Social Determinants of Health Data: Survey Results on the Collection, Integration, and Use

Presented by:
NORC at the University of Chicago (NORC)
American Health Information Management Association (AHIMA)
# Table of Contents

Executive Summary ........................................................................................................... 1  
   Key Findings .................................................................................................................. 1  
Background ...................................................................................................................... 2  
   Methods ......................................................................................................................... 3  
Lack of Standardization & Integration of Data ................................................................. 3  
   Standardization .............................................................................................................. 3  
   Screening Tools ............................................................................................................. 5  
Integration ....................................................................................................................... 6  
Training & Education on Capturing & Using the Data ..................................................... 8  
Communication Between Providers & Community Partners ......................................... 12  
Conclusion ....................................................................................................................... 15  
Limitations ....................................................................................................................... 15
Executive Summary

The American Health Information Management Association (AHIMA), a global nonprofit association of health information (HI) professionals and a leading voice and authority in the health care industry, is dedicated to improving the collection of actionable Social Determinants of the Health (SDOH) data. As part of its mission to empower people to impact health, in 2020 AHIMA called upon then-President-Elect Biden to bolster the country’s health system through the increased collection and use of accurate, timely, and complete patient health information. Two years later, AHIMA continues to pursue and promote this goal by highlighting that more-comprehensive SDOH data can offer additional insights to help enrich clinical decision-making and improve health outcomes.

In 2022, AHIMA tasked NORC with undertaking a comprehensive research survey of AHIMA members regarding SDOH. The survey had three main objectives:

1. Better understand how SDOH is collected, coded and used
2. Inform the development of educational tools and resources needed by HI professionals
3. Inform the development of policy recommendations to further the standardization and use of SDOH data

The survey’s findings and subsequent policy recommendations can be used to help the health care sector and policymakers better understand and address challenges associated with the collection, coding, use, and exchange of SDOH data. Better SDOH data enables the health system to better understand pathways to achieving improved outcomes and solutions.

Key Findings

Nearly eight in 10 survey respondents indicated that their organization was collecting SDOH data. This is an important indicator and demonstrates that there is a growing understanding of the value of SDOH information across health care settings. However, subsequent responses in the survey indicate that there are challenges to collecting complete and accurate data including the following:

- Lack of standardization and integration of the data into an individual’s medical record
- Insufficient training and education on how to capture, collect, code, and use the data
- Limited use of the data to communicate between health care providers and community-based referral organizations

This paper addresses each of these in detail and offers policy recommendations.

---

Background

The U.S. Department of Health and Human Services (HHS) defines SDOH as "the conditions in the environments where 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." As part of its Healthy People 2030 campaign, HHS has identified SDOH as a critical factor in addressing health equity.

SDOH include but are not limited to education, safe housing, access to nutritious foods, transportation, and good air and water quality. A growing body of evidence suggests that social needs play a substantial role in determining health outcomes. One widely cited analysis estimates that social and economic factors alone determine 40 percent of the length and quality of our lives and are twice as influential as factors related to clinical care. The World Health Organization also suggests that SDOH account for 30–55 percent of health outcomes.

These findings have led to increased attention on SDOH by health care industry leaders and policymakers. The Biden-Harris Administration has made numerous announcements, rules, and taken other steps that make it clear that health equity is a core focus and recognize that improved collection and use of SDOH data is critical to bridging the health equity gap. Various sectors of the health care delivery system—including providers, payers, and technology companies—similarly recognize the importance of SDOH on patient outcomes, and are seeking to address these issues in more meaningful ways than before.

Despite the increased attention and emphasis on SDOH, there are real challenges to addressing individual social needs, especially within the health care system. Historically, the health care system has not been oriented to address these issues and significant changes are needed to enable health care providers to affect health outcomes through the use of this data. While a multitude of changes are needed, a focus on the documentation of these needs and translating those needs into coded data for actionable use is foundational. An analysis produced by NORC at the University of Chicago (NORC) found that the claims data of only 1.42 percent of Medicaid enrollees and 1.3 percent of Medicare beneficiaries included documentation of social needs.

Consistent, accurate, and complete collection of actionable data is the first of many steps needed to create a more equitable health care system and to deliver equitable care. Actionable data not only...

---


---

NORC 2022
helps inform decision-making and the development of solutions to address these social needs on an individual level, they are critical to understanding population-level trends related to social determinants.

Methods

NORC sent a 27-question web survey to a 41,215-person AHIMA member and non-member distribution list. Survey recipients had roles related to health information data collection and management. They included coding professionals; managers, directors, and vice presidents of Health Information Management (HIM); HIM teams; and C-Suite executives. A total of 2,637 respondents completed the survey from Aug. 24–Sept. 9, 2022.

Researchers assessed the responses for completeness, and to identify missing, invalid, inconsistent, or otherwise inaccurate records. This included checking for and eliminating invalid responses. To establish significance between responses, NORC performed statistical testing with a confidence level of 95 percent. Statistical significance is noted in the data, where applicable.

Lack of Standardization & Integration of Data

Standardization

More than three-quarters of respondents (78 percent) reported that their organization collects SDOH data (Figure 1). Of the 22 percent who said that their organization does not collect SDOH data, many indicated that it is because their organization does not screen patients for SDOH (Figure 1).

Among respondents who collect SDOH data (78 percent), slightly more than seven in 10 (71 percent) primarily capture SDOH data electronically, via an electronic health record (EHR) (Figure 2). A small percentage (2 percent) collects SDOH data electronically but outside of an EHR, which suggests the use of a stand-alone data collection portal or other homegrown electronic data collection tool. Respondents also mentioned that they collect data verbally or on paper (5 and 4 percent, respectively).
The prioritization of different SDOH data elements is uneven across the health care sector. Nearly six in 10 respondents (59 percent) who collect SDOH data reported that their organization prioritizes health insurance coverage and health behavior information (e.g., smoking, alcohol consumption, etc.) (Figure 3). Health insurance coverage and certain health behavior information have historically been widely collected which might suggest an increased likelihood that an established field exists in the organization’s EHR.

The survey revealed lower levels of prioritization of other SDOH elements. Forty-four percent of respondents reported that their organization prioritized housing security, housing status, and other metrics that impact a patient’s neighborhood, built environment, or living situation. More than a third of respondents said that their organization prioritizes data on economic stability (38 percent) and food insecurity (36 percent). Transportation (28 percent) and education (17 percent) were prioritized the least. These findings suggest that these variables might not have structured fields in the organization’s ’s EHR that would facilitate collection. There may be other reasons for not prioritizing...
collection of this information, such as a lack of incentives for collecting it compared to other elements tied to value-based care contract terms, like smoking status.12

Screening Tools

Which domains are collected reflects more than just the available fields in an organization’s EHR. Organizational priority, the provider’s ability to address these issues, and the type of data-collection tools all play a role. While some data are captured directly by clinicians in clinical notes, others may be collected via screening forms. Respondents cited the Centers for Medicare and Medicaid Services (CMS) Accountable Health Communities (AHC) Core Domains as the most frequently used screening tools for collecting SDOH data (Figure 4). These findings indicate there is no singular preferred screening tool and an overall lack of awareness of available screening tools. It is important to note that each of the tools provided as response options have different structures and focus areas, some of which may align better than others with the diverse needs and clinical settings of organizations collecting this information. These findings suggest a concerted effort to prioritize collection of certain high-priority data elements should be a priority to create meaningful alignment across health care sites and settings as well as raising awareness as to the type of screening tools currently available.

While there is no consensus on which key SDOH domains need to be collected, there is greater alignment on which terminologies are most useful to data collection (i.e., SNOMED, ICD-10-CM diagnosis codes). Eighty percent of respondents used a standardized coding system to code SDOH data elements. Among them, 99 percent use ICD-10-CM ("ICD-10") codes to collect SDOH data (Figure 5). While ICD-10 codes are universally used, respondents mentioned a few other terminologies, including CPT codes (17 percent), SNOMED-CT (4 percent), and LOINC (2 percent). However, these numbers do not reflect how often these codes are used to capture SDOH data. The survey question only asked respondents which coding terminologies, they use to collect SDOH. Although there is consensus on which terminology to use (e.g., ICD-10), a gap remains in using those codes accurately and consistently to capture SDOH data.

Integration

The survey found that while many health systems and organizations are collecting individual SDOH data elements, those data are not necessarily being integrated into EHRs. For the purposes of this paper, the word “integration” refers to the incorporation of SDOH data elements into the EHR regardless of whether the data is collected manually or through automation. When asked about specific SDOH domains, more than nine in 10 (91 percent) survey respondents said that their organization collects SDOH data related to health behaviors and mental health. However, only about six in 10 (61 and 62 percent, respectively) said that they integrate that information into their patient EHRs (Figure 6).

Similar patterns emerged for other SDOH domains. Roughly eight in 10 respondents (81 percent) collect SDOH on homelessness, language (80 percent), and social isolation (78 percent). Yet less than half said that their organization tries to integrate these data into EHRs (53, 57, and 50 percent, respectively). See below.
While health systems increasingly collect SDOH data, integration into the EHR remains a prevailing challenge. The discrepancy between collection and integration is greatest when it comes to mental health, health behaviors, social isolation, and homelessness. The fact that the data may be incomplete, unstructured, and/or buried in inconsistent fields—such as health concerns, goals, social history, etc.—may limit the integration of this information into the EHR.

Broader collaboration among key stakeholders across the health care sector is a critical step to improved collection of SDOH data and ultimately using this data to improve health outcomes. Policy can serve as a crucial lever to advance collaboration between stakeholders with the ultimate goal of improving the collection, coding, and use of clinically-relevant SDOH data to improve health outcomes. Along these lines, AHIMA offers the following policy recommendations:
Policy Recommendation #1:

CMS and other relevant agencies within HHS should establish, in collaboration with standards-setting organizations, health information professionals, physicians, hospitals, and other front-line health care providers and organizations, a set of standardized, clinically valid, and actionable SDOH data elements for collection. This might include a limited set of evidence-based domains, such as food and housing, as priorities while other domains are considered optional. This would allow for a subset of standardized data elements to be collected in a consistent and comparable manner, while recognizing that diverse care settings may not have the same amount of time or resources to collect and act upon these data. Domains prioritized for collection should also align across federal and state healthcare programmatic and reporting requirements.

Policy Recommendation #2:

To enhance use of a prioritized set of clinically relevant data to improve outcomes and health, CMS should consider providing financial incentives to providers, Medicare Advantage plans, Medicaid plans, and commercial payers to collect and share SDOH data. Aligning incentives and protocols across CMS programs, commercial payers, and providers would ensure that stakeholders are working together to meet their community’s needs.

Training & Education on Capturing & Using the Data

Survey respondents reported that the frontline clinical staff was primarily responsible for collecting SDOH data during a patient or caregiver visit. These frontline SDOH collectors were nurses (24 percent), followed by physicians (15 percent), and then registration or patient financial service representatives or operations staff (12 percent) (Figure 7). However, one in four respondents (26 percent) shared that they did not know who the primary collector of SDOH data was in their organization.
Nearly eight in 10 survey respondents said that their organizations offered education and training to support the collection and use of SDOH data. Specifically, respondents indicated that they receive training on privacy protections and security standards (82 percent) and the American Hospital Association’s (AHA) Coding Clinic for ICD-10-CM/PCS guidance using SDOH Z-codes (80 percent) (Figure 8). Seventy-four percent indicated that they were trained to collect SDOH in culturally sensitive ways. Seventy-two percent reported training on document requirements to support accurate SDOH code assessments. These are all strong supporting indicators that SDOH data collection is prioritized at many organizations.
Although nearly eight in 10 respondents said that their organizations offer trainings on collecting and using SDOH data, they also shared recurring challenges in the collection and coding of this data.

A vast majority of respondents reported that workforce-related challenges were the top hindrance to collecting and coding SDOH data. Ninety three percent ranked the lack of a trained workforce as the top collection challenge. Consistent with issues on data collection, 83 percent of respondents listed staff training and education as a top three challenge when coding SDOH data (Figure 9). This suggests that current training and resources, while available, may be insufficient.
Other reported challenges were a lack of organizational policy on data collection and patient distrust in sharing SDOH data (87 and 73 percent, respectively).

Despite 72 percent of respondents indicating that their organization offers training and education on documentation requirements to support accurate SDOH code assessments (Figure 8), 78 percent said that they could not find SDOH information in the patient record (Figure 9). This might suggest that while operations staff know the documentation requirements needed to assign a code, the information might not be readily apparent in the documentation, is not being documented, or is documented in a part of the record that is not readily accessible to operations staff. This highlights the need to further train and educate clinical staff on what documentation is needed to support code assignment. Such training also provides an opportunity to bring together clinical and operations teams, to ensure that they are aligned when it comes to common SDOH terminology, documentation goals, and the value of having this information integrated into the patient’s record.
Policy Recommendation #3:

Federal financial and technical support is needed to train providers and operations staff on how best to collect, code and use social needs information. This should include a focus on cultural competency coupled with the recognition that different care settings may require different approaches. It should also include continued and expanded research on how best to collect and code SDOH data, and the workforce skills needed to do so.

Government agencies, professional societies, and other organizations—such as AHIMA, CMS’ Office of Minority Health, CMS’ Center for Medicare & Medicaid Innovation, HL7’s Gravity Project—should also leverage their learning collaboratives to share best practices and guidance on the collection, coding, and use of clinically relevant SDOH data for care team members and operations staff, so that they can efficiently use existing knowledge.

This may include training appropriate staff on how to use standardized formats to collect and code the data from patients in ways that are effective and adhere to high standards of cultural competency, privacy, and confidentiality.

Communication Between Providers & Community Partners

To address social needs at both the individual and community levels, SDOH data must be incorporated into a variety of organizational goals and activities. A focus on SDOH is new for many providers and hardwiring these changes can be difficult. By meaningfully incorporating SDOH measures or activities into department and system goals, provider organizations can create lasting change. At the same time, it is important to note that an internal focus alone is not enough. Communication between providers and community-based organizations (CBOs) is essential to taking meaningful action on SDOH. However, survey respondents indicated that communication and integration between the health and social services sectors is often limited and inconsistent.

The survey found that the top two ways that organizations use SDOH data are to refer patients to CBOs and to identify and assess community-level needs. Yet, there are prevailing challenges in sharing SDOH information across the health care and social services sectors when working to facilitate community efforts to address social needs.
A majority of respondents (82 percent) said that their organization made electronic referrals to CBOs or referral partners. However, when asked whether their organization had a closed-loop referral process, fewer (64 percent) said yes (Figure 11). The lack of interoperability or communication across organizations that identify needs (e.g., hospitals, health systems, and physician offices) and those most likely to have the expertise and resources to address these needs (e.g., CBOs) may limit the ability to measure the impact of the intervention.

Individual- and community-level interventions to address underlying social risk factors that contribute to health and well-being require cross-sector investment and collaboration. Health care systems and CBOs need better alignment on a core set of SDOH standards that are harmonized across platforms. They also need validated tools and processes to support closed-loop referrals, to demonstrate positive health outcomes as well as return on investment in SDOH interventions. While a limited number of these critical partnerships are in place, the survey indicates that much more must be done to close the loop between stakeholders, to achieve meaningful improvements in patient care and well-being. Federal government agencies, such as the U.S. Department of Health and Human Services and others – including Housing and Urban Development, Justice, and Transportation can play a critical role in facilitating these critical partnerships and should lead the way by allocating funding and technical resources to state and local government to address social needs.

**Policy Recommendation #4:**

Federal government should provide funding, technical resources, and infrastructure to support coordination and connectivity at the state and local level between health care organizations and CBOs.

Many of the solutions to addressing SDOH needs rely on collaboration between the health and social services sectors. This type of cooperation is happening in pockets at the local level. Many providers are reticent to ask their patients about their SDOH needs without first having the community-based support system to which they can refer the patient so that these needs can be met. Federal incentives are needed for states to create better alignment—across coordinating agencies to improve coordination, collection, and, ultimately, impact.
UCLA Health, a leading academic medical center, is collecting SDOH data to enhance patient care.

UCLA Health’s analysis of 15,000 patient records from their emergency department and street medicine efforts determined 85% of ED visits were due to conditions that could have been prevented in the community. To combat this trend, UCLA Health has piloted a variety of data collection and outreach programs specifically devoted to individuals with serious medical conditions and underserved communities who often cannot reliably access medical treatment.

Across the organization, UCLA captures SDOH data on critical factors such as socio-economic status, physical environment, social support, food insecurity, education, and language. Starting in 2021 and 2022 respectively, UCLA Health patients are invited to fill out a Social Factors and All About Me questionnaire in their electronic patient portal before all telehealth or in-person appointments. This data is reviewed by the population health team, which includes representation from clinical and social work departments, to assist care teams with connecting patients to social services organizations that can aid with housing, economic security, and other needs.

UCLA Health is likewise determined to meet people where they are through its Homeless Health Care Collaborative, where a community care team travels directly to people who are unhoused. The community care team deploys medical students from the Geffen School of Medicine at UCLA and nursing care teams to document a patient’s type of built environment and any known medical conditions. Through generous funding and a focus on mission, the Collaborative has equipped vans with Wi-Fi, basic diagnostic services, and medication to address patients in real time. The team leverage the EHR remotely and there is an effort underway to consolidate and analyze this information to understand broader trends in the impact of housing and the built environment on health outcomes.

“When we do find those patients and we are able to create a process in the system to see them on some sort of cadence, we are able to collect data beyond unhoused…but how does the overall environment impact their overall health status? How does communication and transportation factor in? Once we accumulate that data we begin to tell some stories.”

—Maria Caban Alizondo PhD, RHIT, FAHIMA
Director, Health Information Management Services Medical Information Technologies Services,
UCLA Health

https://www.uclahealth.org/why-choose-us/about/homeless-healthcare-collaborative
Conclusion

The complex nature of the collection, coding, use, and exchange of SDOH data requires coordinated action across the health and social services sectors. Despite the difficulty of achieving this, it is vital. Coordination and alignment across stakeholders has the potential to meaningfully improve the lives of the most vulnerable members of our society by advancing health equity.

The health care system is an essential component of this effort. Providers, health care organizations, and operations staff across care settings have a critical role to play in collecting, using, and sharing actionable SDOH data. By focusing on actions that enhance the standardization and integration of this data—including sufficient training and education of key staff so that they can excel at a myriad SDOH-related activities—health care leaders can set the groundwork for future impact. However, it’s important to emphasize that the health care system cannot act alone. Coordination between health care systems, CBOS, and social services agencies at local, state, and federal levels is crucial to delivering services that meet complex needs and lead to success.

Limitations

Surveys can provide meaningful insight into the attitudes, opinions, and experiences of respondents. However, given the nuance of this issue, additional research on this topic is essential to adding further depth and detail to what we have learned here. For example, holding focus groups with respondents and other key stakeholders would provide valuable context and clarity that would help us develop more specific and actionable recommendations. To create greater equity and improve the experiences and outcomes of vulnerable populations, it is critically important that such research also include the voices of those who will be impacted. This may entail conversations with patients and CBOS that deliver critical social services.