions such as:

- What are the primary challenges to accessing and using data on the social determinants of health?
- What are examples of innovative applications of individual-level SDOH data? What can we learn from CMMI's current programs?
- What are the best current federal sources of SDOH data? Which sources come from HHS? Which ones come from other federal agencies?
- What data elements would support better decision-making and problem-solving to address the Social Determinants of Health?
- What lessons can be learned from local applications of SDOH data to help communities? How can HHS help local and state-level stakeholders access and apply federal SDOH data?
- How can HHS best work with other agencies that hold SDOH data on income, environment, education, and other key factors? How can these agencies ensure that their data is at a level of granularity and quality that can be applied to improve individual health?
- What opportunities exist to align data structure of SDOH across federal/state agencies and between electronic health records (EHRs) and other sources of data?