Assessing eHI's Guiding Principles for Ethical Use of SDOH Data During COVID-19

eHEALTH INITIATIVE

Examples from the Field

Background

COVID-19 was declared a pandemic by the World Health Organization in March 2020. Since then, health systems in the United States have been severely challenged by unprecedented demand. The pandemic has highlighted the vulnerabilities of populations whose healthcare access, quality, and affordability are impacted by social determinants of health (SDOH). Many organizations use SDOH data to identify communities at risk of COVID-19. In 2019, eHealth Initiative (eHI) released the *Guiding Principles for Ethical Use of Social Determinants of Health Data*, which proposed recommendations for the ethical use of SDOH data by healthcare organizations. This report provides examples of organizations applying these principles as they address the COVID-19 pandemic.

The Guiding Principles put forth an ethical framework for SDOH data, specifically focused on five principles: employing SDOH in care coordination; recognize risk through analytics; map resources and identify gaps; assess impact; and customize interventions and allow individuals to determine the best fit. More details on each area are outlined in the graphic below:[1]

Five Guiding Principles

Employ SDOH in Care Coordination	Identify individuals with SDOH needs (economic, education, community, healthcare access and environment), coordinate and deliver more holistic care, facilitate connections to additional interventions or services, consistent with privacy and security protections
Recognize Risk Through Analytics	Identify risk using analytic tools in order to develop population health management interventions for individuals and communities
Map Resources and Identify Gaps	Assess individual SDOH needs (economic, education, community, healthcare access and environment) against available community resources to identify gaps that address health and wellness
Assess Impact	Assess the impact of SDOH interventions and services
Customize Interventions and Allow Individuals to Determine Best Fit	Use SDOH as a guide for quality discussions with individuals (or their designated guardians) and caregivers to jointly decide which services and interventions are the best fit

Applying Ethical Principles During COVID-19

As healthcare organizations began using SDOH data to address the COVID-19 pandemic, eHI sought to determine how the Guiding Principles were being applied. Therefore, a year after releasing the Guiding Principles, eHI convened a group of executives at a roundtable entitled *Using Social Determinants of Health Data Ethically During COVID-19*. The purpose of the session was to inform the audience of the various ways that government agencies, healthcare, and other organizations applied the principles to their SDOH programs. In attendance were high-level executives from healthcare programs, providers, and payers.[3]

"We've always been focused on it, but COVID certainly has accelerated it, and it's been within the last couple of years that social determinants were added as one of our main points of influence."

- Caraline Coats
Vice President, Bold Goal
Humana

Participants underscored the importance of harnessing SDOH data to tackle health and social problems.[2] The key questions answered during the roundtable were:

- How do the Guiding Principles work in the real world?
- Do they work in the existing COVID-19 healthcare environment?

Many of the challenges facing healthcare organizations and government agencies this year shone a bright light on health disparities. Examples of populations with health disparities are:

- Homeless individuals
- Underserved rural residents
- Elderly people living in nursing homes
- Patients with underlying chronic conditions
- Low-income and uninsured patients
- Racial and ethnic minorities

This report identifies real-world examples of how each of the five principles can be applied during COVID-19. Studying SDOH, and how they impact disadvantaged populations during times of crisis, will help governments to better manage health emergencies so that every individual has an equal opportunity to be and stay healthy.

1 Employ SDOH in Care Coordination

Use Case: Utilization of SDOH for Care Coordination with Humana's Basic Needs Food Program

"Social determinants data is at the core of our strategy. Now that we have all of this data, we need to turn it into actionable information. There is a lot of sensitivity around that and making sure that we have the right resources… in responding to our members' needs."

- Caraline Coates
Vice President, Bold Goal
Humana

COVID-19 has broadened the definition of food insecurity beyond affordability and providing resources during a pandemic is challenging. Humana, one of the largest healthcare payers in the United States, wants to help make the system a better place through innovation, transformation, and partnership. At the beginning of COVID, Humana collected data through proactive outreach to members and from members who called for assistance. Food insecurity was heightened and amplified by the lack of access caused by limited transportation, instructions for vulnerable populations to stay home, and supply chain interruption. In response to the needs of its members, Humana created the Basic Needs Program in a matter of days. Since its inception, the Basic Needs Program has provided more than 900,000 meals by coordinating with national, local, and regional partners.

Humana learned that providing food was not the only consideration for addressing food insecurity. To solve the problem, they also needed to consider housing barriers such as not having the space to store frozen food. As a result, the Humana team needed to provide shelf-stable food. Humana also considered the sensitivities of using predictive analytics to identify members who might become food insecure in the future. Most importantly, the organization considered future support that could be provided beyond its capabilities to ensure that its members were referred to local resources.

"Community-based organizations before COVID-19 were taxed and they certainly were challenged during all of this. Leveraging data in the right way for the main purpose of creating better sustainability within our community- based organization, and then just continued integration to really make it part of our DNA, became our priority."

- Caraline Coats
Vice President, Bold Goal
Humana

To ensure confidentiality and maintain patient dignity, members provided verbal consent to discuss their food insecurity concerns. After consenting, they were informed of available services and asked about their existing situations and interest in receiving help before their information was submitted to a vendor for assistance.

The Basic Needs Program for food insecurity is just one example of Humana's ethical approach of turning data into action – and employing SDOH in care coordination. Due to COVID, Humana expanded and fast-tracked its telehealth services, resulting in a change from 51,000 visits in 2019 to 25 million in 2020. As of August 2020, it has conducted 3.3 million screenings to identify food-related needs, executed SDOH pilots to more than 60,000 members, potentially reached 6.5 million people in 16 Bold Gold Communities, invested in sophisticated data collection, and integrated SDOH throughout the organization's portfolio of work.

Humana's social determinants strategy has transformed the organization from an insurance company to a fully integrated health company employing SDOH data to coordinate care. Its three-pronged approach consists of collaboration, innovation, and human care to understand the non-clinical needs of the members[4], simplify consumer experiences, and improve health outcomes.

As numerous organizations recognize a growing number of individuals vulnerable to COVID-19, the need to ensure responses are coordinated will only increase. Healthcare organizations should continue to use SDOH data to employ interventions.

2 Recognize Health and Wellness Risks Through Analytics

Use Case: Bringing Together Data Science & SDOH

"Race, ethnicity, and social economic status are really fundamental components of influencing health outcomes."

- Eliseo J. Pérez-Stable, MD
Director. National Institute on Minority Health and Health Disparities (NIMHD)
National Institute of Health (NIH)

The second principle emphasizes that predictive models and data used in algorithms ensure accuracy and relevance related to use cases. Choices made about modeling and analyzing data elements should be free from bias, and standardization may be a means to help eliminate potential bias and discrimination. Further, it is important to recognize and support cultural sensitivities. Parkland Center for Clinical Innovation (PCCI) provided an example of using algorithms to ensure accuracy and relevance, while the National Institute of Minority Health and Health Disparities at the National Institutes of Health (NIH) provides an excellent example of how to standardize data to help eliminate potential bias. Their experiences provided insights into the role of data to inform decision makers, influence stakeholders, and respond to population specific needs.

COVID-19 is a complex disease from a clinical, social, and public health perspective. At the beginning of the pandemic, there were many unknowns about transmission and testing. PCCI and the Department of Health and Human Services (HHS) collaborated to determine how to prioritize resources using data using analytics and incorporate SDOH in figuring out this prioritization. They recognized that communities needed help prioritizing resource allocation and that timely data was required for decision-making.

PCCI developed the framework below to understand, forecast, and reduce community spread and hospitalization. The framework identifies data required at each step of the infection cycle, from exposure to diagnosis.

PCCI Framework

Exposure	→	Activity and Living Situation
Symptom Onset	→	Surveillance and Patient Self-Identification
Health Behavior	→	School and Work Absenteeism
Healthcare Encounter	→	Physician, ER Visit, Hospitalization
Medical Evaluation	→	Tests

PCCI used the data provided by the Dallas County Health System on confirmed cases to create multiple solutions. One of those solutions is the COVID-19 Vulnerability Index, which identifies the communities within Dallas County that are at higher risk for COVID-19. The Vulnerability Index is a method to standardize the data. It incorporates SDOH, COVID co-morbidities, age and demographics, personal mobility, and COVID positive-case data sources to drive the prioritization of additional testing site selection for county leaders. Importantly, the Index also provides real-time surveillance of areas to support cultural sensitivities for engagement and education. Walmart set up testing sites in response to the hot spots that were identified by the Index, demonstrating the importance and influence of the tool.

The data for the Vulnerability Index is collected from several sources and refreshed daily. The SDOH data is based on the Area Deprivation Index (ADI), a multidimensional evaluation of a region's socioeconomic conditions, which have been linked to health outcomes.[5] The Index is a visual representation of existing hot-spots and potential new hot-spots, organized by zip code to easily identify where additional engagement or mask reinforcement are needed. It is publicly available on a website, and the map is then used actively by the Public Health Department of Parkland and other health systems to make sure that their messaging and resources are targeted to the most vulnerable areas. This process also provides transparency.

The mission of the National Institute of Minority Health and Health Disparities is to conduct research that results in improved minority health and reduced health disparities.[6] Dr. Perez-Stable emphasized the importance of data-sharing and data-standardization in research. Collecting standardized data is not always easy when the category is a self-defined construct, such as race, but the data is necessary during a pandemic. The NIH developed a toolkit called PhenX to establish common measurement protocols to inform effective interventions to reduce health disparities.

The misinformation about COVID-19 prompted the NIH to focus on defining common data elements for research that have been posted on its website. For SDOH, NIH suggests that individual measures include things like race, ethnicity, measurement of social economic status, family background, sexual orientation and gender identity, and geographical location. As secondary measures, NIH recommends focusing on structural determinants of health such as broadband access, which has an impact on education and individuals' participation in society. Additional structural determinants are transportation, public safety, green space, healthy food access, and housing. The ability to easily share and combine data from multiple studies has the potential to increase the scientific impact of individual studies.[7]

Standardization can help reduce health disparities that are preventable differences in the burden of disease, injury, violence, or in opportunities to achieve optimal health that are experienced by socially disadvantaged populations.[8] As more healthcare organizations adopt the use of predictive models and algorithms to identify individuals at risk of COVID-19, organizations need to ensure their modeling is standardized to capture accurate demographic data on race and ethnicity. Both indicators are key to identifying specific population needs; however, people may be incorrectly classified based on assumptions from an observer (patient intake, census taker, etc.).[9] For example, some Native Americans are incorrectly identified as white based on their skin color, even though they self-identify as Native Americans. In some cases, race is left blank, so that is a challenge that makes the data less useful. Collecting race and ethnicity data that is accurate and respectful ensures that the unique healthcare needs of various populations are fulfilled.

3 Map Community Resources and Identify Gaps

Use Case: Maryland Task Force on Vulnerable Populations for COVID-19: Assessing Resources and Risk

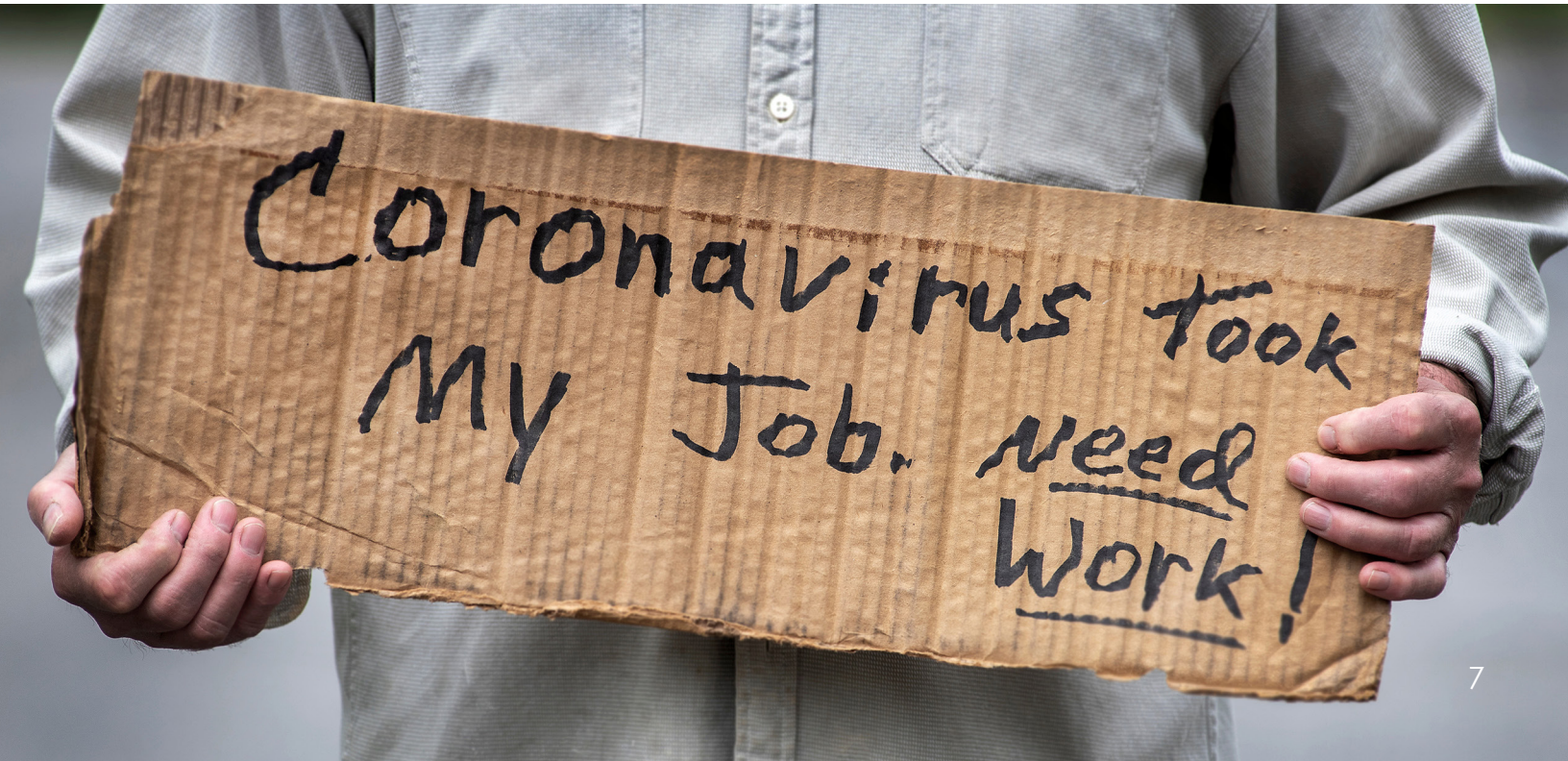
"Vulnerable populations require targeted interventions."

- Susan Mani, MD
Chief Population Officer
LifeBridge Health

The third principle stresses the importance of actually connecting vulnerable populations with interventions and resources. It is not enough to just identify at-risk populations—organizations need to ensure they have programs and interventions to adequately address population-level care obstacles. This is critically important with respect to COVID-19, when at-risk populations have sometimes been identified but not provided with resources to assist them.

An example of this principle in action is the state of Maryland, which recognized the potential disproportionate effect of COVID-19 on populations with underlying chronic conditions or socioeconomic challenges. The State also recognized its own limitations when it came to gaining access to and organizing SDH data integral to designing a data-driven response, so it formed a task force to implement a response strategy to identify gaps and plug in community resources where needed.

The Maryland Task Force on Vulnerable Populations was created to address the needs of specific vulnerable populations in Maryland. It is a public-private partnership comprised of health systems, payers, health agencies, and private organizations that are well-versed in understanding the specific needs targeted by the Task Force.



Maryland's private sector partners are:

- LifeBridge Health
- United Way of Central Maryland
- Meals on Wheels of Central Maryland
- Socially Determined
- Health Choice
- Healthcare for the Homeless
- Maryland Department of Community and Housing Development

The Task Force, headed by Dr. Susan Mani, uses data to map resources and needs for vulnerable populations such as the homeless, elderly, and the uninsured. Each group has unique barriers to healthcare that affects their ability to access resources or practice social distancing to protect themselves.

> *"There are non-clinical impacts to health and identifying those is important, but if our outcome is that we need to fund food banks in certain areas because that community doesn't have access to quality nutrition, there needs to be a stronger partnership and awareness between the commercial sector and what's happening with the community resources."*
>
> - Josh Schoeller
> Chief Executive Officer
> LexisNexis Risk Solutions, Healthcare

Dr. Mani is the Vice President of Clinical Transformation and Ambulatory Quality at LifeBridge Health, and succinctly stated the challenges of data and resources at the state level: "We were able to identify over 150,000 of the highest risk individuals across the state, and looking at that number we just knew it was a task where there is no way one group alone was going to be able to reach out and provide the kind of complex resources required to address the multitude of needs."

Socially Determined, a healthcare analytics organization, was engaged to leverage data from multiple sources to generate a COVID-19 risk index at the city, county, and community levels in Maryland.[10] One of the sources, Chesapeake Regional Information System for our Patients (CRISP), provided data about 2.6 million Medicare and Medicaid patients, which were then put into Socially Determined's Hi-Trust certified system to create indexes that measure community-level susceptibility and individual-level vulnerability. The output of the index is a visual map that allows state representatives to see risk across the state and provide insights for decision-making. The tool's precision calculated risk for every 200 meters, so it was easy to map the locations of homeless shelters, elderly homes, hospitals, and pharmacies against the population density.

Using the risk index to measure age, disease, and social factors, 900,000 individuals from the initial data set were identified as high-risk. Out of 900,000 people, more than 150,000 were identified as highest risk, and their names were provided to health departments, health systems and managed care organizations (MCOs) to begin outreach for testing, telehealth, and care management. The Task Force created a special team of emergency medical services (EMS) and social workers to test people in their homes, inquire about chronic health conditions, perform social needs assessments, and connect individuals with community resources. This approach resulted in 1,000 positive identifications within 25 days, which was more than double the state average at the time. The COVID-positive patients were sent to the emergency room and more than 50 percent of them were connected to previously inaccessible resources.

As researchers learn more about which populations are "at-risk" for COVID-19, it will be critical to map resources to assist these vulnerable populations. In some cases, communities and governments may need to create resources where they do not currently exist.

4 Assess the Impact of Interventions

Use Case: Marshfield Clinic Health System's Community Connection Team addresses social needs to improve health

"We have 1.2 million people in our rural service area. We have about 360,000 patients, so we know that a number of those individuals in the community aren't our patients, and for us it didn't matter during COVID. It still doesn't matter."

- Jason Shrader
Vice President, Community Health and Wellness
Marshfield Clinic Health System

The need to assess the effectiveness of SDOH interventions is the crux of the fourth principle. It is not enough for organizations to simply implement interventions; organizations should ensure there is a standard process in place for tracking outcomes and making improvements when necessary.

The Marshfield Clinic Health System (MCHS) collects data directly from patients through its Community Connections Team (CCT). The team is staffed by AmeriCorps members and student volunteers who screen patients and make referrals to the appropriate resource. Most of their clients are Medicaid- or Medicare-insured. The data elements collected include the number of patients served, the types of services they requested, the status of the referral, and patient satisfaction. This program and these services are available for clients of any federal healthcare program, even if that person is not a patient of MCHS. By tracking referrals, MCHS is also able to track whether or not interventions have actually occurred.

"The health systems themselves are not going to solve it, just as the community-based organizations are not going to solve it and just the public health aspect will not solve it. Everyone will have to come together to do this."

-Vikas Chowdhry
Chief Information Officer
Parkland Center for Clinical Innovation (PCCI)

This year, the Community Connections Team has made more than 11,000 referrals. The three greatest needs identified are utilities, food, and transportation. The Team recognized that due to COVID-19, social isolation has also become a priority to address, so they started an iPad donation program to provide iPads to members of the community to stay in touch with loved ones and, importantly, also have the capability to participate in telehealth. Collecting data about urgent needs helped identify opportunities for new programs – an effective feedback loop that improved services.

In addition, the new program provided an opportunity for patients to provide feedback on whether they were satisfied with their programs and services, including gathering feedback on the quality of the staff. MCHS's program has established ongoing processes to regularly assess their interventions and improved their programs as a result of that feedback. As the pandemic is still raging in the Midwest, this will continue to serve as a ongoing method to gather information about the impact of interventions.

As the majority of the country continues to battle COVID-19, it will be critical for healthcare organizations to regularly assess the impact of their SDOH interventions.

5 Customize Interventions and Allow Individuals to Determine Best Fit

Use Case: Aunt Bertha Connecting People with Resources in the Community

"So much can be done through healthcare, but there are so many places that people eat, live, pray, and work in their communities. We want to make sure that they have not only an equal opportunity, but resources at their fingertips in many of these places as well."

- Jaffer Traish
Chief Operating Officer
Aunt Bertha

The final principle focuses on the need to not only inform individuals that they are at risk, but allow individuals and/or caregivers to decide which services and interventions are the best fit for them. Programs and interventions should never be forced upon individuals, but individuals should be aware they are at risk and be able to make an informed choice to receive the intervention or service. In addition, it is important to provide resources and interventions that are customized or available to individuals at all of the various places they live their lives.

Providing self-navigating tools to select an intervention is an effective way to apply the fifth principle. Aunt Bertha, a non-profit organization, uses the concept of self-navigation as an intervention. The mission of Aunt Bertha is to connect all people in need to programs that serve them and bring dignity to that process. Its network receives 42,000 referrals a month, and its belief is that having an open network ensures that the most people are reached, where they need it the most.

Aunt Bertha provides several solutions to non-profits to assist individuals in navigating the services they need. For example:

- The Camden Coalition provides a tablet and kiosk for patients to enter information anonymously in the waiting room to be matched to local resources. This ensures information is kept private and dignity is maintained.

- AARP collects information on its website for seniors to self-navigate to find home employment, support classes, and tools to reduce social isolation. This allows for individuals to select, based on their own needs, which interventions they want to employ.

- To Write Love on Her Arm uses a click-to-call mechanism that allows individuals to decide when they want to talk to a live person about their mental health. This group's unique approach helps non-profits in the education, healthcare, and corrections sectors provide immediate access to services while maintaining their dignity.

As COVID-19 continues to spread, it will be important to educate individuals on how their SDOH may increase their risk for COVID-19 and impact their health. Clinicians will need to review with patients their risks, necessary interventions, and services available to help, and then jointly agree on next steps.

Final Thoughts

As more healthcare organizations begin to utilize SDOH to identify and treat individuals affected by the COVID-19 pandemic, providers and policymakers must ensure that data is collected and used with clearly defined ethical standards and transparency. The Guiding Principles can help inform the development and optimization of SDOH interventions and services. The organizations highlighted in this report illustrate how the five principles can be applied in the midst of a pandemic. As we continue to face this unprecedented health challenge, the ethical use of SDOH data can improve healthcare organizations' ability to provide the right interventions and services at the right time.

End Notes

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About eHealth Initiative & Foundation

eHealth Initiative Foundation (eHI) convenes executives from every stakeholder group in healthcare to discuss, identify and share best practices to transform the delivery of healthcare using technology and innovation. eHI, along with its coalition of members, focuses on education, research, and advocacy to promote the use and sharing of data to improve health care. Our vision is to harmonize new technology and care models in a way that improves population health and consumer experiences. eHI has become a go-to resource for the industry through its eHealth Resource Center. For more information, visit ehidc.org.

Support for this report was provided by LexisNexis Risk Solutions, Healthcare.

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