

Demonstrating Value with Social Determinants of Health Use Cases of HIE



Introduction

The [Health Information Exchange \(HIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council \(HITOC\)](#) to assist them and the Oregon Health Authority (OHA) with developing a set of strategies and recommendations to accelerate, support, and improve HIE across the state.

Beginning in May 2022, the HIE Workgroup met monthly to discuss priority HIE needs and opportunities in Oregon. Among these opportunities, the Workgroup discussed the importance of HIE in sharing information related to social determinants of health (SDOH) to identify health inequities and support better health outcomes. SDOH refers to the social, economic and environmental conditions in which people are born, grow, work, live and age, shaped by the distribution of money, power and resources at local, national and global levels, institutional bias, discrimination, racism and other factors. Examples of SDOH information include: race/ethnicity, gender, housing availability/quality, access to healthy foods, and income. OHA seeks to eliminate health inequities in Oregon. This concept paper summarizes some of the opportunities and challenges inherent to sharing SDOH information through HIE solutions and includes recommendations from the HIE Workgroup for future efforts.

There is reference throughout this paper to HIE, electronic health records (EHRs), interoperability and other terms used regularly in this policy area. For definitions and other information, please review the [Statewide Vision for HIE](#) concept paper.

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Background

People receive better-informed, more coordinated care when their health information is available wherever they receive medical attention. Oregon health care providers need relevant information about their patients to deliver services and to operate their organizations. To make that possible, HIE is a critical part of the coordinated care model. It allows providers from different organizations to share health information securely and efficiently, so that a patient's providers can see their health record and provide coordinated, whole-person care. Having accurate, timely information enables providers to give the best possible, culturally appropriate care and target interventions for those most at risk. This aligns with OHA's goal to eliminate health inequities by 2030 and create a more equitable, culturally and linguistically responsive health care system. While there are many ways to share health information electronically, there are also gaps that create burdens for patients, providers, Medicaid Coordinated Care Organizations (CCOs), social service providers, and health insurance companies.

Awareness and consideration of a patient's social needs is often important to improving their health outcomes and can impact a patient's course of treatment. For example, a provider may prescribe a medication to a patient that requires refrigeration. If the provider knows the patient is housing insecure and might have inconsistent access to a refrigerator, they may prescribe differently. These insights happen daily in health care provider offices across Oregon. The COVID-19 pandemic shined a light on the importance of providing social supports like rental assistance, food delivery, transportation, etc. for individuals needing to isolate or quarantine because of COVID-19. HIE solutions need to facilitate more exchange of SDOH information to ensure that providers, health plans, and others have insights into patients' needs and can better consider how to address SDOH to improve overall health.

OHA Health Equity Definition:

Oregon will have established a health system that creates health equity when all people can reach their full health potential and well-being and are not disadvantaged by their race, ethnicity, language, disability, age, gender, gender identity, sexual orientation, social class, intersections among these communities or identities, or other socially determined circumstances. Achieving health equity requires the ongoing collaboration of all regions and sectors of the state, including Tribal governments to address:

- The equitable distribution or redistribution of resources and power; and
- Recognizing, reconciling and rectifying historical and contemporary injustices.



Patient Story: Daniel

Daniel is a 30-year-old male with diagnosed schizoaffective disorder, a chronic mental health condition. He occasionally stops taking his medication for this condition and can experience hallucinations, delusions, and other disruptive experiences which has made it difficult for him to hold a job, and recently, to maintain stable housing. Daniel has also experienced substance use disorder (SUD) in the past. Daniel's care team includes his psychiatrist and a clinical social worker.

Daniel was recently hospitalized in Portland for complications related to his kidneys. He is now diagnosed with acute renal disease and will need short-term dialysis. When the hospital tried to discharge Daniel, the discharge nurse discovered that he does not currently have a residence. The hospital social worker was able to help Daniel be placed in a recuperative care program in Portland with a local organization for 30 days. In many other cases, patients like Daniel are discharged to hotels, with the costs sometimes split between the discharging hospital and the patient's insurance company.

Health Information Exchange Questions:

- How will Daniel's behavioral care team and social service providers receive information about this recent hospitalization?
- How and when should the hospital care team be made aware of Daniel's housing status and/or efforts to provide Daniel housing from the housing sector?
- How could the hospital discharge planner receive information related to potential housing placements in cases where the recuperative care program isn't available?
- Are there instances where information, for example SUD information, should not be shared with care team members to protect Daniel from unintended harm?

HIE to Support Oregon's Medicaid Strategy

Oregon has used its Medicaid program to drive many health system transformation and innovation efforts. The coordinated care model requires CCOs to address the physical, behavioral, and oral health needs of Medicaid members through a global budget. This incentivizes use of tools like HIE to coordinate across various providers (for more information, see the [Connecting the Care Team](#) and [Advancing Population Health](#) concept papers). Under the [2022-2027 1115 Medicaid Demonstration Waiver](#) approved by the Centers for Medicare & Medicaid Services (CMS), Oregon will soon offer a Medicaid benefit that provides funding for housing, food assistance, and climate event-related services for specific populations. These benefits are collectively referred to as Health-Related Social Needs (HRSN) Services.

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Technology tools will need to be used to coordinate not just between various health care entities, but also between health care and social service providers that provide non-medical services, such as housing and food. These organizations will need to invoice Medicaid for covered services, participate in referral pathways with health care entities, and share information related to service utilization and outcomes. HIE, as well as [community information exchange \(CIE\)](#), will need to be leveraged to ensure coordination of these new Medicaid benefits and maximize impact on patients.

How SDOH data flows into HIE today

While SDOH data elements are beginning to be included in federal standards, (see for example some SDOH elements included in version 2 of the [United States Core Data for Interoperability \(USCDI\) data standard](#)) much of the SDOH data available to HIE solutions today is not following a federal data standard. The [HL7 Gravity Project](#) is a development project working on SDOH data standards for use by EHRs. While these efforts continue to shape the future of this space, here are examples of how SDOH data is captured and shared by some via HIE today:

- Many providers have SDOH screening assessment tools incorporated into their EHR and the results from these assessments are collected and stored as exportable data elements
- Providers may also use CIE solutions (see definition below) to create referrals for patients to SDOH-related services and this information is sometimes captured or shared with the provider's EHR system and/or existing HIE solution(s)
- SDOH-related information is collected by health plans and sometimes shared with providers via HIE solutions or privately hosted web portals
- EHRs and HIE solutions ingest data manually from other technology systems used in other sectors. Examples of this might include data from housing systems, criminal justice, and state social service programs like SNAP, WIC, etc.
- SDOH-related information is also sometimes captured in the EHR and available through ICD-10 "[z codes](#)" which can be exported via reports or other transfer mechanisms to HIE solutions

HIE and CIE

CIE refers to a network of collaborative partners using a multidirectional technology platform to connect people to the services and supports they need.¹ Partners may include human and

¹ This definition was taken from HITOC's recent report to the Oregon legislature on CIE: <https://www.oregon.gov/oha/HPA/OHIT-HITOC/Documents/HB4150FinalReport.SupportingStatewideCIE.pdf>



social services, educational settings, healthcare, and other organizations. Technology functions must include closed loop referrals, a shared resource directory, and informed consent. HITOC identified CIE as outside the HIE Workgroup’s scope in its charter, but the Workgroup did identify the importance of promoting links between CIE and HIE solutions. According to the Workgroup, CIEs should be treated like data sources for HIEs, much like EHRs and other data systems. The information CIEs contain, particularly data on referrals and outcomes, can be used by health care providers, health plans, and others to better understand and address patient needs. The Workgroup believes that future CIE and HIE strategies need to account for integrations between them so that valuable SDOH information is available to health care teams.²

Regulatory Complexity

The [Health Insurance Portability and Accountability Act](#) (HIPAA) is the federal law that governs how health information is shared. HIPAA allows for certain disclosures without explicit consent for reasons including treatment, payment, health care operations, and public health purposes. HIE solutions are designed to facilitate exchange of information within these HIPAA permitted uses. Consent is sometimes required for data exchange (e.g., 42 CFR Part 2 requires consent for sharing substance use disorder treatment information under certain circumstances), but specific instructions in patient consent forms are not easily automated by HIE solutions. Instead, HIEs err on exchanging data that is freely shareable—within the HIPAA principle of minimum necessary³—between health care entities for permitted purposes.

Robust sources of SDOH information are often regulated by different federal or state privacy rules. For example, most housing services information in the U.S. is collected in what are known as Homeless Management Information System (HMIS) databases. These databases are governed by the HMIS Privacy Rule, not HIPAA. Health records that are created and maintained by educational facilities are governed by the Family Educational Rights and Privacy Act (FERPA), not HIPAA. Most of these rules define the purposes for which information can be shared and what is required in terms of consent. For example, HIPAA permits an HIE to share patient information with a school-based nurse without requiring consent, but that nurse cannot share information back through the HIE solution under FERPA without consent. Individual lawyers and privacy officers may interpret how these rules are applied differently, and in most cases federal agencies and the court system have not clarified these application issues. Lack

² HITOC members reviewing this concept paper also noted the potential need to identify standard or aligned processes around how SDOH data is collected—particularly requirements by providers to collect this information—as it interacts with the Workgroup’s [Consumers](#) concept paper discussion on avoiding re-traumatization.

³ The Privacy Rule generally requires covered entities to take reasonable steps to limit the use or disclosure of, and requests for, protected health information to the minimum necessary to accomplish the intended purpose. <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/minimum-necessary-requirement/index.html>



of clear guidance for how to address these rules in tandem creates a complex landscape, hindering HIE use cases.

Future work might look at the role of regulatory complexity on implementing HIE projects that include SDOH data. While OHA cannot provide legal advice to organizations, the increased use of learning communities and document templates like data sharing agreements may help to address this complexity over time. In addition, the HIE Workgroup recognizes that the U.S. Office of Civil Rights (which enforces HIPAA) announced [proposed changes to HIPAA](#) that would impact how existing HIPAA-covered entities will likely exchange information with some social services providers (these changes are anticipated to occur during the next few years). As discussed below, the Workgroup recommends that future work support organizations as they interpret and implement these proposed HIPAA changes to promote the exchange of information between health and social service sectors.

HIE Workgroup Recommendations and Strategies

Overarching Objectives and Strategies

As described in the [Statewide Vision for HIE](#) concept paper, there are two overarching objectives identified by the HIE Workgroup that relate to Demonstrating Value with SDOH Use Cases of HIE, each with a set of strategies. These overarching components apply to each of the focus areas described in the rest of this paper. For more information about these objectives, refer to the [Statewide Vision for HIE](#) concept paper.

Objective 1: Improve health equity

- **Short-term priority strategy:** Prioritize HIE use cases to support transitions in health insurance status and life events, as well as identify SDOH
- Collect and clarify demographic information on patients that can help inform care and support needs
- Identify health inequities at the population level and inform targeted interventions that address these inequities
- Promote HIE data sharing models that take a vendor-agnostic approach to ensure access across broad populations of providers serving the numerous patient populations in Oregon
- Promote a more diverse health IT workforce within organizations to operate and use these systems. HIE end users often drive strategy and direction of how HIE solutions are used, and thus this workforce should reflect the diversity of Oregon communities



- Encourage governance entities that oversee HIE solutions in Oregon to consider the above ideas to ensure that Oregon’s HIE infrastructure is aiding OHA in its health equity goals

Objective 5: Promote knowledge of HIE and broad contribution of data by all parties

Educate and influence Oregon entities to participate more broadly in HIE. For example:

- Identify and prioritize the standardized and non-standardized data that should be included in HIE efforts
- Prioritize who should contribute data and when
- Identify barriers to information sharing and develop mechanisms to address these barriers and discourage data silos, which may include governance efforts

Priority Focus Areas for SDOH and HIE

One of the challenges of using HIE to support SDOH use cases is the breadth of information available about social needs and the complexity and variety of institutions that provide social services. The Workgroup identified its own priorities for what kinds of information are most valuable within HIEs, and/or what use cases of HIE are the most important in the next few years to address health equity:

HIE Workgroup SDOH Information Priorities (ranked order):

- 1. Housing services information***
- 2. Nutrition insecurity information^{4*}**
- 3. Transportation needs information (tied for third)***
3. Lived environment information (inclusive of social supports and safety concerns in the home) (tied for third)
4. Combined clinical and SDOH data sets (e.g., for home-based interventions)
5. Criminal Justice information (including juvenile justice programs)
6. Pharmacy access and other access information
7. Activities of daily living (ADLs)
8. School-based information (e.g., absences, individual education plans,)
9. Legal services needs

*Of the top ranked priority areas, it is important to note that housing services, nutrition insecurity, and transportation needs information, reflect requirements of Oregon’s CCO SDOH incentive metric on social needs screening and referral.⁵ This is an important indicator of how

⁴ According to the US Department of Agriculture, nutrition security means all Americans have consistent and equitable access to healthy, safe, affordable foods essential to optimal health and well-being.

<https://www.usda.gov/nutrition-security>

⁵ <https://www.oregon.gov/oha/hpa/dsi-tc/pages/sdoh-metric.aspx>



state policies like Medicaid quality measures can help drive the need for HIE solutions to facilitate SDOH data sharing.

Acknowledging the complexity of each of these ten prioritized areas of information in terms of use within HIE, the Workgroup focused its discussion on the top ranked priorities. The following sections briefly touch on the importance of the top five ranked types of SDOH information to HIE efforts in Oregon.

Housing Services Information

Housing is among the most important social needs to address for individuals in order to achieve and maintain optimum health and well-being. Housing insecurity is a very real and complex problem in Oregon, with people of color experiencing houselessness disproportionately,⁶ meaning that it is also a source of health inequity. The housing sector and health care systems have historically not coordinated closely, such that some patients in hospitals are at risk of being discharged without a stable home to recover in. Patients who are waiting for housing services, such as rent assistance or permanent supportive housing, may have access to these services disrupted if they experience a health care crisis and/or are hospitalized.

Workgroup members identified HMIS as a logical starting point for how HIE solutions might facilitate data sharing between health care and housing sectors, as housing providers already use HMIS data systems to collect and track housing services in Oregon. The U.S. Department of Housing and Urban Development has standards for what information is permissible to share in HMIS systems.⁷ These permitted disclosure purposes are similar to but not completely consistent with HIPAA. HIE solutions in Oregon have already begun to receive data from HMIS databases in some regions and are beginning to shape how this information is communicated to providers to promote whole person care and address patient social needs. HMIS databases are governed by local consortiums called continuums of care (CoCs). CoCs may differ in how they decide to share information from HMIS with health care entities. More is needed to align and standardize this work to ensure that health and housing systems are communicating more effectively in the future and that HIE solutions can move faster in facilitating this data sharing.

In addition, the Workgroup noted that health care and housing information should be leveraged together to identify important transitions of care from a health care setting (e.g., a hospital) to a residential setting. Workgroup members identified the importance of assessing patient needs in both settings to ensure they have what they need during these important transitions in care.

⁶ <https://www.oregon.gov/ohcs/get-involved/Documents/01-21-2022-Findings-and-Recommendation.pdf>

⁷ For more information on HMIS, visit <https://www.hudexchange.info/programs/hmis/>



Nutrition Insecurity Information

Whether a patient can access nutritionally beneficial food is another key contributor to health outcomes. Nutrition insecurity is a typical screening question for patients being assessed for SDOH needs and most providers of nutrition services—food boxes and food banks, nutrition and cooking classes, assistance with kitchen equipment, etc.—are not HIPAA covered entities. Thus, data exchange between health care providers and nutrition insecurity services will be governed by consent and not any standing federal or state law. EHRs and CIEs are key data sources for information on nutrition insecurity needs and service provision and should be included in future HIE efforts. Workgroup members noted the importance of partnerships in this space, as data collection is nascent in this area and partnerships with nutrition services providers will likely lead to better interventions for patients.

Transportation Needs Information

Transportation is a particular barrier to some patients getting access to the health care system and the services—both health care and social—that they need. For example, typically after a hospitalization, a patient is encouraged to follow up with their primary care provider. If they lack transportation, this follow-up appointment can be difficult to keep, which can lead to increased risk of re-hospitalization if the patient is confused, has difficulty following discharge instructions, or needs aftercare. Thus, like food and housing, access to transportation has a direct impact on health outcomes. As one of the three domains of social need highlighted by the CCO SDOH incentive metric, the Workgroup recommends that transportation information be collected more systematically and integrated into HIE solutions more effectively in the future.

Lived Environment Information

Lived environment refers to the natural and built environments in which people live, sleep, work, and play.⁸ Information related to lived environment—for example data on housing stock, air quality, or frequency of parks and recreational spaces—can lead to important insights at the population and individual level about health outcomes. For example, a geospatial analysis on where children live, and the air quality and mold concentration of housing stock might suggest increased prevalence of asthma and other respiratory issues. This could then lead to specific interventions addressing these lived environment issues, as opposed to only treating the downstream asthma symptoms. Health care entities, including public health, can use this type of information to change how patients are served and investments in the community

⁸ “The term ‘lived environment’ is preferred to a built environment to reflect this broader assessment of the key features needed to support healthy ageing. This extends beyond the common conception of the built environment, which often includes transportation systems, land development patterns, and microscale urban design (e.g., footpaths). A lived environment reflects the importance of locality and access to good urban design, as well as human-made and natural environments to support health and wellbeing in the local neighborhoods where people live.” <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7588877/>



conditions. HIEs can also ingest this type of information to drive specific insights at the point of care or incorporate these insights into population-level reporting for downstream provider action.

Criminal Justice Information

Jails and prisons do not typically use EHRs⁹ or systems that can interact with health IT and HIE. Health care is provided in carceral settings such as jail and prison, often by contracted entities that are not communicating with health systems or health plans in Oregon. Care needs that patients have while in a carceral setting, for example taking prescribed medications, may go unmet or might be miscommunicated during a stay in jail. The lack of HIE can also make it challenging for individuals being released from a carceral setting to have their clinical records shared with providers in the community. This can exacerbate health inequities for some populations, for example, people experiencing mental illness are overrepresented in jails and prisons.

For all these reasons and more, carceral settings may become silos that can break the continuum of care for individuals with medical needs. Being placed in a carceral setting should not result in adverse medical outcomes due to lack of care coordination between health care and criminal justice entities. In order to avoid this and to instead create a coordinated system, the Workgroup recommends that carceral settings contribute data to HIEs. This could include at minimum booking and release data which identifies an individual's incarceration status for coordination purposes. But future efforts could also include information about care delivered while incarcerated, from either a contracted care provider in the carceral setting itself or an external provider. Lastly, the Workgroup acknowledged that these efforts should include the juvenile justice system, which like the adult criminal justice system, is also siloed from health care and can contribute to care coordination issues and poor health outcomes for patients.

SDOH HIE Recommendations

In addition to the overarching objectives and strategies referenced earlier in this concept paper, the HIE Workgroup offers the following success outcome and focused recommendations related to SDOH use cases of HIE.

⁹ The Oregon Department of Corrections is in the process of implementing an EHR for its incarceration facilities, but this does not include federal prisons, county jails or other facilities that are not operated by the Oregon Department of Corrections.



Success Outcome:

- Oregon health plans and providers are enabled to identify and help address patient health-related social needs through improved access to clinical and SDOH data via HIE solutions.

Focused Recommendations:

1. **Support communication of existing case studies and best practices around SDOH data sharing in HIE.** The HIE Workgroup intended to use this concept paper to highlight specific projects as case studies to illustrate the value of SDOH use cases of HIE. The Workgroup felt this would be more effective as a recommendation for future work, as developing case studies and/or best practices and disseminating this information broadly is beyond the scope of the Workgroup. Oregon's 2022-2027 1115 Medicaid Waiver would be a strong case study for this type of data sharing. HITOC members noted that some of these efforts might also lead to discussion of standardization or alignment of approach for shared populations of concern, like populations experiencing housing insecurity.
2. **HIE efforts in Oregon should prioritize integrating SDOH data sources.** This recommendation encourages HIE solutions to do more in the space of integrating SDOH data and combining it with clinical information already available in HIE to support individual care coordination and population health activities. Some notable examples of SDOH data sources include (but are not limited to):
 - SDOH data collected from EHRs (e.g., ICD-10 z-codes, SNOMED)
 - HIE solutions that already aggregate this EHR-derived SDOH data
 - CIE solutions that collect SDOH data through needs assessments and supporting closed-loop referral workflows
 - Original SDOH data sources used by social service providers, for example, homeless management information systems (HMIS) used by housing providers to track and document housing services.

This recommendation also recognizes the value of HIEs integrating this SDOH information directly back to EHRs in order to maximize its use in providing better patient care. The Workgroup acknowledges that providers are more likely to use this kind of information to drive improved treatment and care planning if it is presented within their existing electronic workflows. HITOC members noted that these integrations need to also consider the role of the patient and their caregiver(s), both in terms of capturing the patient's goals or desires around data sharing, and the need for educating these health care consumers for what this SDOH information is being used for in the HIE context.



3. **Provide support for Oregon communities around implementing anticipated changes to HIPAA.** As the HIE Workgroup discussed, the federal Department of Health and Human Services has announced [proposed changes to HIPAA](#). Anticipated among these changes is the disclosure of protected health information to social services agencies, community-based organizations, home and community based services for care coordination and case management. Given past experience with regulatory changes, the Workgroup recommends targeted implementation or operational support of these HIPAA changes as they are announced and rolled out, which should be used to promote the exchange of SDOH information within HIE wherever possible.
4. **Funding and support for top priority HIE SDOH use cases.** In this concept paper, the HIE Workgroup identified several different types of SDOH information that need to be flowing within HIE solutions more broadly and effectively to support patient coordinated care and population health. Some of these efforts may require direct financial support and/or assistance from experts in Oregon or other states that are achieving measurable success with SDOH HIE use cases. This support may take the shape of technical implementation or set up support, legal interpretation, defining data parameters (most SDOH data is not included in existing federal standards) or operational support on the front line. HITOC Members also suggested that this work consider or identify means to incentivize or scale work beyond initial implementation.
5. **Opportunities for regular coordination between health care and social service providers.** As noted above in supporting SDOH use cases of HIE, this work may require regular and consistent touch points between leaders of health care and social service organizations. As discussed in the [Statewide Vision for HIE](#) concept paper, this might be a promising avenue for exploration of a statewide health data utility model for governance.

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