

Collecting, Documenting, and Using Social Determinants of Health Data:

Patient and Clinician Views

Prepared for the Office of the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology by OpenNotes, at Beth Israel Deaconess Medical Center and Harvard Medical School.

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Background

The Centers for Disease Control and Prevention defines social determinants of health (SDOH) as the “conditions in which people, live, learn, work, and play and affect a wide range of health risks and outcomes.”¹ SDOH definitions vary in their specificity but generally include factors such as food and housing insecurity, social isolation, financial hardship, transportation access, intimate partner violence, educational attainment, neighborhood, veteran status, sexual orientation and gender identity, and demographic information such as race, ethnicity, and preferred language.^{2–8} Some definitions of SDOH, but not all, include behavioral factors along with social factors, adding alcohol and tobacco use to the list of factors.^{3,9,10}

There is growing evidence of the impact of SDOH, with some estimates suggesting that these factors account for 50-80% of patients’ health outcomes with clinical care only accounting for 20%.^{11–13} SDOH also impact hospital readmission rates, lengths of stay, use of post-acute care, healthcare costs, and excess morbidity and mortality.^{11,12,14} The 21st Century Cures Act (Cures Act) requires the Department of Health and Human Services (HHS) and the Office of the Assistant Secretary for Technology Policy and the National Coordinator for Health Information Technology, hereafter known as ASTP, to improve the interoperability of health information.¹⁵ The Cures Act identifies important data elements that should be made electronically available and exchanged through the use of health information technology (HIT).¹⁵ These data elements comprise the United States Core Data for Interoperability (USCDI), a standardized set of health data classes and constituent data elements for nationwide, interoperable health information exchange.¹⁶ There is a growing recognition that by capturing and accessing SDOH data during care, providers can more easily address non-clinical factors impacting health, such as food, housing, and transportation insecurities. As a result, ASTP’s USCDI version 2 includes SDOH data elements in four domains: assessment, goals, interventions, and problems/health concerns. USCDI Version 3 further expanded the data elements to include additional SDOH related information.¹⁷

Despite the growing interest in SDOH and recognition of their significance from healthcare providers, electronic health record (EHR) vendors, payers, and researchers, SDOH data is not collected or documented in the U.S. routinely using uniform, standardized approaches.^{18–20} The lack of standardization has led to a multitude of screening tools, standard terminologies, and differences in how, what, and who is documenting SDOH.^{18,19,21} Subsequently, interoperability of SDOH data is difficult.^{18,19,22}

Some organizations do use structured fields within their EHR systems to capture SDOH data elements.^{5,6,21–23} One of the more common methods of capturing SDOH data is through screening tools, such as Protocol for Responding to and Assessing Patients’ Assets, Risks, and Experiences (PRAPARE) and the Hunger Vital Sign.^{3,18} However, in many cases, SDOH information is recorded as unstructured data in clinical notes or other free text portions of the EHR.

In a 2018 report, researchers conducted interviews with six EHR vendors with large market shares in both ambulatory and inpatient settings.²² Vendors described a number of places where SDOH data could be collected or found. These include EHR specific data sets or forms, problem tables, free-text fields located in various places (e.g., social history section, clinical notes and assessments section, details section of structured screening tools), the demographic section of the patient’s health record, and the patient portal. Researchers also found that in a clinical encounter, the person who collects and enters SDOH data into the EHR varies based on the available resources of the office, time allocated for the visit, availability of kiosks at check-in, and the sensitivity of the data to be captured.²²

An additional concern, largely unaddressed in the literature, is patients' willingness to have SDOH information documented, given the sensitive nature of the data. Patients may not feel comfortable sharing information related to income, intimate partner violence, homelessness, or child abuse directly with their health care provider. Patients may have a number of other concerns including what the information will be used for and whether it could lead to future discrimination. Additionally, patients may feel comfortable sharing with a provider with whom they have an established relationship but would be concerned about the information being shared with others on the care team.

There is a recent heightened importance of data documentation in the current era of patient access to their EHR data. Studies on the effect of sharing clinical notes with patients suggest that some may be upset or offended to find personal descriptors and information that they consider to be sensitive documented in their record.²⁴ Given that access to records through patient portals is now widespread, and given the sensitive nature of many SDOH elements (e.g. financial hardship, food insecurity), it is important to understand how the information is being documented and by whom, and how patients view the need for and acceptability of having this data in the record and shared across providers.

In 2020, The Office of the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP) contracted with OpenNotes/Beth Israel Deaconess Medical Center (BIDMC) to understand the experiences of patients and health care providers with collecting and documenting SDOH, with the goal of enhancing data interoperability and transparency through future standards. Specifically, ASTP sought to explore the current experiences of providers and patients, their views of what SDOH elements are critical to document and how this documentation should occur in the future, and barriers to increased data collection, utilization, and exchange. This report presents the findings of both an environmental scan, conducted in 2020 and updated in 2023, and patient and provider focus groups, conducted in late 2022 and early 2023.

Environmental Scan

The first step to understanding the experiences of health care providers and patients in the collection and documentation of SDOH was conducting an environmental scan of the literature. We began by scanning the literature for (1) current documentation practices of SDOH and (2) patient and provider perspectives of SDOH's role in the EHR.

To better understand SDOH documentation in the EHR as presented in the literature, the research team developed inclusion criteria and search terms (Appendix 1). The research team applied these terms to major databases such as PubMed, as well as Google, for journal articles and grey and online literature. Sixty-three total articles were included in the scan, with over half published between 2017 and 2023.

Overall, the literature confirms that SDOH are not consistently electronically documented.^{8,18} When documentation is present, it is in varying locations across the record. Race, ethnicity, and preferred language were the only factors documented regularly.^{3,5} After these demographic data, housing instability, food insecurity, and social isolation were the most documented. ^{3,5,7,11,23} SDOH factors were documented using standardized medical terminologies such as ICD-10, SNOMED-CT, and LOINC, as well as structured fields in the record and the free text and social history sections of clinical notes.^{7,8} While the practice of documenting SDOH was inconsistent, when providers document SDOH they reported using free text most often.^{3,5}

Physicians, clinical support staff, social workers, and behavioral health providers, such as community mental health workers and therapists, all document SDOH.^{2,3,6,9,25,26} However, the studies suggest that primary care physicians, particularly those in family medicine, pediatricians, social workers, and behavioral health providers were most likely to document SDOH and write in more detail^{3,26} while clinical support staff most often administered and documented structured SDOH screenings.^{2,11} Medical residents, female physicians, and Black, Indigenous, people of color (BIPOC) physicians were more likely to recognize the importance of SDOH factors and to document them.^{25,27,28} Providers identified the importance of more than one clinical role assessing for SDOH with patients and found social workers, case managers, and primary care providers as the most appropriate.^{10,29} Overall, there were major gaps in the literature about specialists documenting SDOH outside of Veterans Affairs (VA) clinicians.^{3,6}

Providers reported a number of barriers to documentation and use of SDOH. First, the lack of consistent standards presents difficulties.^{4,25} Providers report that the available codes do not always match clinical need.³⁰ Further, the literature suggests that the lack of financial incentives or payments linked to coding SDOH factors affects the likelihood that such codes are used.³⁰ Second, clinicians report that much of the useful SDOH information in the EHR is in unstructured free text and it is time consuming to find and use.^{31,32} Third, while providers agreed on the importance of SDOH factors for their patients, they reported reluctance to screen and document if they do not have resources to offer to patients.^{4,25} Kostelentz and colleagues (2022) found that physicians and other advanced practice providers did not routinely assess SDOH with patients due to lack of time, limited resources, and workflow challenges, despite acknowledging their importance to care and outcomes.³³

There was more in the literature on providers' perspectives on SDOH in the EHR than on patients' perspectives.^{34–36} In general, among the patients surveyed, the majority were comfortable with both screening and documentation.^{35,36} However, fewer patients reported being comfortable with providers' documentation than with screening, though most indicated that SDOH factors should be documented in the EHR.³⁵

There are several efforts under way to help with SDOH data standardization, including the Gravity Project which began in 2018. The goal of the Gravity Project is to determine relevant SDOH domains used in health and human services work and identify their respective coded data elements to build consensus and improve interoperability among health and social care. How to collect and document SDOH in the EHR has gained increased attention – likely due to the highlighting and exacerbation of existing disparities related to the COVID-19 pandemic. 33,37 The research literature has grown, with studies focused on SDOH screenings in previously under- researched specialties like cardiology, orthopedics, and neurosurgery as well as the potential for universal screening across departments.37–40 More recent studies explored other ways to identify SDOH in EHRs including natural language processing, text mining, and using AI technology to extract information from unstructured data.41–44

While current documentation practices differ across U.S. healthcare systems, a growing body of research finds agreement among patients and providers that SDOH factors are important to screen and document. This agreement represents a critical first step toward better documentation practices and increased attention to how SDOH information can be more effectively utilized.

Methods

Provider and Patient Focus Groups

We conducted a total of 20 focus groups with health care providers (10 groups) and patients and care partners (10 groups) to understand the current experience of collecting, documenting, and exchanging SDOH information in clinical settings and to assess preferences for future data collection.

Ensuring focus group participants encompassed a diversity of experiences and views and represented the broader community were explicit goals of our project. Working with our Advisory Panel (Appendix 2) we developed a list of patient and provider groups to be as representative as possible within the limits of our methodology (Table 1). In the following sections, we provide more detail on the methodology and findings.

Recruiting Health Care Professionals

The project team engaged a professional market research firm to recruit participants for the healthcare professional groups from a proprietary database of individuals who agreed to be contacted for research purposes. Two hundred and seventeen healthcare professionals completed the prescreening survey and 108 were invited to participate in the focus groups. Health care professionals were recruited for the following groups: primary care (including in urban underserved areas), specialty care, pediatrics, emergency medicine, case management, mental health care, and safety net and rural underserved settings (Table 1). These groups were conducted using an asynchronous virtual “discussion board” platform over a period of three days (Appendix 5). During this time, participants were invited to log on to the virtual platform to answer questions posed by the moderator at their own pace. Participants were also able to respond to each other’s answers and the moderator was able to ask follow-up questions. We refer to these participants as providers in this report unless otherwise noted.

Recruiting patients and care partners

Participants for the patient groups were recruited by a professional market research firm with expertise in patient recruitment. One hundred and thirty-three individuals completed the pre-screening survey and 114 participated in the focus groups. Nine patient focus groups were conducted synchronously using an online video conferencing platform (Appendix 3). One additional patient focus group (E-patients) was conducted using the same asynchronous methodology as used for the health care provider groups (Appendix 4).

Table 1: Number of focus groups

Healthcare Provider Groups	# of groups	Patient Groups	# of groups
Primary care	2	Black/African American	2
Pediatrics	2	Spanish speakers	1
Mental health	1	Parents/guardians	1
Specialty care	1	Individuals with disabilities or multiple chronic health conditions	1
Emergency medicine	1	Aged 65+	1

Healthcare Provider Groups	# of groups	Patient Groups	# of groups
Case management/social work	1	Individuals in underserved/low-income areas	1
Providers serving rural or underserved areas or safety net providers	2	Individuals living in rural areas	1
		LGBTQ+	1
		E-patients	1

All the synchronous patient groups were audiotaped and transcribed. Participants' answers to the questions posed in the asynchronous groups were captured in spreadsheet form. All groups were conducted between September 2022 and February 2023.

Analysis

Rapid assessment procedures were used to analyze and synthesize the focus group transcripts.⁴⁵ This flexible but rigorous approach to qualitative data analysis is appropriate for studies that are conducted over a relatively short time frame with a small number of specific research questions. Following these procedures, the initial set of codes was generated based on the project research questions and revised as needed. Two members of the four-person project team coded each focus group transcript as they were completed and updated the codes as needed. Coding discrepancies were resolved through discussion between each two-member coding team as they completed a given focus group.

The study design was approved by the Institutional Review Board for human subjects research at the Beth Israel Deaconess Medical Center (2021P000036) and by the United States Office of Management and Budget (0955-0021) to ensure the information collection is necessary, efficient, and not overly burdensome.

Results

Current experience with collecting, documenting and using SDOH

PROVIDERS

Most providers, regardless of specialty or role, noted documenting at least some SDOH factors to varying degrees, although they were not collecting them consistently for all patients. Rather, most documented SDOH factors when patients brought them up. Adult primary care providers, pediatricians, mental health providers and case managers mentioned collecting, documenting, and using SDOH information on a more regular basis than other providers. A small minority of physicians reported not collecting any SDOH information. Some healthcare providers noted that they rely on notes from social workers, nurses, or medical assistants for SDOH information.

“The nurse usually documents a very limited Social Determinants of Health based on triage questions.”—Participant in Emergency Medicine Group

“I’m pretty comfortable with our growing approach of screening at visits with intake/vitals etc. (i.e., the MA) and then flagging it for the provider.”—Participant in Rural Primary Care Group

“I usually ask and go in more detail on their first visit with me and explain why I am asking and documenting it.”—Participant in Rural Primary Care Group

“For the most part [I ask at the initial visit], unless the client brings up SDOH in their follow-up visits but usually it’s covered in the initial.”—Participant in Specialty Care Group

We found no consensus on what information is collected and documented in the medical record. Providers reported collecting a wide range of SDOH factors including employment, housing, home environment, transportation, food insecurity, and intimate partner violence. Overall, medical providers most consistently reported collecting and documenting information about housing and food insecurity as well as transportation. Unlike the other provider groups, the case management and mental health groups emphasized social support and discrimination as key SDOH factors to collect from patients.

“In general, I let the family know I am asking about their home, education, employment, public benefits, history of abuse, access to food, etc. to best understand them and what their needs may be.”—Participant in Case Management Group

Providers who were routinely collecting SDOH information reported utilizing structured questionnaires via paper, tablet, or online patient portal prior to the visit with paper forms being by far the most used by clinics. Use of the patient portal prior to the visit or a tablet/kiosk in the waiting room were not regularly mentioned as options. Most, if not all, providers mentioned collecting SDOH informally through conversation in addition to or instead of using a standardized form. Most providers utilized free text notes to document SDOH information, including HPI, assessment, or social history sections of the note.

*“I document in the history section of the EHR note...In my plan section I discuss what the family and I can do to change a concern they have either in the home or the environment.”
—Participant in the Pediatrician Group*

*“The provider looks for clues and may ask direct questions to better understand the underlying issue(s). They complete in the EHR including documentation of SDH....
—Participant in the Emergency Medicine Group*

SDOH information was most often used for individual patient care, mainly to inform treatment and occasionally to provide resources or referrals. Mental health and case management groups were more likely to use SDOH information to provide resources and referrals, with adult primary care providers and pediatricians the second most likely groups.

*“We are alerted if a patient reports an issue at home. Those alerts are sent to the MD or NP seeing the patient. We discuss those with the patient during the exam and if they are an issue, we have an LICSW who may be able to see if public assistance is available”
—Participant in ‘Urban Underserved’ Primary Care Group*

*“I utilize the information to see if we need to consult Social Work or to help disposition the patient. If the patient has major barriers to health based on their Social Determinants, it may sway my decision for a patient from outpatient treatment to inpatient hospitalization.”
—Participant in the Emergency Medicine Group*

“A lot of the information under the heading of ‘SDOH’ contains pertinent information needed by the clinician to get a better understanding of that individuals circumstances and life as it stands today. So, yes, I do utilize the information. I form my treatment plan partly based on the patient’s comfort level, finances, all of these things impact the sort of care I provide to patients.”—Participant in the mental health group

Several providers noted collecting and documenting SDOH but not using the information in any way. Very few providers noted using SDOH data for population health or other practice initiatives outside of individual patient care. The use of SDOH data for practice initiatives appeared to be most common in the urban underserved primary care providers’ group, as several noted that their clinics use SDOH data for tracking disparities.

“We use this for Pop Health as well as identifying health disparities and how we can impact them to achieve better health such as better BP control. This is vitally important. it is better to control hypertension and prevent the stroke than to treat the stroke and care for someone with a lifelong disability.”—Participant in the ‘Urban Underserved’ Primary Care Group

However, most participants were not aware if their clinics or larger institutions use SDOH information for population health.

PATIENTS

Overall, patients did feel that SDOH should be collected and documented in their record. Most patients shared that they had been asked about SDOH factors by their primary care provider or their OB/GYN, most commonly at annual visits. The most consistent patient experience of SDOH collection was a paper form filled out in the waiting or clinic room followed up by a conversation. Collection of SDOH information via portal was not common in the patient groups apart from the LGBTQ+ group, with nearly all participants using the portal to fill out forms ahead of time. Some parent and caregiver group participants reported that they were asked about SDOH factors by their child’s pediatrician more often than in their own medical care.

“When I take my children to the hospital, they have a checklist and they ask certain things. But when I go, my doctor doesn’t ask if I’m facing food insecurities, or if I’m feeling like I’m not able to make ends meet or anything like that, but with the kids, they ask those questions. I don’t know if it’s because it’s awkward to ask it to an adult or what?”

—Participant in the Black/African American Patient Group

Preferred experience for collecting, documenting and using SDOH

PROVIDERS

When asked about the types of SDOH that would be most useful for patient care, clinicians had a wide range of responses. For the majority of clinicians, housing, food insecurity, and transportation are the most useful to collect, followed by preferred language, income, living situation, and social supports. Some clinicians, especially mental health providers and case managers, felt that it was important to collect all possible SDOH factors as they affect each other.

“As a clinician, I don’t feel that there is a rank among these variables. They are all critical to the understanding of the individual and their actual health impact is likely to fluctuate over time.”

—Participant in Pediatrician Group

“Preferred language, and transportation access would be the best determinants and useful, because they can aid in giving the patient good access for follow up care where needed, or specialty treatment that would coincide with their “limitations” i.e., wouldn’t send someone to a specialist 20 miles away if they didn’t have transportation...”

—Participant in ‘Urban Underserved’ Primary Care Group

Health care provider preferences for how SDOH information is collected in the future were mixed. Many said that they would prefer to have this information collected using a structured questionnaire, either electronically or on paper, while others would like to continue collecting SDOH through conversation with patients. Even among those preferring a structured questionnaire, they still wanted the option to supplement that patient-provided information with conversation. Providers were split on whether the information should be collected prior to a visit (either at home or in the waiting room) or during the visit by a staff member. Across the groups, healthcare providers preferred to have the information stored in the EHR in structured fields with an option to include explanatory free text.

“Ideally, much of this could be completed pre-visit through patient portals along with specific health concerns that an individual/family wishes to address at the time of the visit. Knowing that pre-visit entry might not work for many patients, it could then be accomplished in the waiting room and added to or modified during the visit.”—Participant in the Pediatrician Group

“Ideally would like one area in the EHR with only bullet points to prompt screening questions for myself and the staff with the rest of the info open text.”

—Participant in the Rural Primary Care Group

Case managers answered the question of how they would like SDOH documented in the record from a different perspective. Rather than focusing on the mechanics of data collection, these health care providers suggested that only trained professionals should ask patients about and document SDOH. They wanted their healthcare organizations to prioritize this issue and to hire additional trained staff. Finally, they would like to see improvements in their EHRs to make the data easier to find and utilize.

“Unfortunately, not all providers are as well versed in eliciting information directly from families. Sometimes staff will make assumptions and document information as fact....I would rather ask a patient directly and reflect their answers appropriately in their medical chart.”

—Participant in the Case Management Group

“SW’s are obviously the most appropriate when available. As a SW, asking these questions is within our wheelhouse/skill set, not only because we know ‘how’ to ask, but also because we often have the resources to address any concerns.”

—Participant in the Case Management Group

PATIENTS

Across the patient focus groups, there was widespread consensus that SDOH factors are important to care and collecting this information should be a standard practice among providers. Patients noted that such information allows for a better understanding of the patient and can lead to improved trust and doctor-patient relationships. Most patients want their clinicians to ask about access to transportation and safety concerns. However, some patients felt uncomfortable sharing certain sensitive information such as income status, religious beliefs, and nationality for fear of discrimination or having their data used against them.

“So, it’s always up to the person if they share the information or not. But to me, it is having more options rather than none, because I may be going through something, and I’m not even realiz(ing) that’s impacting my health. But when I see that question on the questionnaire or within my chart, then I’m like, wow, maybe this is something that’s affecting me”

—Participant in the Black/African American Patient Group

“I believe that is a thing belonging to each individual, everyone should decide what information to share, or what not. But I do think that the doctor, or whomever it is asking for that information, should explain what... Why they want that information. If they are going to base their treatment, their diagnosis, based on that information, or, what is the objective?”

—Participant in the Spanish Speaking Patient Group (translated into English)

“I would say not having to reintroduce my gender identity and sexual identity to every doctor that needs to know it would be nice. Not having to re-come out every couple of months would be great”—Participant in the Patients with Disabilities Group

Overall, the idea of providing SDOH information through a structured questionnaire, either on the patient portal at home or in the waiting room via a kiosk or iPad, was acceptable to patients, although most preferred to also have the option of having a conversation directly with their provider. Participants noted that using the portal to provide the information in advance would allow them time to answer the questions thoughtfully, to ensure that the data was correct, and to possibly give the clinician time to review the data before their visit – although they

did note that they are often asked the same questions again in person during the visit. Respondents in the Spanish language group were the only participants to strongly prefer conversation alone. Respondents in the LGBTQ+ and over age 65 groups also noted that patients should be given multiple options for answering the questions based on their level of comfort with technology.

“I would prefer using a questionnaire in my patient portal before my visit. I would appreciate my clinicians reviewing this information and having a discussion with me during my visit. I believe this would improve my outcomes.”—Participant in the E-Patients Group

“So, I feel like if I am in front of the person, I can really get a feel of not just about me. I’m trying to get a feel about you as well, too, because it’s just like, who is listening to me? Who is taking my information down?”—Participant in the Black/African American Patients Group, on preferring a conversation with their provider

*“I fill out all of the forms on the portal then they ask me the same questions when I get there...”
—Participant in the 65+ Patient Group*

Most respondents were open to the idea of using a third-party application (app) to provide SDOH information, with some important caveats. First, many expressed concerns about the privacy and security of their data. Second, some participants said they would be more willing to use an app provided by their health care provider, rather than a “random” app. Among those who expressed concerns about using an app for providing SDOH information, they cited concerns about app overload and wanting to be sure that they would have control over who could view their data.

*“I feel like if you are able to have an app that you personally control that gives you the power to say I want to share this information, and this information you can ask me for in person if you want it. That gives you that power that we’ve been talking about.”
—Participant in the Patients with Disabilities Group*

Barriers to collecting, documenting & using SDOH

PROVIDERS

The barrier to collecting, documenting, and using SDOH data that providers mentioned most often was time. Providers consistently noted the time needed for gathering SDOH information, assessing and discussing it with patients, and determining how to utilize/if they can utilize the information to assist the patient with resources or referrals as a significant barrier. The time issue came up very strongly in the emergency medicine group but also cut across all provider groups. When they have limited time to meet with patients for their more urgent and pressing needs it is often not feasible to spend time on SDOH.

“Frequently, there’s not enough time during the physical exam to collect that information. Main reason being that patient usually comes in for physical exam and also has other issues they want to discuss.”

—Participant in “Urban Underserved” Adult Primary Care Group.

“Time in the ED and number of available trained staff are major barriers in the ED. These are reasons for why I don’t really believe that we are addressing these issues well enough or effectively.”—Participant in Emergency Medicine Group

“The main issue is that if we collect the info, we wouldn’t have enough time built into the day to act on the information gathered or provide meaningful help to the patient. It is very concerning that we don’t have the time in medicine we need to properly take care of the whole patient and the patient is getting short changed.”—Participant in Pediatrician Group

Another factor that overlaps with time is limited staff or not having the “right” staff and the related issue of staff not understanding the value of SDOH information. Understaffing at many clinics impacts the time that staff have to focus on SDOH. And not having social workers or other staff who can more directly focus on SDOH also impacts the ability to assist patients. Without the “right” staff those involved in the data collection and documentation may not be aware of the importance of asking about SDOH and/or lack the skills to ask about and discuss these topics. They also are less likely to know about resources and referrals that could assist the patients.

“I think embedding social workers/behavioral health professionals in primary care settings to follow up on issues even after someone leaves would be helpful.”—Participant in Rural Primary Care

*“Providers unwilling to utilize the information... unable to see the value of the information. This is concerning as either of these behaviors could render a treatment ineffective”
—Participant in Specialty Care Group*

Many providers identified patient-specific barriers including discomfort on the part of both patients and clinicians/staff with talking about SDOH, especially in certain areas such as income. They were concerned that asking patients about SDOH may impact the patient’s relationship with the doctor-some said it could build the relationship while others said it could negatively impact the relationship.

*“...And every time thereafter they come, I confirm or update the history. It helps them feel heard and connected as I know what they had told me in previous visits about their personal life aspect.”
—Participant in Rural Primary Care Group*

“Sometimes patients are reluctant to answer SDOH questions because they are uncertain why the information is being obtained and how it will be used.”—Participant in Pediatrician Group

“I would be concerned occasionally about overstepping my bounds when trying to delve deeper into these questions of a patient’s Social Determinants of Health especially if it is my first meeting with the patient.”—Participant in ‘Urban Underserved’ Primary Care Group

“Bringing up some of these issues and how it affects a patient’s care can be awkward sometimes if it is in regards to race or sexual orientation, because I don’t want to offend anyone by talking about those things. But if I feel it is important for the patient to know, I will go ahead and bring it up and hope they understand that I am speaking from a medical standpoint and not being judgmental or anything like that.”—Participant in the Rural Primary Care Group

*“... I need to earn patient’s trust and take care of their concerns first before I ask these other questions, otherwise they would not trust me enough to answer truthfully.”
—Participant in ‘Urban Underserved’ Primary Care Group*

Providers are also worried that documenting SDOH information could lead to bias against the patient.

“Unfortunately not all providers are as well versed in eliciting information directly from families. Sometimes staff will make assumptions and document information as fact. I work for a large health system and various disciplines are charting in the medical record. I will typically tell a family, “I saw this in your medical chart but I want to learn about you myself as well. One example that comes to mind is regarding gender identity and sexual orientation. I would rather ask a patient directly and reflect their answers appropriately in their medical chart. People often make assumptions about pronouns based on gender expression.”—Participant in Case Management Group

“Sometimes biases are revealed in how providers respond to SDOH. SDOH must be viewed through an objective lens as much as possible.”—Participant in Pediatrician Group

Finally, providers suggested that providers/staff may also not be comfortable asking about SDOH if they do not have resources to help patients.

“We can collect the information, but then we do not have the next step in place to help the patients. Giving them a list of resources doesn’t work, since then they need to take the step of calling or contacting an agency or group. These issues need active intervention that is coordinated on a larger scale.”—Participant in Pediatrician Group

*“It varies by the patient and their issues. I do not routinely ask them about food insecurity, housing & transportation issues, because I cannot fix those things.”
—Participant in Rural Primary Care Group*

*“Extensive discussion of this [SDOH factor] just adds to chart bloat if its not something that can be intervened upon, and increases my time at the computer instead of at the patients bedside.”
—Participant in Emergency Medicine*

“We are not against using the information gathered from SDOH and [this] is a concern of ours that with few resources of our own that once we have the information we won’t be able to make a difference.”—Participant in Specialty Care Group

Language and cultural differences were also mentioned as barriers to gathering SDOH information. Case managers emphasized the importance of building rapport before asking about SDOH in order to help patients feel comfortable sharing and getting help without fear of discrimination, and mental health providers shared that having intentional conversations about SDOH with patients can improve trust and strengthen the relationship.

Finally, technology was also noted as a barrier to increased data collection. Some providers reported that EHRs can make it hard to know where to document SDOH information and where to find it when needed. Some providers communicated there is no standardized way to collect it in the EHR. Also, the lack of interoperability makes it harder to share information with others. Other barriers mentioned included lack of standardization in SDOH definitions and screening tools. Finally, some clinicians mentioned a lack of incentives to collect SDOH including lack of reimbursement.

*“I find the structured and drop-down menus to be limited and doesn’t always give the best information. Need to qualify a lot of pt. answers and drop downs tend to cause the staff to just use them and not enter additional info. Would be nice to drag the info into the working note as well when appropriate. Currently, most of the info we get is scattered throughout the chart and notes.”
—Participant in the Rural Primary Care Group*

“The biggest barrier to not utilizing SDH is the difficulty of finding the information in the patient chart and the time required to obtain the information from the patient. Using the epic search for “education” does not bring me to other SDH as well. I need to search for each SDH individually.”
 —Participant in Mental Health Group

Table 2: Provider-Identified Barriers to SDOH data collection, documentation, and utilization

Barrier	Collecting/Documenting	Utilizing
Time	x	x
Overworked/understaffed	x	x
Lack trained staff/SW	x	x
Staff discomfort	x	
Patient discomfort/resistance	x	x
Lack of staff awareness	x	x
Lack of resources to address SDOH needs	x	x
Language barriers	x	x
Usability of EHRs	x	x
Lack awareness of existing/evolving standards	x	x
Staff does not see value in the information	x	x

PATIENTS

The primary patient-identified barrier to greater data collection was fear or worry about how the information would be received or used by individual providers. Across patient groups many expressed distrust and said they would want to know that the information will not be used against them or change how they are treated. Patients were particularly concerned about sharing their financial information, where they live, and their level of education. Patients who have experienced bias or have had other negative experiences in the healthcare system were concerned about these situations being exacerbated because of their SDOH information. This came up most prominently in the groups of Black patients, patients with disabilities, the LGBTQ+ group, and the group of Spanish speakers (this group in particular expressed distrust broadly in the healthcare system).

“If you don’t answer the questions, it’s like they write the notes that you’re difficult.”
 —Participant in Patients with Disabilities Group

“Yes, I’m concerned the information might be used to discriminate against some people. I also am concerned whether the individual gave consent to include such information in their medical record, and whether the person had the option to revise or delete information in their record that they did not want shared. It’s almost impossible to correct errors in EHR.” — Participant in E-Patient Group

“I think we probably just need to change the culture around how I feel like it’s being perceived by the doctor. If I felt like I had a doctor who would read that and never not listen to me because of it

or something like that, then I'm down for him to know...but I think it's when I feel like it's being used almost against me or to not give me the help that I need, that's when it's a problem.”
 —Participant in Black/African American Patient Group

“I just don't want them to base my care on how much money I make or where I live or what I can do. I wouldn't want that in there, I would want the same care that they will give anybody. I wouldn't look at it that way.”—Participant in the ‘Urban Underserved’ Patient Group

Patients also identified several provider-specific barriers. First, they noted the lack of time in a clinical visit to address SDOH factors. Second, many expressed the opinion that providers are not comfortable asking about or discussing SDOH. Finally, many reported a reluctance to provide SDOH information if the provider or the clinical office did not have resources to help with a given issue.

“I have tried to tell my story and what I face as an amputee everyday but that doesn't fit their world. If it doesn't answer the electronic record questions, it doesn't have a place at the appointment. Computers run appointments and not the patient's story.”—Participant in E-Patient Group

“My thing is if they're going to ask us these questions, say for instance, the food deprivation areas, well, then don't ask me if I'm eating noodles every day and gaining 50 pounds because I can't afford healthy food if you don't have a solution. Don't ask me about it if you don't have a solution.”
 —Participant in ‘Urban Underserved’ Patient Group

“I am NEVER given the opportunity to tell my story as it relates to SDOH. It is critically important that clinicians hear and understand my story... because I have on-going health challenges related to years of caregiving (a clear SDOH).”—Participant in E-Patient Group

Table 3: Patient-identified barriers

Barrier	Providing	Sharing with other providers
Poor relationship with clinician	x	
Concerns about how information will be used	x	x
Worries about discrimination	x	x
Digital literacy/digital divide	x	
Primary language other than English	x	

Barriers to exchange of SDOH information

Providers generally had concerns about getting SDOH information from other sources, such as clinicians from other organizations, social service agencies, and schools, among others. They reported worry that they will not get a full or accurate picture of the patient and there is the potential for bias in both the information they receive and the information they might share. Several noted that the information documented in the record would have been filtered through the perceptions of the documenting physician/staff and may reflect assumptions and unspoken bias on their part. If they do get information from others, they then want to discuss this further with the patient to make sure it is accurate. They also have privacy concerns when it comes to sharing SDOH information

with or receiving it from others. Finally, providers discussed the potential for patients to be concerned about how their data might be shared and misused.

“I don't like to rely on 2nd hand Info for SDOH where there is room for bias and judgement. I prefer to hear directly from my patient.” —Participant in ‘Urban Underserved’ Primary Care Group

*“Sometimes biases are revealed in how providers respond to SDOH.”
—Participant in Pediatrician Group*

“I could imagine patients being concerned about sharing personal details if they worry about their information being shared or misused. This is why HIPAA and doctor/patient trust are so important.”—Participant in Pediatrician Group

Considerations for increasing data collection

Health care providers offered a variety of options for what might incentivize or help providers to collect SDOH data more frequently and consistently. Financial incentives were discussed in most of the groups, as was the issue of making the time necessary for data collection and discussions reimbursable. Standardizing EHR workflows and templates was also discussed, with the caveat that clinicians also wanted time to discuss these issues with individual patients. Many mentioned other improvements to the EHR including better templates and easier methods of finding the information. Other options included more education for clinicians and staff about the importance of asking and how to ask, increased availability of resources for patients when they did raise an issue related to SDOH, and increased time to devote to conversations with patients.

*“I don't really see much help on the insurer's side. They do a top-down approach of requiring us on the front lines to collect information, but they don't give us staff or other resources to address any issues that come up. We usually see mandates to do things but not coordinated assistance.”
—Participant in Pediatrician Group*

*“Things that would lead to more documentation are ease of use and required fields; secondly, education with an understanding of why there is a need to do something. You have to be clear that we are not collecting data just to collect it, but show how it helps the community and the patient.”
—Participant in Emergency Medicine Group*

“Embedded behavioral health professionals in primary care settings WITH adequate time to be a part of the team. This relates to the first point - it is hard to afford these qualified professionals and find ways to get reimbursed for the time they have to spend addressing social issues. This is a money drain, often.” —Participant in Rural Primary Care Group

Table 4: Provider-identified facilitators of increased SDOH data collection, documentation, and utilization

Facilitator	Collecting/Documenting	Utilizing
More time in visit	X	X
Better data collection methods/better questions	X	
More trained staff/SW's	X	X
Education about evolving SDOH Standards	X	

Facilitator	Collecting/Documenting	Utilizing
Educate staff	x	x
Incentives or reimbursement for screening/documenting	x	x
Mandates	x	x
Resources accessible to address identified SDOH needs	x	x
EHR usability improvements	x	x

TRUST AS A MEDIATING FACTOR IN INCREASING DATA COLLECTION

Trust in individual providers was noted by patients as a mediating factor in their willingness to have SDOH information documented in their medical record. Patients generally felt comfortable sharing SDOH information with, and having their information recorded by, their primary care provider, especially if they have a good and ongoing relationship with that provider. They feel less comfortable sharing with other providers or having their primary care provider share with other providers. They would like their PCP to ask them before sharing with other providers or give them an opportunity to decide which information they would like to share and with whom. They think only relevant information should be shared (e.g., Why should my dentist know about my sexuality-that doesn't have any relevance to my treatment.) and they do not want information shared with providers they rarely see. Some would prefer to share with each provider directly as they feel appropriate. This theme was particularly strong among patients with disabilities, who specifically noted being worried that their SDOH information would contribute to discrimination against them.

“And I think it's because of the doctor that I do have now that I am more open because we built that relationship. Some doctors I'm like, you will never have to worry about me going back to that doctor again. But it's like where I am now, I trust my doctor, so I do open up and share”
 — Participant in Black/African American Patient Group

“I don't feel like it needs to be access to all areas of the social determinants, but I also feel like if they're going to request this kind of information, number one, they need proper training to know what to do with it. And they should be immediately prepared to provide those resources should something concerning come up.”—Participant in Group for Care Partners of Children

“I'm OK if that stuff is along what [participant] said, like if the current doctor keeps that info, but I feel like I don't want to go into a new doctor and them already have a preconceived notion of, oh, this guy's jerk.”—Participant in Group for Patients with Disabilities

Table 5: Patient-identified facilitators of increased SDOH data collection, documentation, and utilization

Factor	Providing data	Sharing with other providers
Trusting relationship with provider	x	
Ability to give permission to share	x	x
Understanding why the information is being collected	x	
Knowing that the clinician has resources to help	x	

Summary

We conducted 20 focus groups with patients, care partners, and clinicians between September 2022 and February 2023 – examining current experiences with the collection, documentation, and use of SDOH information, as well as their preferences for how this data could be collected and used in the future. A few overall themes emerged:

SDOH INFORMATION IS IMPORTANT

Both providers and patients agreed that SDOH information is important to care – although a minority of providers disagree, suggesting that SDOH data should be outside the realm of health care. Providers reported collecting a wide range of SDOH factors, and stressed the importance of transportation, food insecurity, housing, and safety. Generally, patients wanted to be asked about transportation and safety concerns. Interestingly, about equal numbers of patients did and did not want to be asked about sexual orientation.

SDOH INFORMATION IS SENSITIVE

Patients worry that this information will be used against them and do not want it shared outside of a trusting relationship with a provider. Patients were the most resistant to questions about income, worrying that it would be used to justify limiting their care. Patients were less concerned with being asked about transportation and safety. Patients who had a disability, were Black, Spanish speaking, or LGBTQ+ and more likely to experience discrimination were particularly concerned about how their information would be used. A good relationship with a provider can mitigate this mistrust. It is worth noting that providers discussed using SDOH information such as income and transportation to determine care plans and referrals for patients (e.g., a lack of transportation would determine where the physician referred the patient). Providers saw this as necessary and a benefit to patients while patients viewed it as potentially limiting their care.

DATA COLLECTION IS HIGHLY VARIABLE

We found no consistency in how information is collected and documented, or which SDOH factors are consistently collected. Providers reported using the patient portal, paper forms, and conversation to collect data. Documentation practices ranged from standardized data fields to free text.

PATIENTS AND PROVIDERS WANT TECHNOLOGY AND WORKFLOW OPTIONS

Patients and providers endorsed the standardized collection of SDOH information on paper as well as electronically, both in the office and through the patient portal, in advance of a visit, with the option for additional free text. And they want time to discuss it during a visit. Patients are lukewarm about apps, raising privacy worries and lack of interest in “another app.”

THERE ARE SIGNIFICANT BARRIERS TO CONSISTENT DATA COLLECTION, DOCUMENTATION AND SHARING OF SDOH INFORMATION

Providers were very concerned about their lack of time and staff to both collect and use the information. Other barriers identified by providers included patient mistrust, no standardized definition of what should be collected, and difficult to use EHRs. These difficulties included using standardized tools available in the EHR to record complex, nuanced situations, as well as retrieving information from the EHR in a usable format. For patients, the primary barrier was a lack of trust in how the data would be perceived and used, as well as a lack of resources

at the practice to help mitigate any SDOH-related issues they report. Alternatively, a trusting relationship was seen as a facilitator to data collection and documentation by both providers and patients.

PATIENTS WANT TO KNOW HOW INFORMATION WILL BE USED

Understanding why SDOH information is being collected could help increase patients' trust. Further, patients want to know that providing this information will help them (e.g., result in a referral to needed services). Without knowing how the information will be used, patients are reluctant to provide it.

Recommendations

Findings from the focus groups suggest several options for increasing the collection and documentation of SDOH data in the areas of technology, education, and policy.

Technology & standardization

EHR IMPROVEMENTS

Clinicians relayed experiences with EHR interfaces that are difficult to use and non-intuitive. It is often easier and faster to document SDOH information in free text areas of the chart. Incorporating the principles of user-centered design into changes to EHR interfaces could help to ensure that the end-user (in this case, the clinician or staff) is able to easily enter and retrieve SDOH information in a way that is also usable for data exchange and population health management. Including multiple options or pathways for entering information (e.g., standardized questionnaires with a free text option in notes) while still allowing for that information to be stored in a standardized searchable format could help increase documentation, use, and exchange of SDOH data. There are ways to collect SDOH data in a standardized manner, though providers may not be aware of those structured tools or their EHR may not include this function. This is an evolving landscape.

STANDARDIZATION

Standardization of data elements is a central factor in the interoperability of SDOH information. We found considerable variability in what is collected and how it is documented, which limits the usefulness of SDOH data. Further, clinicians and patients did not agree with each other or amongst themselves on which data elements are most important to collect. There is work going on to standardize both data elements/definitions and tools by initiatives such as the Gravity Project.

PRIVACY CONTROLS FOR PATIENTS

Patients want the ability to segment their data and control who can see sensitive information in the EHR. Patient portals could be configured to give patients control over what SDOH information is shared and with whom. ASTP has recently issued guidance related to patients' right to request restricted information sharing as allowed under the Health Insurance Portability and Accountability Act.¹

INTEGRATION OF ELECTRONIC REFERRALS TO SUPPORT SERVICES

Patients want to know that if they provide SDOH information, their providers will have resources to help. Providers worry about both a lack of time and a lack of access to such resources. Better support for electronic referrals to social services agencies could help to address this barrier.

¹ See, for example: <http://www.hhs.gov/hipaa/for-professionals/faq/3026/under-hipaa-may-an-individual-request-that-a-covered-entity-restrict-how-it-uses-or-discloses-that-individuals-protect-health-information/index.html>, https://www.healthit.gov/sites/default/files/2023-04/HTI-1_Gen_Overview_fact%20sheet_508.pdf

Education

MEDICAL/NURSING/OTHER SCHOOL CURRICULUM

Providers cited the need to ensure that clinicians (including nurses, physical therapists, occupational therapists, etc.) understood the importance of SDOH information. This suggests the need for enhanced curriculum during training (e.g., medical school, nursing school, other clinical degrees) that could include how to have a conversation about SDOH with patients, sharing with the patient why SDOH information should be collected, as well as how to document and use the information for individual patient care and population health.

ONGOING CONTINUING MEDICAL EDUCATION

Providers noted that they were not trained in how to talk to patients about SDOH related issues, how to document this information in a structured and easily accessible format, or how to retrieve/query and use the information for population health management. Continuing medical/nursing/professional education for providers beyond their training years on how to collect, document, and use SDOH information would help to increase the rate at which it is collected. Health care organizations could provide examples to their clinicians and staff of how they are using or plan to use SDOH information to monitor and improve the health of their patient population as a way of increasing buy in. This should also include the perspectives of case managers and mental health providers, who emphasized social support and discrimination as key SDOH factors to collect from patients.

PATIENTS & CARE PARTNERS

The theme of trust and its central role in patients' willingness to share and have documented sensitive information cannot be overstated. Patients want to understand why SDOH information is needed and have a say in how that information is shared. Providers rarely reported explaining to patients why they were collecting SDOH information. Public education materials explaining why SDOH information is collected, and how it is used and disseminated through health care systems and other trusted community partners, could help to reassure patients and family members that their information will not be used to discriminate against them or limit their care. Such patient focused education about SDOH data use could increase their willingness to share information.

Incentive payments

HEALTHCARE PROVIDERS AND ORGANIZATIONS

Paying providers and healthcare organizations to collect and report data is a time-honored tactic that has resulted in changes to the health care system by aligning priorities with payments. Policy makers at the federal, state, and private insurer levels could adopt policies, or in some cases build upon current efforts (payment policies are already shifting at CMS, for example, to begin supporting the collection and documentation of SDOH data, and this landscape continues to evolve), to increase the collection and documentation of SDOH information. The incentives could be structured to first encourage the basic collection and documentation of information, and, in later years, focus on achieving targeted outcomes. Such an effort would likely require the harmonization of SDOH standards for data collection and coding.

MANDATES

Providers noted that mandating the collection of SDOH information would likely result in an increase in data collection. However, it is important to note they did not endorse this idea. Further, mandates without enforcement

may result in increases in data collection among organizations that were already primed to undertake this effort and little action among those who are not already collecting or preparing to collect SDOH information.

This project, which includes the experiences and voices of over 100 clinicians/staff and over 100 patients, highlights that collecting and using SDOH data is important to better health, health care, and health equity. Yet, SDOH data collection is far from universal, is highly variable in both what is collected and how it is documented and is routinely misunderstood and mistrusted by patients and families. However, there is a considerable body of work on the collection, documentation, and use of SDOH data. The collection and use of this data are priorities for many healthcare organizations, insurers, and federal and state governments, as well as patients. With so much time and funding already invested, now is the time to tackle the difficult issues raised by this project through the strategic use of funding, research, and policy making.

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Appendices

Appendix 1: Environmental Scan Search Terms

Terms Related to Documentation		Terms Related to EHR		Terms Related to SDOH, Providers and Patients
unstructured OR unstructured data OR documentation	AND	clinical notes OR notes OR visit notes OR medical record OR electronic health record	AND	social determinants of health
				transportation
				housing
				homelessness
				IPV/interpersonal violence
				employment status
				social risk
				social history
				food insecurity
				housing
				financial stress
				sexual orientation/gender identity
				education
				educational attainment
				employment
				social isolation
				stress
				documentation of stress
				patient experience
				patient perspective
				provider experience
				provider perspective
				physician perspective
				physician experience

Appendix 2: Advisory Panel Members

Panelist	Titles
Anshu Abhat, MD, MPH	Director of Care Transitions and Patient Engagement, Office of Population Health Management, Los Angeles Department of Health Services Internist, Harbor-UCLA Medical Center Assistant Professor of Medicine, UCLA David Geffen School of Medicine
Pedro Carneiro, MPH	Clinical Data Scientist, National Association of Community Health Centers
Grace Cordovano, PhD, BCPA	Founder, Enlightening Results Co-Founder, Unblock Health
Leonor Fernandez, MD	Assistant Professor of Medicine, Harvard Medical School Internist, Beth Israel Deaconess Medical Center
Hadiya Green Guerrero, PT, DPT	Senior Practice Specialist, American Physical Therapy Association
Erin Mackay, MPH	Managing Director for Health Justice, National Partnership for Women and Families
Steve O'Neill, LICSW, BCD, JD	Mental Health Liaison, OpenNotes, Beth Israel Deaconess Medical Center
Urmimala Sarkar, MD, MPH	Professor of Medicine, UCSF Division of General Internal Medicine Associate Director, UCSF Center for Vulnerable Populations Associate Chair for Faculty Experience, UCSF Department of Medicine Primary Care Physician, Zuckerberg San Francisco General Hospital's Richard H. Fine People's Clinic
Mark Savage, JD	Managing Director, Digital Health Strategy & Policy, Savage & Savage LLC
David White	Community Outreach Specialist, Dreyfus Health Policy and Research Center

Appendix 3: Patient and Caregiver Synchronous Focus Group Guides

- I. What are Social Determinants of Health (SDOH)
 - a. Introductory sentence: The Center for Disease Control and Prevention describes social determinants of health as the conditions in the places where people live, learn, work, and play that affect their health and quality of life.
 - b. Before participating in this group had you heard of the phrase Social Determinants of Health? What do you think it means?
 - c. Can you give some examples of things you think may be Social Determinants of Health?
 - i. (Moderator list some: race, ethnicity, preferred language, housing insecurity, food insecurity, social isolation, transportation access, sexual orientation, gender identify, intimate partner violence, veteran status)
 - ii. What do you think of this list? Are there any that you would add?
 - d. Can you give any specific examples of how you think Social Determinants of Health can affect health or health care? (Moderator give some examples if needed to get them talking. For example, how could food insecurity or lack of access to food impact health? How could lack of access to reliable transportation impact health care?)
 - e. Do you think it's important for clinicians to know about some or all of the Social Determinants of Health on this list for their patients? Which ones?
- II. Experiences You've Had with Clinicians/Health Systems Asking About Social Determinants of Health
 - a. Do you use your clinician's online patient portal to view your health information or communicate with your clinicians?
 - b. Can you remember a time when you (or someone you care for) has been asked about any of the Social Determinants of Health we have discussed in this session?
 - i. (Moderator: "Ask" can be someone directly asking, someone giving you something (paper or electronic) to fill out, a request that you complete something ahead of a visit on the patient portal or paper or otherwise)
 - ii. [Probe – tell us more about that time? What were you asked about? Were you asked to fill out a form or were these questions part of a conversation?
 - iii. (Other possible probes: How often are you asked about Social Determinants of Health? At every visit? Who asks you about them?)
 - c. In what format are you asked? (in person-orally, on a tablet or computer, kiosk in waiting room, on paper?)
 - i. If you fill out a form with Social Determinants of Health questions (paper or electronic) does the clinician discuss it with you?
 - ii. If you don't fill out a form, does the clinician you are seeing discuss Social Determinants of Health with you? Are you given opportunities to "tell your story" as it relates to Social Determinants of Health or are you asked only structured questions?
 - d. Have you ever been told why you are being asked these types of questions?
 - e. Have you ever been told you can choose to answer or not answer these types of questions?)

- III. What Kind of Social Determinants of Health Information Would You Feel Comfortable Having in the Medical Record
 - a. Do you think it is important to record this information in your medical record?
 - i. If yes, why? If no, why not? (Probe if needed: All of it? Some of it?)
 - b. Do you have any concerns about recording it in the record?
 - i. What if you knew that the information would be shared with other clinicians involved in your care?
 - ii. Do you think this information should be available to all or some of the clinicians involved in your care?
 - 1. Why or why not?
 - iii. If you think some of the Social Determinants of Health information should be shared and some shouldn't be, which types do you think should be and why?
 - c. Would giving your permission to share the information with specific clinicians make you more comfortable with sharing your Social Determinants of Health information?
 - d. What kind of Social Determinants of Health information would you feel comfortable discussing vs. being documented?
- IV. Preference for how Social Determinants of Health Information is Collected
 - a. How would you like Social Determinants of Health information to be collected?
 - i. (probes include: During the visit with someone directly asking the questions? In the clinic via tablet, kiosk, computer, or paper form? Before the visit by questionnaire online in the patient portal? Other? If you prefer a person directly asking, who would you feel most comfortable talking to about this?)
- V. Final question: Do you have any thoughts on the term Social Determinants of Health and if there are other terms that you think would be clearer to patients?
- VI. Parking lot question (if time): Would you be willing to use apps to send Social Determinants of Health information to your clinicians?

Appendix 4: Focus Group Interview Guide: Asynchronous Patients/Care Partners Groups

- I. What are Social Determinants of Health (SDOH)
 1. Before participating in the group, had you heard of the phrase “Social Determinants of Health”?
 2. What do you think it means?
 3. Can you give some examples of things you think may be Social Determinants of Health?
 4. (Moderator list some: race, ethnicity, preferred language, housing insecurity, food insecurity, social isolation, transportation access, sexual orientation, gender identify, intimate partner violence, veteran status): What do you think of this list? Are there any that you would add?
 5. Can you give any specific examples of the way you think Social Determinants of Health can affect health or health care? (Moderator give some examples if needed to get them talking. For example, how could food insecurity or lack of access to food impact health? How could lack of access to reliable transportation impact health care?)
 6. Do you think it’s important for clinicians to know about some or all of the Social Determinants of Health on this list for their patients? Which ones?
- II. Experiences You’ve Had with Clinicians/Health Systems Asking About Social Determinants of Health
 1. Do you use your clinician’s online patient portal to view your health information or communicate with your clinicians?
 2. Have you (or someone you care for) been asked about any of the Social Determinants of Health we have discussed in this session? (Moderator: “Ask” can be someone directly asking, someone giving you something (paper or electronic) to fill out, a request that you complete something ahead of a visit on the patient portal or paper or otherwise)
 - a. If yes, which ones?
 3. How often are you asked about Social Determinants of Health? At every visit?
 4. Who asks you about them?
 5. In what format are you asked? (in person-orally, on a tablet or computer, kiosk in waiting room, on paper)?
 6. If you fill out a form with Social Determinants of Health questions (paper or electronic) does the clinician discuss it with you?
 7. If you don’t fill out a form, does the clinician you are seeing discuss Social Determinants of Health with you?
 8. Are you given opportunities to “tell your story” as it relates to Social Determinants of Health or are you asked only structured questions?
 9. Have you ever been told why you are being asked these types of questions?
 10. Have you ever been told you can choose to answer or not answer these types of questions?
- III. What Kind of Social Determinants of Health Information Would You Feel Comfortable Having in the Medical Record
 1. Do you know if your clinician/clinician’s office is documenting your responses in your medical record? (For example, they may have told you the information goes in the medical record or you may have seen it on the patient portal or in printed information from the clinic) What is your reaction to this possibility/how does that make you feel? Do you agree or disagree with the information being documented?
 2. Do you think it is important to record this information in your medical record?
 - a. If yes, why? If no, why not?
 3. Do you have any concerns about recording it in the record?
 - a. What if you knew that the information would be shared with other clinicians involved in your care? Do you think this information should be available to all or some of the clinicians involved in your care?
 - I. Why or why not?
 - b. If you think some of the Social Determinants of Health information should be shared and some shouldn’t be, which types do you think should be and why?
 - c. Would giving your permission to share to specific clinicians make you more comfortable with sharing your Social Determinants of Health information?

4. What kind of Social Determinants of Health information would you feel comfortable discussing vs. being documented?
- IV. Preference for how Social Determinants of Health Information is Collected
1. How would you like Social Determinants of Health information to be collected?
 - a. During the visit with someone directly asking the questions?
 - b. In the clinic via tablet, kiosk, computer, or paper form?
 - c. Before the visit by questionnaire online in the patient portal?
 - d. Other?
 - e. If you prefer a person directly asking, who would you feel most comfortable talking to about this?
- V. *Final question:* Do you have any thoughts on the term Social Determinants of Health and if there are other terms that you think would be clearer to patients?
- VI. Parking Lot Questions for Patient Groups if Have Time:
1. How do you think clinicians should utilize Social Determinants of Health information?
 2. Have you ever seen your story/responses as documented by the clinician? What did you think?

Appendix 5: Clinician and Healthcare Provider Asynchronous Focus Group Guide

- I. Defining Social Determinants of Health (SDOH)
 - a. Introductory sentences: The Center for Disease Control and Prevention describes social determinants of health as the conditions in the places where people live, learn, work, and play that affect a wide range of health and quality-of life-risks and outcomes.
 - b. Have you heard of Social Determinants of Health (SDOH)?
 - c. How would you define Social Determinants of Health?
 - d. What are some examples of Social Determinants of Health? (Moderator give list of some that aren't mentioned after participants share their thoughts)
- II. Current Practices for Documenting Social Determinants of Health
 - a. Talking to patients about Social Determinants of Health
 - i. Do you/your practice ask patients about Social Determinants of Health? Why or why not? Who asks the patients about Social Determinants of Health?
 - ii. Do you explain to patients why you are asking about Social Determinants of Health? Do you call them Social Determinants of Health or something else?
 - iii. Does your practice use an Electronic Health Record?
 - iv. Do you/your practice document Social Determinants of Health information in the patient's medical record? Why or why not? Who documents the Social Determinants of Health?
 1. [if practice documents SDOH in the EHR] Do you tell patients that you are documenting Social Determinants of Health in their medical record? Do you explain to patients why you are documenting Social Determinants of Health?
 - v. Do you have any concerns about asking patients about or documenting Social Determinants of Health?
 - b. Social Determinants of Health Information Collection Practices
 - i. What Social Determinants of Health do you ask about?
 1. (Moderator give list of the following: race, ethnicity, preferred language, housing insecurity, food insecurity, social isolation, transportation access, sexual orientation, gender identify, intimate partner violence, veteran status, also option to say you don't know and option to include additional items)
 - ii. When do you collect Social Determinants of Health information (in clinic before, during, after visit; in waiting room; at patient's home computer/tablet, other)?
 - iii. How do patients respond (orally, on tablet, through patient portal, kiosk in waiting room, on paper form, other)?
 - iv. Do you capture Social Determinants of Health information from any other sources besides the patient (e.g. social service/community-based organizations/first responders)?
 1. How are those documented?
 - v. Where do you document Social Determinants of Health information in the patient's record (Notes? Assessments? In structured questionnaires? Other fields? Other?)

- vi. Is there any training provided to clinicians in your practice on how to ask about/discuss/document Social Determinants of Health information?
 - vii. Do you (or your staff) routinely obtain social determinants of health information about your patients from any other sources (e.g., other providers, social services agencies)? If yes, from whom?
 - c. Using Social Determinants of Health Information
 - i. Do you/your care team utilize the collected Social Determinants of Health information? How do you utilize this information? Can you give any examples of specific instances where you have utilized it?
 - 1. When do you/your staff act on Social Determinants of Health information: during a visit, after a visit, not at all, etc.?
 - ii. How does your practice/health system utilize this information (e.g. For population health data tracking? For research purposes? To coordinate an individual's care? Other?) (Probe if doesn't come up: Does your practice/health system use Social Determinants of Health information to identify health disparities and opportunities to reduce them at the individual and/or practice level?)
 - iii. Have you heard any concerns from patients about using their Social Determinants of Health information?
 - iv. Do you have any concerns about using Social Determinants of Health information provided by other clinicians or service providers in providing patient care or care coordination?
- III. Preferred Practices for Documenting Social Determinants of Health Information
 - a. What Social Determinants of Health information do you believe would be most useful to a patient's care?
 - i. Why do you believe these would be most useful?
 - b. How would you like Social Determinants of Health information to be collected?
 - c. When? (in clinic before, during, after visit; in waiting room; at patient's home computer/tablet, other)?
 - d. By whom? (for example, doctor, nurse, MA, social worker, other? Not by a person but via a form?)
 - e. How do you prefer patients share Social Determinants of Health information? (orally, tablet, patient portal, kiosk in waiting room, paper, other)?
 - f. What is your preference for documentation of Social Determinants of Health information in the medical record?
 - i. Open-text field/notes/assessment vs. structured fields?
 - ii. Why?
- IV. Increasing Documentation and Use of Social Determinants of Health Information
 - a. What do you think would lead to more documentation of Social Determinants of Health information in your practice/in health systems?
 - b. What are barriers to collecting and documenting Social Determinants of Health information?
 - c. What barriers are there to utilizing Social Determinants of Health information for a patient's care?
 - d. Are there policies/practices within a health system and in other entities (e.g. vendors, government, insurers, etc.) that could facilitate the documentation/utilization of Social Determinants of Health information?

- i. (Moderator ask if this didn't come out in earlier questions in section IV or use this as probe.)
- V. Parking Lot question (if time)
 - a. Do you currently send Social Determinants of Health information to others or get requests for Social Determinants of Health information?