



Office of the National Coordinator
for Health Information Technology

Social Determinants of Health Information Exchange Toolkit

FOUNDATIONAL ELEMENTS FOR COMMUNITIES

February 2023

Office of the National Coordinator for Health Information Technology (ONC)

Prepared by EMI Advisors for ONC



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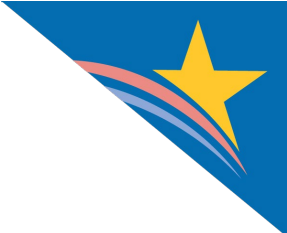
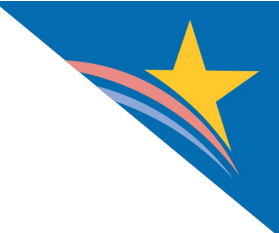


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Executive Summary

“Social determinants of health (SDOH) are the nonmedical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life.”¹ The federal government, U.S. Department of Health and Human Services (HHS), and other stakeholders have identified the critical role that addressing SDOH plays in addressing health inequities, improving care quality, achieving better health outcomes, and reducing healthcare costs.² Addressing SDOH holistically is complex given the multisector nature of services that address SDOH. This can present challenges to service coordination due to non-uniform data collection, varied system designs, and differences in information technology (IT) capacities (including for exchange purposes).

ONC recognizes the potential of data-driven technologies, including certified health IT, to impact health equity. ONC takes an equity-by-design approach to our work. We are committed to advancing the use of interoperable, standardized data to represent social needs and the conditions in which people live, learn, work, and play. Strategic implementation of health IT can facilitate increased and improved collection, documentation, reporting, access, exchange, and use of SDOH data. This information can provide valuable insights for individuals, service providers, and communities working to take action, including in areas such as the referral to services that address social needs/SDOH, strategic outreach, service coordination, and public health. Such insights can be powerful tools to address and reduce inequities in health.

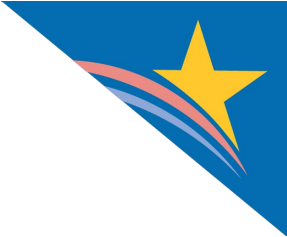
The *Social Determinants of Health Information Exchange Toolkit* (Toolkit) can support communities working toward achieving health equity through SDOH information exchange and the use of interoperable, standardized data to represent SDOH. Stakeholders are increasingly planning and implementing information exchange initiatives to better coordinate and address SDOH service delivery challenges.

Underpinning the information exchange efforts are the IT systems that collect, share, and use SDOH data, which can include both community- and individual-level data on access to food, housing, education, transportation, and other factors associated with health. With improved capacities to share electronic SDOH information, service providers can deliver coordinated, high-quality, person-centered care to improve the health of individuals and communities.

¹ <https://www.cdc.gov/socialdeterminants/index.htm>

² <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/>





Purpose of the Toolkit

The Social Determinants of Health Information Exchange Toolkit is intended to:

- Provide information on the SDOH information exchange landscape to stakeholders of all experience levels.
- Identify approaches to advance SDOH information exchange goals through the consideration of Foundational Elements:
 - Community Readiness and Stewardship
 - Mission and Purpose
 - Values and Principles
 - Policy
 - Legal
 - Measurement and Evaluation
 - Financing
 - Implementation Services
 - Technical Infrastructure and Data Standards
 - User Support and Learning Network
 - Governance
- Provide examples of common challenges and opportunities in SDOH information exchange.
- Present questions and resources to inform SDOH information exchange implementation.

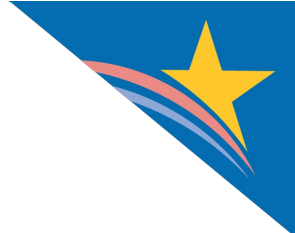
Who May Find This Toolkit Helpful?

There are many stakeholders and implementers of SDOH information exchange, and the participants in SDOH information exchange initiatives can vary across communities and contexts.

The audience for this Toolkit includes:

- Community resource referral initiatives, platforms, and technologies
- Government agencies, including federal, state, local, and tribal
- Healthcare provider networks
- Health information exchanges (HIEs)
- Human services providers
- Individuals, patients, and patient organizations
- IT platform developers and managers
- Networks of community-based organizations (CBOs)
- Payers
- Policymakers
- Other health and human services entities





How To Use this Toolkit

This Toolkit is intended to support conveners, facilitators, implementers, and the health IT community in the process of collaborative assessment, design, implementation, and governance to integrate information systems across sectors.

The SDOH information exchange landscape is continuously evolving, and the needs and interests of SDOH information exchange stakeholders will vary by initiative and community. The information provided in this Toolkit is meant to be a practical starting point and to support ongoing processes that include iteration, learning, and improvement.

Those using this Toolkit can prioritize and sequence their focus on the Foundational Elements in a way that works for their purposes. The Foundational Elements framework is not a one-size-fits-all approach, but rather a conceptual framework to assist the planning, design, implementation, and evaluation processes of SDOH information exchange initiatives.

Limitations

This Toolkit is an informational resource developed by a technical expert panel and is not legal advice or guidance from ONC. The Toolkit is not comprehensive, but rather is a broad, curated list of resources and considerations as informed by the technical expert panel.

This Toolkit focuses on identifying the “Foundational Elements” that can support successful and sustainable implementation of SDOH information exchange. This approach may not be fully representative of all entities, efforts, challenges, opportunities, and resources. In addition, SDOH information exchange is an evolving field and, as the landscape continues to advance, new promising practices and lessons will emerge.

While data standards and similar topics are mentioned in the Toolkit, such references and/or information are not technical or implementation guidance.

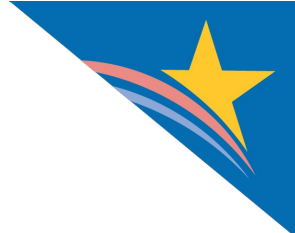
Selection of the Term ‘SDOH Information Exchange’

There are numerous terms to describe the concept of SDOH information exchange that were identified by the technical expert panel in developing the Toolkit. The terminology that is used to describe SDOH information exchange initiatives is evolving, varies across contexts and sectors, and is based on varying perspectives, community characteristics, and technology.^{3,4} The phrase “SDOH information exchange” is used in this Toolkit to describe the activities associated with the collection, sharing, use, integration, and interoperability of SDOH data to facilitate care coordination and improved individual and population health outcomes.

³ <https://www.healthaffairs.org/doi/10.1377/hblog20190115.234942/full/>

⁴ <https://www.milbank.org/quarterly/articles/meanings-and-misunderstandings-a-social-determinants-of-health-lexicon-for-health-care-systems/>





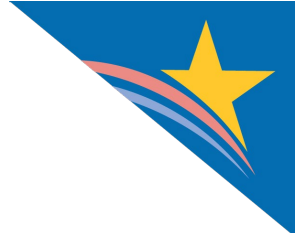
ONC Social Determinants of Health Information Exchange Learning Forum

The Social Determinants of Health Information Exchange Framework and Toolkit helped to inform the ONC Social Determinants of Health Information Exchange Learning Forum. The Learning Forum brought together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. Visit the [ONC SDOH Information Exchange Learning Forum webpage](#) to view recordings and slides on SDOH information exchange topics.

ONC Social Determinants of Health Webpage

For more information on ONC's work as relates to SDOH, visit the [ONC social determinants of health webpage](#).





Acknowledgements

We would like to thank the technical expert panel, contractors, and ONC staff who assisted in the development and review of this document.

Technical Expert Panel

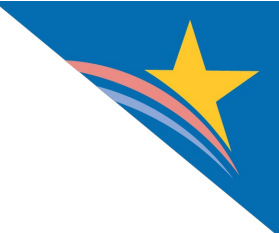
- Philip Ashlock, General Services Administration (GSA)/Data.gov
- Lisa Bari, Civitas Networks for Health (formerly Strategic Health Information Exchange Collaborative [SHIEC])
- Kelly Cronin, U.S. Department of Health and Human Services (HHS)/Administration for Community Living (ACL)
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ONC and Contractors

The following ONC staff and contractors supported the development of this Toolkit:

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- Elizabeth Palena Hall, HHS/ONC
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Background

SOCIAL DETERMINANTS OF HEALTH

There has been growing awareness across the United States regarding how social determinants of health (SDOH), “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life,” affect health and human services’ outcomes and costs.^{5,6} Efforts that address SDOH are integral to achieving the HHS Healthy People 2030 Framework vision of “a society in which all people can achieve their full potential for health and well-being across the lifespan.”⁷ Health equity has been a concept of increasing national focus, which the CDC describes as “the state in which everyone has a fair and just opportunity to attain their highest level of health.”⁸

The Healthy People 2030 Framework outlines five SDOH domains that influence an individual’s and/or population’s health outcomes:

- **Economic Stability**, including financial security, food security, and housing stability;
- **Education Access and Quality**, including early childhood education and development, higher education, language, and literacy;
- **Health Care Access and Quality**, including insurance coverage and access to primary care;
- **Neighborhood and Environment**, including air quality, water quality, rates of crime, and discrimination; and
- **Social and Community Context**, including community support and services.



Figure 1: Healthy People 2030: Social Determinants of Health

Identifying and understanding individuals' social needs and risks enables service providers to better coordinate care and services. However, health services and services that address social needs are delivered across sectors, often making it difficult to provide coordinated, person-centered care that comprehensively addresses SDOH. This impacts individuals’ access to and uses of resources to support their health and wellness, which contributes to population-level health inequities reflected in differences in quality of life, rates of disease, length of life, disability, and death.⁹ Recognition of the importance of addressing SDOH and striving for health equity has led many communities and states to increase investments in initiatives focused on cross-sector coordination

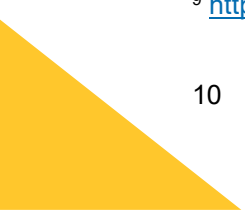
⁵ <https://www.cdc.gov/about/sdoh/index.html>

⁶ <https://academic.oup.com/qjmed/article/110/2/61/2681813>

⁷ <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>

⁸ <https://www.cdc.gov/chronicdisease/healthequity/index.htm>

⁹ <https://health.gov/healthypeople>





to address gaps and inequities related to SDOH.¹⁰ Healthy People 2030 defines health equity as the “attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.”¹¹

The COVID-19 pandemic highlighted the importance of working towards health equity in the United States, as the pandemic disproportionately impacted disadvantaged and other vulnerable communities.¹² In response, an interagency Presidential COVID-19 Health Equity Task Force was convened to assess the national response to the COVID-19 pandemic and create priorities for addressing health equity. The Task Force specifically highlighted the need for a data ecosystem that promotes equity-driven decision making.¹³

Additionally, the Health Information Technology Advisory Committee (HITAC), in collaboration with ONC, held a hearing in March 2022 to address the topic of health equity by design.¹⁴ HHS also developed a Strategic Approach to Addressing Social Determinants of Health to Advance Health Equity, a whole-of-government, multi-sector strategy to address the underlying systemic and environmental factors that affect health status.¹⁵

This Social Determinants of Health Information Exchange Toolkit can serve as a resource for initiatives that support the collection and use of SDOH data in communities across the United States.

SOCIAL DETERMINANTS OF HEALTH DATA

The overall SDOH data landscape continues to evolve as new standards are developed and adopted to fill pre-existing data gaps. SDOH data may be collected by healthcare providers, community-based organizations, social workers, human services agencies, or other stakeholders in the community. The capacity to capture, exchange, analyze, use, and integrate individual-level and aggregated population-level health and SDOH data is a critical factor in supporting initiatives that address individuals’ social needs, SDOH, and health inequities.¹⁶

¹⁰ <https://aspe.hhs.gov/topics/health-health-care/addressing-social-determinants-health-federal-programs>

¹¹ <https://health.gov/our-work/healthy-people/healthy-people-2030/questions-answers>

¹² <https://aspe.hhs.gov/sites/default/files/documents/53fc356858b67f5e9810d107f09ce169/sdoh-covid-19-scoping-review-report.pdf>

¹³ https://www.minorityhealth.hhs.gov/assets/pdf/HETF_Report_508_102821_9am_508Team%20WIP11-compressed.pdf

¹⁴ <https://www.healthit.gov/hitac/events/health-it-advisory-committee-43>

¹⁵ <https://aspe.hhs.gov/sites/default/files/documents/aabf48cbd391be21e5186eeae728ccd7/SDOH-Action-Plan-At-a-Glance.pdf>

¹⁶ <https://www.ncbi.nlm.nih.gov/books/NBK552597/>





Core to this capacity is interoperability, and an interoperable information technology (IT) ecosystem makes the right data available to the right people at the right time across products and organizations in a way that can be relied upon and used by recipients.¹⁷ Through investments in IT, states and communities are extending the capabilities of electronic health records (EHRs), HIEs, community resource referral networks, and other care coordination platforms to identify social needs, coordinate services, deliver services, measure individual and population-level outcomes, assess community needs and gaps in services, implement predictive analytics, conduct research, engage in collaborative community resource planning, and more.

As SDOH information exchange evolves, compliance with federal and state privacy laws must be at the center of this advancement. Depending on the nature of the entity that collects, maintains, and/or stores SDOH data, the data may be protected health information (PHI), and therefore, the entity would need to have appropriate safeguards in place to protect the privacy and security of the SDOH data.^{18,19} Generally, information thought of as SDOH is considered PHI when it is collected by a healthcare provider or other covered entity (or someone operating on their behalf, a business associate)²⁰ as defined by the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

More information is available on the HHS.gov Health Information Privacy website ([Link](#)), including on the following topics:

- Covered Entities and Business Associates (HHS website) [Link](#)
- FAQ on Providers Sharing PHI For Continuity of Care Purposes (HHS website) [Link](#)
- HIPAA Privacy Rule and Care Coordination (HHS website) [Link](#)
- Special Topics in Health Information Privacy (HHS website) [Link](#)

Other federal, state, or local laws may apply to SDOH data. For example, SDOH data may be considered [electronic health information](#) under the [information blocking regulations](#) in 45 CFR 171, and some individuals or entities who hold the data may be considered “[actors](#)” subject to those regulations. For more information about “[electronic health information](#),” “[actors](#),” and the information blocking regulations, please review ONC’s [Information Blocking resources](#), including FAQs, fact sheets, and webinars.

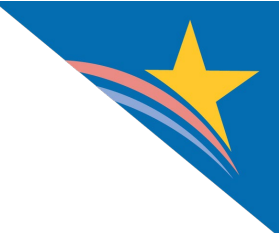
¹⁷ <https://www.healthit.gov/topic/interoperability>

¹⁸ <https://www.hhs.gov/answers/hipaa/what-is-phi/index.html>

¹⁹ <https://www.healthit.gov/buzz-blog/information-blocking/say-hi-to-ehi>

²⁰ <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/business-associates/index.html>





SDOH Information Exchange: Foundational Elements

This section provides detailed information on each of the Social Determinants of Health Information Exchange Foundational Elements, including an overall graphic, summary descriptions, as well as challenges, opportunities, resources, and questions to consider.

Though each community is unique, there are important Foundational Elements to consider in order to facilitate interoperability as information systems are developed and information is shared across community sectors and stakeholders. This Toolkit is structured around these interrelated Foundational Elements, represented by the following graphic:

SDOH Information Exchange Foundational Elements

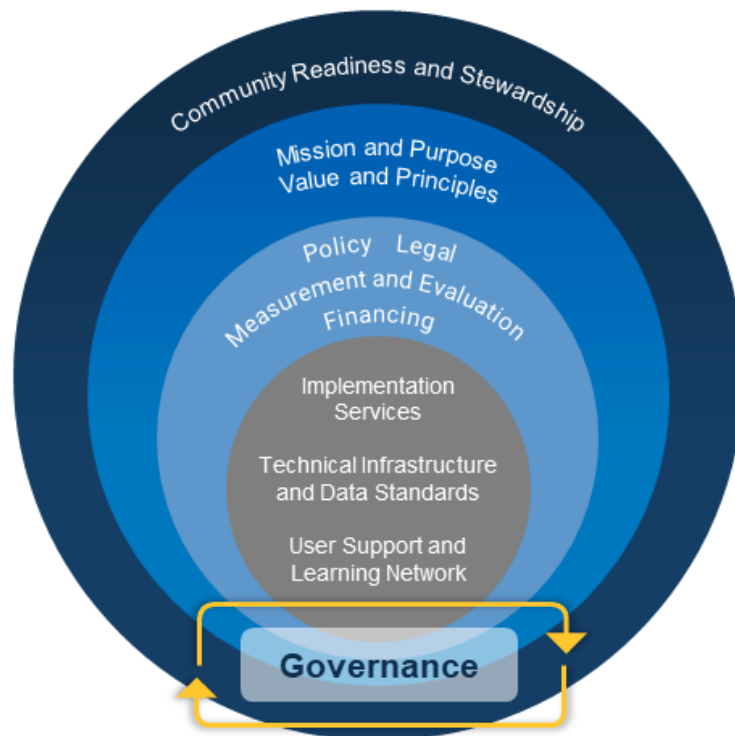


Figure 2: Social Determinants of Health Information Exchange Foundational Elements





The Foundational Elements described in this Toolkit underpin the implementation of SDOH information exchange initiatives, and ultimately may affect an initiative’s capacity to build interoperable infrastructure components.

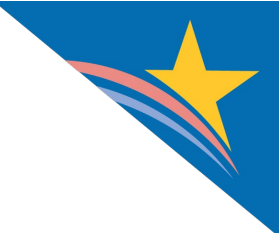
The Foundational Elements inform each other, and governance intersects with all of the other Foundational Elements.

Different stakeholders can prioritize and sequence their focus on the Foundational Elements as appropriate. The Foundational Elements framework is not a one-size-fits-all approach, but rather a conceptual framework to guide the planning, design, implementation, and evaluation processes of SDOH information exchange initiatives.

Foundational Elements Summary Descriptions

- **Community Readiness and Stewardship:** Exploring the existing landscape in the geographic area and/or population of focus, assessing the capacity and willingness of the community to participate, and developing stakeholders’ shared rights and responsibilities through the process of co-design, evaluation, and decision-making.
- **Mission and Purpose:** The intention of an initiative, ideally explicitly stated, that addresses the various value propositions of stakeholder groups, as well as the vision, scope of services, and expected benefits.
- **Values and Principles:** Standards for establishing a framework for action, including ethical decision-making in pursuit of health equity.
- **Policy:** Consideration of federal, state, and local policy levers to advance the ability to collect, share, and use standardized SDOH data, as well as collaboration and alignment with other relevant efforts in the community, region, and/or state for collective impact and improved outcomes.
- **Legal:** Establishing the framework of processes and operations, along with rights and obligations, to support data use and sharing and to support compliance with federal, state, local, and tribal laws.
- **Measurement and Evaluation:** Monitoring and evaluation of performance metrics, individual and population outcomes, program effectiveness, and quality management and improvement.
- **Financing:** Funding opportunities, sources, and plans for investments, ongoing costs, opportunities for blended approaches, and incentives for community adoption and use.
- **Implementation Services:** Inclusive of technical services (e.g., defining requirements, standards specifications, and integration with existing infrastructure and services) and programmatic services (e.g., defining use cases, workflow design/redesign), as well as support for adoption and utilization by individuals and the community.
- **Technical Infrastructure and Data Standards:** Alignment of hardware, software, data, processes, and standards to enable scalable and interoperable data and IT systems.





- **User Support and Learning Network:** User support and learning network activities include assessment of community challenges and needs, education, communication, training, technical assistance, peer-to-peer learning, and identification of promising practices and lessons learned.
- **Governance:** Decision-making processes and groups, including as relates to institutional, administrative, and data governance.

FOUNDATIONAL ELEMENT: COMMUNITY READINESS AND STEWARDSHIP

Summary Description: Exploring the existing landscape in the geographic area and/or population of focus, assessing the capacity and willingness of the community to participate, and developing shared rights and responsibilities through a process of co-design, evaluation, and decision-making.

Overview

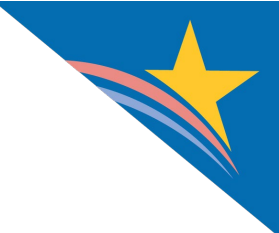
Community readiness reflects the existing landscape of needs, assets, initiatives, opportunities, and challenges in the community of focus, including shared interests and capacities. Community stewardship entails the development of shared rights and responsibilities in the process of co-design, evaluation, and decision-making. The meaning of “community” can vary across contexts, population, geography, infrastructure, and arrangements.

Challenges

The following community readiness and stewardship challenges that may impact successful and sustainable SDOH information exchange include, but are not limited to:

- Communities are diverse in that they contain a multitude of populations, interests, institutions, and technologies, and different perspectives may exist within a single community.
- Collaboration takes time and energy, and community stakeholders may have limited capacities, including workforce capacity, data and technology infrastructure, and empowered leadership.
- Cross-community collaboration is needed in areas where individuals regularly receive services across jurisdictional boundaries, resulting in a need to align community visions, priorities, and technological infrastructure.
- Community stakeholders may lack trust in some systems and initiatives.
- Approaches and investments may be primarily focused on technology and data collection, without sufficient involvement of diverse groups. This can lead to interventions that do not reflect interests or values and may pose new burdens or inequities for providers and communities.





Opportunities

Opportunities and promising approaches related to community readiness and stewardship for implementers of SDOH information exchange include, but are not limited to:

- Identifying roles and responsibilities for stakeholder representation early in the process of planning and launching an initiative with clear expectations and objectives for these roles.
- Engaging and partnering with existing local human service networks and stakeholders which have the potential to help align governance processes and advance the adoption of technology.
- Establishing appropriate and accessible governance structures and processes through which community representatives can share their lived experiences, help set priorities, establish accountability, and have collective leverage in the change-making process.
- Conducting regular mapping of assets and needs as part of a participatory assessment process, including information that can serve as inputs for decision-making.
- Incentivizing community participation in the initiative by providing compensation and/or ensuring that they otherwise benefit from the activities of the initiative.
- Promoting alignment and coordination of initiatives across jurisdictions (local, regional, tribal, and/or state), service domains, and philanthropic sectors.
- Fostering transparency and participation in all activities and aspects of the initiative.



Spotlight! Community Readiness and Stewardship

Community providers, organizations, and individuals came together in Rochester, New York, to initiate the [Monroe County Systems Integration Project](#). The project stakeholders developed a vision statement and plans for a data hub to better integrate service delivery across sectors to improve the health and economic well-being of individuals and families in Monroe County. [A United Way Innovation Case Study](#) includes details on the project's process for **engagement and collaborative decision-making with the local community**.

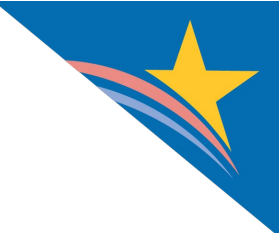
Questions To Consider

The following questions to consider for community readiness and stewardship may help SDOH information exchange implementers identify and address gaps, needs, priorities, and motivating factors.

Community Readiness:

- Which organizations play what roles in the community relevant to your efforts to implement a SDOH information exchange initiative?
- Which organizations are interested in collaborating?
- How can you assess and discuss readiness with the communities and interested organizations?





- What landscape scans and needs assessments have been conducted with the community about needs and opportunities for change?
- What gaps have been identified and how will your initiative align with the identified needs?
- How will your initiative be designed to continue the process of learning and assessment through each phase of the initiative’s lifecycle?

Community Stewardship:

- Who should be involved in the SDOH information exchange initiative?
- Are there individuals in leadership positions who represent the community’s interests in governance and decision-making activities?
- What existing trust has been established to begin collecting data?
- What steps might still be needed to establish sufficient trust?
- How will this trust be preserved over time?
- How will individuals from diverse populations participate in the process, especially individuals from historically disadvantaged communities, those experiencing systematic barriers, or those with high needs?
- What capacities (time, resources, support, etc.) do service providers and participants need to participate fully as partners in the initiative?

Resources and Relevant Initiatives

The following table provides information on relevant resources and initiatives on community readiness and stewardship.

Resource	Author	Summary Information	Link
Arnstein's Ladder of Citizen Participation	“The Citizen’s Handbook”	Sherry Arnstein, writing in 1969 about citizen involvement in planning processes in the United States, described a “ladder of citizen participation” that displayed levels of participation, ranging from high to low.	Link Link
Building Shared Outcomes with Community-Based Organizations	Better Care Playbook	This playbook outlines steps to help health systems and CBOs build relationships that draw on each other’s strengths, put patients first, and support ecosystem development in local communities.	Link
CACHI: Building, Diversifying, Transforming: Three-Year Interim Evaluation Brief (2017-2019)	California Accountable Communities for Health Initiative (CACHI)	This brief presents interim evaluation findings of the California Accountable Communities for Health Initiative (CACHI), covering approximately three years of implementation (2017-2019). The purpose of the brief is to summarize the status, primary accomplishments and challenges of the initial six Catalyst sites in their implementation of the seven key elements of the CACHI model. It also provides an assessment of progress toward systems change in each of the communities.	Link





Resource	Author	Summary Information	Link
Community Health Assessments and Health Improvement Plans	CDC	A community health assessment (CHA), also known as community health needs assessment (CHNA), refers to a state, tribal, local, or territorial health assessment that identifies key health needs and issues through systematic, comprehensive data collection and analysis. This resource contains plans, models, frameworks, and other resources for community health assessments.	Link
Improving Population Health by Working with Communities: Action Guide 3.0	National Quality Forum (NQF)	The Action Guide is a framework to help multisector groups work together to improve population health by addressing 10 interrelated elements for success and using the related resources as needed. It is intentionally brief and written in plain language to be as accessible as possible for all types of stakeholders at the local, state, regional, and national levels to take action.	Link
ONC's Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brought together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The April 2022 Learning Forum Webinar was on the topic, "Vision, Purpose, and Community Engagement."	Link
Parkland Center for Clinical Innovation (PCCI) Building Connected Communities of Care Playbook	Parkland Center for Clinical Innovation (PCCI)	This book proposes an approach to the coordination of medicine and social services through the use of people, process, and technology, with the goal of streamlining coordination between medical and community-based organizations and promoting true cross-sector patient and client advocacy.	Link
Patient Access to Health Records The Guide to Getting & Using Your Health Records	ONC	These websites contain information about patients' rights to access their health records, how providers can use EHRs to connect with patients, how developers can help patients get their records easily, and other information regarding patient access to their records. These resources are relevant for involving patients and participants in SDOH information exchange initiatives.	Link Link
Social Determinants of Health Data Sharing at the Community Level	HHS Office of the Assistant Secretary for Planning and Evaluation (ASPE)	This report represents a landscape review of community-level efforts to address SDOH, followed by interviews with participants in three community-level initiatives that have built networks to coordinate clinical and social services. This report presents a cross-site analysis of the three initiatives, highlighting facilitating factors, challenges faced, plans for continued expansion, and opportunities for federal and state entities, among other actors, to contribute their efforts.	Link





Resource	Author	Summary Information	Link
Social Innovation & Universal Opportunity Lab (SOUL)	Social Innovation & Universal Opportunity Lab	SOUL is the first joint research lab between the University of California San Francisco and San Francisco State University. The lab focuses on combining culturally and community responsive design with new digital technologies to increase racial and spatial justice and improve health equity.	Link
The One-Stop Shop for Healthcare & Community Partnerships	HealthBegins	This site includes resources for community partnerships, including resources for healthcare organizations, community-based organizations, and existing partnerships.	Link

FOUNDATIONAL ELEMENT: MISSION AND PURPOSE

Summary Description: The intention of an initiative, ideally explicitly stated, that addresses the various value propositions, as well as the vision, scope of services, and expected benefits.

Overview

The stated mission and purpose of a SDOH information exchange initiative should:

- Address the various value propositions held by interested groups, as well as the vision and scope of services, and
- Articulate the expected benefits for collecting, sharing, and using data.

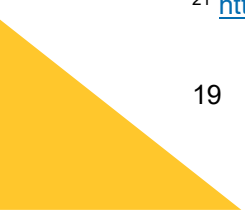
Health equity is at the center of SDOH information exchange initiatives, and inclusion of this value proposition in the mission and purpose can highlight the importance of SDOH data in the advancement of health equity. Health equity is “the state in which everyone has a fair and just opportunity to attain their highest level of health.”²¹

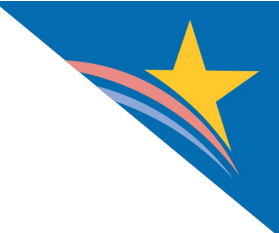
Challenges

Challenges for SDOH information exchange initiatives related to defining the mission and purpose include, but are not limited to:

- Community members might have diverse interests, misaligned incentives, and varying ideas about what success looks like.
- Power imbalances among groups can inhibit the alignment of incentives and interests that are necessary for mutual benefit.
- Communities may need to build and preserve trust in order for cooperation to emerge and to sustain the mission and purpose.

²¹ <https://www.cdc.gov/chronicdisease/healthequity/index.htm>





Opportunities

Opportunities and promising approaches for defining an initiative’s mission and purpose for SDOH information exchange include, but are not limited to:

- Facilitating dialogue among diverse groups to articulate common goals and shared visions. For example, considering the definition of health equity in the context of communities’ expressed needs and interests.
- Identifying the value propositions for diverse parties (CBOs, individuals, payers, providers, states, etc.) through outreach and collaboration and articulating a mission that can align these diverse value propositions.
- Setting interim goals that align with the overall mission and purpose to help build momentum for the overall initiative.
- Developing a mission and purpose centered on health equity that can facilitate alignment.



Spotlight! Mission and Purpose

Highlighted through the [San Diego Community Information Exchange® \(CIE®\)](#) in California, CIE® is built as an **ecosystem to support multidisciplinary partners with the goal of providing person-centered community care planning**. The impact is rooted in the individual/family (micro), agencies (mezzo), and community at-large (macro) to improve health outcomes and quality of life and address health inequities.

Questions To Consider

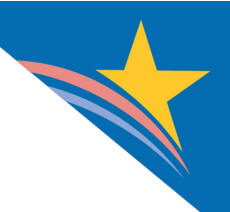
The following questions to consider can support communities in defining the mission and purpose for a SDOH information exchange initiative:

- Who will decide what your mission and purpose will be?
- How will communities that may be impacted by your initiative be represented in this process?
- What would health equity look like in your community?
- By working together, what steps could you take to promote health equity?
- What progress is expected to be achieved through the work?
- How will you know if you’ve succeeded in achieving the mission and purpose?

Resources and Relevant Initiatives

The following table provides information on relevant resources and initiatives for developing the mission and purpose of a SDOH information exchange initiative.





Resource	Author	Summary Information	Link
211 San Diego CIE® Toolkit	211 San Diego CIE® Toolkit	The CIE® Toolkit is designed to assist communities interested in learning how to harness the value of cross-sector collaboration and data sharing to develop a Community Information Exchange® (CIE®) that enables a network of health, human, and social service providers to deliver coordinated, person-centered care to address social determinants of health and improve population health. The CIE® Vision and Governance section could assist in developing the mission and purpose of SDOH information exchange initiatives.	Link
Advancing Health, Equity, and Well-Being through Community-State Data-Sharing Partnerships: Thought Leader Insights	Data Across Sectors for Health (DASH)	This document describes contributing success factors and emerging opportunities for advancing community and state-level, multi-sector data sharing partnerships to improve health, well-being, and advance equity. The document highlights current priorities, new and emerging opportunities, and ingredients for successful data-sharing efforts that can be considered when articulating an initiative’s mission and purpose.	Link
Connect2 Community Network	HealthierHere	Connect2 Community Network is a unified exchange entity collaboratively developed by health and social service organizations in King County, WA. Community-owned and governed by a multi-sector advisory group, it is dedicated to reducing health disparities and improving outcomes. The website for the network details the shared vision and framing of the effort.	Link
Develop SMART Objectives	CDC	This resource includes helpful tools when establishing a collaborative mission and vision, including SMART objectives, SWOT analysis, and an innovation tracking tool.	Link
ONC’s Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The April 2022 Learning Forum Webinar was on the topic, “Vision, Purpose, and Community Engagement.”	Link
Quality Health Network, Community Resource Network	Quality Health Network, Community Resource Network (CRN)	The Community Resource Network (CRN) is a person-centric, SDOH-focused social information exchange (SIE) integrated with the Quality Health Network health HIE. The “About QHN” section of the website contains information on the history, mission, and values of the Quality Health Network.	Link



Resource	Author	Summary Information	Link
What Counts: Harnessing Data for America's Communities	Federal Reserve Bank of San Francisco and the Urban Institute	This document brings together authors from a variety of backgrounds to consider new ways of analyzing and collecting information, including transforming data sets into useful evidence, sharing data across organizations and sectors, and arming stakeholders with the skills they need to use data. The insights shared can be used when brainstorming and working to define the mission and purpose of SDOH information exchange initiatives.	Link

FOUNDATIONAL ELEMENT: VALUES AND PRINCIPLES

Summary Description: Standards for establishing a framework for action, including ethical decision-making in pursuit of health equity.

Overview

Initiatives to integrate health and SDOH processes/information should include a collaborative process of articulating, documenting, and applying values and principles that reflect the interests and priorities of people and the institutions that serve them. Ethical and equitable principles focus on accountability to and fairness in actions and outcomes for the community. Some principles of ethics and equity may overlap with legal considerations.

Challenges

Challenges related to defining and establishing the core set of values and principles of a SDOH information exchange initiative include, but are not limited to:

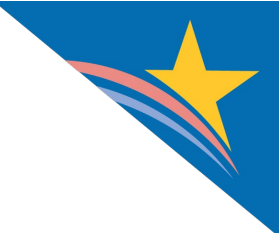
- Sufficient time needs to be allocated to successfully articulate values and principles and to achieve ongoing collaborative engagement with interested groups.
- There may be different incentives and value systems among interested groups. There may also be imbalances in power among stakeholders. Without intentional alignment around shared statements of principles and values, these dynamics can lead to conflicts and inequitable outcomes.
- Technology-driven approaches for care management (such as data sharing, risk profiling, and algorithmic decision-making) can offer significant potential benefits but also pose risks of unintended and inequitable outcomes.
- Different initiatives may have underinvested in capacities to anticipate and mitigate risks, assess ethical tensions, monitor for unforeseen consequences, and take action to prevent, reduce, and repair possible harms.

Opportunities

Opportunities and promising approaches for defining and establishing values and principles for implementers of SDOH information exchange include, but are not limited to:

- Involvement of the community in each phase of an initiative's lifecycle to promote equity and prevent harm.





- Recognizing the potential for data and IT infrastructure to promote or hinder health equity and address or exacerbate discrimination and systemic racism.
- Conducting risk assessments and mitigation throughout each phase of the initiative's lifecycle to prevent harm (e.g., from de-anonymization, loss of access to services, misuse of data, inequitable algorithmic decision-making, etc.), and developing institutional processes to identify and address incidences of harm to individuals and communities.
- Leveraging existing statements of principles for equitable initiatives (see examples in the Resources section).



Spotlight! Values and Principles

HealthierHere's Connect2 Community Network, has **equity principles that are core to the community-governed Network**. These include components such as transparency, accountability, cultural responsiveness, using the community as experts, and recognizing unintended consequences as core values to drive its model.

Questions To Consider

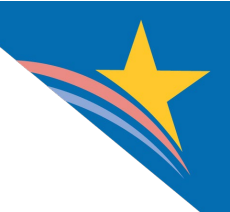
The following questions to consider can support implementers of SDOH information exchange initiatives as they think through the core values and principles that will guide their activities.

- How does your community define “stakeholders?” Does this definition include the end-users of the services and those involved in the direct provision of services? How is the initiative defining the scope of the interested community?
- What are the most common concerns shared by community stakeholders, and how will those concerns be equitably addressed through a governance process?
- How will the initiative address the interests of different types of stakeholders in such a way that prioritizes the interests of people in need and their communities?
- What are the ethical principles and values that your initiative commits to uphold and reflect in the approach to data and IT?
- What is your community's approach to preventing harm to communities and individuals in the course of the initiative? Ensuring alignment with ethical and equitable principles? Assessing gaps and addressing them?
- In accordance with your initiative's defined principles and values, how will the interests of individuals and the community as a whole be represented and prioritized through each phase of the initiative (e.g., start-up, ongoing operations) and IT system life cycle (e.g., planning, design, development, testing, implementation, and operations)?

Resources and Relevant Initiatives

The following table provides information about relevant resources and initiatives focused on values and principles for SDOH information exchange.





Resource	Author	Summary Information	Link
Achieving Health Equity: Community-Led Alternatives to Health Care-CBO Partnerships	Nonprofit Finance Fund	This blog discusses the relationship between community-based organization and healthcare organization partnerships, and how to incorporate values and principles through community-centered and led models of care.	Link
Aligning Systems with Communities to Advance Equity through Shared Measurement	American Institute for Research	The principles in this document can inform measurement that effectively aligns systems' actions with the needs and priorities of the communities those systems serve, particularly communities that historically have been harmed the most by inequities.	Link
Assembling Accountability: Algorithmic Impact Assessment for the Public Interest	Data & Society	Report that maps the challenges of constructing algorithmic impact assessments (AIAs) and provides a framework for evaluating the effectiveness of current and proposed AIA regimes. This framework is a practical tool for regulators, advocates, public-interest technologists, technology companies, and critical scholars who are identifying, assessing, and acting upon algorithmic harms. Such considerations can inform values and principles.	Link
A Toolkit for Centering Racial Equity Throughout Data Integration	Actionable Intelligence for Social Policy (AISP)	Since 2019, AISP has led a diverse workgroup of civic data stakeholders to co-create strategies and identify promising practices to center racial equity in data integration efforts. A Toolkit for Centering Racial Equity Throughout Data Integration describes positive and problematic practices for centering racial equity across the six stages of the data lifecycle.	Link
Charting a Course for an Equity-Centered Data System	National Commission to Transform Public Health Data Systems	The National Commission to Transform Public Health Data Systems was charged with reimagining how data are collected, shared, and used, and identifying the public- and private-sector investments needed to modernize our public health data infrastructure and improve health equity. This report summarizes the recommendations that emerged from the commission's deliberations, including for health equity, equitable governance, community engagement, and measuring and addressing inequities.	Link
Develop Equitable Data Practice	Urban Institute	To guide their work and protect people participating in studies, research organizations use the Belmont Report's three principles of beneficence, respect for persons, and justice. The authors suggest that data experts could adopt these principles to move toward more equitable data practice.	Link



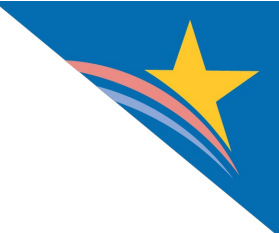
Resource	Author	Summary Information	Link
HealthierHere Equity Definition and Guidelines	HealthierHere	HealthierHere provides guidelines and definitions for incorporating equity values and principles into its work.	Link
Leveraging Community Information Exchanges® for Equitable and Inclusive Data	211 San Diego CIE®	These resources may inform early planning and community member engagement efforts for institutions building Community Information Exchanges (CIEs)®. Organizations, communities, and institutions can use this resource to initiate and inform conversations around building social and health data systems with an equity and anti-racism lens.	Link
ONC’s Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The April 2022 Learning Forum Webinar was on the topic, “Vision, Purpose, and Community Engagement.”	Link
The Consentful Tech Project	Consentful Tech Co.	The Consentful Tech Project raises awareness, develops strategies, and shares skills to help people build and use technology conscientiously, and with consent. This includes a framework for good digital consent as a value and principle.	Link
The Gravity Project Data Principles	HL7/Gravity Project	The Gravity Project has articulated Principles of Data Exchange for Equitable Health and Social Care to establish an ethical framework to guide any initiative that might apply the products of Gravity’s work.	Link

FOUNDATIONAL ELEMENT: POLICY

Summary Description: Consideration of federal, state, local, and tribal policy levers to advance the ability to collect, share, and use standardized SDOH data, as well as collaboration and alignment with other relevant efforts in the community, region, and/or state for collective impact and improved outcomes.

Overview

Federal, state, local, and tribal policy can impact the planning, implementation, and management of SDOH information exchange initiatives. Policies may also support interoperability and the collection, sharing, and use of SDOH data. Understanding the policy landscape can help in launching and scaling SDOH information exchange efforts.



Challenges

Challenges related to policy for SDOH information exchange initiatives include, but are not limited to:

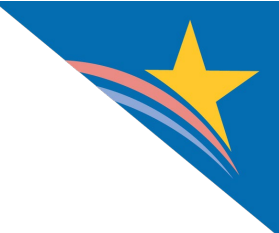
- Monitoring new and pending federal, state, local, and tribal legislation and policy directives to understand the implications at the community level with consideration for how to implement the policies at the applicable levels.
- Translating technical and policy challenges across audiences with different backgrounds and applying technical and policy frameworks to various challenges.
- Encouraging stakeholder engagement, user participation, and coordination within existing networks for policy efforts.
- Patient and individual confidentiality, informed consent, and fostering understanding and transparency among patients and individuals regarding the purpose of SDOH information exchange and use of their data.

Opportunities

Policy opportunities and promising approaches for implementers of SDOH information exchange include, but are not limited to:

- Identify applicable policies from the planning stages, including how they may facilitate or impede SDOH information exchange.
- Where available, communities can utilize laws and policy directives to support facilitation of data sharing between health and social service providers.
- Through policy and awareness-raising efforts, communities can increase understanding, interest, and investment in addressing social needs and supporting data and IT systems.
- Communities can work with policymakers to align with regulatory frameworks at different levels, including, federal, state, local, and tribal government.
- Policy initiatives can be used to coordinate and align across systems, including the use of IT standards and leveraging existing infrastructure and investments.
- Communities can partner with state programs to use SDOH information exchange for referrals to SDOH resources.
- Stakeholders can inform patients and individuals on the purpose of SDOH information exchange, how their data are used, and privacy and consent policies.
- Implementers can search for policy-related informational materials, which are available through conferences, workshops, written publications, and blogs from industry experts.





Spotlight! Policy

Colorado Health Institute connects local policy efforts with implementation initiatives through governance and engagement, including the Metro Denver Partnership for Health’s social-health information exchange activities. **These policies influence approaches to address local community health and social issues that are unique to the state of Colorado.**

Questions To Consider

The following questions to consider can support implementers of SDOH information exchange initiatives as they think through policy considerations that will guide their activities.

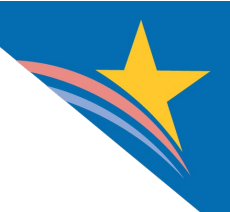
- What existing policies or legislation can support or create barriers for your IT infrastructure?
- What assessments have been done on the existing federal, state, local, and tribal policy landscapes?
- What entities or efforts are in alignment with or differ from your objectives, and how will you orient your strategy for collective impact to improve outcomes?
- Whose role will it be to regularly research and review policies that could impact your SDOH information exchange effort?
- How does policy inform the development of the SDOH information exchange technical infrastructure? How can technical capabilities inform policy?

Resources and Relevant Initiatives

The following table provides information on relevant policy resources and initiatives for SDOH information exchange.

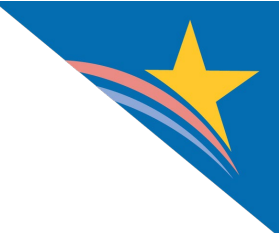
Resource	Author	Summary Information	Link
CMS Letter to State Health Officials	CMS	This State Health Official (SHO) letter describes opportunities under Medicaid and CHIP to better address SDOH and to support states with designing programs, benefits, and services that can more effectively improve population health, reduce disability, and lower overall healthcare costs in the Medicaid and CHIP programs by addressing SDOH.	Link
Confidentiality Toolkit	Administration for Children and Families (ACF)	This Toolkit is intended for staff at all levels of government who work within offices and agencies that promote the well-being of children and families and would like to know more about responsibly sharing records, successfully recording and sharing goals, and confidentiality considerations. This includes information about legal requirements, security frameworks, stakeholder engagement, and record-sharing frameworks and processes.	Link





Resource	Author	Summary Information	Link
Delivery System Reform Incentive Payment (DSRIP) Program	New York State	Waiver allowed the state of New York to reinvest \$8 billion in federal savings generated by Medicaid Redesign Team (MRT) reforms. The waiver amendment dollars address critical issues throughout the state and allow for comprehensive reform through a Delivery System Reform Incentive Payment (DSRIP) program. The DSRIP program promotes community-level collaborations and focuses on system reform, including avoidable hospital use reduction. This is an example of the use of a policy lever to facilitate SDOH information exchange.	Link
<i>Federal Register</i>	National Archives	Each day, federal agencies publish documents in the <i>Federal Register</i> , including proposed rules, final rules, public notices, and presidential actions. This site includes tools for sharing these documents with associates and communities via email notification subscriptions, RSS feeds, and social networking applications.	Link Link
Laws, Regulation, and Policy	ONC	ONC webpage providing information on health IT legislation and regulations, including provisions of the 21st Century Cures Act, to improve the exchange of electronic health information.	Link
North Carolina Department of Health and Human Services	North Carolina Department of Health and Human Services (NC DHHS)	North Carolina’s Department of Health and Human Services details Healthy Opportunities for North Carolinians. The strategies used are examples of policy levers to facilitate SDOH information exchange.	Link
ONC’s Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The July 2022 Learning Forum Webinar was on the topic, “Policy and Funding.”	Link





FOUNDATIONAL ELEMENT: LEGAL

Summary Description: Establishing the framework of processes and operations, along with rights and obligations, to support data use and sharing and to support compliance with federal, state, local, and tribal laws.

Overview

Legal considerations for SDOH information exchange include activities, either required by law, policy, or contract, to establish a framework of:

Processes and operations:

- Contractual agreements with vendors, community members, and other partners.
- Documents and actions addressing issues such as monetary fees, technical requirements, liability, indemnity, and insurance.
- Documenting internal policies to comply with legal requirements, third-party agreements, and other procedures and guidelines established through governance processes.

Data use and rights:

- Individual privacy rights.
- Data use and disclosures.
- Privacy and security obligations related to data sharing (e.g., HIPAA business associate agreements, data use agreements, consent model, and de-identification).
- Other federal, state, or local laws may apply to SDOH data. For example, SDOH data may be considered [electronic health information](#) under the [information blocking regulations](#) in 45 CFR 171, and some individuals or entities who hold the data may be considered “[actors](#)” subject to those regulations. For more information about “[electronic health information](#),” “[actors](#),” and the information blocking regulations, please review ONC’s [Information Blocking resources](#), including FAQs, fact sheets, and webinars).

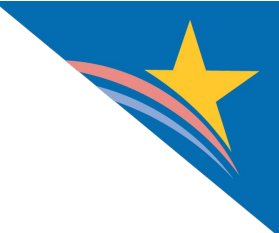
Challenges

Key challenges related to the legal activities of SDOH information exchange initiatives include, but are not limited to:

- Knowledge of the HIPAA Privacy, Security, and Breach Notification Rules among stakeholders, and awareness of who is subject to HIPAA requirements (e.g., who is a HIPAA covered entity or a HIPAA business associate).²²

²² <https://www.hhs.gov/hipaa/for-professionals/training/index.html>





- Knowledge of the FTC Act (consumer protection) and Health Breach Notification Rule.^{23 24}
- Variation between stakeholders in knowledge and approach to operations and processes, such as consumer protections and individual consent policy and management.
- Consideration and observance of applicable federal, state, local, and tribal laws.
- Concerns of some parties or users regarding data ownership and how it applies in vendor contracts or other components of the initiative.
- Limited no-cost, publicly available resources to assist community stakeholders with legal activities and documentation.
- Apportionment determination of liability, requirements for insurance, and indemnification, particularly among stakeholders with unequal resources for data collection, sharing, and use for the initiative.

Opportunities

Opportunities and promising approaches for addressing SDOH information exchange legal activities include, but are not limited to the following:

- Inform stakeholders of HIPAA rules, individual rights, and covered entities and business associate requirements, as applicable.^{25 26 27}
- Collaborate with health and human service stakeholders to develop and adopt appropriate consent policies and practices that align with federal and state laws.
- Examine existing agreements to determine how they may apply to SDOH information exchange initiatives.
- Incorporate legal compliance considerations into procedures and operations, such as consumer protections.²⁸
- Deploy standard technical authorizations and role-based permissions to facilitate understanding of data governance and to support appropriate access and use of data.

²³ <https://www.ftc.gov/enforcement/rules/rulemaking-regulatory-reform-proceedings/health-breach-notification-rule>

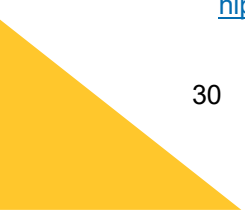
²⁴ <https://www.ftc.gov/tips-advice/business-center/guidance/sharing-consumer-health-information-look-hipaa-ftc-act>

²⁵ <https://www.hhs.gov/hipaa/for-professionals/regulatory-initiatives/index.html>

²⁶ <https://www.hhs.gov/hipaa/for-professionals/covered-entities/index.html>

²⁷ <https://www.hhs.gov/hipaa/for-professionals/faq/3008/does-hipaa-permit-health-care-providers-share-phi-individual-mental-illness-third-party-not-health-care-provider-continuity-care-purposes/index.html>

²⁸ <https://www.ftc.gov/tips-advice/business-center/guidance/sharing-consumer-health-information-look-hipaa-ftc-act>





Spotlight! Legal

The University of California San Francisco-based Social Interventions Research and Evaluation Network (SIREN) and the Robert Wood Johnson Foundation sponsored Manatt to develop [Data Sharing and the Law: Overcoming Health Care Sector Barriers to Sharing Data on Social Determinants](#), which highlights **use cases, legal analysis, and promising practices around information disclosures** between health and social services.

Questions To Consider

The following questions to consider can support implementers of SDOH information exchange initiatives with thinking through legal considerations and implications.

- How do legal considerations relate or apply to governance structures, including data governance?
- What entities are subject to specific legal obligations?
- What federal, state, local, and tribal laws are applicable to the initiative?
- What procedures will be in place for legal contract development? What are the gaps in these procedures, and how will they be addressed?
- Have vendor contracts and data-sharing agreements been reviewed and supported by legal counsel?
- What are your organization's role-based permissions for service providers and individuals to access and use data? Where can you get guidance on legal provisions for your organization's policies?
- Are your organization's consent policies and practices clearly stated and made widely available? Were the individuals, service providers, and other relevant stakeholders engaged in the development and periodic review and revisions of these policies?
- Are the policies and practices of the SDOH information exchange initiative covered by the HIPAA rules, Family Educational Rights and Privacy Act (FERPA), and other applicable federal, state, local, and tribal health and human services laws and policies, including individual consent policies and restrictions?
- What are the approaches to prevent and mitigate data breaches, promote cybersecurity, maintain privacy, and address organizational liability?

Resources and Relevant Initiatives

The following table provides information on relevant legal resources and initiatives related to SDOH information exchange.





Resource	Author	Summary Information	Link
211 San Diego CIE® Toolkit	211 San Diego CIE®	The CIE® Toolkit is designed to assist communities interested in learning how to harness the value of cross-sector collaboration and data sharing to develop a CIE® that enables a network of health, human, and social service providers to deliver coordinated, person-centered care to address SDOH to improve population health. The “Prepare a Legally Compliant Framework” and “Legal Agreement Examples” could be used when considering legal aspects of SDOH information exchange.	Link
Confidentiality, Privacy, and Security	Stewards of Change Institute (SOCi)	SOCI leaders have been developing and applying security and trust-based approaches to advance responsible information-sharing across silos, while also protecting the privacy and confidentiality needs of the people and organizations to whom that information belongs. In order to accelerate progress and achieve broader impact, SOCI published several privacy and confidentiality toolkits that governments, agencies, and other organizations can use to further their own interoperability and information-sharing objectives. These resources can assist when considering legal aspects of SDOH information exchange.	Link
DASH/Network for Public Health Law Legal Bibliography	Community Commons	The Legal Bibliography is a collection of 100+ papers, toolkits, and other materials focused on privacy, consent, and policy documentation.	Link
Data Sharing and the Law: Overcoming Health Care Sector Barriers to Sharing Data on Social Determinants	Social Interventions Research and Evaluation Network (SIREN)	This report, prepared with support from SIREN and the Robert Wood Johnson Foundation, Manatt Health examines the circumstances in which health care organizations can exchange personal information outside the health care sector in compliance with federal and state law.	Link
Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration	Actionable Intelligence for Social Policy, University of Pennsylvania	Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration was created by Actionable Intelligence for Social Policy (AISP) to support the essential and challenging work of exchanging, linking, and using data across government agencies. This resource was created to frame out key considerations and provide effective practices for agencies working to “find a way forward” to share and integrate data.	Link
Health Insurance Portability and Accountability Act (HIPAA)	HHS	These links include informational resources (e.g., special topics and FAQs) on HIPAA.	Link Link Link Link Link



Resource	Author	Summary Information	Link
Laws, Regulation, and Policy	ONC	ONC webpage providing information on health IT legislation and regulations, including provisions of the 21st Century Cures Act that will improve the flow and exchange of electronic health information.	Link
Patient Consent for Electronic Health Information Exchange	ONC	ONC notes aspects of meaningful consent for electronic health information exchange on this page. This includes patient education and engagement, technology, and law and policy.	Link
Patient Consent for Electronic Health Information Exchange and Interoperability	ONC	This ONC page from contains information on patient consent and interoperability, including consent and privacy laws, scenarios, considerations, and principles for patient choice.	Link
Privacy, Security, and Health IT	ONC	ONC website on federal policies and regulations that are in place to help protect patient privacy and guide the nation's adoption of health IT. This information can inform discussions of legal considerations for SDOH information exchange.	Link
The Gravity Project Principles	HL7/Gravity Project	This page includes Gravity Project materials (e.g., charter, use cases) and is updated on a regular, ongoing basis. These documents may provide examples of relevant governance considerations for SDOH information exchange.	Link

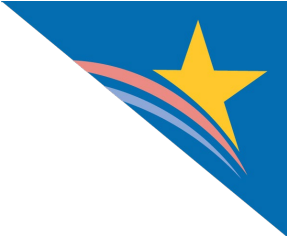
FOUNDATIONAL ELEMENT: MEASUREMENT AND EVALUATION

Summary Description: Monitoring and evaluation of performance metrics, individual and population outcomes, program effectiveness, and quality management and improvement.

Overview

The CDC describes program evaluation as “a systematic method for collecting, analyzing, and using data to examine the effectiveness and efficiency of programs and, as importantly, to contribute to continuous program improvement.”²⁹ SDOH information exchange efforts include measurement and evaluation processes and protocols for program monitoring, assessment of the overall implementation process, quality measurement of the services provided (including information exchange services), financial analysis, research, and more. It is important to establish the purpose of the measurement and evaluation strategy, including important questions that need to be answered.

²⁹ <https://www.cdc.gov/eval/index.htm>



Evaluation frameworks and approaches for measurement and evaluation may include (non-exhaustive list):

- CDC Framework for Program Evaluation³⁰
- Performance monitoring
- Formative evaluation
- Summative evaluation
- Culturally responsive evaluation
- Empowerment evaluation
- Systems-oriented evaluation
- Theory of change
- Logic models
- Outcome mapping³¹
- Evaluation methods: quantitative, qualitative, and mixed methods³²

Measurement activities are central to the evaluation process and include monitoring and evaluation of performance metrics, individual and population outcomes, program effectiveness, and quality management and improvement. This also includes measuring ethical and equitable practices, approaches, and impact on individuals.

³⁰ <https://www.cdc.gov/eval/materials/index.htm>

³¹ <https://evaluationguide.wkkf.org/>

³² https://www.atsdr.cdc.gov/communityengagement/pce_program_methods.html





Using different types of data, stakeholders can engage in the following types of measurement as related to SDOH information exchange:

- **Process measurement:** Tracking individual-level impacts, such as screenings and closed-loop referrals to community-based organizations. For example, this may also include assessment of the time, ease of use, participant satisfaction, or effectiveness of individual steps within the information exchange and referral processes. This may also include identification of potential barriers and facilitators to engaging in a SDOH information exchange process to foster equitable and ethical practices.
- **Utilization measurement:** Monitoring the use of SDOH information exchange, including utilization, service volume, and participation. For example, measuring the number of individuals, patients, service providers, logins, hospitalizations, referrals, visits, or services provided. This may also include measurement and monitoring of equity as relates to utilization.
- **Quality measurement:** Conducting measurement activities to assess the association between improved population-level health outcomes and improvements in SDOH information exchange, referrals, and use of services. Disparities in health outcomes can be examined through quality measurement activities, and the results can inform ethics and equity approaches.
- **Financial measurement:** Measuring cost savings for improved health outcomes, reduced costs, and cost-benefit analysis.

Challenges

Challenges related to measurement and evaluation of SDOH information exchanges services and activities include, but are not limited to:

- Access to current, structured data (e.g., clinical, social, administrative) for monitoring, evaluation, and measurement.
- Defining quality measures to understand impact on health and wellness outcomes.
- Staff capacity and skill sets to support quality improvement activities.
- Implementing appropriate methodologies for establishing baselines, denominators, and timeframes for measures.
- Balancing the information privacy considerations of individuals with the interests of institutions to increase data collection for long-term evaluation needs.
- Understanding of and expectations around short-term and long-term outcomes as related to SDOH, and the length of time required to observe these outcomes.
- Identifying measurement and evaluation strategies that meet the needs of all institutions, sectors and individuals involved.
- Defining return on investment of SDOH interventions, taking into consideration the time needed to observe the potential return on investment.





Opportunities

Opportunities and promising approaches for implementers of SDOH information exchange to utilize measurement and evaluation activities in their operations include, but are not limited to the following:

- Emerging person-centered social determinant quality measures to assess impact on health outcomes and individual well-being.
- Involving the community in an equitable process of measurement and evaluation so that diverse stakeholders participate in choosing the evaluation methodology, engage in the evaluation process, identify evaluation priorities, define metrics, assess tradeoffs and risks posed by data collection and use, develop measurement methods, and interpret data.
- Considering how to align and streamline measurement and evaluation activities when working across federal, state, local, tribal, and private sectors.
- Implementing short-term and mid-term feedback loops and impact assessments to inform and improve coordination efforts with community stakeholders. Examples include efforts to assess efficiency, integration, accuracy, community engagement, impact, community needs, transparency, and trust building.
- Setting appropriate expectations, given the initiative's complexity and assumptions, along with meaningful measurement and evaluation goals.
- Enabling funders, sponsors, managers, and community stakeholders to understand and assess return on investment and cost savings.
- Embedding standards in the SDOH information exchange initiative to facilitate consistent and accurate data collection to support measurement activities.



Spotlight! Measurement and Evaluation

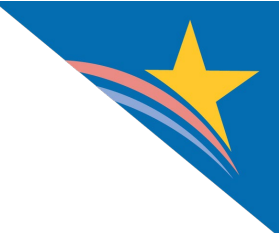
The Oregon Health Authority convened a [SDOH Measurement Workgroup focused on screening for social needs](#) in 2020 to **recommend a measure that would incentivize screening for individual health-related social needs** to Oregon's Metrics and Scoring Committee and Health Plan Quality Metrics Committee. The Workgroup outlined its process and recommendations in a [2021 report](#).

Questions To Consider

The following questions to consider can support implementers of SDOH information exchange initiatives in thinking through measurement and evaluation approaches for their work.

- What evaluation methodology will you use?
- How have you woven ethics and equity considerations into the evaluation process?
- What are your evaluation priorities? How were these determined?
- How will you measure success over time?





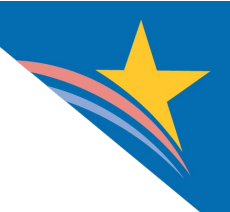
- What are the primary metrics for success: for clients, community organizations, and the community as a whole? How are these selected, and what is the measurement process?
- How will you capture baseline data and measure quality or success over time?
- How are you evaluating the success of your quality management and evaluation approach?
- How are participants' experiences and outcomes considered in the measurement process?
- How are you addressing gaps in your program?
- How will you establish targets, measure progress toward these targets, and evaluate the appropriateness of the metrics?
- How are you measuring community trust?
- How will you share results, and with whom?
- How can the information collected be used to drive future funding opportunities?
- How can the information collected be used to support eligibility requirements for enrollment in various social support programs, assess unmet need for services, and reduce healthcare costs?

Resources and Relevant Initiatives

The following table provides information on relevant measurement and evaluation resources and initiatives for SDOH information exchange efforts.

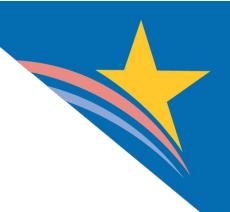
Resource	Author	Summary Information	Link
A Framework for Evaluating Social Determinants of Health Screening and Referrals for Assistance	Chagin et al., <i>Journal of Primary Care and Community Health</i>	A framework based on sequential steps that may be used to evaluate SDOH screening and assistance programs.	Link
Aligning Systems with Communities to Advance Equity Through Shared Measurement	American Institutes for Research	These principles can inform measurement that effectively aligns systems' actions with the needs and priorities of the communities those systems serve, particularly communities that have been historically disadvantaged.	Link
CDC Evaluation Resources	CDC	Contains evaluation resources, including tips for conducting strong evaluations, framework-based materials, documents, workbooks, tools, and a study guide for program evaluation for public health programs.	Link
HRSA-Supported Patient Centered Medical Home Training	The National Committee for Quality Assurance (NCQA)	Training on the "Patient Centered Medical Home," which includes recordings for trainings on measurement and quality.	Link





Resource	Author	Summary Information	Link
Measuring Social Determinants of Health Among Medicaid Beneficiaries: Early State Lessons	Center for Health Care Strategies	This brief, made possible by The Commonwealth Fund, explores strategies that states are using to capture SDOH information for Medicaid beneficiaries. The insights gleaned from interviews with early state innovators can help policymakers drive greater and more consistent collection of individual-level SDOH information, which can inform patient-level interventions, population health management, research and evaluation, and broader delivery system reform.	Link
Measuring the ROI of Social Determinants of Health Interventions	RISE	RISE presents a framework for assessing the return on investment of SDOH interventions.	Link
NQF Disparities Resources	National Quality Forum (NQF)	This page contains NQF efforts to foster the use of accurate and meaningful metrics that consider socioeconomic and demographic patient factors, and measures that address healthcare disparities and culturally competent care.	Link
NQF Health IT Resources	National Quality Forum (NQF)	NQF provides information on health IT initiatives designed to improve care safety, affordability, and coordination through the use of electronic health records, and other clinical IT systems to capture data needed to measure performance.	Link
Quality Framework for Integrated Data Systems	Actionable Intelligence for Social Policy (AISP)	Quality framework from the Actionable Intelligence for Social Policy (AISP) with consideration of governance, legal, technical, capacity, and impact components.	Link
Resource Domains	Health Information Technology, Evaluation and Quality Center (HITEQ)	The HITEQ Center collaborates with Health Resources and Services Administration (HRSA) Partners including Health Center Controlled Networks (HCCNs), Primary Care Associations (PCAs) and other National Cooperative Agreements (NCAs) to support health centers in full optimization of their EHR/Health IT systems. The center includes publicly available resources on health IT-enabled quality improvement, health information exchange, workforce development, value-based payment, and more.	Link
Resources for Evaluation	Innovation Network	The Innovation Network has a resource library of reports and guides for evaluation, including making data and evaluation work, evaluation capacity building, data visualization, theory of change, evaluation planning, logic models, coalition assessment, and more.	Link





Resource	Author	Summary Information	Link
Social Determinants of Health Measurement Workgroup	The Oregon Health Authority (OHA)	OHA convened the SDOH Measurement Workgroup: Screening for Social Needs from late 2020 to early 2021. The purpose of this workgroup was to recommend a measure related to the SDOH for consideration by Oregon’s Health Plan Quality Metrics Committee and Metrics and Scoring Committee. Specifically, the SDOH Measurement Workgroup was charged with recommending a measure that would incentivize screening for individual health-related social needs. Following the workgroup’s recommendations, OHA developed, pilot tested, and refined detailed measure specifications.	Link
Social Determinants of Health Resource Guide	National Committee for Quality Assurance (NCQA)	The NCQA Social Determinants of Health Resource Guide is a reference for health plans, clinically integrated networks, and clinicians to design and implement strategies that SDOH for commercially insured populations. The SDOH Resource Guide centers around SDOH strategy and is organized into six sections: <ul style="list-style-type: none"> • Assessment Design • SDOH Data • Data Sharing, Integration, and Quality • Collaboration with Community-Based Organizations • Measurement and Evaluation • Quality Improvement 	Link
The Step-by-Step Guide to Evaluation: How to Become Savvy Evaluation Consumers	W.K. Kellogg Foundation	This document details principles to guide evaluation, including evaluation types and methodologies, the process for evaluative thinking, evaluation preparation, stakeholder engagement in evaluation, logic models, evaluation questions, data collection and analysis, and summarizing and communicating evaluation findings.	Link
Using Data to Reduce Disparities and Improve Quality	Advancing Health Equity (AHE)	This document explores how providers, governmental organizations, health plans, and community-based organizations can use data to reduce disparities and improve quality. Three topics are included in the document with recommended strategies: discovering and prioritizing differences in care, outcomes, and/or experiences across patient groups; planning equity-focused care transformations and measuring impact; and telling the story of how patients experience healthcare.	Link





FOUNDATIONAL ELEMENT: FINANCING

Summary Description: Funding opportunities, sources, and plans for investments, ongoing costs, opportunities for blended approaches, and incentives for community adoption and use.

Overview

Financing encompasses funding for start-up investments (e.g., hardware, software, capacity building, community engagement, and human resources) and ongoing costs (e.g., data and IT infrastructure, legal services, service delivery, administration, and/or stakeholder capacity) that is supported by a revenue model and/or sustainability plan. This funding may include funding opportunities (e.g., private-sector funding, public-sector funding, and partnerships), leveraging multiple funding streams, and incentives for community adoption and use.

Challenges

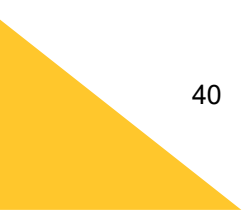
Challenges related to financing the start-up, coordination, and operations of SDOH information exchange initiatives include, but are not limited to:

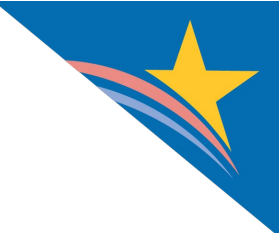
- Lack of sustainable funding focused on stakeholder capacity for managing and operating the IT infrastructure, governance approach, evaluation activities, and increased demand for services.
- Stakeholders may make different investments and take on varying risks with differences in realization of returns and benefits.
- Articulating the need for infrastructure can be a complex process, including the need for information technology related to service delivery.
- There are challenges in coordinating and aligning funding in a meaningful, strategic, and sustainable way.
- Stakeholders may focus on cost-savings and shorter-term return on investment without a clear understanding of resource needs, the community's capacity to address systemic social needs, or the time needed to realize and measure returns on investment.
- Some market-driven financing solutions may yield siloed networks and/or favor certain kinds of services and organizations over others.

Opportunities

Opportunities and promising approaches for supporting and evaluating the financing model for implementers of SDOH information exchange include, but are not limited to:

- State and local grants.
- Private foundation grants.
- Healthcare payers' funding initiatives.
- Community stakeholder funding.
- Federal funding opportunities.
- CMS waivers, demonstrations, and other authorities.





- Opportunities to address SDOH through Medicaid and CHIP (as described in January 2021 State Health Official Letter from CMS).³³
- Health system transformation programs (e.g., CMS Innovation Center).
- Human services programs (e.g., Administration for Community Living No Wrong Door program³⁴).
- Challenge grants and innovation projects.
- Collaborative strategies for shared IT infrastructure financed through multiple stakeholders' investments and shared ownership.
- Services provision (e.g., evaluation, research, writing) and generating sustainable revenue for infrastructure through those services.
- Developing membership fees, including structures that enable reduced membership fees for smaller organizations.
- Other funding opportunities that can support SDOH information exchange needs and priorities.



Spotlight! Financing

Alliance for Better Health, located in Troy, New York, established a **Healthy Alliance IPA**, which focuses on **contracting opportunities between managed care plans and community-based organizations**. This is an example of a financing structure to support services that address SDOH to drive value-based care.

Questions To Consider

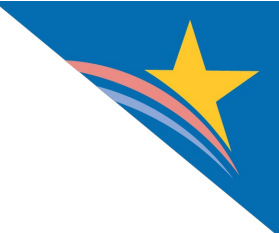
The following questions to consider can support implementers of SDOH information exchange initiatives with thinking through the financing model that will guide their activities, including investments in data and IT:

- In an equitable partnership arrangement: (1) who should finance each aspect of the initiative?; and (2) how should the funds be managed and distributed?
- How will the costs of developing the initiative and IT infrastructure be funded?
- What are the advantages and risks of different funding strategies?
- Who will design the funding strategy, and through what process?
- How do financing considerations relate to the scale of the initiative?
- Can multiple funding streams be leveraged for the initiative while meeting requirements of all funders and not duplicating effort?
- What financial resources are already being spent in the community on SDOH, including SDOH information exchange?

³³ <https://www.medicaid.gov/federal-policy-guidance/downloads/sho21001.pdf>

³⁴ <https://nwd.acl.gov/>



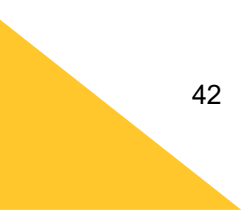


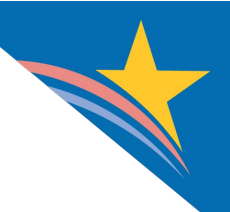
- How are the initiative’s values reflected in the financing strategy?
- Can existing resources be leveraged or combined to support broader community efforts and reduce duplication?
- What funding opportunities are available, and could the available funding be used for information technology, including SDOH information exchange?
- Does the community, health department, or state program have a similar initiative underway? If so, is there a way to leverage and expand what they have already built? If not, can they be a partner or help with financing or cost sharing?
- How can cost savings and benefits be measured and factored into financial planning?
- What start-up and ongoing costs and benefits will stakeholders incur? How do these costs align with their needs, capacities, and priorities?
- What capacities do service providers need to participate fully as partners in the initiative?
- What resources do providers need to adapt to new workflows and tools?
- What resources do providers need to accommodate new methods of service referral and delivery?
- Are there areas or activities where it is appropriate and useful to attach financial incentives to encourage participation?
- What are the risks of inequitable outcomes from various incentive structures, and how can such risks be mitigated?
- What is the sustainability plan for covering ongoing operational costs?
- What financing, revenue models, and/or funding opportunities can cover ongoing costs?
- Does the cost structure account for technology, governance, stakeholder capacity, and other critical elements?

Resources and Relevant Initiatives

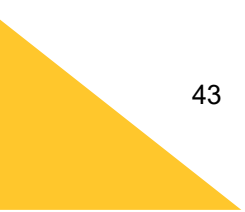
The following table provides information on relevant resources and initiatives related to financing for SDOH information exchange.

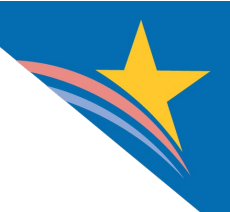
Resource	Author	Summary Information	Link
211/CIE® San Diego Toolkit	211/ CIE® San Diego	The CIE® Toolkit is designed to assist communities interested in learning how to harness the value of cross-sector collaboration and data sharing to develop a CIE® that enables a network of health, human, and social service providers to deliver coordinated, person-centered care to address social determinants of health to improve population health. There is a “Cultivate Sustainability” section of the toolkit that can inform financing strategies.	Link





Resource	Author	Summary Information	Link
Beyond the Grant: A Sustainable Financing Workbook	ReThink Health, A Rippel initiative	This workbook answers common financing questions and develops action plans for sustainability.	Link
Braiding and Blending Funds to Support Community Health Improvement: A Compendium of Resources and Examples	Trust for America's Health	This report is a compendium of resources on braiding and blending funding. The report includes examples of how state and local leaders leverage funding mechanisms to support health improvement efforts in their communities.	Link
Challenge: Innovative Technology Solutions for Social Care Referrals	Administration for Community Living (ACL)	The U.S. Department of Health and Human Services' ACL announced a competition for state and community leaders in the aging and disability network, healthcare systems, health plans, and health IT vendors to cultivate care coordination by developing and/or optimizing interoperable and scalable technology solutions. This is an example of a challenge that could be leveraged to develop or fund SDOH information exchange initiatives.	Link
CMS Innovation Models	CMS	The Innovation Center develops new payment and service delivery models in accordance with the requirements of section 1115A of the Social Security Act. Additionally, Congress has defined – both through the Affordable Care Act and previous legislation – a number of specific demonstrations to be conducted by CMS. A 2021 strategy refresh aims to embed health equity in every aspect of CMS Innovation Center models.	Link
CMS Value-Based Care Opportunities in Medicaid	CMS	This resource provides information on how states can advance value-based care (VBC) across their healthcare systems, with a particular emphasis on Medicaid populations, and pathways for adoption of such approaches with interested states. VBC seeks to hold providers accountable for providing high-quality care. It can also be a part of the solution to reduce health disparities in the healthcare system, maximize benefits to patients, and eliminate unnecessary procedures.	Link
Committee on Accounting for Socioeconomic Status in Medicare Payment Programs	The National Academies of Sciences, Engineering, and Medicine	This resource includes reports from the National Academies of Sciences, Engineering, and Medicine on accounting for social risk factors in Medicare payment.	Link





Resource	Author	Summary Information	Link
Grants.gov	Office of Management and Budget (OMB)	Managed by the U.S. Department of Health and Human Services, Grants.gov is an E-Government initiative operating under the governance of the Office of Management and Budget. Under the President's Management Agenda, the office was chartered to deliver a system that provides a centralized location for grant seekers to find and apply for federal funding opportunities. Today, the Grants.gov system houses information on over 1,000 grant programs and vets grant applications for federal grant-making agencies. The website also has a Grants Learning Center with information on the grant application and management process.	Link
Learn: Insights, Reports, Articles, and Commentary	Nonprofit Finance Fund®	Nonprofit Finance Fund® (NFF®) works toward a more equitable, responsive, and valued social sector. The "Learn" section of the website includes reports that detail lessons learned as they relates to financing for multisector initiatives.	Link
Leveraging Value-Based Payment Approaches to Promote Health Equity: Key Strategies for Health Care Payers	Center for Health Care Strategies	This report identifies six strategies to guide payers in developing equity-focused value-based payment approaches to mitigate health disparities at the state and local level. These strategies include articulating an equity goal, assessing the payment and care delivery environment, selecting performance measures, setting performance targets, designing the payment approach, and addressing operational challenges.	Link
ONC's Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brought together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The July 2022 Learning Forum Webinar was on the topic, "Policy and Funding."	Link
Opportunities to Advance SDOH Efforts Through Pooled Funding	National Alliance to impact the Social Determinants of Health (NASDOH)	This issue brief discusses how pooled funding is one mechanism to encourage cross-sector collaboration and ensure that a broad array of sectors jointly fund and share the benefits of SDOH investment.	Link



Resource	Author	Summary Information	Link
Return on Investment (ROI) Calculator for Partnerships to Address the Social Determinants of Health	The Commonwealth Fund	This calculator is designed to help community-based organizations and their health system partners plan sustainable financial arrangements to fund the delivery of social services to high-need, high-cost patients.	Link
Social Determinants As Public Goods: A New Approach to Financing Key Investments in Healthy Communities	<i>Health Affairs</i>	This article suggests that underinvestment in social determinants of health stems from the fact that such investments are in effect public goods. As such, benefits cannot be efficiently limited to those who pay for them, which makes it more difficult to capture the return on investment.	Link

FOUNDATIONAL ELEMENT: IMPLEMENTATION SERVICES

Summary Description: Inclusive of technical services (e.g., defining requirements, standards specifications, and integration with existing infrastructure and services) and programmatic services (e.g., defining use cases and workflow design/redesign), as well as support for adoption and utilization by individuals and the community.

Overview

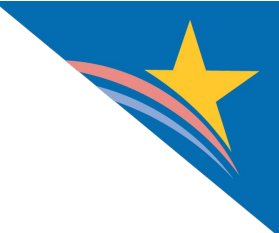
Implementation services relate to the implementation of technology, programmatic considerations, and user and community support as part of a SDOH information exchange initiative. The implementation process for SDOH information exchange initiatives is complex, multifaceted, and iterative.

Challenges

Technical and programmatic implementation challenges for SDOH information exchange initiatives include, but are not limited to:

- Initiatives may be focused on technical implementation of technology products without sufficient consideration of other aspects—for example, ensuring key leaders are included in the development and/or selection of the products to support execution.
- Community stakeholders may not regularly and consistently be engaged in designing the flow of information and how it is used, which can result in provider burnout if the process is too prescriptive or requires additional workarounds.
- Community stakeholders may be tasked with joining multiple platforms or platforms outside of their existing systems without vendor support and/or financial capacity to integrate systems.
- Stakeholders can have different viewpoints and priorities for implementation steps and timelines.
- Resource and referral directories may not always be updated or current.
- There are many facets to successful implementation of complex multisectoral projects, requiring intensive technical assistance, time, and resources to achieve improved health outcomes.





Opportunities

Opportunities and promising approaches for implementation of SDOH information exchange include, but are not limited to:

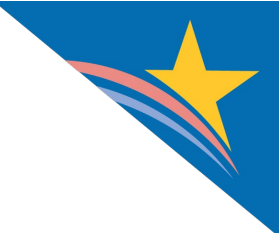
- Starting with stakeholder engagement and process design (e.g., use case articulation, workflow development, agreements, monitoring, etc.) before technology design and implementation.
- Leveraging governance structures to engage and educate community stakeholders in the adoption of technical and programmatic services, as well as to solicit and act upon feedback about implementation priorities and risks.
- Designating specific roles at adopting institutions to steward internal change-management processes and to represent the organization and community's interest through governance processes.
- Conducting a landscape analysis to understand the technical capabilities and capacity of existing data systems, including data types and data flow.
- Providing incentives for the adoption of technical resources to support community stakeholders.
- Establishing capacity for evaluation of regulatory compliance and ethical responsibility in each phase of implementation processes.
- Leveraging existing community and healthcare networks for implementation support and to act as communication vehicles to establish efficient and effective rollout efforts (e.g., United Ways, 211s, Accountable Communities for Health, and HIEs).
- Mapping out workflows and data flow processes to facilitate interoperability, including how data are captured, shared, and standardized across systems.
- Seeking out informational resources, technical assistance, and peer initiatives to help inform complex implementation processes.



Spotlight! Implementation Services

Trenton Health Team (THT) supports multisector partnerships through its community advisory board and in its role as one of four “State-designated Regional Health Hubs” in New Jersey. THT collaborates with clinical and community-based organizations to improve health and well-being, with a focus on health equity, chronic diseases, adverse childhood experiences, maternal child health, healthy food, and other pressing SDOH issues. THT operates the region's HIE, which matches patient health records across providers, contains Medicaid claims data, connects to the state's HIN (NJHIN), and integrates SDOH data with clinical records to further enrich population-level data analysis.





Questions To Consider

The following questions to consider can support implementers of SDOH information exchange initiatives with thinking through implementation services that will guide their activities:

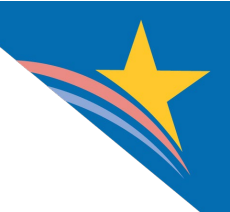
- Have assessments been done to identify existing data systems, processes, and workflows for referrals or data sharing?
- Who will assist agencies and providers in integrating SDOH information exchange into their workflows?
- How will the community promote adoption of SDOH information exchange?
- Will committed resources and staff assist providers and agencies with workflow redesign?
- What agreements are needed to support expectations of the appropriate use and effective adoption of the SDOH information exchange (e.g., service level agreements and memoranda of understanding)?
- What technical support and training will be provided to community stakeholders during implementation and operations?
- What use cases and workflows will be supported?
- How is the effort being shared with the community? How will individuals and patients be made aware of the system? How are they engaged in implementation?
- How will the SDOH information exchange initiative be kept up to date with referral resource network information, and whose responsibility will this be?
- How does the implementation support adoption and utilization and ensure sustainable ongoing support for clinicians, support staff, case managers, and other staff working with the system?

Resources and Relevant Initiatives

The following table provides information on relevant implementation resources and initiatives for SDOH information exchange.

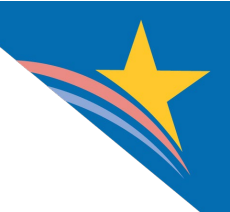
Resource	Author	Summary Information	Link
211/ CIE® San Diego Toolkit	211/ CIE® San Diego	The CIE® Toolkit is designed to assist communities interested in learning how to harness the value of cross-sector collaboration and data sharing to develop a Community Information Exchange® (CIE®) that enables a network of health, human, and social service providers to deliver coordinated, person-centered care to address SDOH to improve population health. The “Adopt Interoperable and Scalable Technology” section can inform implementation efforts for SDOH information exchange.	Link





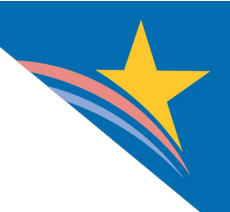
Resource	Author	Summary Information	Link
Accountable Health Communities Model	CMS	The Accountable Health Communities Model addressed a critical gap between clinical care and community services in the current healthcare delivery system by testing whether systematically identifying and addressing the health-related social needs of Medicare and Medicaid beneficiaries through screening, referral, and community navigation services will impact healthcare costs and reduce healthcare utilization. This webpage contains evaluations, screening tools, and case studies and lessons learned from the Accountable Health Communities Model.	Link
Advancing Interoperability: Social Determinants of Health Workshop	ONC	This ONC-hosted public workshop provided stakeholders with information and tools needed for the development of the SDOH data management in clinical practice guidelines and maintenance of certification activities. Takeaways (included in the video and slides) from this workshop can inform SDOH information exchange efforts.	Link
Electronic Exchange of Data and “Closing the Loop”	National Center for Medical-Legal Partnership	This case study provides a concrete example of how a medical-legal partnership (MLP) in Iowa set up electronic referrals in the EHR as well as the ability to “Close the Loop” via electronic updates from the legal partner. Those updates are delivered directly to the EHR and describe whether the patient connected with legal assistance and the legal outcomes of that assistance.	Link
Guide to Implementing Social Risk Screening and Referral-making	Social Interventions Research and Evaluation Network (SIREN), Kaiser Permanente Center for Health Research, OCHIN, Inc.	This guide was developed by teams at the Kaiser Permanente Center for Health Research and OCHIN, Inc. as part of an NIH-funded study (1R18DK114701). The purpose of this study was to test the effectiveness of targeted implementation support at enhancing social risk screening adoption in primary care settings and community health centers.	Link
Healthcare Information and Management Systems Society (HIMSS) Social Determinants of Health	HIMSS	HIMSS provides information on standards, SDOH health assessments, workflow considerations, and policy considerations for SDOH information exchange implementation.	Link





Resource	Author	Summary Information	Link
Implementing a Community Referral Platform: Recommendations From a Real-World Implementation Experience	National Committee for Quality Assurance (NCQA)	There are many community resource referral platforms on the market, and the journey to implementation is not straightforward. This catalog of implementation challenges, lessons learned, and recommendations is designed to be a guide for organizations implementing a community resource referral platform.	Link
ONC's Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data.	Link
Project Resources Archives	Agency for Healthcare Research and Quality (AHRQ)	The Project Resources Archives is a collection of resource documents that have been collected from the AHRQ Digital Healthcare Research projects. The documents include example data collection forms, logging tools, and checklists, among many others. All documents may be used as examples and adapted to local needs. Some of the materials in this archive can support implementation activities and include a communications tracking document, letter for patients to inform them about a new program, sample data analysis protocol, focus group consent form, governance considerations document, sample timeline, usability testing script, and more.	Link
Roundtable Report: Leveraging Data on the Social Determinants of Health	Center for Open Data Enterprise (CODE), HHS Office of the Chief Technology Officer (CTO)	<p>This report summarizes three roundtables that focused on finding ways to improve how health data are shared and utilized for the public good. The report includes recommendations and solutions for SDOH information exchange implementation, including:</p> <ul style="list-style-type: none"> • Defining and standardizing SDOH data • Improving and aligning open source assessment tools • Adopting data standards • Developing a data governance body • Financing sustainable SDOH data infrastructure • Creating a SDOH strategy • Other considerations 	Link
SHARP Function Checklist	Aging and Disability Business Institute, Partners in Care Foundation	This tool is designed to help community-based organizations (CBOs) that are already beginning to work with Social Health Access Referral Platforms (SHARPs) or those that may be considering working with SHARPs in the future by providing information on the issues and impact that working with a SHARP may have on your CBO.	Link





Resource	Author	Summary Information	Link
You've Got Mail! A Spotlight on Using Email to Screen for Health-Related Social Needs	CMS	This spotlight describes Denver Regional Council of Governments' approach to designing, implementing, and tracking the success of an email campaign to screen for health-related social needs as part of an Accountable Health Communities model. This is an example of innovation to address workflow and implementation challenges.	Link

FOUNDATIONAL ELEMENT: TECHNICAL INFRASTRUCTURE AND DATA STANDARDS

Summary Description: Alignment of hardware, software, data, processes, and standards to enable scalable and interoperable data and IT systems.

Overview

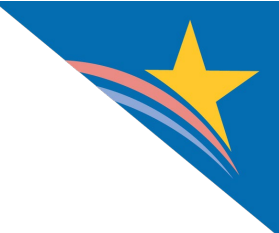
SDOH information exchange initiatives have important considerations, particularly since they often involve information exchange across systems and between many organizations and entities in the community. Standards and vendor-agnostic approaches help to facilitate interoperability in the capture, exchange, and use of SDOH data.

Challenges

Challenges related to IT infrastructure that supports and enables SDOH information exchange initiatives include, but are not limited to:

- Communities may have diverse technology landscapes, and some organizations and networks may not desire or be able to start using a new technology system.
- Standards are evolving, making it challenging to consistently implement technical solutions.
- Vendors have varying levels of readiness for and interest in emerging standards or interoperability.
- Software with limited interoperability capacity can result in the emergence of new silos.
- Implementing entities may be tasked with bearing the costs of establishing and developing interoperable solutions.
- Business and governance models may not be designed to accommodate the needs of human services organizations, community-based organizations, and other community stakeholders.
- Maintenance costs may exceed community stakeholders' available resources.
- Stakeholders, service providers, and individuals can have varying device and internet access and connectivity or face other digital access barriers.
- Service providers may have differing understandings of and capacities to use IT standards or receive the technical support and training needed for staff.
- Existing technical infrastructure may be based on healthcare contexts and may not account for standards across SDOH domains and community contexts.





- Some initiatives may initially focus on the technical infrastructure to begin health and social data exchange, rather than data standards and other Social Determinants of Health Information Exchange Foundational Elements that can help drive a holistic implementation approach.
- Technical infrastructures must protect and secure SDOH information and address any cybersecurity incidents or breaches when they may occur.
- Competing technical infrastructures, differing screening tools, and limited use of data standards in the same community can result in burden for users, fragmented adoption, duplicative data entry, and multiple logins.

Opportunities

Opportunities and promising approaches for implementing IT infrastructure for SDOH information exchange include, but are not limited to:

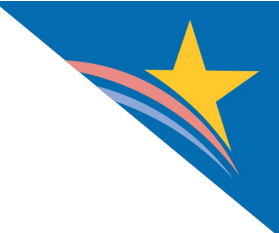
- Emerging technology standards from the Gravity Project that expand available SDOH core data for interoperability using HL7[®] FHIR[®] and standards from ONC's 360X Project that support social care referrals using IHE profiles.^{35 36}
- Open Referral's Human Service Data Specifications (HSDS) are emerging standards that can enable resource directory data sharing.³⁷
- Standardized open APIs can enable vendor-neutral implementation strategies, as any compliant third-party system can access the same data and functionality.
- Nimble technical solutions using open APIs can support the secure, appropriate flow of information across disparate systems and with care teams working in the field.
- Existing HIEs' technology infrastructure can be leveraged for exchanging client information among human services providers.
- Authentication processes can be standardized to enable resource-to-resource directory exchange and standardized directories.
- A designated steward of the resource directory data can be established and funded, prioritizing the involvement of organizations that already maintain resource directories in a community.
- Cooperative strategies for bundling costs of interoperability among many users of a software system can be developed.
- Independent validation and verification can be required and resourced to ensure IT vendors' compliance with standards.
- Security and privacy considerations can be included in the design of technical infrastructure and processes can be established to continuously monitor information security threats and privacy considerations.

³⁵ <https://oncprojecttracking.healthit.gov/wiki/display/TechLab360X/360X+Home>

³⁶ <http://hl7.org/fhir/us/sdoh-clinicalcare/2022Jan/>

³⁷ <https://openreferral.org/faqs/what-is-the-human-service-data-specification-hsds/>





- Other management information systems, such as homeless management information systems, can be leveraged or examined for how they are standardized and used for care coordination.



Spotlight! Technical Infrastructure and Data Standards

Based in Colorado, [Quality Health Network](#) focuses on **sharing information across health information exchange (HIE) and social service organizations**, which supports care coordination, referrals, and data analytics utilizing the complete health picture, including medical, behavioral, and social information.

Questions To Consider

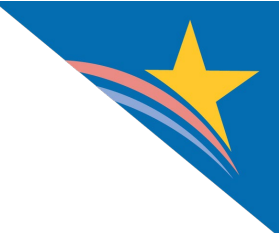
The following questions to consider on IT infrastructure can support implementers of SDOH information exchange initiatives:

- What technical assessments have been done to understand the landscape of existing technology tools and data fields, and what lessons have been learned?
- What are the hardware and software needs to support priority services and use cases for the community? How will these investments be sustained and scaled?
- What are the applicable health IT standards (i.e., vocabulary/terminology, content/structure, services/exchange, administrative) to support community needs and use cases?
- Are IT solutions and services being designed for data and system interoperability? What are the relevant health IT standards that should be used?
- What technical infrastructure and capacity building is needed to support community-based organizations to meet technical requirements?
- How are you taking security and privacy considerations into account in your design and technical infrastructure?

Resources and Relevant Initiatives

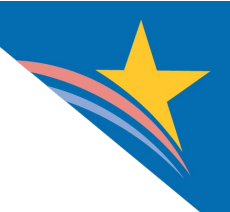
The following table provides information on relevant resources and initiatives focused on implementing technical infrastructure and data standards for SDOH information exchange.





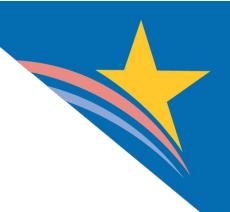
Resource	Author	Summary Information	Link
360X: Closed Loop Transitions of Care Project	ONC	360X is a series of Integrating the Healthcare Enterprise (IHE) approved, and in process, specifications that describe functionality to be deployed directly from the initiating (referred or transferred by) clinical EHR to the receiving (referred or transferred to) clinical EHR to track patient care transitions across the spectrum of care. 360X requires only ubiquitously adopted technology standards. Therefore, it represents a relatively low bar for EHR development and implementation. It is important to note that the 360X specifications are freely available and are themselves not a product.	Link
360X: SDOH Referrals	ONC	Building upon the clinical use cases, work is underway to finalize a specification for referrals to community-based organizations to support SDOH.	Link
ACF Human Services Interoperability Innovations (HSII)	Administration for Children and Families (ACF)	The ACF Interoperability Initiative provides leadership and technical support to increase the capacity and efficiency of social service data systems to share data in a consistent, reliable manner. These efforts include creating common vocabularies for more consistent capture of data, providing promising practices for interoperability architecture planning and system integration, and understanding and mitigating risks associated with the privacy and confidentiality of the information.	Link
Broadband Progress Reports	Federal Communications Commission (FCC)	High-speed broadband and the digital opportunity it brings are increasingly essential to innovation, economic opportunity, healthcare, and civic engagement in today's modern society. With this Report, the commission fulfills the Congressional directive to report annual progress in deploying broadband to all Americans.	Link
Civitas Networks for Health	Civitas Networks for Health	The Network for Regional Healthcare Improvement (NRHI) and Strategic Health Information Exchange Collaborative (SHIEC) joined forces to form Civitas Networks for Health in 2021. Civitas Networks for Health is a national collaborative comprised of member organizations working to use health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health. Communities can contact Civitas to be connected with local member organizations.	Link





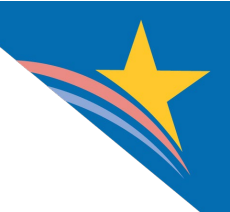
Resource	Author	Summary Information	Link
Closed Loop Referrals Implementation Guide	Michigan Health Information Network (MiHIN)	This implementation guide may serve as a resource for those implementing electronic referral and care coordination functions. Relevant sections in the guide include message content, data flow and actors, standards, message formats, onboarding, legal processes, initial connectivity process, specifications for referral and general messages, and troubleshooting.	Link
Community Resource Referral Platforms: A Guide for Health Care Organizations	Social Interventions Research and Evaluation Network (SIREN)	To help healthcare organizations understand what new technologies offer, SIREN has developed a guide that explores the landscape of community resource referral platforms and the experiences of early adopters. Drawing upon a review of nine commonly used platforms and interviews with 39 organizations in the process of selecting or implementing a platform, the guide provides a primer on the current features and functionalities of these technologies and distills lessons learned and recommendations on how to implement a community resource referral platform.	Link
Health Center Controlled Networks (HCCNs)	Health Resources and Services Administration (HRSA)	Health Center Controlled Networks (HCCNs) are groups of health centers working together to use health IT to improve operational and clinical practices. HCCNs help health centers leverage health IT to increase participation in value-based care by enhancing the patient and provider experience, advancing interoperability, and using data to enhance value. HCCNs are an example of a collaborative strategy for technical infrastructure.	Link
Health IT Playbook	ONC	In the ONC Health IT Playbook, providers will find strategies and promising practices, researched and gleaned from a variety of clinical settings, to help them find the support they need. The playbook is intended to help with implementing and using health IT in practices to advance care information and delivery.	Link
Health IT Standards	ONC	ONC is working to enable the health IT community to convene and rapidly prioritize health IT challenges and subsequently develop and harmonize standards, specifications, and implementation guidance to solve those challenges. ONC is also responsible for curating the set of standards and specifications that support interoperability and ensuring that they can be assembled into solutions for a variety of health information exchange scenarios. These standards may be applied to SDOH information exchange initiatives.	Link





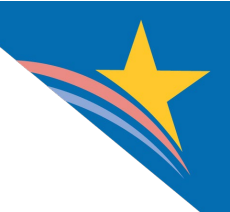
Resource	Author	Summary Information	Link
HL7 Gravity Project	HL7/Gravity Project	The Gravity Project seeks to identify data elements and associated value sets to represent SDOH information documented in the clinical care setting across the four primary activities of care: screening, diagnosis, goal setting, and intervention activities.	Link
Human Services Data Specification (HSDS)	Open Referral	The Human Services Data Specification (HSDS) is Open Referral's core data exchange format. HSDS is designed to support the publication of open, interoperable community resource directory data.	Link
Interoperability Standards Advisory (ISA)	ONC	ISA is ONC's catalog of curated standards and implementation specifications for health information interoperability that is updated annually and reflects extensive feedback from industry and federal agencies. ISA includes standards that support SDOH and health equity.	Link
Leading Edge Acceleration Projects (LEAP) in Health Information Technology (Health IT)	ONC	LEAP in Health IT advances the development and use of interoperable health IT by addressing emerging and future challenges. The healthcare field must quickly innovate and leverage the latest technological advancements and breakthroughs to optimize real-time solutions, especially in areas that are ripe for acceleration. LEAP in Health IT projects address these challenges by encouraging a new generation of health IT development and refining and implementing relevant standards, methods, and techniques. This page includes information on the LEAP projects.	Link
NIST Privacy Framework: A Tool for Improving Privacy Through Enterprise Risk Management	National Institute of Standards and Technology (NIST)	This privacy framework offers a tool for organizations to enable better privacy engineering practices that support privacy design concepts and help organizations protect individuals' privacy. It offers flexibility to address diverse privacy needs, enables more innovative and effective solutions that can lead to better outcomes for individuals and organizations, and stays current with technology trends.	Link
ONC Health IT Framework for Advancing SDOH Data Use and Interoperability	ONC	Addressing health inequities can be supported in part through the collection, documentation, reporting, access, and use of SDOH data. This data can be used to help identify and eliminate health disparities and to improve health outcomes at an individual and population level. ONC focuses on four key areas with respect to how health IT can be used to help achieve this: (1) standards and data, (2) infrastructure, (3) policy, and (4) implementation. This framework can inform SDOH information exchange efforts.	Link





Resource	Author	Summary Information	Link
ONC SDOH	ONC	ONC provides information on health IT-related SDOH projects and activities, including standards and certification, and activities of other federal agencies that can be incorporated into SDOH IT infrastructure.	Link
ONC's Social Determinants of Health Information Exchange Learning Forum	ONC	The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The June 2022 Learning Forum Webinar was on the topic, "Technical Infrastructure and Interoperability."	Link
Patient Identity and Patient Record Matching	ONC	Patient matching is a critical component of interoperability and the nation's health information technology infrastructure. This ONC webpage provides background information on patient matching efforts at ONC.	Link
Project Unify	National Interoperability Collaborative	Project Unify is exploring the use of existing and draft standards to implement secure information sharing and interoperability across healthcare, behavioral health, and human services, as well as other domains (e.g., education, child welfare, etc.) that encompass SDOH and wellbeing for individuals, families, and communities.	Link
Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE)	The National PRAPARE Partnership	PRAPARE is a national standardized patient risk assessment protocol designed to engage patients in assessing and addressing SDOH. PRAPARE is evidence-based, designed through stakeholder engagement, paired with an Implementation and Action Toolkit, and standardized across ICD-10, LOINC, and SNOMED.	Link
Security Risk Assessment (SRA) Tool	ONC	ONC, in collaboration with the HHS Office for Civil Rights (OCR), developed a downloadable Security Risk Assessment (SRA) Tool to help healthcare providers conduct security risk assessments as required by the HIPAA Security Rule and the CMS Electronic Health Record (EHR) Incentive Program.	Link





Resource	Author	Summary Information	Link
Social Determinants of Health Data Interoperability	National Alliance to Impact the Social Determinants of Health (NASDOH)	NASDOH, with guidance from the work of the CARIN Alliance, developed this brief to describe a pathway to develop a secure consumer- and community-centric, open, interoperable SDOH data ecosystem. It focuses on creating a data ecosystem where SDOH data are shared seamlessly, privately, and securely. Such data sharing is foundational to addressing the impacts of SDOH on individuals and to informing public and population health policy actions that impact SDOH upstream.	Link
State Innovation Model Resource Center	ONC	This comprehensive set of tools provides technical support and expertise to State Innovation Model (SIM) states and can be leveraged to support health IT innovation in care delivery and payment systems. These tools include interoperability, alerting and clinical messaging, ID management, provider directory, and other resources.	Link
Substance Abuse Confidentiality Regulations FAQs and Fact Sheets	Substance Abuse and Mental Health Services Administration (SAMHSA)	This resource contains information on regulations for substance abuse confidentiality, including fact sheets and frequently asked questions. These regulations should be considered when creating technical infrastructure.	Link
The DC Community Resource Information Exchange: Phase One Report	Open Referral	The District of Columbia's (DC) Department of Health Care Finance (DHCF) initiated the DC Community Resource Information Exchange (DC CoRIE) to develop data infrastructure that supports coordinated screening, referral and tracking across a range of health, human, and social services in DC. The approach used was "vendor-agnostic" and has been adopted in other communities to enable interoperable exchange of SDOH data.	Link Link
The electronic Long-Term Services and Supports (eLTSS) Implementation Guide	Security Risk Solutions, Carradora Health, Ready Computing, By Light Professional IT Services	The eLTSS Implementation Guide (IG), based on FHIR® R4 , is a standard that was developed to support the creation, exchange, and re-use of interoperable service plans for use by healthcare and community-based long-term services and supports providers, payers, and the individuals they serve.	Link
U.S. Core Data for Interoperability (USCDI) Webpage	ONC	The USCDI is a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange. USCDI v2 includes SDOH data elements such as SDOH assessment, SDOH goals, SDOH problems/health concerns, and SDOH interventions.	Link



FOUNDATIONAL ELEMENT: USER SUPPORT AND LEARNING NETWORK

Summary Description: User support and learning network activities include assessment of community challenges and needs, education, communication, training, technical assistance, peer-to-peer learning, and identification of promising practices and lessons learned.

Overview

Training and collaborative learning can help to build and sustain the workforce and collaborative networks to support SDOH information exchange efforts.

Challenges

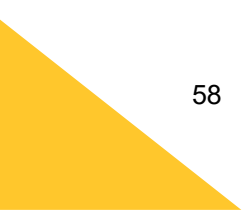
Challenges related to user support and learning networks for SDOH information exchange initiatives include, but are not limited to:

- Few available networks supporting peer-to-peer learning for community stakeholders, including opportunities for healthcare and community-based organizations to interact together.
- Limited funding to support learning and information sharing among key stakeholders.
- Difficulty ensuring ongoing training support with staff turnover.
- Existing gaps in community stakeholder workforce capacity.
- Unmet digital literacy needs across community stakeholders.
- Understanding of local community needs, populations, and disparities in order to address SDOH in the community of focus.

Opportunities

Opportunities and promising approaches for user support and learning across SDOH information exchange initiatives include, but are not limited to:

- Sharing promising practices, case studies, and data-driven examples of impact and other lessons learned with stakeholders, collaboratives, and other similar initiatives.
- Engaging with individuals to learn from their experiences and inform improvements.
- Investing in community stakeholders' workforce capacity.
- Supporting working groups, technical assistance, and ongoing user support and adoption assistance.
- Establishing feedback loops from user support systems to governance processes for learning networks to inform decision-making in the overall systems.
- Having an ongoing training plan to support new member organizations, service providers, and staff.





Spotlight! User Support and Learning Network

Data Across Sectors for Health (DASH), a national initiative of the Robert Wood Johnson Foundation, led in partnership by the Illinois Public Health Institute and MPHI, bridges new possibilities in data sharing to advance equity. Through its work, DASH connects multisector collaborations and communities to each other to learn and gain deeper understandings, enhancing the capacity-building potential to shift power and increase wellbeing. In addition to this work, DASH also serves as the convening partner of All In Data for Community Health, which includes the **All In-Network** as an online platform for collaborative learning, resource sharing, engaging in promising practices, and tools to build equitable systems.

Questions To Consider

The following questions to consider can support implementers of SDOH information exchange initiatives with thinking through user support activities and learning networks to engage in information sharing.

- How is the initiative's engagement with service providers, individuals, and stakeholders sustainable and ongoing?
- Do community stakeholders have sufficient awareness, training, and experience? How will gaps be addressed?
- Who leads training, support, technical assistance, and an ongoing peer-to-peer learning network?
- What are the data literacy and digital literacy capabilities of users and stakeholders, and what resources and training can support building their capacity?
- How can learning networks support training on health equity and SDOH concepts?
- How will communication and promising practices be shared across the network?
- How will you gather feedback from users on needs, challenges, and opportunities? How will you consider that feedback?
- What are the relevant initiatives or use cases that this learning network could support?
- What target populations or sectors would experience the most impactful outcomes using SDOH information exchange, and how could the learning network be leveraged in this process?

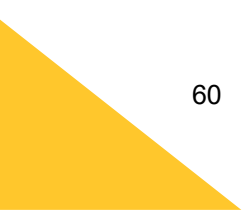
Resources and Relevant Initiatives

The following table provides information on relevant user support and learning network resources and initiatives for SDOH information exchange implementers.





Resource	Author	Summary Information	Link
211 Network	United Way	211 is a source of information on local resources and services around the country. The 211 Network in the United States responds to more than 20 million requests for information/help every year (e.g., emergency information, shelter and housing options, utilities assistance, supplemental food and nutrition programs, etc.). The tools and postings on this website could be used in user support and learning network activities.	Link
AISP Resource Library	Actionable Intelligence for Social Policy (AISP)	This resource library contains reports and tools on data integration, including information on systems linkage, research, evaluation, funding, equity, community engagement, privacy, and other considerations.	Link
Civitas Networks for Health	Civitas Networks for Health	The Network for Regional Healthcare Improvement (NRHI) and Strategic Health Information Exchange Collaborative (SHIEC) joined forces to form Civitas Networks for Health in 2021. Civitas Networks for Health is a national collaborative comprised of member organizations working to use health information exchange, health data, and multi-stakeholder, cross-sector approaches to improve health. Lessons shared through this group can be used in user support and learning network activities.	Link
Communities of Practice (CoPs)	CDC	Communities of Practice (CoPs) provides a collaborative framework for public health professionals to work together to identify and leverage promising practices and standards. Through these evolving collaborative efforts and sharing of lessons learned in the community building process, the community of practice approach is being implemented in many public health areas as a model for how public health partners work together. This website includes a CoP Resource Kit, which includes insights for launching, sustaining, evolving, and evaluating a CoP.	Link
Community Health Peer Learning Program	AcademyHealth	In partnership with ONC, AcademyHealth's Community Health Peer Learning (CHP) Program engaged 15 communities in a peer learning collaborative to identify data solutions, accelerate local progress, and disseminate promising practices and lessons learned. Resources on this page include bright spots, blog posts, and learning guides that could be used as informational resources for communities looking to implement similar efforts.	Link



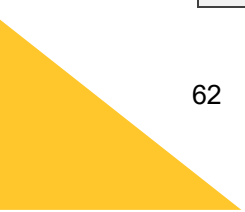


Resource	Author	Summary Information	Link
Data Across Sectors for Health (DASH)	DASH	<p>The Robert Wood Johnson Foundation (RWJF) is working to foster alignment among healthcare, public health, and other community systems to address the multiple determinants of health and improve the health of communities. DASH aims to support community collaborations in their efforts to:</p> <ul style="list-style-type: none"> • Address locally determined problems or goals associated with better community health • Enhance communities’ ability to plan, make decisions, implement health improvement activities through sharing data and information in a sustainable way • Identify methods, models, and lessons that can be applied locally and shared with other communities that wish to improve their ability to share data and information across sectors 	Link
Introduction to Data Sharing and Integration	Actionable Intelligence for Social Policy (AISP)	<p>This Introduction to Data Sharing & Integration was created by Actionable Intelligence for Social Policy (AISP) as a primer on the basics of using, sharing, and integrating administrative data. This resource is designed to help partnerships, collaboratives, agencies, and community initiatives enter into that process of repurposing administrative data thoughtfully and of building the capacity to do so routinely with strong governance in place.</p>	Link
Moving Health Care Upstream	Nemours Children’s Health	<p>The Tools and Resources section of the Moving Health Care Upstream initiative contains resources for navigating the healthcare system, financing and payment models, healthcare and community partnerships, leading change, and policy strategies.</p>	Link
ONC’s Social Determinants of Health Information Exchange Learning Forum	ONC	<p>The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data.</p>	Link





Resource	Author	Summary Information	Link
ONC SDOH Workshops	ONC	These six recorded workshops from ONC are on topics related to SDOH information exchange and interoperable referrals. They could be used to provide stakeholders with background information and include examples of SDOH information exchange initiatives in the field.	Link Link Link Link Link Link
ONC Workforce Development Programs	ONC	Health IT curriculum resources on topics such as healthcare and public health, information and computer science, population health, care coordination, interoperable health IT systems, workflow process improvement, quality improvement, working in teams, project management, leadership, value-based care, healthcare data analytics, and patient-centered care.	Link
Resource Domains	Health Information Technology, Evaluation, and Quality Center (HITEQ)	The HITEQ Center collaborates with Health Resources and Services Administration (HRSA) partners including Health Center Controlled Networks (HCCNs), Primary Care Associations (PCAs) and other National Cooperative Agreements (NCAs) to support health centers in full optimization of their EHR/Health IT systems. The center includes publicly available resources on workforce development, and topics for learning network activities, such as privacy and security, patient engagement, population health, and more.	Link
Resource Library	Health Leads	This resource library contains information on SDOH information exchange, SDOH screening tools, data mapping, community engagement, equity, and more.	Link
Siren Evidence & Resource Library	Social Interventions Research and Evaluation Network (SIREN)	The SIREN Evidence & Resource Library includes both peer-reviewed publications and other types of resources such as webinars and screening tools/toolkits on medical and social care integration. These resources may be useful for peer-to-peer learning, training, and identification of promising practices as relates to SDOH information exchange.	Link
Training and Professional Development	CDC	Training and professional development strengthen the public health workforce by helping professionals learn new skills and advance their careers. This webpage contains resources for professional development and continuing education, including for topics such as leadership, systems thinking, public health, informatics, health economics, public health law, and more.	Link





Resource	Author	Summary Information	Link
Voices from the Field: Recruiting and Hiring for Social Determinants of Health Screening	Corporation for Supportive Housing (CSH)	This self-paced resource includes modules exploring the success and challenges of recruiting, hiring, and retaining staff to provide screenings for Social Determinants of Health within community health centers. Learn from the voices of professionals in the field on how to address barriers and amplify the role of peer specialists.	Link
What is CIE®?	Community Information Exchange® (CIE®)	The webpage provides an overview of the CIE® concept and opportunities for peer-to-peer learning.	Link

FOUNDATIONAL ELEMENT: GOVERNANCE

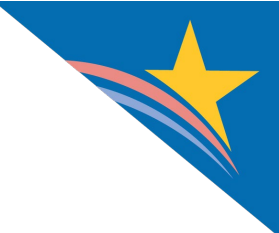
Summary Description: Decision-making processes and groups, including as relates to institutional, administrative, and data governance.

Overview

Governance consists of several levels of decision-making, including:

- Institutional governance:** Context in which the terms of participation are established, including the processes by which leadership and service providers are organized, administered, and removed; priorities are set and adjusted; rulemaking processes are established and changed; outcomes are evaluated; and institutional conflicts are resolved.
- Administrative governance:** Context in which policies, as prioritized by institutional governance, are designed, implemented, monitored, and enforced—including those pertaining to regulatory compliance, agreements for information sharing and use, and operational standards.
- Data governance:** Context in which policies established by administrative governance are implemented and enforced through processes of data stewardship, such as rules for technical standards and data collection, management, storage, exchange, verification, validation, contestation, and deletion.





Challenges

Challenges related to governance of SDOH information exchange initiatives include, but are not limited to:

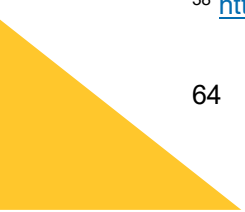
- There may be limited stakeholder engagement and representation in governance models, resulting in stakeholders having limited agency in priority-setting, decision-making, evaluation, and shared ownership.
- Governance models may be primarily focused on data governance concerns, without addressing concerns of institutional design, such as member rights and responsibilities, authority related to decision-making and conflict resolution, monitoring and compliance, and harm reduction and remediation.
- Stakeholders may have differing understandings of institutional, administrative, and data governance principles and practices.
- There may be existing governance processes underway across local, regional, tribal, and/or state jurisdictions, which highlights the need for coordination and alignment.
- Implementing governance considerations takes time and resources, which may be limited for the stakeholders involved.

Opportunities

Opportunities and promising approaches for governance of SDOH information exchange initiatives include, but are not limited to:

- Establishing appropriate and accessible governance structures and processes through which designated stakeholder representatives can help set priorities, establish accountability, and wield collective leverage in the change-making process.
- Identifying trusted, community-led organizations to convene and steward initiatives.
- Designing and documenting clear arrangements for making, evaluating, and updating agreements over time, such as a project charter, procedures, and nested working group structure.
- Considering legal mechanisms for establishment of fiduciary responsibilities and participatory oversight, such as a “data trust.”³⁸
- Clearly identifying different kinds of stakeholders and establishing appropriate roles for and processes with them.
- Developing principles of equitable governance that individuals and entities adhere to and that are accessible to individuals, service providers, and other stakeholders.
- Aligning governance processes across various jurisdictions and service domains.
- Seeking out resources, technical assistance, and information on governance for community initiatives related to multisectoral information exchange in communities.

³⁸ <https://docs.google.com/document/d/118RqyUAWP3WlYyCO4iLUT3oOobnYJGibEhspr2v87jg/edit>





Spotlight! Governance

St. Louis Regional Data Alliance in Missouri is an example of a promising data governance initiative whose mission is to build shared data infrastructure and support strong data actors to improve people's lives. Its work is shaped by over 350 local members who guide efforts to develop responsive data practices across sectors, including social services, public health, education, and community development.

Questions To Consider

The following questions to consider can support implementers of SDOH information exchange initiatives with thinking through governance models and approaches that will guide their activities.

Institutional governance:

- How will the terms of membership and participation in the system be established?
- Who will decide the terms of membership and participation, and who will decide the rules of the system?
- How will decision-makers be chosen, and how will they be held accountable to the service providers and individuals?
- How are the diverse interests, needs, and experiences of stakeholders reflected in the governance structure?
- What actions are taken so participants are supported, informed, and actively engaged in decision-making?
- How can the governance processes of the system effectively align with related governance systems at the local, tribal, and/or state level?
- How can all relevant community stakeholders receive the information required in order to be meaningfully involved?

Administrative governance:

- How will the policies pertaining to information sharing, incentives, and evaluation be made and changed?
- Who will be responsible for facilitating policy making, implementation, and enforcement? Who should be subject to mechanisms of accountability?
- How can activities be monitored, and how will rules be enforced?
- What is the plan for identifying, mediating, and addressing conflicts or potential harms?
- How will individuals and service providers be continuously informed of the purpose of data collection; how data will be used; governance structures; privacy considerations; and other important characteristics of the SDOH information exchange initiative? How can they share their concerns, feedback, and experiences?





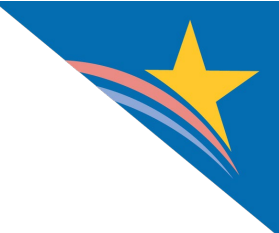
Data governance:

- Given the agreements and policies pertaining to information collection, sharing, management, and use set through administrative governance processes, who should be allowed to use data and for which situations?
- How will consent, data access, and other permissions be made and managed? Does this vary across context, data type, data source, use case, or population?
- How will changes in social risks (i.e., changes in housing or employment status) be consistently captured in screening tools and be reflected across systems?
- How does your data governance model align or not align with the values and principles of the SDOH information exchange initiative?
- What data standards and technical system design will your initiative adopt, and how will those standards be implemented and monitored?
- To what extent will the initiative’s infrastructure be “vendor-agnostic,” and what provisions should be in place to ensure such terms?
- How will data be captured, stored, shared, and secured throughout the data’s lifecycle?
- What data are shared with other entities, and how is such sharing made known to individuals, service providers, and other stakeholders?
- How will metadata and other administrative data processes be managed?
- What roles should service providers and individual users have in data governance, and how can they manage permissions and access to data?
- What agreements and processes need to be established and maintained as part of the data governance process?
- How will errors, data gaps, and other concerns be identified and addressed?
- What policies and/or controls are in place within organizations and communities regarding data access and data quality?

Resources and Relevant Initiatives

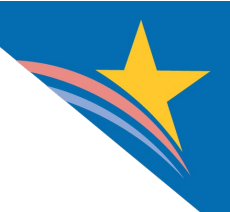
The following table provides information on relevant resources related to governance in SDOH information exchange.





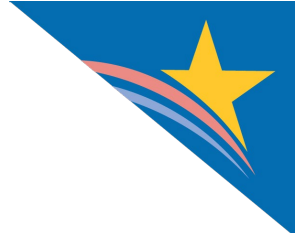
Resource	Author	Summary Information	Link
211 San Diego CIE® Toolkit	211 San Diego CIE®	The CIE® Toolkit is designed to assist communities interested in learning how to harness the value of cross-sector collaboration and data sharing to develop a Community Information Exchange® (CIE®) that enables a network of health, human, and social service providers to deliver coordinated, person-centered care to address social determinants of health to improve population health. The toolkit includes a section titled “Identify the CIE Vision and Governance” that can be used to inform governance considerations.	Link
About the Patient Demographic Data Quality (PDDQ) Framework	ONC	The PDDQ Framework allows organizations to evaluate themselves against key questions designed to foster collaborative discussion and consensus among all involved stakeholders. Its content reflects the typical path that most organizations follow when building proactive, defined processes to influence positive behavioral changes in the management of patient demographic data. The PDDQ Framework enables organizations to quickly assess the current state of data management practices, discover gaps, and formulate actionable plans and initiatives to improve management of the organization’s data assets across functional, departmental, and geographic boundaries.	Link
Insight Spotlight Series: Amplifying Stewardship Together Project	ReThink Health	The Amplifying Stewardship Together (AST) Project clarifies stewardship mindsets and practices and helps develop such mindsets and practices into widespread norms across the country. The project is exploring two big questions: <ul style="list-style-type: none"> • How can we acknowledge our limitations, amplify our strengths, and expand our horizons? • Could we better achieve our goals if we work more cohesively and with a greater level of accountability to one another? 	Link
Integrative Activities	ReThink Health	This document details integrative activities for regional efforts, such as convening stakeholders, designing infrastructure and governance, and monitoring and evaluation. Each of these activities has specific roles and leadership functions.	Link





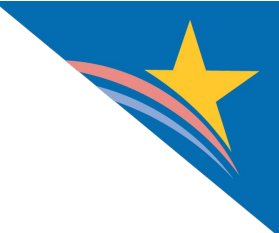
Resource	Author	Summary Information	Link
<p>ONC’s Social Determinants of Health Information Exchange Learning Forum</p>	<p>ONC</p>	<p>The ONC Social Determinants of Health Information Exchange Learning Forum brings together healthcare providers, community-based organizations, government, payers, health information exchange networks, IT platform developers, innovators, and other partners to share lessons learned, challenges, and promising practices related to exchanging SDOH data. The May 2022 Learning Forum Webinar was on the topic, “Governance.”</p>	<p>Link</p>
<p>Principles for Good Governance and Ethical Practice Resource Center</p>	<p>Independent Sector</p>	<p>The Principles for Good Governance and Ethical Practice outlines 33 principles of sound practice for charitable organizations and foundations related to legal compliance and public disclosure, effective governance, financial oversight, and responsible fundraising.</p>	<p>Link</p>
<p>Regional Transformation Efforts Conduct Governance and Management Activities Differently Than We Thought</p>	<p>ReThink Health</p>	<p>This article discusses the impact of many stewards of multisector partnerships leading and collaborating around the common purpose of transforming health and well-being.</p>	<p>Link</p>
<p>Trenton Health Team: A Holistic Approach to Social Services</p>	<p>Trenton Health Team</p>	<p>The acknowledgement that one individual was receiving services across healthcare and social service providers that often didn’t coordinate or communicate with one another prompted a call to action, one that demanded a means to communicate, share information, and hold referral receiving agencies accountable. This April 2019 report outlines Trenton Health Team’s efforts to address that need, including integrating a social care referral resource directory platform for closed-loop referrals. Integrating a referral platform with the Trenton Health Information Exchange (HIE) enables users to make referrals based on a client’s health and social needs and helps other members of a patient’s care team see the full picture of what is needed, and what referrals have been made.</p>	<p>Link</p>





Resource	Author	Summary Information	Link
Trusted Exchange Framework and Common Agreement	ONC	The overall goal of the Trusted Exchange Framework and Common Agreement (TEFCA) is to establish a universal floor of interoperability across the country. The Common Agreement will establish the infrastructure model and governing approach for users in different networks to securely share basic clinical information with each other—all under commonly agreed-to expectations and rules, and regardless of which network they happen to be in. The Trusted Exchange Framework describes a common set of non-binding principles for trust policies and practices that can help facilitate exchange among HINs.	Link Link





CASE STUDIES

211 San Diego CIE®

Relevant Foundational Elements: Governance, User Support and Learning Network

The San Diego CIE® is a multidisciplinary partner network used to coordinate care using a shared language, an essential resource database, and an integrated technology platform. The exchange has allowed organizations across the country to use real-time data to respond to the rapidly evolving needs of individuals and resource landscape that include healthcare, food, housing, and mental health services. The San Diego CIE® was created in 2011 by representatives from the City of San Diego Emergency Medical Services (EMS), a local homeless shelter, and 2-1-1 San Diego. With \$1 million in funding from the Alliance Health Foundation, this alliance developed an online platform to connect the siloed databases of housing providers and other CBOs to better coordinate health and human services needs of the city’s most vulnerable individuals.³⁹

The first San Diego CIE® use case focused on the downtown, vulnerable, homeless population, and its high use of emergency medical services (EMS) transport services. By providing access to the CIE®, service providers then intervened and connected homeless individuals with services. An analysis of the year one (2016 – 2017) homeless cohort identified a 26 percent reduction in EMS transports post-CIE® enrollment, and a 44 percent improvement in those individuals remaining in housing.⁴⁰

Additional 211 San Diego CIE® use cases have emerged, such as:

- Accessing an individual’s longitudinal health and human services record;
- Tracking emergency department visits;
- Identifying food insecure individuals to connect with services; and
- Prioritizing housing services for homeless individuals with high social needs, and other use cases.⁴¹

Individuals consent to enroll in the CIE® when they receive services from 2-1-1 San Diego or a CIE® network partner. Today over 250,000 individuals have consented to have their information shared to enable the participating organizations to access their longitudinal health and human service records to better coordinate services.⁴² In addition, over 1,500 users across more than 100 healthcare and social services organizations participate in the San Diego 2-1-1 CIE®, including housing providers, food service providers, hospitals, clinics, and more.

³⁹ http://ciesandiego.org/wp-content/uploads/2018/08/2-1-1-San-Diego-Case-Study_080918.pdf

⁴⁰ Community Information Exchange: Addressing Social Determinants of Health through Person-Centered Care, <https://www.himss.org/sites/hde/files/CIE%20Presentation%20HIMSS%202019.pdf>

⁴¹ <https://ciesandiego.org/toolkit/>

⁴² <http://ciesandiego.org/wp-content/uploads/2020/04/CIE-Network-Partner-Meeting-Minutes-04.23.2020.pdf>





The shared governance structure of the San Diego CIE[®], stewarded by 2-1-1 San Diego through an advisory board of senior officials across the San Diego community, provides direction and guidance for the development, adoption, innovation, and sustainability of the CIE[®]. Additionally, related workgroups include the Network Partner Meeting, where more than 90 providers meet to discuss promising practices, workflows, system improvements, and community voice.

CommonSpirit Health

Relevant Foundational Elements: Governance, Financing

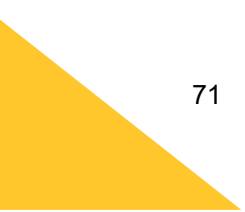
CommonSpirit Health addresses the social, economic, and environmental conditions that influence health and health equity in communities by engaging in strategic objectives that:

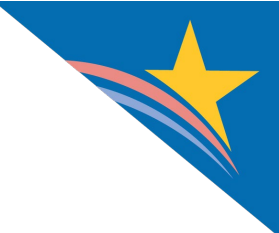
- Advance community health alignment and integration;
- Build capacity for more equitable communities;
- Expand clinical-community partnerships and linkages; and
- Innovate and scale high-impact initiatives across the system’s 21-state footprint.

The Connected Community Network (CCN) is one initiative scaling systemwide that connects patients and community members to healthcare and social services through a financially sustainable, community-owned model. Participating community-based organizations make referrals through a collaborative technology platform that enables care coordination and tracking of outcomes. A neutral trusted broker convenes and facilitates the CCN for each community with the aim of establishing governance, managing funds gathered from public and private stakeholders, and aligning the CCN with local initiatives. Community advisory groups gather feedback from participating organizations and work to improve processes and facilitate data availability and transparency.⁴³ Within CommonSpirit, the CCN serves to accelerate integrating social care into standard healthcare delivery.

The Total Health Roadmap is CommonSpirit’s model for universal screening and referral for social needs in primary care. Community health workers are embedded in primary care teams to help individuals and families find the resources they need, and the success of these efforts is boosted by an effective network of health and social services partners. Understanding the needs and challenges their patients face, combined with better information and referral exchange with community partners, supports CommonSpirit’s ongoing efforts to provide equitable and effective care for the whole person, and enhance healthcare’s role in cross-sector collaborative efforts to strengthen the social fabric of local communities.

⁴³ <https://www.commonspirit.org/what-we-do/advancing-health-equity/community-health-initiatives>





Moreover, CommonSpirit has a long history of addressing housing insecurities and homelessness across its communities. The Homeless Health Initiative (HHI) builds on local collaborations to develop a systemwide effort that focuses on strengthening the homeless continuum of care through partnerships, data sharing, and innovation. From street outreach efforts to medical respite and scattered site permanent housing, HHI prioritizes the identified needs of the local communities and works closely with direct service providers to improve transitions of care and build capacity.

Lastly, CommonSpirit has established the Social Needs Analytics (SoNA) Platform to aggregate and analyze social needs data collected from Community Health initiatives and electronic health records. SoNA uses data and analytics to better understand a community’s social needs, identify areas for further investment, and evaluate community health initiatives that address social injustices in the community.

District of Columbia Community Resource Information Exchange (DC CoRIE)

Relevant Foundational Element: Technical Infrastructure and Data Standards

The District of Columbia (DC) Department of Health Care Finance (DHCF) regulates the DC Health Information Exchange (DC HIE), which is a marketplace of registered and designated HIEs. Over the last five years, the District leveraged funding streams to connect over 13,000 users to the DC HIE, provide technical assistance through partnerships, and develop and implement HIE infrastructure.⁴⁴ Providers have articulated the need to incorporate social determinants of health (SDOH) to best serve their patients. Launched in 2019, the Community Resource Information Exchange (CoRIE) initiative’s goal is to support person-centered care by connecting health and social services through existing DC HIE infrastructure.⁴⁵

The CoRIE initiative is a partnership of DHCF, CRISP DC, the DC Primary Care Association, and the DC Hospital Association. There are three major components of the CoRIE: screening for social risks, lookup through a centralized community resource inventory (CRI), and enabling referrals to appropriate services.

A District-wide Community Resource Inventory (CRI)

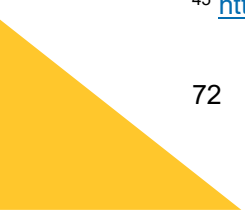
CoRIE initiative funded a District-wide aggregation of resource data from a range of already-existing resource directory databases. DC CRI live prototype currently contains approximately 500 records and represents directories contributed by District organizations. As of early 2022, DC CRI can be accessed via web browser or through the DC HIE. District organizations can also retrieve and contribute content via application programming interface (API). The District is also convening stakeholders through the DC HIE Policy Board to develop standards related to the use, exchange, sustainability, and governance of CRI data through the DC HIE infrastructure.

Screening for social risks and referrals to appropriate services

CoRIE included tools for capturing screening information based on whether organizations export social need screening questions and answers; entering screening data through CRISP’s Direct Entry Screening Tool; or assigning and sending Z codes that identify social needs.

⁴⁴ <https://dhcf.dc.gov/publication/community-resource-information-exchange-technical-solution-corie-development-grant-001>

⁴⁵ <https://openreferral.org/the-dc-community-resource-information-exchange-phase-one-report/>





Participating organizations that use social need assessments and structured questionnaires are now able to export that data to CRISP to ingest, convert to a FHIR resource, and display within the “Assessments” subtab of the “Social Needs Data” Tab in the CRISP DC portal. Alternatively, for organizations that do not have an electronic screening tool, CRISP DC leveraged a prototype direct entry screening tool that can be accessed through its CRISP DC portal.

Through the CoRIE initiative, CRISP DC and its partners at the DC Primary Care Association also began engaging federally qualified health centers (FQHCs) to test mapping ICD-10 diagnosis codes for SDOH (z-codes) to existing social need screeners. Participating FQHCs are now actively documenting social need screening responses and results using z-codes within their electronic health record systems’ progress note which is then transmitted to the DC HIE.

A vendor-agnostic approach to social needs screening and referrals

The CoRIE initiative takes a “vendor-agnostic” approach to social needs screening and referrals. Depending on their workflows and technical capabilities, organizations have the option to send either assessment data (i.e., social needs questions and answers) or conditions data (i.e., diagnoses indicating health-related social conditions). CRISP enables organizations to share referrals and responses with the DC HIE using third-party social need referral platforms and to display the information at the point of care.

For organizations without a vendor, CRISP developed a referral tool designed to allow providers and select members of their staff to refer patients to CBOs and specific programs offered by those organizations, including services that address a patient’s social needs or address underlying causes of poor health outcomes. Providers are able send social need referrals to CBOs, track follow-up to services, and receive disposition on referrals made. CBOs can also participate in the closed-loop referral tool by receiving and responding to referrals from participating organizations.

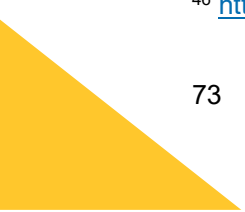
HealthierHere

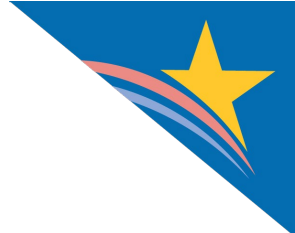
Relevant Foundational Elements: Community Readiness and Stewardship, Values and Principles

HealthierHere brings together community, tribal, and clinical organizations to identify opportunities, co-design solutions, and implement ways of delivering care to better meet the needs of King County residents. The organization was established in 2017 and serves as one of nine Accountable Communities of Health (ACH) in Washington state, implementing the state’s Medicaid Transformation Project (1115 Waiver). HealthierHere envisions a community where “All people in King County are healthy and achieve their optimal physical, mental and social well-being.” The organization’s core values include equity, community voice and engagement, collective action and equitable partnership, innovation and transformational change, and a focus on health equity outcomes.⁴⁶

HealthierHere provides backbone support and leadership for the Connect2 Community Network, a cross-sector collaborative that is building a community-governed unified CIE[®] to support care coordination and advance health equity in King County. This collaborative network of social service, community, tribal, government, and physical and behavioral health organizations is working to responsibly share information electronically to coordinate services in order to provide whole-person care. This is accomplished through

⁴⁶ <https://www.healthierhere.org/about/>





a unified network infrastructure that provides shared access to data. The infrastructure will include functionalities like a longitudinal record and bi-directional closed-loop referrals that provide visibility of other organizations providing care.⁴⁷

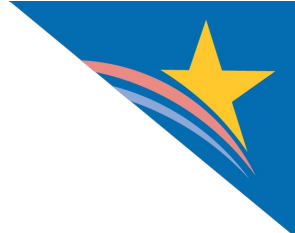
HealthierHere is community-owned and governed by a 27-member Governing Board, which includes community members, consumers, tribal representatives, behavioral health, community-based organizations, hospitals and health centers, local government, managed care organizations, social service providers, and philanthropy. With a commitment to transparency, the Governing Board's meetings are open to the public. The Governing Board oversees the overall mission and strategic plan with support from the Community and Consumer Voice Committee, Executive Committee, Finance Committee, and Indigenous Nations Committee.⁴⁸

Using a collective action approach, HealthierHere addresses health equity, social determinants of health, and delivery system reform by making sure the voices of community members, consumers, tribal healthcare providers and traditional medicine practitioners are embedded in health system transformation planning and decision-making efforts early and often.

⁴⁷ <https://www.connect2.org/>

⁴⁸ <https://www.healthierhere.org/our-committees/>



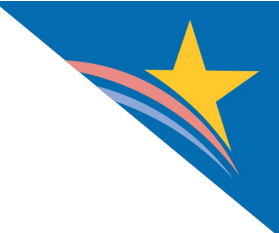


Conclusion

Through deliberate consideration and action related to the interrelated Foundational Elements in this Toolkit, SDOH information exchange initiatives can establish organizational, governance, and IT structures that support community needs to improve service coordination, service delivery, and health and social outcomes. As communities initiate and advance SDOH information exchange initiatives, they can use this Toolkit to guide the planning, design, implementation, and evaluation processes.

The nature of this work continues to grow and evolve, and challenges and opportunities experienced in the process will vary by community and context. Implementers of SDOH information exchange initiatives can use the Toolkit as they think through these challenges and opportunities. Community-led SDOH information exchange initiatives, based in standards to facilitate interoperability, can play an important role in addressing health equity and improving health outcomes.

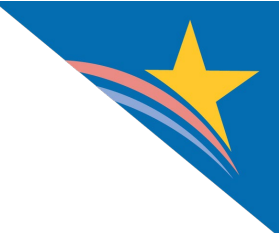




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