Playbook for Social Determinants of Health (SDOH) Referral Management and Data Exchange

INTRODUCTION

Background

The U.S. Department of Health & Human Services (HHS) Office of Disease Prevention and Health Promotion defines social determinants of health (SDOH) as the conditions in the environments where people are born, grow, live, work, and age that affect a wide range of health and quality-of-life outcomes and risks.[1] Evidence demonstrates that SDOH significantly impact individuals' health outcomes, with nearly 50 percent of health outcomes linked to SDOH.[2] Accordingly, stakeholders representing health care, health information technologies (HIT), and public health have become increasingly invested in addressing SDOH for individuals and communities. While health care providers can address acute health-related social needs (HRSN), they are rarely well-positioned to deliver the range of social care services necessary to ameliorate negative health outcomes on their own. Rather, addressing SDOH demands collaboration and innovation between health care organizations and community-based organizations that support social services, as well as the government agencies able to support the ecosystem.

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[1] U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2030. Social Determinants of Health. Available at: https://health.gov/healthypeople/priority-areas/social-determinants-health.

[2] Whitman A, De Lew N, Chappel A, Aysola V, Zuckerman R, Sommers B D. Assistant Secretary for Planning and Evaluation. Addressing Social Determinants of Health: Examples of Successful Evidence-Based Strategies and Current Federal Efforts. Available at: https://aspe.hhs.gov/sites/default/files/documents/e2b650cd64cf84aae8ff0fae7474af82/SDOH-Evidence-Review.pdf.

Definitions

As several terms within this space are often used interchangeably, it will be helpful to level-set by providing definitions of two key terms: *health-related social needs* and *social determinants of health*.

Health-related social needs (HRSNs) are an individual's unmet, adverse social conditions that contribute to poor health. Efforts to address HRSNs provide assistance at the *individual* level but don't address the underlying *economic or social conditions* that lead to these needs. For example, an effort to address HRSNs could involve connecting individuals to a food bank.

As stated earlier, **social determinants of health (SDOH)** are the conditions in which people live. Efforts to address SDOH focus on the *underlying social and economic conditions* that lead to individual-level needs, rather than the specific needs of any individual. For example, an effort to address SDOH could involve incentivizing a grocer to establish a store in a food desert.

This playbook focuses on workflows to exchange individual-level data. We believe that the more accurate term for this data is "HRSN data," however, because stakeholders in this space generally refer to this concept as "SDOH data," we will generally refer to this data as "SDOH data."

Vision and Goal

This playbook envisions an interoperable ecosystem where SDOH information is shared seamlessly, privately, and securely across both public and private entities representing health care, HIT, public health, and community-based organizations. It is intended to empower stakeholders to implement, enhance, or sustain various SDOH interventions using a person-centered approach that relies on data to inform policy and practice. As such, this playbook provides an overview of the current policies and programs influencing the delivery of social care services and offers practical suggestions for identifying, addressing, and monitoring unmet social needs in individuals and communities. This playbook strives to bridge the gap between current programs that address individual unmet HRSNs and broader SDOH programs capable of influencing deeper, less obvious conditions that perpetuate negative health outcomes.

As Leavitt Partners and CyncHealth, organizations that carry deep expertise in federal digital health policy and SDOH data collection workflows, respectively, we see two significant, interrelated barriers to the exchange and use of SDOH data. First, a lack of stakeholder understanding of key federal policies affecting the collection and exchange of such data. Second, a lack of understanding of core workflows of SDOH data collection and exchange. Accordingly, we have divided up this document into two distinct but interrelated sections.

In the first section, we provide an overview of significant federal policies that affect the collection and exchange of SDOH data, including the *Health Insurance Portability and Accountability Act of 1996* (HIPAA). From there, we explore two concepts that are fundamental to any regulatorily-compliant collection and exchange of such data: *consent* and *identity management.*

In the second section, we provide overviews of three key workflows and activities within SDOH data collection and exchange: SDOH screenings (or assessing and collecting data regarding SDOH), referrals to social services once social needs are identified, and planning for financial sustainability of SDOH workflows and processes.

Our aim is for readers to walk away from the first section with an understanding of high-level concepts that are critical to SDOH data collection and exchange, and to learn from the second section a handful of nuts-and-bolts workflows that build on the concepts in the first section.

This playbook has been designed to complement other resources already available (*e.g.*, the *U.S. Playbook to Address Social Determinants of Health* and the *Social Determinants of Health Information Exchange Toolkit*) by marrying an understanding of key concepts around SDOH data collection and exchange with exploration of SDOH data collection and exchange workflows and activities.[3,4]

While this playbook focuses on data collection and sharing as core components of an ecosystem that addresses SDOH and HRSN, it acknowledges that data is necessary but not sufficient for building such an ecosystem. Therefore, it touches on other necessary pieces, including engaging community partners and utilizing organizational-wide key performance indicators (KPIs) in order to get buy-in.

Audience

This playbook is a resource for those who need to design, implement, or manage cross-sector social care programs, as well as those strengthening their overall understanding of SDOH, such as:

- Community-based organizations (CBOs)
- Health care, human service, and social care providers
- Health care payors
- Federal, state, and local policymakers
- Standards development organizations
- HIT vendors and digital health companies

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[3] The White House. The U.S. Playbook to Address Social Determinants of Health. November 2023. Available at: https://www.whitehouse.gov/wp-content/uploads/2023/11/SDOH-Playbook-3.pdf.

[4] Office of the National Coordinator for Health Information Technology. Social Determinants of Health Information Exchange Toolkit. Foundational Elements for Communities. February 2023. Available at: https://www.healthit.gov/sites/default/files/2023-02/Social%20Determinants%20of%20Health%20Information%20Exchange%20Toolkit%202023_508.pdf.

## SECTION 1.0: CORE CONCEPTS FOR AN SDOH DATA STRATEGY

In order to build an ecosystem of SDOH data that is exchanged and used efficiently, it is critical that stakeholders—including the readers of this document—understand several concepts that, if not accounted for during planning of an SDOH data strategy, will inhibit the use and exchange of such data. To that end, we have provided overviews of three core concepts that stakeholders will need to understand in order to build and execute a SDOH data strategy.

First, we describe the two primary *federally regulated environments* of health data—entities governed by HIPAA, and those governed by the *FTC Act*. Each law governs different types of entities and carries with it different requirements for the use and exchange of health data, including SDOH data.

Second, we "zoom in" to the HIPAA framework and describe a concept that is core to legal compliance within the HIPAA regulatory environment: patient consent. We also describe some of the challenges of today's unstandardized landscape of consent workflows, and outline why it is critical to build in effective consent workflows in an SDOH data ecosystem.

Finally, we focus in on a concept on which any consent workflow hinges: patient identity, or verifying that the patient is who they say they are. We explore tools such as ID.me and CLEAR, which can be used to verify patient identity so that patients can access their health care data safely and securely.

While a full analysis of each of these sections is not feasible in such a brief document, our intent is to expose readers to each of the concepts necessary to developing an SDOH data collection and exchange strategy. We hope that readers will then further investigate those concepts that they are less familiar with.
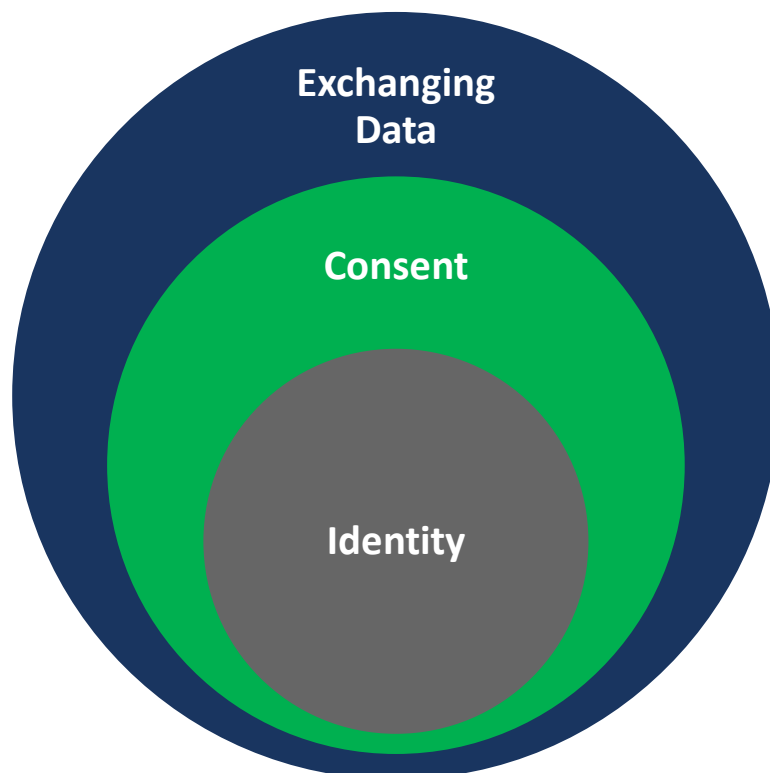
SECTION 1.1: EXCHANGING DATA BETWEEN REGULATED ENVIRONMENTS

Entities that collect and exchange health data, including SDOH data, are generally governed by one of two federal laws: the *Health Insurance Portability and Accountability Act of 1996* (HIPAA)*,* primarily promulgated through the HIPAA Privacy Rule, or the *Federal Trade Commission (FTC) Act.* In order to understand how each law affects the exchange and use of health data, it's important to understand who the laws apply to and what they require.

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule

The HIPAA Privacy Rule generally governs the use or exchange of *protected health information* (PHI) by "HIPAA-covered entities" or their "business associates." Information is generally considered PHI if it contains enough data points to identify an individual and is related to:

1. The health (physical or mental) of an individual.

2. The administration of health care to an individual.

3. The payment for the administration of health care to an individual.[5]

Under HIPAA, there are three types of covered entities: health care providers that electronically send claims information, health insurers, and health care clearinghouses (*i.e.,* businesses that manage transactions between plans and providers);[6] business associates of covered entities, which are generally defined as people that create, maintain, or transmit PHI on behalf of a covered entity; or a person who receives PHI while providing certain services (*e.g.*, actuarial or administrative) for a covered entity.

One of the main purposes of the HIPAA Privacy Rule is to ensure the privacy of PHI. To that end, the Privacy Rule generally mandates that a covered entity may only use or disclose (*i.e.*, send to another entity) PHI without patient consent for one of three purposes: treatment, billing, or health care operations. Disclosing PHI for *any other reason* requires the patient's consent, unless one of several exceptions applies, including disclosures required by other laws (*e.g.*, in cases of child abuse), made to law enforcement, or in cases of threats to health or safety.

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[5] Congressional Research Service. Protection of Health Information Under HIPAA and the FTC Act: A Comparison. July 28, 2022. Available at: https://crsreports.congress.gov/product/pdf/LSB/LSB10797.

[6] Ibid.

One of the unintended consequences of HIPAA has been the hindrance of health data exchange, as HIPAA-covered entities often err on the side of caution when determining whether disclosure of health data requires patient consent. However, HIPAA permits more sharing of PHI than many covered entities recognize. For example, HIPAA allows for a covered entity to share PHI with a patient's case manager at a domestic violence shelter as long as the case manager is part of the patient's care team.[7] Indeed, the HHS Office for Civil Rights (OCR) has explicitly confirmed that HIPAA permits covered entities to disclose PHI to social service organizations without patient authorization in cases where disclosure of PHI "are a necessary component of, or may help further, the individual's health or mental health care."[8]

For example, HIPAA allows a provider to disclose PHI describing a patient's mental health needs to a housing service agency in order to arrange mental health care supportive housing.[9]

In devising an SDOH data collection and exchange strategy, there are several things to keep in mind relative to HIPAA.

Key organizations in SDOH data workflows, such as social service organizations and community-based organizations (CBOs), often do not qualify as covered entities under HIPAA, nor are they considered business associates. Because of this, such organizations are often not required to comply with HIPAA (although there may be other privacy laws, such as state laws, with which they must comply).

Many such organizations, however, are understandably nervous when they begin receiving PHI from HIPAA-covered entities and believe they require a business associate agreement (BAA) with each HIPAA-covered entity from which they receive PHI. Such agreements present significant hurdles to the commencement of data sharing between covered entities and CBOs—particularly if they must be established for each CBO/social service organization that a single covered entity wants to disclose PHI to in the interest of addressing the SDOH of their patient population.

In cases where covered entities and/or CBOs believe that they ought to secure a BAA before disclosing or receiving PHI, one workaround to a formal BAA is for covered entities to require patients to consent to the release of their PHI to organizations such as CBOs. This, however, presents its own challenges as consenting workflows today are not yet standardized and can be challenging to implement.

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[7] Stewards of Change Institute. Modernizing Consent to Advance Health and Equity. Available at: https://stewardsofchange.org/wp-content/uploads/sites/2/2022/01/Button-1-19-22-SOCI-Consent-Scan-Report-Final-11-22-21.pdf?result=success.

[8] U.S. Department of Health & Human Services. Guidance Portal. FAQ 3008: Does HIPAA permit health care providers to share protected health information (PHI) about an individual with mental illness with a third party that is not a health care provider for continuity of care purposes? Available at: https://www.hhs.gov/guidance/document/faq-3008-does-hipaa-permit-health-care-providers-share-protected-health-information-phi.

[9] Ibid.

Ultimately, stakeholders in this space should consult with their legal counsel to best understand their status as a covered or non-covered entity and the degree to which a formal BAA or consenting workflows are required. Once their legal requirements are fully understood, they can determine how to most efficiently satisfy those requirements, such as through developing consenting workflows—as we will later explore.

Section 5 of the FTC Act

Many entities that collect health data aren't HIPAA-covered entities or business associates—these include CBOs and social service organizations but also smartphone apps that collect health data on behalf of the individual. While these entities and their data exchange activities aren't regulated by HIPAA, they *are* subject to Section 5 of the *FTC Act* (referred to as "the *FTC Act*" in this section) and its associated rules. This is because the individual who is receiving services or care is not a covered entity or business associate under HIPAA.

The *FTC Act* and its privacy and security rules apply to all for-profit entities, regardless of sector, that collect consumer data (including health data), unless they are covered by a superseding regulatory requirement. In contrast to HIPAA, the *FTC Act* doesn't impose specific data privacy standards on covered entities, such as obtaining consumer consent before disclosure. However, the Act does prohibit such entities from engaging in "unfair or deceptive acts or practices." This generally requires companies to adhere to any promises they make to consumers via their terms of service about how they will safeguard or disclose their data.

Entities that collect and store health information for consumer use that are not covered by HIPAA are subject to the FTC Health Breach Notification Rule. The Rule requires vendors of personal health records *and related entities* to alert consumers/users of a breach and follow similar remediation actions as HIPAA Covered Entities follow.[10]

For stakeholders in the SDOH space, there are a few key considerations to keep in mind regarding the *FTC Act.* First, whether health data falls under HIPAA or the *FTC Act* does not depend on the nature of the data—rather, it depends on the entity holding the data. Therefore, most health care organizations will likely not be subject to the Act's rules, as they are already covered under HIPAA. For CBOs and social service organizations that are not considered HIPAA-covered entities or business associates, they *will* be subject to *FTC Act* rules.

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[10] Federal Trade Commission. Health Breach Notification Rule. Available at: https://www.ftc.gov/legal-library/browse/rules/health-breach-notification-rule.

Second, for those CBO and social service organizations that are subject to the *FTC Act,* they are subject to the terms of service and agreements they have made with the individual as well as ensuring they avoid "unfair or deceptive acts or practices." Therefore, it is critical that those organizations ensure they keep the promises made to consumers about how they are handling consumer data.

Last, while the FTC Health Breach Notification Rule is generally narrow in construction, the expansion to include "related entities" that touch consumer data may include SDOH entities in some contexts. Therefore, SDOH entities should take care to ensure they have the capabilities to notify all affected consumers in the event of a data breach.

Addendum: A Call to Action to Establish Voluntary Best Practices

Many say the passage of a national privacy act (*e.g.*, the *American Data Privacy and Protection Act*—or ADPPA) would solve the problem of inconsistencies between apps' terms of service. While it's not the intent of this paper to discuss the pros or cons of proposed legislation, it's important to remember that even if the ADPPA does get signed into law, it would not solve the complexities of moving data between regulated environments. In order to help address this, consensus solutions are needed to help align organizations within regulated environments around agreed-upon best practices for collecting and safeguarding consumer data.

As one example of such a consensus solution, in 2018, more than 60 organizations developed the CARIN Alliance code of conduct, a voluntary set of principles and best practices for data holders who are accessing health related information in the FTC-regulated environment.[11] The code of conduct built upon the privacy and security standards required by HIPAA and included other best practices such as the General Data Protection Regulation (GDPR), *California Consumer Privacy Act* (CCPA), and other state laws. As a result, the VHA, CMS, and dozens of payers, providers, and applications (such as Apple Health and others) have adopted the CARIN Alliance code of conduct as the voluntary standard for protecting data in the FTC space.[12,13]

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[11] PR Newswire. Voluntary code of conduct developed by more than 60 industry stakeholders can help facilitate health data exchange with entities not covered by HIPAA. November 27, 2018. Available at: https://www.prnewswire.com/news-releases/voluntary-code-of-conduct-developed-by-more-than-60-industry-stakeholders-can-help-facilitate-health-data-exchange-with-entities-not-covered-by-hipaa-300755734.html.

[12] VA API Platform home page. Available at: https://developer.va.gov/production-access/request-prod-access.

[13] A full list of applications that have attested to the CARIN Alliance Code of Conduct is available here: https://www.myhealthapplication.com/.

In fact, CMS said in their Interoperability and Patient Access Final Rule (CMS-9115-F) that "payers can look to industry best practices, including the CARIN Alliance's Code of Conduct...for other provisions to include in their attestation request that best meet the needs of their patient population" and the FTC included comments made the CARIN Alliance in their final health breach notification rule.[14] The CARIN Alliance also has a voluntary CARIN code of conduct certification program administered by DirectTrust.

The Assistant Secretary for Technology Policy (ASTP), who is working with The Sequoia Project—the Recognized Coordinating Entity (RCE) in charge of implementing the Trusted Exchange Framework and Common Agreement (TEFCA) has referenced the CARIN Alliance code of conduct for individual access service (IAS) providers who are acting on behalf of individuals.[15,16] Those IAS providers fall under the FTC's regulatory jurisdiction and could include community-based organizations. Therefore, we now have a volunteer, trusted data exchange framework that is being used by ASTP, CMS, and the VHA within the FTC regulated environment.

As a result of this progress, rather than CBOs paying significant amounts of money to become HITRUST certified to comply with HIPAA privacy and security standards, CBOs can voluntarily attest to a set of best practices similar to the CARIN code of conduct.[17] In doing so, the data privacy, security, and consent of the individual's data will exceed the standards described in the HIPAA privacy and security rules and avoid the costly requirements associated with HITRUST certification.

We call upon stakeholders to consider developing and adopting a voluntary, agreed upon set of best practices like the CARIN Alliance code of conduct for entities, including CBOs, that are in the FTC regulated environment and acting on behalf of the individual.

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[14] U.S. Department of Health & Human Services. Federal Register Volume 85. May 1, 2020. Available at: https://www.govinfo.gov/content/pkg/FR-2020-05-01/pdf/2020-05050.pdf.

[15] U.S. Department of Health & Human Services. Federal Register Volume 89, May 30, 2024. Available at: https://www.govinfo.gov/content/pkg/FR-2024-05-30/pdf/2024-10855.pdf.

[16] ONC TEFCA Recognized Coordinating Entity. Standard Operating Procedure (SOP): Individual Access Service (IAS) Provider Requirements. Available at: https://rce.sequoiaproject.org/wp-content/uploads/2024/07/SOP-IAS-Provider-Requirements-v2_508.pdf.

[17] The California data exchange framework requires CBOs to follow HIPAA privacy and security guidelines, which often means they need to become HITRUST certified. California Health and Human Services. CalHHS Data Exchange Framework Policy and Procedure. Available at: https://www.cdii.ca.gov/wp-content/uploads/2023/11/CalHHS_Privacy-Standards-and-Security-Safeguards-PP_Final_11.15.23.pdf.

SECTION 1.2: MANAGING CONSENT

Overview

As explored above, consent workflows are often critical for HIPAA-covered entities and business associates to comply with HIPAA. A critical component of exchanging health information is informed, meaningful patient consent to the release of their data. This is especially true given the need to exchange information between entities regulated by different laws (*e.g.*, HIPAA and FTC Section 5 or the CCPA). With appropriate consent data sharing partners can more effectively share information between their regulated environments while ensuring consumer engagement, consumer preference, and security are maintained.

Clearly, consent workflows are often key to legal compliance. Yet implementing consent workflows in today's data exchange landscape is challenging for a number of reasons:

- Consent is often applied to an entire patient record, without allowing patients to specify which parts of their record they want to release for a certain purpose.
- Consent is often difficult for patients to track and assess what information they have and have not consented to disclose.
- A lack of trust and understanding relating to consent- and privacy-related rights.

Perhaps the biggest challenge of all is the lack of a national framework or standardized digital means to allow stakeholders to consent and track approval by patients to share their data within and across programs and systems. **This is a particularly thorny challenge for addressing SDOH, which inherently requires coordination across multiple types of organizations and domains in order to serve even a single patient.**

Recognizing this challenge, there are several initiatives underway intending to ameliorate this problem by developing national frameworks to streamline consent collection and tracking. Most recently, the Stewards of Change Institute developed a white paper, "Catalyzing Whole-Person Care: Consent-to-Share is the Key," which outlines a conceptual model for efficiently, routinely, and ethically obtaining and sharing consent to share data across service providers.[18]

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[18] Stewards of Change Institute. Catalyzing Whole-Person Care: Consent-to-Share is the Key. Available at: https://stewardsofchange.org/wp-content/uploads/sites/2/2024/09/SOCI_report.pdf.

If initiatives such as the Stewards of Change Institute's conceptual model are successful, there are a number of exciting benefits that a national framework for consent could offer stakeholders, including those in the SDOH space, including:

- Smoother and faster exchange of health and social data that could help health care providers, CBOs, and social service organizations better coordinate SDOH interventions for their clients and patients.
- Making it easier for individuals and their families, especially from disadvantaged populations and communities, to navigate the many programs and social services available to them.[19]

Although these initiatives are being developed, they will take time to finalize and will be very difficult to implement. In the meantime, there are several key considerations for stakeholders in the SDOH space to keep in mind when developing consent workflows:

"Informed consent" (described more fully below) is the gold standard for consent and should be pursued.

Until a national framework is developed, significant resources will need to be spent to collect and share consent across data systems. There is an opportunity to ensure individual consent across regulatory frameworks by adopting digital identity workflows that include informed, proactive consent user experiences.[20]

Successful identity management is necessary for consent—if organizations are not certain that patients are who they say they are, then consent is impossible. (We explore identity management more fully in the next section.)

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[19] Stewards of Change Institute. Modernizing Consent to Advance Health and Equity. November 2021. https://stewardsofchange.org/wp-content/uploads/sites/2/2022/01/Button-1-19-22-SOCI-Consent-Scan-Report-Final-11-22-21.pdf.

[20] The CARIN Alliance has developed a set of best practices for how to educate consumers on how their data is being used by applications, available at: https://carinuxguide.arcwebtech.com/.

Meaningful Consent

The CARIN Code of Conduct calls for "informed, proactive consent" from users prior to disclosing their data—in other words, *meaningful consent.* What is meaningful consent? The Consentful Tech Project defines meaningful consent for the use of data, or "good digital consent," as:

- Freely given: consent is given by the user (or patient) without pressure or manipulation.
- Reversible: the decision to consent is able to be changed at any time.
- Informed: consent is given after the user/patient receives clear and accurate information about the risks of sharing their data.
- Enthusiastic: the user/patient is consenting to share the data because they want to.
- Specific: the technology only uses data in certain ways to which the user/patient has consented to. [21]

Similarly, ONC has defined "meaningful consent" as:

- Made only after the patient has had enough time to read educational materials.
- Not conditional on receiving medical treatment.
- Revocable at any time.
- Consistent with patient expectations.[22]

ONC recommends the following strategies for achieving meaningful patient consent:

1) Patient education and engagement, including by giving patients information around:
   a. What parts of their medical information could be accessed or shared.
   b. Who can access the data they share.
   c. How their data is protected.
   d. Why their data is being shared.
   e. Choices they have to share or not share their data.[23]
2) Technology, including to capture and maintain consent decisions, identify sensitive data to restrict it from access, and communicate data restrictions electronically.[24]
3) Studying laws and policies that impact consenting requirements, including:
   a. HIPAA, which permits but does not require health care providers to obtain consent for HIPAA-covered purposes (*i.e.*, treatment, payment, and health care operations).
   b. Other federal and state privacy laws that *do* require health care providers to obtain patient consent before sharing data.[25]

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[21] The Consentful Tech Project. Homepage. Available at: https://www.consentfultech.io/.

[22] The Assistant Secretary for Technology Policy, Office of the National Coordinator for Health Information Technology. Meaningful Consent Overview. Available at: https://www.healthit.gov/topic/meaningful-consent-overview.

[23] The Assistant Secretary for Technology Policy, Office of the National Coordinator for Health Information Technology. Patient Education and Engagement. Available at: https://www.healthit.gov/topic/patient-education-and-engagement.

[24] The Assistant Secretary for Technology Policy, Office of the National Coordinator for Health Information Technology. Health Information Technology. Available at: https://www.healthit.gov/topic/health-information-technology.

[25] The Assistant Secretary for Technology Policy, Office of the National Coordinator for Health Information Technology. Health Information Privacy Law and Policy. Available at: https://www.healthit.gov/topic/health-information-privacy-law-and-policy.

SECTION 1.3: MANAGING IDENTITY

In information sharing, the concept of "identity proofing," or proving one's identity, is defined as "the process of providing sufficient information (*e.g.*, identity history, credentials, documents) to establish an identity."[26] This practice is crucial when handling health care information to ensure that patient health information does not fall into the wrong hands. In addition, as described above, it is a prerequisite for collecting patient consent.

Despite being integral to information sharing workflows in health care settings, patients and health care organizations often encounter the following issues while trying to prove identity:

- When patients schedule appointments, health care office staff must manually obtain demographic information from the patient. This process is often repeated when the patient shows up for their appointment.
- Patients may forget proof of ID or insurance cards.
- Office staff often manually copy information from IDs or insurance cards, which is inefficient and subject to errors.

These issues are likely compounded at CBOs, which may or may not have reliable identity-proofing workflows. In addition, because of the challenges described above with consent workflows, patients may need to provide proof of identity at each CBO they are referred to, making navigation of social services even more onerous.

One solution to this is for health care organizations and CBOs to move towards adopting *digital identity.* Generally, this involves tools and technologies that can provide solutions to the above issues, such as:

- A digital identity credential that patients can create through the smartphone app of their choice, allowing them to maintain a single credential for validating their identity across health care organizations.
- Patient applications that can populate digital intake forms prior to appointments.
- Patient applications that allow patients to schedule appointments themselves, without having to call provider offices.
- In person or remote phone-based identity proofing (often called a "trusted referee") for those who may not have government issued credentials or smart phones.[27]

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[26] Computer Security Resource Center. Identity Proofing. Available at: https://csrc.nist.gov/glossary/term/identity_proofing.

[27] National Institute of Standards and Technology. A.9: Use of Trusted Referees. Available at: https://pages.nist.gov/800-63-3-Implementation-Resources/63A/referees/.

The CARIN Alliance, in partnership with the Department of Health and Human Services, the Office of the National Coordinator for Health Information Technology (ONC), the Centers for Medicare and Medicaid Services (CMS), and 25 other public/private sector stakeholders, developed a health care digital identity federation Proof of Concept (PoC) illustrating how modern digital technologies, such as CLEAR or ID.me, can enable the health care system to move toward a more interoperable, equitable, privacy-centric, and secure federated digital identity ecosystem.[28]

The PoC report lays the foundation for how individuals can voluntarily digitally identity-proof themselves once and use that same digital credential with multiple data holders of their health information. Once implemented in production, the PoC's work eliminates the need to create separate "portal" accounts for data holders. Acceptance of such a credential by stakeholders in the SDOH space can reduce burden on patients—for example, as they are referred to various CBOs in their community.

In sum, there are several key considerations for stakeholders in the SDOH space regarding identity management:

- Having a robust identity management strategy is a prerequisite for obtaining consent, which is necessary for HIPAA-covered entities and business associates, but also important for CBOs.
- Embracing digital identity credentials as an option for patients can help smooth identity verification processes for them, which is particularly important as they may have to prove their identity at multiple locations if they are referred out to CBO and social service organizations.
- Moving towards innovative solutions that cut down on the amount of times that patients have to prove their identity, such as the CARIN Alliance PoC, will ultimately benefit patients and help ensure the safe, efficient exchange of data in both a health care and SDOH ecosystem.

SECTION 2.0: A CROSS-SECTOR SOCIAL CARE NETWORK

While the previous section outlined high-level concepts that are key to complying with federal regulations governing the collection, exchange, and use of health data, including SDOH, this section describe *the workflows through which* such data are collected and exchanged, as well as considerations for how to make an SDOH data ecosystem financially sustainable.

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[28] Leavitt Partners (an HMA Company) and CARIN. Healthcare Digital Identity Federation Proof of Concept Report. March 2023. Available at: https://cdn.prod.website-files.com/66635361bd8176cd6413cb12/66635361bd8176cd6413cb97_Proof-of-Concept_Final-Report.pdf

As a step to creating a seamless social care ecosystem and developing actionable data, we suggest adopting or enhancing the activities below for organizations within a social care network. Ideally, organizations would utilize the workflow to assess for HRSN, address an individual's needs, and use data to address SDOH and community gaps. Below is a review of three processes that empower organizations to interact effectively and efficiently in the network.

Work Process Overview

Assessment/Screening

- Identify screening needs/content
- Identify workflow preferences
- Implement and refine

Referral/Linkage

- Identify community partners
- Identify workflow opportunities
- Implement and refine

Sustainability Planning

- Identify unmet needs and opportunities through data
- Identify aligned initiatives/partners
- Identify funding sources

SECTION 2.1: ASSESSMENT/SCREENING

Brief screening tools are effective modes to identify SDOH needs within a population, particularly when paired with a workflow that links community resources through referrals. Most experts agree that the best workflow and screening tool is the one that fits the organizational approach and meets the individuals' needs.[29] The screening tool most appropriate for your organization might be an EHR-based tool, validated and established commercial assessment (*e.g.*, dictated by funding or grant requirements), or a brief custom screener. Selecting the best screening tool is often determined by cost, availability, and relevance to population needs (*e.g.*, language, delivery approach). Some common tools used in clinical settings to identify HRSN are identified below.

After identifying an appropriate screening tool, organizations benefit from cementing a process that ensures routine screening through clear accountabilities and workflows. Workflows should not be driven by technology—or lack thereof—but a standardized process that identifies needs and supports a routine referral process. Successful organizations often find the following elements helpful when designing their screening workflow.

Workflow Considerations

The location of the screening activity, functional needs, and desired outcomes likely impact the best screening approach for an organization. Based upon options for privacy, personal engagement, space, and technology available, organizations may choose any of the following options:

- Paper self-assessment
- Phone outreach and assessment
- In-person interview (*e.g.*, ED or PCP office)
- Patient portal or other application
- Community-based screening or community events

Available personnel and staff skill set are also important considerations for organizations. Individuals administering or compiling the results from screenings should have a clear understanding of roles in identifying and resolving social needs. Some organizations choose administrative staff, who collect other self-report documents, to gather documents completed before the visit or onsite independently by the patient. Other organizations may use social workers, community health workers, or similar disciplines to meet with higher risk individuals to complete a structured social and/or behavioral health assessment. For example, staff may inquire about HRSN within a visit and if a patient identifies needs move to engage social work for further exploration of need and linkage to services.

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[29] Yan A F, Chen Z, Wang Y, Campbell J A, Xue Q L, Williams M Y, Weinhardt L S, Egede L E. Effectiveness of Social Needs Screening and Interventions in Clinical Settings on Utilization, Cost, and Clinical Outcomes: A Systematic Review. Available at: https://pubmed.ncbi.nlm.nih.gov/35801145/.

Alternatively, staff with minimal training may use a social needs screening platform to prompt HRSN questions, and guide referrals to appropriate organizations for services-independently or with support of the staff. Ultimately, depending on the administration strategy and screening assessment sophistication, organizations may employ different workflows to support patients in connecting with social services as needed. However, when organizations use recommended screening guidelines for consistent assessment of HRSN, a cross sector social care network is successful at supporting individual needs, while gathering crucial data for assessing community gaps.

Another consideration of determining screening workflows is how and when the workflow can be automated. Standard tools sometimes take too much time to be used in a clinical encounter—in these cases, prompting the patient before the encounter to complete a screener is a more efficient way to collect the data. Such automation can then be leveraged to free up staff time from screening workflows and redirected to responding to findings of screenings. However, while automation can be beneficial, it is not always appropriate for all screening data—for example, it should generally not be used to collect information about personal safety or domestic violence. Such information should only be collected in person, when the patient is alone, and should be handled with an additional level of security (*e.g.*, not shown on the patient portal).

After selecting an appropriate screening tool and adopting a workflow, organizations likely benefit from piloting the process to identify gaps or barriers to a successful implementation. Often, a designated staff member overseeing the initiative can coordinate the pilot, as well as engage necessary stakeholders if problems arise. Some organizations find a rapid cycle improvement strategy helps guide the pilot.[30] When appropriate, organizations can extend the initiative to new sites or positions while assessing ongoing effectiveness.

Finally, ensuring an efficient and effective screening process requires organizations to document the designated workflow and update the process as needed. Formalizing the who, how, and what of the process supports the integration of the activity into other critical workflows.

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[30] Agency for Healthcare Research and Quality. Section 4: Ways To Approach the Quality Improvement Process. Available at: https://www.ahrq.gov/cahps/quality-improvement/improvement-guide/4-approach-qi-process/sect4part2.html.

Key Stakeholders	Tools Used
- Health Care Providers (providing screenings, sending referrals) - Social Care Organizations (providing screenings, receiving referrals, sending referrals) - Patients/Clients (participating in screenings, receiving services) - Vendors (providing screening tools)	- Protocol for Responding to & Assessing Patients' Assets, Risks & Experience (PRAPARE)[31] - Accountable Health Communities (AHC)[32] - Health Leads[33] - WellRx[34] - We Care[35] - Sync for Social Needs[36] - EveryONE Project[37] - Health Begins Upstream[38] - Your Current Life Situation[39]

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[31] Protocol for Responding to and Assessing Patients' Assets, Risks, and Experience. The PRAPARE Screening Tool. Available at: https://prapare.org/the-prapare-screening-tool/.

[32] Centers for Medicare & Medicaid Services. The Accountable Health Communities Health-Related Social Needs Screening Tool. Available at: https://innovation.cms.gov/files/worksheets/ahcm-screeningtool.pdf.

[33] Health Leads. The Health Leads Screening Toolkit. Available at: https://healthleadsusa.org/resources/the-health-leads-screening-toolkit/.

[34] WellRx Landing Page. Available at: https://www.wellrx.com/.

[35] Boston Medical Center. The WE CARE Model. Available at: https://www.bmc.org/pediatrics-primary-care/we-care/we-care-model.

[36] Confluence. Discovery Sprint – Industry Support for Capturing Assessments. Available at: https://confluence.hl7.org/display/S4SN/Discovery+Sprint+-+Industry+Support+for+Capturing+Assessments.

[37] AAFP. The EveryONE Project Toolkit. Available at: https://www.aafp.org/family-physician/patient-care/the-everyone-project/toolkit.html.

[38] AAMC. HealthBegins. Upstream Risks Screening Tool & Guide. Available at: https://www.aamc.org/system/files/c/2/442878-chahandout1.pdf.

[39] Kaiser Permanente. Systemic Review of Social Risk Screening Tools. Your Current Life Situation (YCLS). Available at: https://sdh-tools-review.kpwashingtonresearch.org/screening-tools/your-current-life-situation.

Summary

Technology and efficient workflows offer promise to reducing the burden of identifying HRSN in health care settings, but organizations must identify and adapt workflows for ongoing adoption and success. While variability exists in how social care screening occurs across organizations, using recommended tools facilitates effective referrals and offers promise for identifying future opportunities. While federal, state, and community efforts exist to standardize approaches, organizations benefit from understanding national directives and community needs to create a standardized approach initially.

Case Study

A large Federally Qualified Health Center located in the Midwest initiated screening for HRSN in Fall 2021. After identifying their screening needs and discussing with community referral sources, they trialed the following screening workflow:

- ✓ While checking in a patient at the front desk, patients (older than 19 years of age) are asked to complete the PRAPARE paper screening tool in the lobby.

  - o Medical and behavioral health providers may also screen patients with the PRAPARE tool on an ad-hoc basis.

- ✓ The completed PRAPARE form is sent to an employed SDOH coordinator, who reviews the domain scores while the patient is visiting the provider.

  - o The Coordinator has administrative responsibilities for data entry and management following a Standard Operating Procedure (SOP).

- ✓ The Coordinator alerts clinical staff, social work, or Community Health Workers (CHW) for urgent needs, and supports any community referrals using the Unite Nebraska Closed Loop Referral Platform.

- ✓ The Coordinator inputs the data into the EHR and when possible, he/she includes corresponding ICD-10 Z codes for positive screenings.

The facility identified the following "lessons learned" as opportunities critical to a sustainable screening program:

- Clearly defined roles and responsibilities are crucial to having a successful screening process. Using administrative staff is efficient and reduces multiple requests of the client, however, respecting administrative staff's other roles is critical to avoiding failure of responsibilities. A separate SDOH Coordinator is better prepared to enter data in a back office and alert care staff as needed to ensure follow-up.

- Collaboration with community organizations is key to ensure referral sources can respond adequately to needs identified within the population. Maintaining regular contact with referral sources ensures referrals are not sent in vain and avoids confusion and concern with patients.

- Time established for the SDOH Coordinator to aggregate data and review population needs and community gaps is critical to maintaining the program and assisting with grant and other funding approaches. Having a clear documentation protocol for administrative staff, social work, CHW, and providers was critical to ensuring data was available for these efforts.

SECTION 2.2: REFERRAL AND LINKAGE

After establishing an SDOH screening process that is reliable, sustainable, and scalable, organizations should expand the workflow to include referral management. Increased screening increases identified needs, leading to an influx of internal and external social needs in the population. Referral management (or case management) ensures an individual with identified needs is connected to an active, appropriate social service to address the unmet need. Effective referral management ensures an individual receives the service, the service meets the need (and there are no other needs), and the accepting and referring agency is clear about the status and outcome.

Successful organizations often partner early with key social service organizations. Partnerships with various organizations throughout a geographical area, with diverse hours and language offerings, are advantageous to most referring organizations. As building blocks to success, organizations often consider the following elements when designing their referral management process.

Workflow Considerations

Understanding your current referral process and level of effort for change is crucial to identifying a sustainable new process. Organizations without positions capable of supporting individual case management often rely on external sources to be available and collaborative with their patient needs. In these cases, partnering with larger or national entities that have processes in place to efficiently accept and manage referrals—without the referring organization—is helpful.

Unfortunately, some geographical locations lack adequate resources for certain social needs, and referral organizations must be mindful of funding or limiting factors before sending an individual to the site. Smaller community food banks, for example, may have limitations around how often individuals can receive a food disbursement or close when they lack donations. Therefore, the referring organization must use outreach strategies and track resource availability in order to meet the needs of its patients. In some instances, organizations may use manual processes to reach out to and track community services, but more sophisticated SDOH programs find online directories or partners, like 2-1-1, valuable to reduce staff time and patient frustration. Finally, as explored above, understanding when and how consent needs to be obtained from patients is critical—working with legal experts to understand what is required by state and federal law (*e.g.*, HIPAA) is crucial as referral workflows and infrastructure are finalized.

Ultimately, stakeholders understanding their infrastructure, community resources, and population needs before designing a referral workflow is critical to a successful implementation and overall outcomes.

Once identified, most organizations use one of three types of referral management strategies, including:

- Self-service referrals, which include distributing an updated list of organizations to a patient or family member who initiates contact independently using the provided information. The lists may include several categorical needs (*e.g.*, food banks, transportation companies, housing resources) or be directed at a specific need (*e.g.*, social support groups). Generally, the referral organization maintains and updates the list using key positions, such as care management staff or social workers.

- Case management facilitated referrals involving personal contact with a staff member and a patient expressing social needs. This strategy often requires the highest level of effort from the referring site. Specifically, the case manager meets with an individual to understand needs and preferences and supports the referral process to an appropriate organization external organization or internal resource. Often, after the receiving organization or staff accepts the patient, the case management ends, and documentation occurs using an existing process—usually in an EHR clinical note.

- Social Health Access Referral Platforms (SHARPs) involve the use of a technology platform to refer patients to community-based organizations for services to address health-related social needs. SHARPs can guide the referring person or patient using a series of questions about needs and preferences. SHARPs often assess and address multiple social needs simultaneously, creating an advantage for the individual receiving services and the referring organization. Many SHARPs facilitate the referral process by using a predetermined network of providers maintained by the SHARPs organization. SHARPs also offer standard consent and documentation practices and readily provide outcome data. While SHARPs offer efficiencies, they may be cost-prohibitive for some referral organizations.

Regardless of the approach, ensuring community resources exist to augment needs is a joint effort. Referring and sending organizations collaborating on policy and funding initiatives often reduce community resource gaps more effectively, benefiting the referring and receiving organizations. Specifically, aggregating data to share referral stories can compel policymakers and donors to invest in sustainable ecosystem interventions.

In addition, it is important to consider the role of organizations that serve as intermediaries between health systems and CBOs. Referred to as "backbone organizations" by the White House Playbook on SDOH, these entities can serve as single points-of-entry for individuals seeking help across a broad spectrum of services.[40] They are often invaluable to CBOs as well since they can centralize administrative functions and other operations—including payment operations, contractual arrangements, referral management, and IT—for a group of CBOs. At a high level, they serve as "connective tissue," joining organizations sending and receiving referrals.

Key Stakeholders	Tools Used
• Health Care Providers (creating referrals, receiving referrals, tracking referrals) • Public Health and Social Service Agencies (sending referrals, receiving referrals, tracking referrals) • Individuals (accepting referral services) • Vendors (providing technology) • Backbone Organizations (connecting CBOs and health systems)	• Unite Us • Find Help • Activate Care • 360X • Healthify/Wellsky

Summary

Providing a high value referral requires understanding a patient's social needs and connecting him/her with appropriate resources. When possible, educating an individual on expectations for the service and following up to ensure the need was met is helpful. Ongoing communication between community and referral organizations reduces future barriers by refining appropriate referral types and strategies, understanding availability, and supporting community resource development. As mentioned, successful data exchange can enhance joint requests of donors or policymakers.

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[40] The White House. The U.S. Playbook to Address Social Determinants of Health. November 2023. Available at: https://www.whitehouse.gov/wp-content/uploads/2023/11/SDOH-Playbook-3.pdf.

Case Study

A large, midwestern hospital which previously used self-service approaches to social service referrals transitioned to a SHARP. Their population frequently needed social services that exceeded resources available in the hospital. The SHARP was a national product that onboarded social service organizations of varied sizes and updated the resource directory regularly. The SHARP also had an integrated, nationally-recognized screening tool, allowing for multiple social needs to be identified and addressed in a single encounter. Their referral workflow involved:

- ✓ Consenting the individual using one of many methods to agree to sharing personal data that supports the referral.
  - o The SHARP offered consent management using in-person, phone, text, online, and attestation.
  - o The consent is currently translated into approximately 50 languages.
- ✓ Assessing the patient's social needs across 11 categories using a standardized assessment and reviewing the highest priority needs and preferences with the patient.
- ✓ Providing the referral information to both the suggested social service agency and the patient to empower the individual with choices. If desired, the patient can receive a call from the 2-1-1 Coordination Center.
  - o The Coordination Center can reduce the risk that health disparities interfere with a successful referral by exploring transportation needs, home and childcare demands, and other preferences in more depth.
- ✓ After the referral is complete, the update is reflected in the EHR and identified as resolved/closed in the SHARP.
- ✓ Data is reviewed quarterly by a social care team to ensure network adequacy and successful placements, as well as by the SHARP.

The hospital identified the following "lessons learned" as opportunities critical to a sustainable referral program:

- Clearly defined community partners and an updated, active resource directory are crucial to having a successful referral process. Providing referrals for services no longer available, reduces confidence in the system and lends to less disclosure of need in future circumstances.
- Reviewing the outcome of the referral is helpful to understand the impact on health outcomes. For example, a food bank referral that was not attended, likely has little impact on overall diabetic control, and changing medications without adequate knowledge may even be harmful to an individual's overall health.
- Evolving data standards will have a significant impact on ability to successfully use data for pilot and grant programming applications, as well as identifying needs and potential sustainability.

SECTION 2.3: SUSTAINABILITY PLANNING

Ensuring the sustainability of the personnel, tools, and services supporting an interoperable social care ecosystem is vital to an effective delivery system. Currently, organizations use multiple strategies to fund their SDOH activities and programs, including:

- Member fees
- Donations
- Grant funds
- Participant fees
- Reimbursement for services
- Alternative payment mechanisms (*e.g.*, Value-Based Care contracts, Medicaid waivers)

Unfortunately, many organizations focus on sustainability when future funding is questionable; however, a prospective approach to modeling available resources, community engagement, intervention effectiveness, and policy landscape is beneficial. Prospective modeling informs a current business plan while identifying action plans needed to replenish operational and emergency funds.

Workflow Considerations

Establishing Coalitions — Using Data — Leveraging Social Marketing — Influencing Policy

Successful approaches to sustainability often involve establishing community coalitions, using data to assess status, leveraging social marketing, and influencing local and national policy on SDOH. This strong base of support bolsters the case for ongoing action. The information below highlights key tasks in sustainability planning.

Organizational Buy-In

Building a lasting ecosystem for addressing SDOH requires an engaged, dedicated group of individuals throughout the organization. Specifically, it necessitates buy-in from leadership as well as individuals at the ground level, such as primary care providers.

Leadership buy-in sets the expectation for the rest of the organization that building an SDOH ecosystem is an organizational-wide priority. This can take several forms, including clear messaging that communicates that these initiatives are a key component of the organization's strategic roadmap, or clear, tangible, and achievable key performance indicators (KPIs), possibly tied to employee compensation, that measure progress in constructing the SDOH ecosystem. Such KPIs could include, for example, a decrease in avoidable ED use. Additionally, using stories of patients to illustrate the kinds of situations that they are living through—and critically, tying the improvement of those situations to the construction of the SDOH ecosystem—is help for achieving buy-in at the ground level. Regardless of how leadership signals its commitment to constructing an SDOH ecosystem to the rest of the organization, it is critical they do it in a way that galvanizes support and commitment from the rest of the organization.

Establishing Coalitions

Having a community-wide understanding of what it means to have sustainability for SDOH programming is vital to lasting partnerships. Coalitions should not only consider ongoing operational needs, but methods to expand and improve offerings. Creating and maintaining a shared vision and goals fosters trust, accountability, alignment in actions, and transparency. Organizations with experience in community convening suggest involving community members, community activists or trusted leaders, faith-based organizations, and other nonprofit partners in planning sessions. After introductory meetings to establish the coalition structure, identify governance processes, and cement the objectives, members should complete an action plan with assigned roles and responsibilities. An action plan assists members in assessing progress and communicating outcomes.

Using Data

Making a data-driven case for the impact of HRSN on health and health outcomes is one of the best methods to engage and retain funders, influence policy makers, and sustain community services. Specifically, data helps identify successes and improvement opportunities when successfully collected and interpreted over time. Ideally, organizations use data from different sources to gain insight into the delivery system and influence policy considerations. Potential sources of data include:

- Participant information (*e.g.*, demographics, health information)
- Satisfaction (*e.g.*, survey results, interviews)
- Program information (*e.g.*, service type, location)
- Service need (*e.g.*, housing, economic assistance)

Also, national data sources for benchmarking or creating a community outlook include:

- U.S. Department of Housing and Urban Development
- U.S. Census Bureau
- U.S. Department of Agriculture
- U.S. Department of Education
- U.S. Department of Transportation
- Community Health Needs Assessment
- Centers for Disease Control and Prevention (*e.g.*, PLACES)
- Office of Disease Prevention and Health Promotion (*e.g.*, Healthy People 2030)
- Centers for Medicare and Medicaid Services

Data is the foundation for targeted action. Establishing a baseline, benchmark, and stretch goals helps track progress, evaluate efficacy, and communicate success. As discussed above, while analyzing data yields key insights, data must be collected in a way that supports exchange and measurement—that is, standardizing data is essential for it to be useful.

Leveraging Social Marketing

Social marketing generates awareness and influences opinions pertinent to a stakeholder's coalition's goals. Understanding what motivates the audience is critical to an effective marketing strategy. As such, messaging may vary subtly to appeal to the audience. For example, providers may desire patients take prescribed medications more regularly, while patients may want medications that address health needs to be affordable. Communicating successful outcomes of an SDOH coalition that connects patients with needed services to keep them healthy may appeal to both audiences (*e.g.*, the coalition connected 70 percent of patients unable to afford medications with a prescription benefit program). Using a variety of methods to disseminate messaging and results gains public and policy support for key efforts.

Influencing Policy

Achieving sustainability requires a policy strategy that impacts the priority population in a way consistent with coalition goals. Favorable policy decisions are the most sustainable long-term approaches compared to other funding strategies (*e.g.*, VBC contract). Policy initiatives often impact more people and benefit broader populations by forcing programmatic or practice change to meet the policy demands. The widespread implementation generally has an accompanying revenue model, meaning the activity has longer-term financial sustainability. However, developing a policy strategy is a process and requires commitment across sectors. Within the base of support, a strong policy champion, respected in local or national organizations, helps generate visibility to the need and potential of the proposed solution. This base for support should use the data sources above and communicate outcomes in a persuasive manner through social marketing strategies. Successful campaigning can convince policy makers, funders, and communities of the value of the proposed SDOH activities.

Below are some examples of how current programs and policies support sustainability for the SDOH ecosystem.

- 1115 Medicaid waivers offer states the flexibility to address health-related social needs (HRSNs) and SDOH in Medicaid.[41]As of fall 2022, 18 states have approved Section 1115 waivers with SDOH-related provisions and eight states have pending SDOH requests. For some states, these waiver demonstrations covered under Medicaid include reimbursements for screening for SDOH.
- The Centers for Medicare and Medicaid Services Innovation Center (CMMI) Accountable Health Communities (AHC) model offers the opportunity to participate in a model with payment for screening and addressing SDOH.
- Closing the Gap with Social Determinants of Health Accelerator Plans is a CDC-funded opportunity that encourages addressing SDOH with a focus on closing care gaps.
- Data Across Sectors for Health offers resources and funding to promote work on sharing data across stakeholders in the SDOH space.
- The Accountable Care Organization Realizing Equity, Access, and Community Health (ACO REACH) Model focuses on the improvement of quality of care.[42] ACO REACH primarily targets Medicare beneficiaries via Federally Qualified Health Centers, Critical Access Hospitals, and Rural Health Centers. As of 2023, the model encourages collecting and reporting beneficiary demographic data that optionally includes SDOH data.
- The Medicare Advantage (MA) Value-based insurance design (VBID) Model gives participants the opportunity to improve health outcomes and address social needs through insurance benefits. These benefits allow for reimbursement of social services, such as transportation to grocery stores. Starting in 2024, participating MA plans will report SDOH data to CMS.
- In Lieu of Services and Settings (ILOS) was finalized in the 2016 Medicaid and CHIP managed care rule[43] and is defined as the practice of directly reimbursing for services or settings that deviate from those explicitly covered in state Medicaid programs. Services provided under ILOS can address health-related social needs, such as food insecurity and housing instability.
- Medicare's Inpatient Prospective Payment System (IPPS) compensates hospitals that provide inpatient services covered under Medicare Part A based on prospectively set rates. Reporting SDOH screening measures were required in 2024 on five domains: food insecurity, housing instability, transportation needs, utility difficulties, and interpersonal safety.

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[41] Centers for Medicare & Medicaid Services. Accountable Health Communities Model. Available at: https://innovation.cms.gov/innovation-models/ahcm.

[42] Centers for Medicare & Medicaid Services. ACO REACH. Available at: https://innovation.cms.gov/innovation-models/aco-reach.

[43] Medicaid. In Lieu of Services and Settings. Available at: https://www.medicaid.gov/medicaid/managed-care/guidance/lieu-of-services-and-settings/index.html.

Key Stakeholders

- Health Care Providers (creating referrals, receiving referrals, tracking referrals)
- Individuals (accepting referral services)
- Vendors (providing technology)
- Governing agencies (receiving insights)

Summary

Building the infrastructure necessary to create an interoperable ecosystem is a long-term investment, often without the benefit of an immediately identified funding source. Nonetheless, identifying incremental, sustainable funding strategies applicable across the ecosystem is essential to fundamentally improving individual and community health. Current grant-funding opportunities may allow for eligible entities to develop short-term interventions that advance social care services; however, long-term sustainability necessitates innovative financing to support and sustain an SDOH ecosystem which allows entities from across sectors to share information, provide services, and monitor and track outcomes. While many funding opportunities are available, it is vital that more sustainable, diversified financing mechanisms are made available which allow for blending of investments in health care, health technology, public health, and social care.

CONCLUSION

This Playbook has sought to accomplish two goals. First, to provide education around high-level concepts that are critical to SDOH data collection and exchange, second, to provide details of some key workflows within such data collection and exchange. It is our hope that this document will serve as a guide to all organizations that can play a part in SDOH data collection and exchange—including health care providers, CBOs, and HIEs. Additionally, we hope that this will serve as a resource to policymakers and others that are working to make SDOH data collection and exchange a simpler endeavor by demonstrating areas in the current paradigm that would benefit from action—for example, the lack of voluntary best practices for entities in the FTC regulated environment. CyncHealth and Leavitt Partners hope to continue to push stakeholders in the SDOH space forward and make SDOH data collection and exchange simpler, faster, more efficient, and more effective for all those involved, particularly patients.

APPENDIX

SDOH Data – Categories and Standardization Efforts

Data on SDOH helps improve health system and community interactions and focuses efforts to improve health at a population level. Advancing data standards is critical to effective SDOH programming. Standardized data elements are those consistent across sites and between formats. Currently, SDOH are classified according to several categories and can be further subdivided into data elements as shown below.

SDOH Category	Data Elements[44]
Physical Infrastructure	- Housing - Transportation - Migration - Internet connectivity - Environment - Industry composition - Social services - Food access - Access to personal wellness - Neighborhood infrastructure and walkability - Crime - Water and air quality
Health Care Context	- Health insurance status - Characteristics of available health care providers - Characteristics of available health care facilities - Distance to health care providers - Health care utilization and out-of-pocket costs

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[44] U.S. Department of Health and Human Services. Office of Disease Prevention and Health Promotion. Healthy People 2030. Social Determinants of Health. Available at: https://health.gov/healthypeople/priority-areas/social-determinants-health.

SDOH Category	Data Elements[44]
Social and Community Context	• Demographics • Living conditions • Immigration status • Socioeconomic disadvantage indices • Redlining • Community values and priorities • Places of worship/religion • Community centers
Economic Context	• Income • Employment • Poverty • Wage discrimination • Minimum wage standards • Inequity
Education	• Attainment • School system • Educational funding • Literacy • Numeracy • Career growth and trajectory

Unfortunately, there are few widely adopted standardized methods for organizing and sharing SDOH information. Instead, organizations have adopted a wide array of data collection methods that work for each organization individually but limit the ability for data to be communicated across organizations and technologies. SDOH data, like other health care data, must be captured in a consistent and structured way for it to be effectively used for clinical and policy improvement, as well as for Medicaid reimbursement.

The following is a list of current initiatives focused on SDOH data standardization.

- **The Gravity Project**[45] was launched in 2019 to create and study data standards to support the exchange of SDOH data across stakeholders using the Fast Health care Interoperability Resources (FHIR) standard. The initiative is focused on assessment and diagnosis, interventions, and goals of the treatment or intervention. The FHIR SDOH Clinical Care Implementation Guide outlines several use cases, including collecting SDOH data during care encounters and referring patients to partner organizations through electronic workflows.

- In April 2023, the **Gravity Project Pilots Affinity Group**[46] announced four new pilots in collaboration with Civitas Networks for Health with funding from the Robert Wood Johnson Foundation to explore previously developed standards in the real world. The pilots highlighted the challenges of exchanging social needs data.

- The **United States Core Data for Interoperability (USCDI)**[47]is a standardized data set that contains different data elements designed to exchange data between stakeholders in the health care space. USCDI is updated through versions, where stakeholders consider comments and proposed data elements. In recent years, SDOH data elements have been added, including sexual orientation, gender identity, and SDOH goals.

- **ICD-10-CM SDOH Z Codes** create a standard way for organizations to document SDOH data, including problems related to education, employment, housing, and family circumstances.[48] While adoption has been slow—a CMS report found that only 1.59 percent of Medicare fee-for-service claims in 2019 had Z codes[49]it offers opportunities for stakeholders to better identify and understand the social needs of the populations they serve, and potentially methods for identifying the value of meeting SDOH needs.

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[45] HL7 International. SDOH Clinical Care. Available at: https://build.fhir.org/ig/HL7/fhir-sdoh-clinicalcare/.

[46] Ibid.

[47] The Office of the National Coordinator for Health Information Technology. Cures Act Final Rule: United States Core Data for Interoperability. Available at: https://www.healthit.gov/sites/default/files/page2/2020-03/USCDI.pdf.

[48] Ibid.

[49] Centers for Medicare & Medicaid Services. Utilization of Z Codes for Social Determinants of Health among Medicare Fee-for-Service Beneficiaries. Available at: https://www.cms.gov/files/document/z-codes-data-highlight.pdf.

- **360X** is an **Office of the National Coordinator for Health Information Technology (ONC)** initiative dedicated to advancing data standardization and transparency in health care.[50] One of their recent projects was developing a series of SDOH referral workflows that involve EHRs, with the primary goal to make adoption of the workflows easy by utilizing commonly adopted technologies.[51]

- The **Sync for Social Needs Initiative** supports the mission to expand interoperability of SDOH data through the adoption of the health care data standard Fast Health care Interoperability Resources (FHIR)[52] and research into how screening for food insecurity can be improved.[16] FHIR is a data standard separated into different categories of data resources that enables the transfer of health care information over different systems. Sync for Social Needs conducted research with various stakeholders using the AHC questionnaire for screenings and FHIR to explore the feasibility of more standardization in screening workflows. Through interviews, it was determined that the FHIR Observation resource[53] was preferred over the FHIR Questionnaire Response resource,[54] prompting a change to the January 2023 U.S. Core ballot to offer guidance on how third-party applications can access SDOH data. In February 2023, it was announced that the National Quality Forum, Joint Commission, and the National Committee for Quality Assurance joined the Sync for Social Needs initiative to offer support in FHIR-based SDOH data collection.

The recent proliferation of these programs and groups signals an interest in successful SDOH data collection and exchange, as well as possibly an increase in government-supported standardization of SDOH data collection techniques. The standardization could ease the burden of organizations focused on SDOH and facilitate processes for screening and referring patients with HRSN. Ideally, data obtained through a standardized workflow would inform clinical decisions and equitable resource allocations, creating a feedback loop to identify and resolve gaps in care.

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[50] Ibid.

[51] Office of the National Coordinator for Health Information Technology. 360X and Social Determinants of Health (SDOH) Referrals. Available at: https://oncprojecttracking.healthit.gov/wiki/display/TechLab360X/360X+and+Social+Determinants+of+Health+%28SDoH%29+Referrals.

[52] Confluence. Discovery Sprint – Industry Support for Capturing Assessments. Available at: https://confluence.hl7.org/display/S4SN/Discovery+Sprint+-+Industry+Support+for+Capturing+Assessments.

[53] HL7 International. Resource Observation – Content. Available at: https://www.hl7.org/fhir/observation.html.

[54] HL7 International. Questionnaire Response. Available at: https://hl7.org/fhir/questionnaireresponse.html.

Workforce and Training Development

With the advancement of technology and the push to capture SDOH data, there is a need to implement and continue training and education on social care programming. An educated workforce ensures that individuals receive screening and referrals as needed, and communities have data available to build a business case for sustainability. CMS and other federal agencies have provided guidance and training resources to address SDOH.

Further, positions, such as Community Health Workers, extend the social service ecosystem into communities. The State Community Health Workers Map[55] was developed by The National Academy for State Health Policy to highlight funding sources to assist in integrating CHWs into individuals' care. The map indicates whether funding is provided through Medicaid reimbursements and where a Managed Care Plan or state entity will reimburse for the services if Medicaid does not.

Quality Measures with a Social Care Focus

There are many initiatives dedicated to creating standards and resources for measuring quality in the SDOH space, including:

- In the 2023 National Quality Strategy[56] initiative, CMS set a target to embed a Universal Foundation of equity into the measurement strategy of every CMS quality and value-based program to reward high-quality care by 2026. The Universal Foundation[57] will focus on identifying disparities, developing "interoperable, digital quality measures," and identifying measurement gaps. The areas to be highlighted include maternal and mental health and equity.
- The Merit-Based Incentive Payment System (MIPS)[58] in 2023 added a measure on "Screening for Social Drivers in Health," which measures the percentage of patients over the age of eighteen who were screened for food insecurity, housing instability, transportation problems, utility help needs, and interpersonal safety. This reporting ties into the program's goal of promoting high-quality patient care[59] through advancing health equity.

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[55] National Academy for State Health Policy. State Community Health Worker Policies. Available at: https://nashp.org/state-community-health-worker-models/.

[56] Centers for Medicare & Medicaid Services. CMS National Quality Strategy. Available at: https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/CMS-Quality-Strategy.

[57] Centers for Medicare & Medicaid Services. Aligning Quality Measures Across CMS – the Universal Foundation. Available at: https://www.cms.gov/aligning-quality-measures-across-cms-universal-foundation.

[58] American Medical Association. Quality ID #487: Screening for Social Drivers of Health. Available at: https://qpp.cms.gov/docs/QPP_quality_measure_specifications/CQM-Measures/2023_Measure_487_MIPSCQM.pdf.

[59] Centers for Medicare & Medicaid Services. 2023 Annual Call for Quality Measures Fact Sheet. Available at: https://mmshub.cms.gov/sites/default/files/2022-Annual-Call-for-Quality-Measures-Fact-Sheet-508.pdf.

- A new Health care Effectiveness Data and Information Set (HEDIS)[60] measure was announced for 2023, titled the Social Need Screening and Intervention (SNS)[61] measure. The measures will screen for unmet social needs related to food, housing, and transportation. The measures conform to the Gravity Project's data elements, which promotes data interoperability of the quality measure through ease of data transfer.

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[60] National Committee for Quality Assurance. HEDIS and Performance Measurement. Available at: https://www.ncqa.org/hedis/.

[61] National Committee for Quality Assurance. Social Need: New HEDIS Measure Uses Electronic Data to Look at Screening, Intervention. Available at: https://www.ncqa.org/blog/social-need-new-hedis-measure-uses-electronic-data-to-look-at-screening-intervention/.

ABOUT THE AUTHORS

CyncHealth[62] is a progressive health data utility committed to developing healthier communities by driving the advancement of interoperability (*i.e.*, the easy exchange of data across stakeholders) and leveraging public-private partnerships to ensure that equity and data governance remains at the forefront. Their vision is a frictionless data experience for providers, policymakers, public health, individuals, payers, and other community stakeholders to enable ready access to the right data at the right time to the right stakeholder.

Leavitt Partners,[63] an HMA company, is a leading health care consulting firm that has consistently been at the forefront of navigating and advancing change in health care, including in digital health. Leavitt Partners achieves this through convening multisector alliances to address some of the most complex issues in health care; these groups include the CARIN Alliance, which since 2016 has worked to advance interoperability in health data.

CyncHealth and Leavitt Partners are joining together to address a glaring need: a lack of guidance for stakeholders seeking to address social determinants of health in today's digital health landscape. For both nascent stakeholders and more savvy practitioners, there are minimal resources to highlight best practices, regulatory requirements, funding opportunities, and lessons learned in this space, and Leavitt Partners has created this playbook to fill this knowledge gap. It is their goal for this document to collect and disseminate knowledge and tools to support partner organizations addressing social determinants of health.

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[62] CycnHealth Landing Page. Available at: https://cynchealth.org/.

[63] Leavitt Partners Landing Page. Available at: https://leavittpartners.com/.