Developing, Advancing and Harmonizing Social Determinants of Health Standards

GAP ANALYSIS REPORT

August 2021
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Executive Summary

Purpose

The purpose is to examine the gaps in technology, financing, education, information protection, reference directories, policy, and governance that impact the ability to effectively exchange Social Determinants of Health (SDOH) information between and among the various participants in the delivery of the health and social services to affected individuals and their families.

Approach

A set of key stakeholder groups were identified and selected to participate in interviews. This included providers, payers, community-based organizations, and technology vendors such as electronic health record (EHR) systems, health information exchange (HIE) organizations, and community-based referral platforms. Members of the team developing this gap analysis are also participants of the Gravity Project, a national industry collaborative, focused on building consensus-driven data standards to support the use and exchange of SDOH data within and among health care and other sectors. Finally, a literature review was conducted to better understand the current state of the ecosystem related to interoperability and use of SDOH data. This included but was not limited to peer-review articles, presentations, national reports, as well as news articles.

Results

Based on these interviews and the information from the literature review the following gaps were identified:

1) Insufficient funding and financial incentives to support broad adoption of technologies
2) Lack of funding methods to support the increase in referrals to community-based organizations
3) A need for a sustainable, trustworthy source of resource directory information to support the delivery of social and healthcare services
4) Ability to implement closed-loop referrals for clinical and social service providers
5) The need to develop and adopt standards to represent SDOH information and to facilitate electronic exchange of this information
6) Addressing the confidentiality, security, and consent to share information
7) Recognizing and addressing the potential for misuse of SDOH information
8) Providing for appropriate governance structures to appropriately manage the equitable delivery of health and social care services
Introduction

Over the past year and a half, national initiatives have been centered around the COVID-19 pandemic, hoping to understand this deadly virus and curtail its devastating effects. This pandemic has highlighted the severity and entrenchment of health inequities faced by people of racial and ethnic minority groups, particularly Black Americans, who are more at risk of getting sick and dying from COVID-19. Without question, social and racial injustice is a public health crisis.

While these harmful injustices have existed for centuries, it has become a priority from a clinical perspective to identify social risks and needs of the most vulnerable populations to better understand their impact and effectively target interventions. It is important to note that the term “social risk factors” refers to specific adverse social conditions that are associated with poor health, like social isolation or housing instability. The term “social determinants of health” (SDOH) reflects the conditions in the places where people live, learn, work and play that affect a wide range of health and quality of life risks and outcomes. This report will use SDOH to reflect both individual and population health-related social needs, risks and problems, though the ongoing national dialogue regarding the appropriateness of this terminology is acknowledged.

As described in the Notice of Funding Opportunity, the Office of the National Coordinator for Health IT (ONC) partnered with Health Level 7 (HL7) to prioritize and expedite the accelerated development and deployment of five gap and opportunity areas identified by ONC to advance the diagnoses, treatment, and care of patients of COVID-19 and other public health emergencies:

1) Expanding the clinical domains supported by HL7® Standards
2) Privacy, Security, and Consent
3) Application Programming Interface (API) for Population Level Services
4) Social Determinants of Health (SDOH) Standards
5) Advancing Public Health Standards

This analysis focuses on the fourth area of SDOH standards. Now, more than ever, capturing and integrating information related to social needs, risks, goals, and interventions holds promise for providers across the continuum of health and human services to support individuals and populations most disproportionately impacted by the COVID-19 pandemic.

The SDOH analysis conducted in this report begins with an evaluation of the current technology solutions in the market. The current market is evolving, as many vendors compete for users among health care...
systems, community-based organizations, government agencies and related institutions. These software solutions offer a range of common functionalities to support care coordination, yet they are often not compatible with each other. The promise of interoperability is to ensure that stakeholders can seamlessly communicate among different software systems – such that coordination of care and evaluation of activities can be conducted across institutional and technological boundaries. Additionally, through the establishment of interoperability standards, researchers, policymakers, government administrators, community leaders and funding organizations can aggregate and analyze data across sectors to better monitor trends across communities and populations and gain insights which may have never been possible before. The advancement and harmonization of terminology and data exchange standards is a foundational and necessary process in the effort to promote holistic, coordinated care that best meets the needs of individuals and communities.
Approach

A literature review was conducted to better understand the current state of the ecosystem related to interoperability and use of SDOH data. This included but was not limited to peer-review articles, presentations, national reports, as well as news articles. Throughout this gap analysis, citations, and references to relevant sources of information will be included to help provide additional context and information related to the challenges and barriers cited by interviewees. In addition, members of the team developing this gap analysis are also participants of the Gravity Project, a national industry collaborative, focused on building consensus-driven data standards to support the use and exchange of SDOH data within and among health care and other sectors.

A set of key stakeholder groups were identified and selected to participate in interviews. This included providers, payers, community-based organizations, and technology vendors such as electronic health records (EHR) systems, health information exchange (HIE) organizations, and community-based referral platforms. The individuals and organizations identified were selected intentionally because of their current operational experience in identifying and addressing SDOH related issues. It is also important to acknowledge, due to capacity and timing of this project, government service providers were not interviewed but also play a key role in addressing and supporting individuals with SDOH related issues. The interviews served a dual purpose: a) understand current gaps to achieving SDOH data interoperability and b) understand what interviewees would like to see from policymakers to improve interoperability and use of SDOH data to support the individuals they serve, their organization's priorities, and improve population health overall.

From April to June 2021, 57 individuals representing 18 organizations were interviewed using one hour video conference calls.

Table 1: Interviewee Breakout

<table>
<thead>
<tr>
<th>Stakeholder Type</th>
<th># of Organizations</th>
<th># of Participants</th>
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<td>11</td>
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<tr>
<td>Providers</td>
<td>2</td>
<td>8</td>
</tr>
</tbody>
</table>

In some instances, interviewees provided follow up information, resources or information from other colleagues that were reviewed and synthesized into the findings of this report. The interviewees were asked to provide their thoughts and feedback about the following areas:
Analysis of Gaps and Challenges

Significant progress has been demonstrated over the last few years in the collection, aggregation, and exchange of SDOH information to support value-based care and delivery system transformation efforts. However, consistent themes emerged from all stakeholder groups related to current challenges, obstacles, and most salient risks for advancing SDOH data interoperability and exchange. The following encompasses a description and analysis of these themes:

1) Lack of financial support and incentives.

Most interviewees brought up financial constraints as a major obstacle to SDOH interoperability and data exchange. Several interviewees used the Meaningful Use Program as an example to illustrate issues where providers are not given incentives to adopt technology. For example, long-term and post-acute care providers did not meet eligibility criteria for participation in the Meaningful Use Program and, as a consequence, significantly lagged in technology adoption. Similarly, interviewees viewed the cost of adopting technology and information exchange services as a significant barrier to the integration of social risk and needs data. Many interviewees, across both health and social services sectors, advocated that community-based organizations should receive financial support for technology adoption and information exchange services. In addition, funding is needed for supportive services such as training, technical assistance, staff augmentation, and stakeholder engagement that health care has often benefited from to support new models of care and health IT adoption. Moreover, interviewees representing community-based organizations or coalitions thereof also cited that underlying incentives and financing structures for participation in referral partnerships with health care systems may not be appropriate and commensurate with the scale of the challenge. In addition to interoperability standards and incentives for technology adoption, social care sectors will need deliberate institutional arrangements to ensure that partnerships with health care systems are equitable and do not create new administrative burdens or new barriers to social care. Finally, most of the interview participants recognized the need to provide additional financial assistance to community organizations that are providing specific social services (e.g., food). This will allow them to support the increased referral volumes without sacrificing quality and/or the ability to provide services to individuals that do not have specific funding (e.g., insurance coverage).

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5 https://www.healthit.gov/topics/meaningful-use-and-macra/meaningful-use
2) **Fragmented and redundant silos of resource directory information.**

The availability of reliable information about accessible services is a critical element in efforts to enhance social care coordination, yet stakeholders often struggle with a proliferation of incompatible, unreliable, or otherwise unusable sources of this information. In many areas, 2-1-1s are considered the most validated source of community-based organization directory information. This is not consistent across the country since 2-1-1 is a decentralized system provided by various kinds of organizations with varying technologies and only some 2-1-1s have made their resource data available as a machine-readable web service. The emergence of web-based resource referral platforms has only increased the challenge of resource data maintenance. Social service providers are commonly asked to update their information in multiple directories, yet many lack strong incentives to comply with these requests. The proliferation of competing sources of information makes it harder for any one source to be considered reliable. Throughout the interviews, the majority of participants cited this as a barrier to SDOH interoperability and exchange, especially as referral is a priority use case among nearly every interviewed organization. In 2018, it should be noted that the Alliance of Information and Referral Systems (AIRS) recognized Open Referral’s Human Service Data Specifications (HSDS) and application programming interface (API) protocols as “an open-source data exchange format (a technical specification on the fields and structure of a resource database record)...and is the most widely accepted structure that allows for the interoperability of resource databases, and for data to import/export through APIs.” About half of the interviewees stated that they are using HSDS for resource directory exchange, however there is more work needed to ensure the standard is recognized by an accredited standards development organization. Despite this progress toward interoperability, more research and development are needed to establish sustainable business models through which reliable resource data can be effectively provisioned as an infrastructural public good.

3) **Need for closed loop referral standards.**

As mentioned above, most interviewees identified sending, receiving, and exchanging data regarding referrals as a priority for their organization. Interviewees familiar with existing closed loop referral standards such as the Integrating Healthcare Enterprise (IHE) 360x Profile and the Gravity SDOH Clinical Care Fast Healthcare Interoperability Resources (FHIR) Implementation Guide (IG), acknowledged the challenge of using these clinically oriented standards to bound social service referrals. A number of interviews cited the challenge with using clinically oriented standards to support referrals across health care and social service organizations that related primarily to the perception that clinical referrals were more discreetly bounded than social services referrals. In addition, many interviewees cited the need for more real-world implementation and maturation of standards to support electronic closed loop referrals. Along with the development and maturation of standards, multiple interviewees indicated more support is needed to align proprietary methods of data exchange currently being deployed across various software solutions.

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8 http://build.fhir.org/ig/HL7/fhir-sdoh-clinicalcare/
4) **Proliferation of diverse screening and assessment tools to identify social risk.**

There is a vast number of screening and assessment tools, such as PRAPARE, the CMS Accountable Health Community tool, and the Health Leads Screening Tool, being used across the country to help drive individuals to appropriate social services. While the Gravity Project is working to develop standards for the terminology used among these tools, interviewees believe there will continue to be a proliferation of tools used and did not anticipate this changing in the near term. Some believe that it would be nearly impossible to standardize screening and assessment across all contexts, especially as the tools and processes to identify social needs may be dynamic and highly context dependent. Furthermore, some interviewees representing community-based organizations indicated that structured screening is not always an appropriate method to identify an individual’s needs in the context of social care, as they can undermine efforts to build trust, and might even yield unreliable data. This presents a significant challenge to the interoperability of screening and assessment information across sectors.

5) **Lack of widespread adoption of FHIR API standards to support SDOH interoperability.**

Most interviewed organizations indicated that they were implementing or planning to implement FHIR based APIs. However, many interviewees representing health information exchange organizations that aggregate data from providers across the ecosystem cited that data exchange related to SDOH is currently occurring primarily through the Consolidated Clinical Document Architecture (C-CDA) standard (e.g., for exchange between providers and HIEs) or via other standards (e.g., IHE, HL7 V2, Direct and custom interfaces). All interviewees saw value in mapping to FHIR® resources. However, another challenge some cited is in relation to keeping up with the FHIR standard itself as some vendors are still on earlier releases (e.g., DSTU 2 or STU 3) and may require mapping when moving to R4. Since ONC and CMS are mandating FHIR R4 in regulation, this issue can be considered temporal but worth noting.

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10 [https://www.healthit.gov/topic/standards-technology/consolidated-cda-overview](https://www.healthit.gov/topic/standards-technology/consolidated-cda-overview)
6) Limited understanding policies for sharing data among HIPAA and non-HIPAA entities.

Another consistent theme raised by interviewees was the lack of clear understanding between health and social service sectors for data sharing under current policy and regulation. To begin, many social service providers may not be as familiar with HIPAA\(^\text{13}\) and therefore time is needed to learn and understand what requirements must be adhered to once they enter into Business Associate Agreements. Additionally, interviewees cited limitations with interpretation of current rules. For example, while CMS has issued guidance which allows for the exchange of minimum data necessary for referrals with non-covered entities, the current interpretation of this guidance does not allow for health care and social service providers to have a more robust ongoing dialogue about the intervention that the individual received.\(^\text{14}\) Lastly, there are other policies, such as 42 CFR Part 2\(^\text{15}\), Family Educational Rights and Privacy Act (FERPA)\(^\text{16}\), state privacy laws, and others that govern information exchange across SDOH domains which need further analysis and alignment. Collectively, providers and organizations interviewed want to ensure they are meeting the requirements of regulations and policies to support protection of an individual’s privacy and securely share data.

7) Variation in consent management leads to implementation delays and obstacles.

In addition to a lack of clear understanding of and alignment among policies, many interviewees cited the current variation in consent procedures and management across health and social service providers as an additional obstacle to SDOH interoperability. While consent models vary, they typically fall into two general categories of opt-in and opt-out. Per ONC definition, *meaningful consent* is when the patient makes an informed decision and the choice is properly recorded and maintained.\(^\text{17}\) One issue that interviewees cited is that community-based organizations often lack established protocols for ascertaining consent to share data, especially as a non-HIPAA covered entity. Also, interviewees indicated that organizations’ technology systems may have not broadly embedded this type of functionality into their tools and workflow. Interviewees articulated concerns that access to services may in some contexts become contingent upon

\(^{13}\)https://www.hhs.gov/hipaa/index.html
\(^{15}\)https://www.samhsa.gov/about-us/who-we-are/laws-regulations/confidentiality-regulations-faqs
\(^{16}\)https://www2.ed.gov/policy/gen/guid/fpco/ferpa/index.html
\(^{17}\)Per ONC definition, a meaningful consent decision has six aspects: a) made only after the patient has had sufficient time to review educational material, b) commensurate with circumstances for why health information is exchanged (i.e., the further the information-sharing strays from a reasonable patient expectation, the more time and education is required for the patient before he or she makes a decision), c) not used for discriminatory purposes or as condition for receiving medical treatment, d) commensurate with circumstances for why individually identifiable health information is exchanged, e) consistent with patient expectations, and f) revocable at any time. Link: https://www.healthit.gov/topic/meaningful-consent-overview
an individual’s consent to have their data collected and shared – which may result in inequitable outcomes of various kinds. These issues are anticipated to only become greater as interoperability of SDOH data becomes more widespread and there is no concerted effort to create national policy regarding privacy, security, and consent.

8) Varying maturity levels of health IT systems among community-based organizations.

Community-based organizations encompass a diverse group of organizations with varying levels of technology adoption. A few operate very sophisticated technical systems while others operate on mostly paper-based, manual processes. There is equal diversity in the tools and technologies used to support day to day operations, client, and program management. Many interviewees indicated that community-based organizations’ IT systems are often not enabled with functionality to support more sophisticated methods of data interoperability and exchange, such as APIs. Furthermore, community-based organizations are often required to use a given technology as a condition of funding and may lack agency over the selection of software and development of functionality. Many cited that the prospect of duplicate entry across multiple systems is a drain on resources and may diminish the quality of data. Organizations that aggregate data from community-based organizations ascertain the time-consuming nature of exchange when receiving data via spreadsheets or comma separated values (CSV) files.

9) Lack of terminology standards used in the social service sector.

Interviewees shared that community-based organizations providing social services do not code to clinical terminologies and code systems like ICD-10 or SNOMED, given the services they provide and requirements from their sources of funding. They also noted that some domains of service providers – like homeless services, child welfare, and eldercare and disability services – are required to collect specific kinds of information in accordance with federal reporting requirements standards, and that this data may not readily comport with the needs for information at the point of care. Interviewees mentioned that some domains completely lack standard terminologies, and that ongoing involvement of providers from those domains will be important for the process of using standard vocabularies for semantic interoperability. While most interviewees recognize the ongoing work of the Gravity Project in developing consensus based SDOH terminology, there may be a need to expand the effort to include mapping to terminologies that are more
10) Lack of governance processes across communities, regions, and states.

With the adoption of value-based care models, the health care ecosystem has developed strategies and deployed technology to address SDOH as one component to help maintain quality of care while reducing costs. In many parts of the country, stakeholders indicated that this has led to situations in which the decisions made by health care systems – such as the selection of a community-based resource referral platform – significantly affect the landscape of social care without establishing meaningful access to mechanisms of decision-making for community-based organizations and the communities they serve. Given that there is likely to be competing technology solutions in any given market, the implementation of interoperability standards is necessary to ensure that these markets evolve in equitable ways that do not create new burdens and barriers to care. However, the adoption and use of interoperability standards is not sufficient. Current governance processes often focus on establishing technical agreements for data sharing but rarely address stakeholders’ participation in decision-making processes, or accountable methods of incentive design, monitoring, enforcement, resolving conflict, and evaluation of results pertaining to those agreements. In addition, when governance processes are established, they are operating at different scales (local, regional, state) without clear accordance among them. Lastly, the power differential between the institutions driving deployment of these platforms and the ones expected to use the platforms leaves stakeholders at risk of inequitable arrangements in which they have little agency. The lack of established practices and institutional designs for governance of social care coordination and individual data exchange may jeopardize the health and well-being of the populations that these interventions are intended to serve.

11) Potential misuse and misinterpretation of SDOH data.

As SDOH data interoperability becomes more widespread, stakeholders cited potential misuse and misinterpretation of data as potential unintended consequences. Issues related to misuse or misinterpretation could range from a lack of efficacy of survey instruments, to a lack of understanding of how data will be used to a lack of methods of accountability and redress if information is not used for its intended purposes. For example, one interviewee noted that some individuals receiving social services are concerned about their SDOH information being used to raise their insurance premiums; others expressed concern that expanded collection and use of coded data in service delivery systems might end up creating more barriers to care. While all interviewees cited the value of collecting and sharing SDOH information to better serve individuals, families, and communities, moving forward it will be critical for stakeholders to address any concerns collectively and proactively about potential misuse or misinterpretation of this information and have appropriate mechanisms in place to hold entities accountable.
12) Diverse operating models used by health and social sectors.

The key stakeholders interviewed representing community-based organizations or coalitions of community-based organizations indicated that health care and social service sectors can be broadly viewed as having different capacities, technologies, processes, and even paradigms. Often, organizations providing social services are very focused on serving the needs of specific target populations, and also provide very nuanced, holistic sets of services. While this may be true for some individual health care providers, this is not necessarily applicable at a broader organizational or health systems level. In addition, many community-based organizations are entering into contracts with their health system provider or health plan partners that focus on addressing short-term needs with quantifiable outcomes, which is often at odds with the culture and objectives of social care. There is also concern that applying a more prescriptive, medicalized framework – as per the concept of “warm referrals” with “closed loops” – may end up distorting incentives in ways that clash with more relational, longitudinal practices of social work. Some interviewees suggested that efforts to help improve care coordination among social service sectors may be as important as, or more important than, efforts to establish interoperability between healthcare and social services. An appreciation of these critical differences is imperative to understanding and addressing the barriers to interoperability – and equitably governing the interoperable systems that emerge as a result.

18 https://nff.org/blog/achieving-health-equity-community-led-alternatives-healthcare-cbo-partnerships
Recommendations

This gap analysis suggests a set of general recommendations that will need to be considered as part of the roadmap associated with this work effort. The following list is intended to provide a conceptual framework on which further clarification, coordination, and detailed recommendations can be based. This analysis suggests that to adequately address the issues associated with the exchange of SDOH information between and among stakeholders to provide both health and social support for an individual and their family, the following actions should be considered:

1. Creating supportive business, cultural and regulatory environments.
2. Addressing funding of both technology adoption and expansion of social services capacity.
3. Enabling a closed loop referral process by addressing current limitations of service directory information and technology access by service delivery organizations.
4. Addressing the need for the development of a Social (and Health) Services Directory that meets technology, policy, financing, and data governance requirements.
5. Ensuring privacy and security protections for SDOH related information.
6. Advancing domain specific terminology and exchange standards within and among health and social sectors.
Conclusion

In summary, the gaps that exist in the ability to successfully exchange SDOH information between providers, payers, and community-based organizations are based on:

1) Insufficient funding and financial incentives to support broad adoption of technologies required to effectively enhance the exchange of SDOH data between providers and community-based organizations.

2) Lack of funding methods to support the increase in referrals to community-based organizations that typically accompany the involvement of provider and payer organizations in addressing social risks that impact an individual’s health.

3) A need for sustainable, trustworthy sources of resource directory information – categorized with a non-proprietary, standardized taxonomy – that can be accessed as open data infrastructure by any compliant third-party system.

4) Ability to implement closed-loop referrals that respect both the needs of clinical and social service providers in addressing the needs of individuals and families.

5) The need to develop and adopt standards to represent SDOH information and to facilitate electronic exchange of this information. The standards should address exchange methods, syntax, and semantics to improve the ability to share social risk information appropriately and meaningfully.

6) Absence of consistent ways to manage the confidentiality, security, and consent to share information regardless of its origin or intended use that allows both clinical and social service providers to effectively work together to address the needs of individuals and families.

7) A lack of clarity about the potential for misuse of SDOH information and the need to establish appropriate guardrails to address potential harm to individuals, providers, organizations, and communities that may result from expanded collection, aggregation and use of SDOH information.

8) A lack of appropriate governance structures that enable various stakeholders to effectively address the needs of individuals and communities with regard to appropriate management of equitable delivery of health and social care services.

The findings and themes which emerged from the interviews are consistent with evidence presented in the literature review as cited in the related sections above. The interviews provided more granularity, greater insight and real-world examples that are consistent with the technical, financial, policy and operational issues that have been captured in current reports, publications, and articles.

The information and perspectives provided by interviewees across the SDOH ecosystem, who are working daily to address these issues and advance SDOH interoperability, will be used to inform a strategic
roadmap. The roadmap will address the specific gaps identified in this report by proposing strategies, policy opportunities, and tactical considerations for ONC and HL7 to work collaboratively with other stakeholders to advance the appropriate exchange of SDOH information to improve health and human services for underserved populations.
# Appendix A

The following table summarizes the gaps defined in this report and places them into the following categories:

1) Current capabilities of technology (Technology)
2) Identification of barriers (Barriers)
3) Issues related to interoperable SDOH data exchange (Exchange)
4) Risks of SDOH data exchange (Risks)
5) Policy priority areas (Policy)

The table also indicates if the identified issue is considered a (an):

- **Gap (G)** where something is missing that can be addressed,
- **Challenge (C)** that is not a gap but impacts the ability to implement a interoperability, and / or
- **Opportunity (O)** that generally encourages / requires implementation of interoperability.

<table>
<thead>
<tr>
<th>Gap</th>
<th>Description</th>
<th>Technology</th>
<th>Barrier</th>
<th>Exchange</th>
<th>Risk</th>
<th>Policy</th>
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