Guiding Principles for Ethical Use of Social Determinants of Health Data

eHEALTH INITIATIVE

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Overview

eHealth Initiative's (eHI) Guiding Principles for Ethical Use of Social Determinants of Health Data offers guidance on the evolving matter of Social Determinants of Health (SDOH) and its related data use for healthcare purposes. Using SDOH is unchartered territory in both policy and practice. eHI puts forth an ethical framework for SDOH data, specifically five guiding principles in the areas of:

- Care Coordination
- Recognizing Risk Through SDOH Analytics
- Mapping Community Resources and Identifying Gaps
- Service and Impact Assessment
- Customizing Health Services and Interventions

The Guiding Principles for Ethical Use of Social Determinants of Health Data were developed as part of a SDOH collaborative. eHI is an independent, non-profit organization that convenes executives from various healthcare stakeholder groups to discuss, identify, and share best practices, which transform the delivery of healthcare. The work of the SDOH collaborative focused on educating and guiding industry stakeholders and policy makers on the value of leveraging SDOH data for maximum good in healthcare, while addressing SDOH privacy and security concerns.

eHI and its coalition of members focus on education, research, and advocacy to improve quality, safety, and efficiency in healthcare. eHI promotes data sharing, technology, and innovation to enhance population health, consumer experiences, and lowers costs. The eHealth Resource Center is a clearinghouse and go-to resource for industry. For more information, visit ehidc.org.

Background

Health encompasses many facets of our lives and is more than physical well-being. Health begins in our homes, neighborhoods, schools, communities, and workplaces and is influenced by a number of factors. According to the World Health Organization, "social determinants of health are the conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels."[1]

According to Healthy People 2020, a U.S. Department of Health and Human Services (HHS) initiative providing science-based, 10-year national objectives for improving the health of all Americans, SDOH are typically categorized in five areas—Economic Stability, Education, Social & Community Context, Health & Healthcare, and Neighborhood & Built Environment—and can affect a wide range of health, functioning, and quality-of-life outcomes and risks.[2] The County Health Rankings (CHR) model, developed by the Robert Wood Johnson Foundation and the University of Wisconsin Population Health Institute, demonstrates that factors related to social and economic status and physical environment exert a greater influence on health than other individual modifiable factors, such as health behaviors and clinical care.[3]

[1] https://www.who.int/social_determinants/sdh_definition/en/
[2] https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health
[3] http://www.countyhealthrankings.org/sites/default/files/Hood_AmJPrevMed_2015.pdf

By integrating SDOH insights into care plans, healthcare stakeholders can recognize the need for, and enable access to, additional services or interventions for individuals, such as programs related to accessing healthy food, providing reliable housing, or helping patients manage isolation and loneliness, ultimately driving better health and wellness outcomes. The move to value-based care models makes it imperative for providers and care givers to have access to complete patient information, which enables care of the individual beyond the clinical condition.

Organizations and researchers have recognized the impact of SDOH. Research and programs that evaluate and address the social, economic, and environmental factors that influence health are increasingly important and their relevance is demonstrable. Some examples include:

- The World Health Organization created the Commission on Social Determinants of Health to draw the attention of governments and society to SDOH and to eliminate health inequities for local communities and nations throughout the world.
- The Centers for Medicare and Medicaid Services (CMS) is testing the Accountable Health Communities Model, which provides support to community bridge organizations that link beneficiaries with community services that may address their health-related social needs.
- The County Health Rankings & Roadmaps program is an innovative collaboration between the Robert Wood Johnson Foundation and the University of Wisconsin Population Health Institute, which compares the health of counties in the U.S. to others within the state, and provides strategies that communities can use to put education into action.

Purpose

As the benefits of addressing SDOH become further substantiated and data insights become more mainstream, it is important to ensure that data is collected and used with clearly defined ethical standards and transparency. SDOH data should be used to inform the development and optimization of healthcare interventions and services aimed at improving health outcomes, meaningfully engaging patients, and providing enriched, realistic care regimens.

Organizations must consider the potential impact of the use of SDOH data on vulnerable populations and ensure that data is collected and used in a fair, unbiased, and scientific manner. SDOH should be used in accordance with all applicable state and federal laws and should not be used for discriminatory practices; denial of healthcare services, such as denying or limiting medical care or access to medical benefits; or unfair marketing practices.

The Guiding Principles for Ethical the Use of Social Determinants of Health Data were developed as part of eHI's SDOH collaborative. The collaborative is dedicated to educating and guiding industry stakeholders and policy makers on the value of leveraging SDOH data for maximum good in healthcare, while addressing privacy and security concerns. eHI recommends that traditional and non-traditional healthcare entities, as well as social and governmental entities, adhere to the principles. Participating organizations include those representing various public and private healthcare stakeholders that impact millions of patients annually. These organizations are listed at the end of the document.

Goals

- Guide the healthcare industry in improving care management with clear articulation of the ethical use of SDOH data
- Assist the healthcare industry as it transitions to value-based care with tools to improve care management
- Encourage the development of robust policies and procedures related to data collection, and the accountability and evaluation of SDOH programs including, but not limited to:
  - ✓ Standards for collecting and protecting data through proper data governance measures, with a focus on accuracy, clinical relevance, and elimination of bias
  - ✓ Standards for accountability when accessing, storing, and tracking SDOH data
  - ✓ Standards to evaluate the effectiveness of SDOH programs

Guiding Principles for Ethical Use of SDOH Data

The ethical use of SDOH data is predicated on improving the health of individuals and providing the right interventions and services at the right time.

1 Care Coordination

Identify individuals with SDOH needs, coordinate and deliver more holistic care, facilitate connections to additional interventions or services, consistent with privacy and security protections

SDOH health data can lead to better care management and personalized care by providing a unique lens into the health and well-being of individuals. For instance, recognizing issues such as food insecurity, lack of transportation, and unsteady employment or housing, offers meaningful insights into circumstances that directly affect lives. With the right patient data, providers, community health workers, and other key stakeholders can create personal care plans that combine both medical and SDOH needs, ensuring patients have what they need to successfully follow their care plans. SDOH data should be collected, maintained, used, and disclosed in accordance with privacy and security protections.

Example

If a health plan is able to identify an individual as being food insecure through an SDOH data model, the individual can be referred to a social or governmental service which expands access to healthy, home delivered meals.

2 Recognizing Health & Wellness Risks Through SDOH Analytics

Identify risk through the use of analytic tools, in order to develop population health management interventions for individuals and communities

SDOH data can be used to forecast future health outcomes. By leveraging their SDOH data, a healthcare stakeholder may be able to predict if an individual is at an increased risk of a certain adverse health outcome, such as being readmitted to the hospital or not adhering to a medication regimen. This information can be used to coordinate the appropriate action. In preparing a predictive model, it is important that the data used in algorithms ensure accuracy and relevance related to use cases. It is also important that choices made about modeling and analyzing data elements are free from bias. Standardization may be a means to help eliminate potential bias and discrimination.

Example

Women facing certain SDOH challenges, such as low health literacy, structural and environmental factors that negatively affect access to exercise and nutrition, and limited social support, are at higher risk of experiencing complications during pregnancy and poor birth outcomes. Identifying pregnant women who have these SDOH attributes and working to address these risks with non-clinical traditional approaches, including patient advocacy, may help prevent low infant birth weight, pre-term births, hospitalization, and other possible adverse maternal and neonatal outcomes. [Note: Racial and ethnic disparities for maternal and infant birth outcomes remain pervasive in the U.S., regardless of education, income, or health literacy.[4,5]]

[4] https://socialequity.duke.edu/sites/socialequity.duke.edu/files/site-images/EradicatingBlackInfantMortality-March2018-DRAFT4.pdf
[5] https://www.cdc.gov/mmwr/volumes/68/wr/mm6818e1.htm?s_cid=mm6818e1_w

3 Mapping Community Resources and Identifying Gaps

Assess individual SDOH needs against available community resources to identify gaps that address health and wellness

SDOH data positions healthcare & community stakeholders to be able to map existing resources, local to the populations they serve. Data can be used to identify resource gaps so new programs and interventions can be developed to adequately address population-level care obstacles. Care should be taken to maintain confidentiality and privacy if any specific patient and health related data is mapped.

Example

To help address individuals' unmet social needs, organizations are developing and deploying tools to identify, catalogue, and document local community-based services, refer individuals to these services, and help providers, health plans, and communities build partnership networks across the continuum of care. Broadly speaking, tools like these serve as a 'directory' that provides information about the social service resource (type, location, conditions, availability of services). These tools can also support referrals between providers, health plans, and social service organizations, and serve to document and provide better understanding of social, non-medical needs within communities.

4 Service and Impact Assessment

Assess impact of SDOH interventions and services

Stakeholders should measure and monitor SDOH interventions and their correlations to better health outcomes, specifically whether the intervention positively impacts the SDOH needs and their related health outcomes. There should be standard processes in place for tracking referral outcomes. These processes are needed to coordinate between social service organizations and healthcare stakeholders to evaluate and track results and make any necessary adjustment to the interventions.

Example

SDOH factors, such as home instability or lack of transportation access, may put individuals discharged from an inpatient hospital setting at a high risk of 30-day readmissions.

5 Customizing Health Services and Interventions

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

It is important to involve potentially impacted individuals in the discussion when SDOH is being used to improve their care. This includes educating individuals on how their SDOH impact their health, reviewing interventions and services available to help, and jointly agreeing on next steps.

Example

If an individual is unable to pick up their monthly prescription from the pharmacy due to a lack of reliable transportation, the physician, pharmacist, or social worker can discuss arranging for at home delivery or ride service to the pharmacy.

Stakeholders

American Health Information Management Association (AHIMA) • America's Health Insurance Plans (AHIP) • Allscripts • Amazon Web Services (AWS) • American Cancer Society • American College of Cardiology • American College of Physicians • American College of Radiology • American Heart Association • American Hospital Association • Association of State and Territorial Health Officials (ASTHO) • athenaheath • BDO • Care Compass Network • CareSource • Cerner • Change Healthcare • CHRISTUS Health • Cognizant • CRISP • CVS Health • eHealth Initiative • EHNAC • Epstein Becker & Green • George Washington University—Milken Institute School of Public Health • Google Cloud • HealthCore • HL7 International • Hogan Lovells • Inovalon • InterSystems • Johnson & Johnson • LexisNexis Health Care • LifeWIRE • Lilly • Manatt Health • Marshfield Clinic • Mayo Clinic • Med Allies • Medical Group Management Association (MGMA) • National Alliance of Healthcare Purchaser Coalitions • National Institute of Mental Health (NIMH) • NextGen Healthcare • Noridian Healthcare Solutions • Ohio Health • Orion Health • Point-of-Care Partners • pwc • Providence St. Joseph Health • RELX • Robert Wood Johnson Foundation • Salesforce • Solera Health • Sonora Quest Laboratories • Strategic Interests • University of Chicago Medicine • UnitedHealthcare • Updox • Validic • Verato • Walgreens • Wellmark • WellDoc • Zipnosis

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