

Data for Better Health Advocacy Agenda

Health equity is the situation in which everyone has a fair and just opportunity to be as healthy as possible. Advancing health equity is necessary to improve overall quality of care, patient outcomes, population health, and reduce costs. Studies suggest that disparities cost an estimated \$93 billion in excess medical costs and \$42 billion in lost productivity per year as well as economic losses due to premature deaths. Today, communities including racial and ethnic minorities, sexual and gender minorities, individuals with disabilities, and those living in rural areas experience a disproportionate share of acute or chronic diseases and adverse outcomes. The COVID-19 pandemic exposed and exacerbated existing health inequities globally.

Addressing social determinants of health is a critical step to achieving health equity.¹ Social determinants of health (SDOH) are “conditions in the environment 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.” A growing body of evidence suggests that these factors impact the health and health outcomes of individuals and communities. One analysis estimates only 20 percent of our health is related to access to care and quality of healthcare services, whereas 80 percent is determined by social determinants.

These findings have led to increased attention to SDOH by healthcare industry leaders and policymakers. The Biden-Harris Administration has made numerous announcements, rules, and taken other steps that make clear health equity is a core focus and improved collection, sharing, and use of SDOH data is critical to not only improving individual and community health and healthcare outcomes but advancing health equity.^{2,3,4}

Despite increased attention to SDOH, there are operational challenges associated with the collection, sharing and use of SDOH data. A recent survey of health information (HI) professionals conducted by NORC at the University of Chicago on behalf of AHIMA found:

- **Lack of standardization and integration of the data into an individual’s medical record.**⁵ 73 percent of survey respondents said their organization collects SDOH data related to housing security. However, only 48 percent said they integrate that information into an individual’s electronic health record.
- **Insufficient training and education on how to capture, collect, code, and use the data.**⁶ 93 percent of respondents cited lack of a trained workforce in collecting SDOH data. 83 percent of respondents cited lack of staff training as a top challenge in coding SDOH data.⁷
- **Limited use of the data to communicate between healthcare providers and community-based referral organizations.** 32 percent of respondents said they use SDOH data for patient referrals to community-based organizations (CBOs).⁸

¹Available at:

<https://www.cdc.gov/nchhstp/socialdeterminants/faq.html#:~:text=Addressing%20social%20determinants%20of%20health%20is%20a%20primary%20approach%20to,other%20socially%20determined%20circumstance'%E2%80%9D.>

² Available at: <https://www.cms.gov/about-cms/agency-information/omh/health-equity-programs/cms-framework-for-health-equity.>

³Available at: <https://www.cms.gov/newsroom/press-releases/cms-proposes-policies-advance-health-equity-and-maternal-health-support-hospitals#:~:text=Improving%20Maternal%20Health%20Outcomes,outcomes%20and%20maternal%20health%20equity.>

⁴ Available at: <https://www.cms.gov/files/document/data-highlight-april-2022.pdf.>

⁵Available at: https://www.ahima.org/media/03dbonub/ahima_sdoh-data-report.pdf.

⁶ Available at: https://www.ahima.org/media/03dbonub/ahima_sdoh-data-report.pdf.

⁷ Id.

⁸ Id.

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Only 64 percent of respondents who made electronic referrals to CBOs have a closed-loop referral process.⁹

To improve health and healthcare outcomes, more attention must be given to the collection, sharing, and use of SDOH data. To accelerate this effort, AHIMA believes that public policy must:

1. **Establish technical standards to promote the collection, sharing, and use of social determinants of health data.** Public policy must identify a set of standard concepts and definitions for SDOH. Identification of existing medical coding vocabulary gaps is also needed to document and capture standardized SDOH data elements. Public policy must also ensure that the processes for updating vocabularies and code sets routinely include consideration of SDOH data needs. Finally, public policy must prioritize a set of standardized, clinically valid, and actionable SDOH data elements to be included in electronic health records (EHRs). This includes the development and testing of consensus-based standards to enable the electronic exchange of SDOH data.
2. **Prioritize a limited set of evidence based SDOH domains for collection.** The Centers for Medicare & Medicaid Services (CMS) and other agencies within the US Department of Health and Human Services (HHS) should start with promoting the collection of a limited set of SDOH evidence-based domains, such as food and housing while other domains are 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.
3. **Promote healthcare delivery and financing models designed to integrate SDOH data into the clinical setting in ways that are culturally respectful.** Policy must leverage patient-centered care models such as CMS' Center for Medicare & Medicaid Innovation (CMMI) Accountable Health Communities (AHC) Model to incentivize the incorporation of SDOH data into care decisions. CMS should also consider financing models for providers, Medicare Advantage plans, Medicaid plans, and commercial payers to encourage the collection, use and sharing of SDOH data. Aligning incentives and protocols across CMS programs, commercial payers, and providers would ensure stakeholders are working together to meet their community's needs.
4. **Build patient trust and foster positive patient-provider relationships to encourage patients to share their social challenges.** Public policy must encourage providers to be transparent and communicate clearly about the purposes for which SDOH data is collected and used, while raising awareness of how different patient populations may participate in the collection and use of SDOH data.
5. **Enhance the sharing of SDOH data across clinical and community-based organizations.** Public policy must encourage a digitally secure infrastructure to support functional, structural, and semantic interoperability between clinical and non-clinical settings. Federal funding, technical resources, and infrastructure are needed to support coordination and connectivity at the state and local level between healthcare organizations and CBOs. Many solutions focused on addressing social needs rely on collaboration between the health and social services sectors at the state and local level. Federal incentives are needed for states to create better alignment across coordinating agencies to improve coordination, collection, and, ultimately, impact. Public policy must embrace data governance policies to support data sharing and data integrity, while promoting positive referral feedback

⁹ Id.

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loops to enhance care coordination.

6. **Prioritize privacy.** The sharing of SDOH data across clinical and non-clinical organizations requires consideration of privacy issues, including consent management and the appropriate sharing of information (while ensuring that only the minimum necessary information is exchanged and limited to the transaction in question). This includes consideration of privacy and security issues that arise when collecting and sharing electronic health information outside of the scope of HIPAA.
7. **Recognize workforce training needs related to the collection, sharing and use of SDOH data.** Financial and technical support is needed to train providers and operations staff on how best to collect, use, and share SDOH data. This includes a focus on standards of cultural competency, privacy, and confidentiality, coupled with the recognition that different care settings may require different approaches. Such support must include continued and expanded research on how best to collect, share, and use SDOH data and the workforce skills needed to do so.
8. **Promote the ethical collection and use of SDOH data.** Developing social risk profiles based on SDOH data may lead to discrimination, stigmatization, and implicit bias. It could also limit access to care options, exacerbate poor outcomes and existing health inequities, and impede data integrity. Public policy must safeguard against the perpetuation or aggravation of such occurrences.

Proper collection, sharing and use of clinically valid and actionable SDOH data is critical to improving health outcomes and advancing health equity. As policymakers continue to consider efforts to address health inequities, AHIMA stands ready to lend its expertise and perspective to the conversation.