

# Trust and Patient-Centeredness Workgroup: Action Plan to Collect and Use Social Determinants of Health Data in Patient-Centered Clinical Decision Support

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## PURPOSE

The Trust and Patient-Centeredness Workgroup is charged with (1) supporting the design, implementation, and uptake of patient-centered clinical decision support (PC CDS) to enhance trust, foster shared decision making, and engage patients and clinicians as partners alongside all members of the care team; (2) promoting and enabling the use of PC CDS and developing related outputs that can support clinicians and patients as partners in a care team, equally committed to creating effective treatment and care coordination plans; and (3) ensuring that PC CDS products are understandable by the care team, designed with end-users (including both clinicians and patients) in mind, and involving them from the very beginning of PC CDS development. The Workgroup is composed of thirteen experts and stakeholders who represent diverse perspectives within the CDS community. This report is intended to serve as an action plan that identifies needs, key challenges, current efforts, and future opportunities to advance the use of social determinants of health (SDOH) data in PC CDS. All qualitative research activities conducted by the CDSiC are reviewed by the NORC at the University of Chicago Institutional Review Board (FWA00000142).

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# Executive Summary

## Background

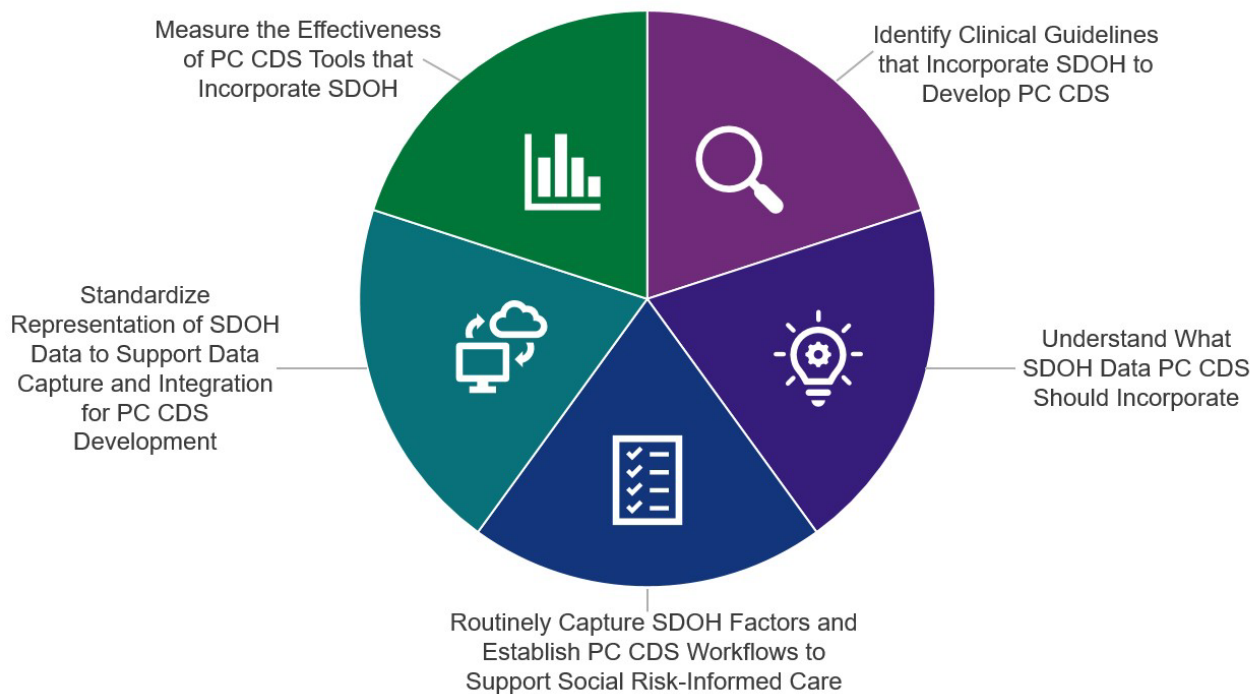
The growing recognition of the impact of social determinants of health (SDOH), social risk factors, and health-related social needs on health outcomes has heightened efforts to understand and, in some cases, address these variables in clinical care. Patient-centered clinical decision support (PC CDS), which significantly incorporates patient-centered factors related to knowledge, data, delivery, and use to support patient-centered care, may be strengthened by integrating information about SDOH factors to provide individualized and holistic care recommendations. While there is agreement that SDOH are important to PC CDS, there is a need to identify opportunities that will advance the use of this information in PC CDS tools to strengthen the integration of health and social care systems and comprehensively address patients' health-related social needs. Developed through a literature review and key informant interviews with clinicians, researchers, and patient advocates, this action plan identifies needs, key challenges, current efforts, and future opportunities to support the collection and use of SDOH data for PC CDS.

## Action Plan

This action plan describes critical needs for ensuring the incorporation of SDOH factors across the PC CDS lifecycle. Within each need, current efforts or initiatives that aim to address these gaps and related challenges are described. The plan also outlines opportunities for health system leaders, PC CDS developers, researchers, and community-based organizations to advance the incorporation of SDOH in PC CDS.

## Needs, Current Efforts, and Challenges to Collect and Use SDOH Data for PC CDS

There are five needs related to the collection and use of SDOH data in PC CDS.



**Identify Clinical Guidelines that Incorporate SDOH to Develop PC CDS Tools.** While there is growing awareness of the role of SDOH and health-related social needs on clinical outcomes, guidance is needed to support clinicians with incorporating these needs within the context of clinical care. The design and development of PC CDS tools that incorporate SDOH require the identification of clinical guidelines that provide evidence-based recommendations about these factors.

- **Current Efforts and Initiatives.** Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) published a feasibility brief outlining new or updated clinical practice guidelines (e.g., guidelines for the diagnosis and management of substance use disorders, post-traumatic stress disorder, and hypertension) that integrate SDOH data and health-related social needs. The U.S. Preventive Services Task Force (USPSTF) is also implementing a health equity framework for the development of evidence-based clinical practice recommendations.
- **Challenges.** Despite these efforts, there is a lack of clinical guidelines that incorporate SDOH for translation into PC CDS. Furthermore, when guidelines exist, their interpretation and translation into computable condition logic is often inconsistent across CDS tools. Finally, perspectives from patients and individuals with lived experience are needed in the development of clinical practice guidelines to support trust and patient-centeredness in PC CDS.



**Understand What SDOH Data PC CDS Should Incorporate.** While there is growing recognition of SDOH and health-related social needs that can influence an individual's health and well-being, there is limited understanding of those most relevant to PC CDS. Additionally, it is important to note that though there are several domains of SDOH, not all are feasible to integrate into PC CDS. The CDS field must identify the domains of SDOH that are most relevant to PC CDS to ensure that tools incorporating SDOH data are effective.

- **Current Efforts and Initiatives.** There are several efforts that can serve as a starting point for CDS developers to identify SDOH data that may be relevant to PC CDS. The United States Core Data for Interoperability (USCDI) Version 4, developed by ASTP/ONC, includes standardized data elements for some SDOH factors such as food insecurity, housing instability and homelessness, inadequate housing, transportation insecurity, financial strain, social isolation, stress, interpersonal violence, education, and veteran status. As described above, ASTP/ONC also published a feasibility brief that describes clinical practice guidelines that include SDOH. Health-related social needs included in these guidelines focus on factors related to housing, family environment, employment, personal safety, and food insecurity. Additionally, hospitals participating in the Centers for Medicare and Medicaid Services (CMS) Hospital Inpatient Quality Reporting Program are now required to report SDOH data related to food insecurity, interpersonal safety, housing insecurity, transportation insecurity, and utilities. A screening tool for the CMS Accountable Health Communities model also identifies risk factors related to the domains of SDOH, as well as financial strain, employment, family and community support, education, physical activity, substance use, mental health, and disabilities. The Agency for Healthcare Research and Quality (AHRQ) developed a Digital Healthcare Equity Framework that synthesizes digital healthcare equity domains and subdomains. Examples include cultural language, broadband access, digital literacy, chronic poverty, physical environment, functional needs, digital determinants of health, and access to care.
- **Challenges.** There is limited evidence on which SDOH data can be incorporated into PC CDS to support healthcare decision making.



**Routinely Capture SDOH Factors and Establish PC CDS Workflows to Support Social Risk-Informed Care.** There are gaps in routinely screening for individual social risk factors at the point of care and limited research on making these data actionable for clinicians. To generate reliable recommendations, PC CDS tools require routine collection and updates of social risk factor data. Additionally, appropriate workflows must be established for integrating these data into PC CDS, facilitating shared decision making, adjusting care plans, and providing tailored clinical recommendations based on identified health-related social needs.

- **Current Efforts and Initiatives.** There are many initiatives and resources available to support the collection of social risk factor data and implementation of workflows that facilitate SDOH-informed PC CDS. Numerous screening tools are now available within the electronic health record (EHR) to support the routine capture of social risk factor data. Additionally, natural language processing (NLP) methods are also being leveraged to extract and synthesize SDOH information from clinical notes efficiently. There are a

few pilot initiatives underway that are establishing and implementing workflows that collect and use social risk factor data for CDS.

- **Challenges.** While these efforts signify progress in the routine collection of SDOH factors in clinical care, there are some challenges that remain. Patients continue to be hesitant to share information on social risk factors and health-related social needs due to stigma and lack of trust within their healthcare organization. Moreover, the added work required to conduct comprehensive social risk factor screenings and adjust care plans may create additional burdens for care teams.



### **Standardize Representation of SDOH Data to Support Data Capture and Integration for PC CDS Development.**

There are inconsistencies in how SDOH data are captured across different care settings and within the EHR. It is crucial to standardize the collection and presentation of SDOH data in EHRs to help developers of PC CDS tools integrate high-quality SDOH data and support care teams incorporating such data into healthcare decision making and adjustment of care plans.

- **Current Efforts and Initiatives.** Major medical vocabularies/terminology standards such as the International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM), Logical Observation Identifiers Names and Codes (LOINC), and the Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT) used in health information and technology now support the standardized capture of SDOH data. Similarly, the Gravity Project is advancing both terminology and data exchange standards for SDOH. ASTP/ONC has also led efforts to promote the standardized electronic exchanges and use of SDOH data.
- **Challenges.** Despite these resources, CDS developers face challenges with standardizing SDOH data representation. The lack of uniform standards adoption creates barriers to sharing and integrating SDOH data in PC CDS. Moreover, the standardization of SDOH data may also limit the ability to meaningfully record related nuances or complexities. Current standards for SDOH data capture are often limited to discrete responses and may not adequately capture details about patients' social needs or match narrative descriptions of SDOH.



**Measure the Effectiveness of PC CDS Tools that Incorporate SDOH.** Evidence demonstrating the benefits of integrating SDOH in PC CDS is limited and it is crucial for driving health and payment systems to support the collection and use of SDOH data. As an essential part of the CDS lifecycle, ongoing evaluation of PC CDS tools that incorporate SDOH is necessary to ensure their effectiveness in improving health outcomes.

- **Current Efforts and Initiatives.** CDS researchers may leverage two efforts related to measuring SDOH data and interventions. ASTP/ONC developed a Social Determinants of Health Information Exchange Toolkit that can support PC CDS researchers with evaluating SDOH information exchange. The Social Interventions Research and Evaluation Network (SIREN) is developing a conceptual framework to evaluate interventions that address SDOH in healthcare settings.








- **Challenges.** Since the incorporation of SDOH is a relatively new direction for CDS, there are no common measures and metrics to evaluate the effectiveness of CDS tools that collect and use SDOH data.

## Opportunities

There are eleven opportunities (see below) across the identified needs to advance the collection and use of SDOH data in PC CDS.

### Opportunities to Collect and Use SDOH Data for PC CDS

 <b>Identify Clinical Guidelines that Incorporate SDOH to Develop PC CDS</b>
<b>Opportunity 1:</b> Encourage the inclusion of SDOH in clinical guidelines
<b>Opportunity 2:</b> Ensure that guideline development includes patients and those with lived experience of health-related social needs
 <b>Understand What SDOH Data PC CDS Should Incorporate</b>
<b>Opportunity 3:</b> Identify SDOH currently incorporated in clinical care that are most relevant to PC CDS
<b>Opportunity 4:</b> Build the evidence base to understand how PC CDS that incorporates SDOH data can help address health-related social needs and impact health outcomes
 <b>Routinely Capture SDOH Factors and Establish PC CDS Workflows to Support Social Risk-Informed Care</b>
<b>Opportunity 5:</b> Ensure transparent practices in the collection and use of SDOH data for PC CDS
<b>Opportunity 6:</b> Use patient-centered and user-centric approaches to develop optimal PC CDS implementation workflows for documentation of social risk factors and health-related social needs
<b>Opportunity 7:</b> Engage PC CDS stakeholders to support the design, development, and implementation of PC CDS that can support social risk-informed care
 <b>Standardize Representation of SDOH Data to Support Data Capture and Integration for PC CDS Development</b>
<b>Opportunity 8:</b> Develop training programs and resources to assist healthcare organizations in adopting available SDOH standards to support PC CDS
<b>Opportunity 9:</b> Design flexible data collection processes that allow for the documentation of nuanced SDOH data while maintaining standardization
 <b>Measure the Effectiveness of PC CDS Tools that Incorporate SDOH</b>
<b>Opportunity 10:</b> Identify measures and metrics to evaluate the impact of PC CDS tools that incorporate SDOH data
<b>Opportunity 11:</b> Develop reliable methods to evaluate PC CDS interventions that address identified health-related social needs

## Additional Considerations

In addition to the eleven opportunities identified under the five needs, there are two additional considerations:

**Mitigate Bias and Improve Accuracy of Artificial Intelligence (AI) Algorithms Underlying PC CDS Tools that Incorporate SDOH.** As the use of AI expands to support CDS, there is a risk of outputs being inherently biased due to multiple factors, such as unrepresentative training datasets or insufficient demographic information in training models. As PC CDS technology evolves and focuses on the identification and use of SDOH data to inform decision making and improve patient outcomes, Fair, Appropriate, Valid, Effective, and Safe (FAVES) principles emphasized by a White House Executive Order outline potential opportunities to ensure that PC CDS remains free from bias and the potential to exacerbate health disparities.

**Cross-Sector Data-Sharing of SDOH Data Relevant for PC CDS and Closed-Loop Referrals.** Creating PC CDS tools that promote social risk-informed healthcare requires partnerships between health and social care systems to develop an integrated, cross-sector data infrastructure. Patient-specific SDOH data are often collected by social service providers, public health agencies, and community organizations. State- or community-level PC CDS pilots are needed to establish robust SDOH information exchange ecosystems, supported by secure information systems and reciprocal data-sharing relationships. Additionally, developing a resource database would streamline closed-loop referrals, connecting patients with community resources more efficiently.

## Conclusion

Contextualizing clinical recommendations based on individual social risk factors and health-related social needs is vital for patient-centered care. PC CDS tools that integrate these data can provide holistic care recommendations that positively impact clinical and quality of care outcomes, facilitating progress toward addressing health inequities. This action plan identifies five key needs to effectively integrate social risk factor data into PC CDS tools, acknowledging recent efforts. However, the evidence base for using social risk factor data in PC CDS is still limited. This plan highlights barriers and provides recommendations for overcoming them through coordinated efforts among clinicians, researchers, health information technology (IT) developers, public health experts, Federal agencies, and community organizations. PC CDS interventions should be advanced iteratively to make care delivery more equitable, impactful, and tailored to the diverse needs of patients.

# 1. Introduction

Across the healthcare field, there is a growing recognition of the significant impact that nonmedical, social factors have on an individual's health and well-being.<sup>1</sup> These **social determinants of health (SDOH)** include the “conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”<sup>2</sup> While SDOH encompass a variety of factors, they can be grouped into five key domains: economic stability, education access and quality, healthcare access and quality, neighborhood and built environment, and social and community context.<sup>2</sup>

SDOH have the potential to “shape health for better or worse”<sup>3</sup> and affect everyone. In contrast, **social risk factors** are “adverse social conditions associated with poor health,”<sup>4</sup> such as housing instability or a low literacy level.

Further, it is necessary to distinguish between social risk factors and **health-related social needs**. Health-related social needs reflect a patient's individual priorities and may shift in importance over time.<sup>3</sup> For instance, a patient may screen positive for multiple social risk factors, but the patient may identify one health-related social need that is the most critical to address in collaboration with their care team.

The increased understanding of the impact that health-related social needs have on health outcomes has heightened efforts to collect and use SDOH data in clinical care. For example, starting in 2024, the Centers for Medicare and Medicaid Services (CMS) requires hospitals participating in the Hospital Inpatient Quality Reporting program to screen patients and report on measures related to five specific SDOH domains and social risk factors: food insecurity, housing instability, transportation needs, utility difficulties, and interpersonal safety.<sup>5</sup>

Patient-centered clinical decision support (PC CDS) that integrates information about SDOH factors can support patient-centered care that accounts for patients' health-related social needs. PC CDS encompasses a spectrum of decision-making tools that significantly incorporate patient-centered factors related to knowledge, data, delivery, and use. Knowledge refers to the use of comparative effectiveness research (CER) or patient-centered outcomes research (PCOR) findings. Data focuses on the incorporation of patient-generated health data, patient preferences, social determinants of health, and other patient-specific information. Delivery refers to directly engaging patients and/or caregivers across different settings. Finally, use focuses on facilitating bi-directional information exchange in support of patient-centered care, including shared decision making.<sup>6</sup>

Previous work by the Clinical Decision Support Innovation Collaborative (CDSiC) has explored PC CDS efforts related to SDOH and described the need for data and interoperability standards to define, collect, and integrate SDOH data for effective use in PC CDS.<sup>7</sup> While there is agreement that SDOH are important to PC CDS, there is a need to identify opportunities that will advance the use of this information in PC CDS tools to strengthen the integration of health and social care systems and comprehensively address patients' health-related social needs. This action plan expands on our previous work to identify needs, key challenges, current efforts, and future opportunities to advance the use of SDOH data for PC CDS.

## 1.1 What Does the Action Plan Cover?

The action plan identifies opportunities to support the collection and use of SDOH data for PC CDS. This includes both individual social risk factors and health-related social needs, which are immediate, actionable, and stem from a person’s social risk factors.

The plan was informed by a rapid analysis of 78 peer-reviewed and grey literature publications and key informant interviews with seven individuals who were researchers, clinicians, and patient advocates. A detailed description of the methods used to develop the action plan is provided in **Appendix A**.

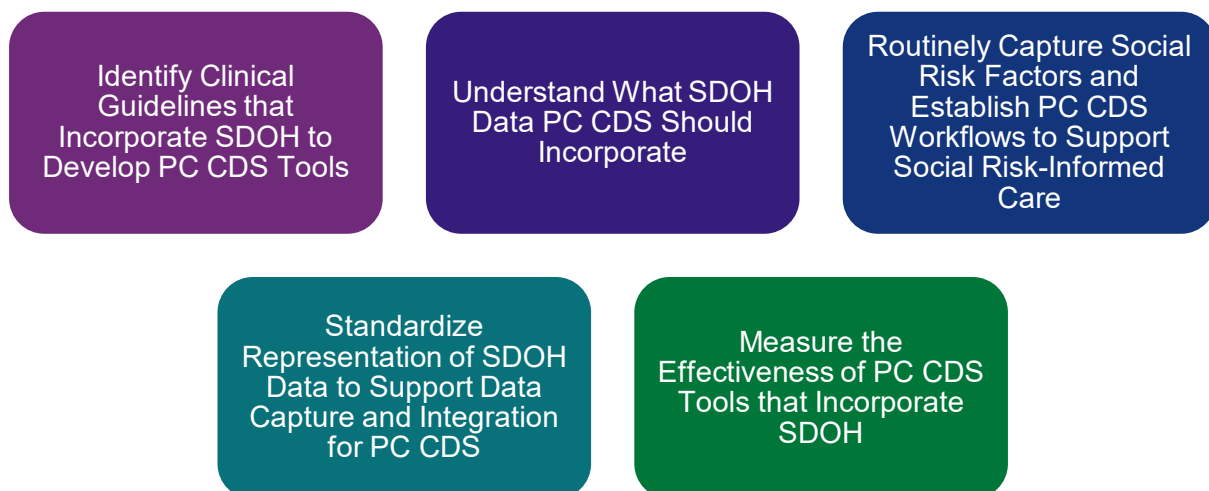
This action plan can be used by health system leaders, PC CDS developers, researchers, and community-based organizations to inform ongoing and future efforts to improve health outcomes by not only targeting medical needs, but also addressing health-related social needs using PC CDS.

The remaining parts of the action plan are organized into three sections. Section 2 lays out critical needs we must address in the PC CDS design, development, and implementation lifecycle in order to use SDOH data. For each of the identified needs, in subsections 2.1-2.5, we contextualize the current state by describing key challenges and current efforts. We then outline opportunities that serve as an action plan for the CDS field. Section 3 includes two additional considerations related to PC CDS when using and sharing data related to SDOH factors, health-related social needs, and social interventions. Section 4 provides a conclusion summarizing the action plan, limitations, and future directions.

## 2. An Action Plan to Collect and Use SDOH Data for PC CDS

As shown in **Exhibit 1**, we identified five key needs that relate to one or more phases of the PC CDS lifecycle. Some existing initiatives or efforts partially address these needs, which we highlight under each need below. We also report key challenges associated with each need, as well as suggest opportunities to advance PC CDS by considering data related to SDOH and health-related social needs.

**Exhibit 1.** Five Needs Related to Incorporating and Using SDOH Data for PC CDS



## 2.1 Identify Clinical Guidelines That Incorporate SDOH to Develop PC CDS Tools



The first step in the PC CDS lifecycle is to identify clinical evidence that can be translated into computable clinical knowledge to support the development of PC CDS tools.<sup>8</sup> However, a few informants noted that while there is growing awareness of the role of SDOH and health-related social needs on clinical outcomes, guidance is needed to support clinicians with incorporating these needs within the context of clinical care.

To develop PC CDS tools that incorporate SDOH, we must first identify clinical guidelines that provide evidence-based recommendations about these factors. Below, we discuss challenges, current efforts and initiatives, and opportunities to address this need.

### 2.1.1 Current Efforts and Initiatives

Authorities that develop clinical recommendations are undertaking initiatives to identify and create clinical guidelines that incorporate SDOH data and considerations for health-related social needs.

**In response to growing awareness of the impact of SDOH on clinical outcomes, the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) published a brief that identified seventeen clinical practice guidelines that incorporate SDOH into CDS.**<sup>9</sup> This ASTP/ONC brief describes new and updated guidelines for diagnosing and managing medical conditions using SDOH data and health-related social needs. Using the practice guidelines described in this brief, CDS developers can determine those that may be primed for translation into PC CDS.

The practice guidelines curated in this brief identify clinical areas where SDOH and health-related social needs are considered, including care related to substance use disorders, post-traumatic stress disorder, cervical cancer, Alzheimer's disease and other dementias, hypertension, and pediatric care. For example, the American Academy of Pediatrics' Guidelines for Perinatal Care (8<sup>th</sup> Edition) recommends that the minimal criteria for discharging newborn infants include an assessment for family, environmental, and social risks.<sup>10</sup> The Substance Abuse and Mental Health Services Administration's guidelines for the treatment of stimulant use disorders note that clinicians should coordinate care with social support services to address health-related social needs associated with income and housing instability.<sup>11</sup>

**The U.S. Preventive Services Task Force (USPSTF) is prioritizing the development of recommendations that promote health equity and may be applied to PC CDS.**<sup>12</sup> The USPSTF provides evidence-based recommendations about clinical preventive services to inform clinical guidelines. Recognizing the importance of understanding SDOH for disease prevention and preventive care, the USPSTF developed a health equity framework to guide the development of evidence-based recommendations that incorporate health equity, race, and racism for clinical preventive services.

Using a health equity lens, the framework provides a checklist of key items to be considered for each phase of the recommendation-making process: topic selection and prioritization, development of the workplan, evidence review and deliberation, development of the recommendation statement, and dissemination of recommendations. For example, checklist items for topic nomination, selection, and

prioritization include consideration of health equity information in background documents and outreach to key stakeholders for identification of topics specific to health equity and related social risk factors.<sup>11,12</sup> As a part of evidence review, the framework suggests outlining specific populations in which risk assessment models have been evaluated and requesting review by experts and Federal partners with expertise in health equity or in populations experiencing disparities.<sup>12</sup>

The USPSTF intends to use this framework to guide the development of evidence-based recommendations for clinical preventive services.<sup>12</sup> Recommendations that result from this effort may serve as foundational evidence for the development of PC CDS tools that incorporate SDOH.

### 2.1.2 Challenges

Because the formal recognition of the importance of considering SDOH in clinical guidelines is relatively new,<sup>13</sup> there are some key challenges with identifying clinical guidelines that include SDOH for translation into PC CDS.

**There is a lack of clinical practice guidelines that incorporate SDOH for translation into PC CDS.** Findings from our literature review and key informant interviews indicate that despite increasing efforts to incorporate SDOH in clinical practice, guidelines and/or tools that use this information are limited.<sup>14</sup>

A few informants highlighted that most clinical guidelines do not address or acknowledge how SDOH and health-related social needs may impact a patient's ability to adhere to certain clinical recommendations, making it difficult for clinicians to apply considerations for these factors in clinical decision making and treatment plans. Therefore, there are still relatively few clinical areas using SDOH-based practice guidelines and recommendations, limiting the resources available to develop PC CDS tools.

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*“Just thinking about the clinical guidelines that I teach and know for my work... I feel like most guidelines don't really account for [SDOH]... [For example,] here's the guideline for healthy eating. They don't usually account for what you should do if the person lives in a food desert.”*

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**Guideline interpretation and translation into computable condition logic can vary across CDS tools.**<sup>9,15</sup> The translation of narrative guidelines into computable formats has been previously identified as a challenge for PC CDS.<sup>16</sup> This same challenge may be found with translating written clinical guidelines that incorporate SDOH into computational logic. This process is likely prone to ambiguities, subjective interpretations, and potential loss of nuance, especially when dealing with complex health-related social needs and their interplay with clinical conditions and recommendations.<sup>17</sup> As a result, a key challenge for PC CDS developers is ensuring that the interpretation and translation of clinical practice guidelines that incorporate SDOH are consistent.

**Perspectives from patients and individuals with lived experience are needed to develop patient-centered clinical practice guidelines.**<sup>18</sup> Some key informants highlighted the importance of including patients and those impacted by health-related social needs in the development of PC CDS tools that incorporate SDOH, as they can provide valuable insight into managing certain medical conditions in light of these factors. However, as one informant explained, clinical care is often framed *“from the perspective of the healthcare system, not the perspective of the person.”*

While many medical societies and organizations encourage the involvement of patients in clinical guideline development,<sup>19</sup> there is no standard approach for including patients and individuals with lived experience in this process.<sup>18,20</sup> The potential lack of perspectives from patients and individuals with lived experience in clinical practice guidelines presents a challenge for CDS developers when translating these guidelines and developing SDOH-based tools that are patient-centered.

## 2.1.2 Opportunities

There are two opportunities to support the development of effective PC CDS tools that incorporate SDOH using clinical practice guidelines.



**Opportunity 1: Encourage the inclusion of SDOH in clinical guidelines.** While there are some emerging clinical practice guidelines that incorporate SDOH, there is opportunity for more clinical guidelines to include these factors. Similar to the initiatives of the USPSTF, key actors that develop clinical guidelines (e.g., professional societies) should prioritize the inclusion of SDOH. It is important that tools that incorporate SDOH are relevant to PC CDS and support healthcare decision making. Therefore, expanding the number of clinical practice guidelines that incorporate SDOH will provide a wider range of practice guidelines to draw from when developing PC CDS tools that are more SDOH-based.



**Opportunity 2: Ensure that guideline development includes patients and those with lived experience of health-related social needs.** As with all innovations in PC CDS, it is critical that the voices of patients are heard in the development process.<sup>21</sup> For PC CDS tools that incorporate SDOH data and provide considerations for certain health needs, it is important that individuals impacted by those needs are also included.

National professional societies and organizations developing clinical guidelines that incorporate SDOH should similarly engage with patients and other relevant stakeholders to ensure that recommendations adapted for health-related social needs appropriately reflect patients' lived experiences. Such organizations can leverage existing resources such as Patient-Centered Outcomes Research Institute's Engagement Tool and Resource Repository that includes engagement-related tools and resources<sup>22</sup> or the Office of the Assistant Secretary for Planning and Evaluation's brief that describes methods and emerging strategies to engage people with lived experience.<sup>23</sup> Including patients and those with lived experiences in the development of clinical practice guidelines will promote patient-centeredness. Furthermore, in order for CDS developers to better translate these guidelines into computational logic for SDOH-based PC CDS tools, CDS developers could also engage with patients and those with lived experiences, as well as clinical guideline developers, during the co-design process.

## 2.2 Understand What SDOH Data PC CDS Should Incorporate



Incorporating data on SDOH in PC CDS can inform evidence-based recommendations that reflect the needs of patients and support patients, caregivers, and care teams in making healthcare decisions. In turn, understanding relevant health-related social needs in tandem with care recommendations may improve patient outcomes. While there is growing recognition of SDOH and health-related social needs that can influence an individual's health and well-being, there is limited understanding of those

most relevant to PC CDS. Additionally, it is important to note that though there are several domains of SDOH, not all are feasible to integrate into PC CDS. To develop tools that enhance healthcare decision making by incorporating data on SDOH, the CDS field must first understand the domains of SDOH that are most relevant and actionable for PC CDS.

### 2.2.1 Current Efforts and Initiatives

There are several resources that may support the CDS community with identifying SDOH data that are appropriate for integration into PC CDS.

**ASTP/ONC developed the United States Core Data for Interoperability (USCDI), which includes a standardized set of SDOH data elements.** Version 4 (v4) of the USCDI, which was published in July 2023, includes standards for some key SDOH data elements under the “SDOH Assessment” data element section, which falls under the overarching “Health Status Assessments” section.<sup>24</sup> SDOH data elements specified under the USCDI v4 are food insecurity, housing instability and homelessness, inadequate housing, transportation insecurity, financial strain, social isolation, stress, interpersonal violence, education, and veteran status; these elements are established by value sets in National Library of Medicine’s Value Set Authority Center. CDS developers can identify and prioritize SDOH data for inclusion into PC CDS tools by referencing these SDOH data elements described in USCDI v4.

**ASTP/ONC also published a feasibility brief for CDS describing clinical practice guidelines that incorporate SDOH.**<sup>9</sup> The SDOH and health-related social needs included in these guidelines focus on factors related to housing, family environment, employment, personal safety, and food insecurity. The ASTP/ONC feasibility brief may serve as a starting point for CDS developers to understand the SDOH and health-related social needs that are being identified and addressed in certain areas of clinical care and may be similarly relevant to PC CDS.

**The Centers for Medicare and Medicaid Services (CMS) Hospital Inpatient Quality Reporting Program now requires reporting on SDOH.** Hospitals participating in the program must screen admitted patients for domains of SDOH related to food insecurity, interpersonal safety, housing insecurity, transportation insecurity, and utilities. CMS also developed a screening tool for the Accountable Health Communities model to identify social and behavioral risk factors related to the core domains of SDOH, as well as those associated with financial strain, employment, family and community support, education, physical activity, substance use, mental health, and disabilities.<sup>25</sup> The CDS community may further investigate if the SDOH domains and health-related social needs prioritized by CMS are feasible to incorporate into PC CDS.

**The Agency for Healthcare Research and Quality (AHRQ) developed a Digital Healthcare Equity Framework that synthesizes digital healthcare equity domains and subdomains.**<sup>26</sup> The AHRQ framework links social determinants, needs, and risk factors to facilitate digital healthcare equity. The framework lists three main domains, of which the patient and community characteristics domain includes a list of SDOH data elements that are relevant for PC CDS. Examples include cultural language, broadband access, digital literacy, chronic poverty, physical environment, functional needs, digital determinants of health, and access to care. The corresponding implementation guide also provides a step-by-step plan and real-world examples for users to implement the framework and incorporate equity in each phase of the digital healthcare lifecycle.<sup>27</sup>



## 2.2.2 Challenges

Despite these initiatives, a key challenge remains in understanding what SDOH data are most relevant to PC CDS.

**There is limited evidence on which SDOH data can be incorporated into PC CDS.** CDS developers must rely on evidence to design effective PC CDS tools that incorporate SDOH data and focus on patients' health-related social needs that impact treatment plans. However, a significant barrier to this is the lack of evidence on what SDOH are most relevant and actionable in PC CDS. Additionally, evidence is needed to demonstrate that the integration of SDOH data in PC CDS will contribute to improved health outcomes.

Given the lack of supporting evidence, CDS developers face a significant barrier to understanding the SDOH that are relevant and data that should be incorporated into PC CDS to support healthcare decision making.

## 2.2.3 Opportunities

In response to this challenge, there are some opportunities for CDS developers to better understand SDOH appropriate for PC CDS.



**Opportunity 3: Identify SDOH currently incorporated in clinical care that are most relevant to PC CDS.** To ensure the development of practical, effective tools, CDS developers must systematically identify SDOH that clinical areas are incorporating and may be adapted for PC CDS. The CDS community can leverage foundational work conducted by ASTP/ONC and CMS to understand clinical areas currently incorporating SDOH and determine if it is similarly feasible to incorporate SDOH in PC CDS in these clinical areas. CDS developers may also examine the SDOH domains that are addressed by these guidelines to understand if these are relevant for PC CDS. The AHRQ Digital Healthcare Equity Framework and guide can be referenced by PC CDS developers to select SDOH domains and ensure that the proposed PC CDS tool is relevant to the needs of the target population.<sup>26,27</sup>

Key informants highlighted that CDS developers should include input from patients, caregivers, and clinicians to identify SDOH and health-related social needs that may be impacted by PC CDS in other areas of clinical care. This will ensure the inclusion of SDOH data is patient-centered and can inform healthcare decision making.



**Opportunity 4: Build the evidence base to understand how PC CDS that incorporates SDOH data can help address health-related social needs and impact health outcomes.** CDS researchers must prioritize investigations that can be used to develop PC CDS tools that effectively collect and incorporate SDOH data to facilitate healthcare decision making. Understanding what SDOH enhance healthcare decision making and contribute to improved health outcomes will ensure the incorporation of this information is constructive for PC CDS. As one informant also noted, concentrating on SDOH that are pertinent to PC CDS will also demonstrate return on investment and support user buy-in for CDS tools.

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*“[One thing that drives these changes] is being able to suggest more studies that show the benefits of a system like this... because there are skeptics on SDOH interventions... So I think better studies that show those linkages is important.”*

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## 2.3 Routinely Capture Social Risk Factors and Establish PC CDS Workflows to Support Social Risk-Informed Care



For PC CDS tools to generate reliable and effective recommendations, individual social risk factor data must be routinely collected at the point of care and updated for the purpose of integration into PC CDS tools. In general, there is a lack of consensus on whether or not to screen for these factors during a clinical encounter and which factors to screen for,<sup>28,29</sup> which may contribute to the inconsistencies in data collection.<sup>30</sup>

Research studies have shown that even the limited social risk factor data consistently collected within the EHR, such as race and ethnicity, continue to suffer from quality problems.<sup>31</sup> Similar issues may arise as data collection expands to a more comprehensive set of social risk factor data that is relevant for PC CDS. For instance, one study found that social risk factor data on financial strain and social isolation is not routinely captured in the EHR.<sup>32</sup> Frequent collection of social risk factor data, particularly in high-risk populations, is important as patient-specific social risk factors and health-related needs can change over time. For instance, outdated data on homelessness, lack of transportation, food insecurity, and/or financial strain can lead to inappropriate or ineffective PC CDS guidance to address a clinical diagnosis whose management is directly dependent on one of these factors.

Additionally, it is important to establish appropriate workflows to collect and use these data in the context of PC CDS in order to facilitate shared decision making, adjust care plans, and provide tailored clinical recommendations in accordance with the identified health-related social needs.<sup>30</sup> Most informants shared that while many health organizations have implemented social risk screening measures due to recent CMS regulations, they have not moved much further beyond data collection such that this information can be acted upon by care teams (e.g., clinicians, social workers, case managers, patient navigators). As noted previously, there is a need to identify what SDOH data are applicable to PC CDS and data collection workflows should focus on social risk factors that are actionable within the context of PC CDS and healthcare decision making. This is due to the limited research on how to make the collected data actionable for clinicians and optimize workflows to efficiently integrate social risk factor screenings and deliver social risk informed care by leveraging PC CDS tools.<sup>33</sup>

### 2.3.1 Current Efforts and Initiatives

A few efforts promote routine capture of social risk factor data and may be available for PC CDS use.

**Standardized screening tools available for integration in the EHR.** Numerous screening tools such as Accountable Health Communities Screening Tool (ACHS),<sup>34</sup> Health Leads Screener,<sup>35</sup> Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE),<sup>36</sup> and the SDOH tool in Epic<sup>37</sup> are now available within the EHR and are being administered across health systems to routinely capture a comprehensive set of social risk factor data across a variety of SDOH domains –

economic stability, neighborhood and built environment, health and healthcare, education, and social and community context.<sup>29</sup> However, not all tools have the same validity, reliability and utility.<sup>38</sup>

**Natural language processing (NLP) methods have been used to extract existing SDOH categories from clinical narratives.** NLP methods have been leveraged to explore free-text documentation to extract specific social risk factors such as financial constraint, lack of transportation, and poor social cohesion.<sup>39,40</sup> The primary advantage of such methods is that clinical workflows do not need to be modified to screen for social risk factors in a structured manner and can facilitate use of existing social risk factor data for PC CDS development and implementation before standard collection systems are established.<sup>41</sup> For example, Moonstone, a rule-based NLP system, has been used to automatically extract eight social risk factors (living alone, instrumental support, impaired activity of daily living, medical condition, medication compliance, depression, dementia, language barrier) from clinical notes within the Veterans Affairs' EHR system over four broad cohort categories (congestive heart failure, acute myocardial infarction, pneumonia, and stroke) with good to excellent performance.<sup>42</sup>

**Recent pilot efforts have established and evaluated workflows to collect and utilize social risk factor data for healthcare decision making and/or PC CDS for specific use cases.** We identified several examples through our literature review and key informant interviews (see **Exhibit 2**).

#### **Exhibit 2. Pilot CDS Efforts that Collect and Use Social Risk Factor Data**

**The ASCEND (Approaches to Community Health Clinic Implementation of SDOH Data Collection and Action) provided tailored, scalable, pragmatic implementation support to help five community health centers adopt social risk screenings and address needs.**<sup>43</sup> In order to improve social risk factor screening, the research team developed a health workflow planning tool and guide to help community health centers select when the data can be collected, who will administer the screening tool, and what method will be used for capturing the data based on their local needs.<sup>44</sup>

**AHRQ has funded CDS projects that include social risk factor data.** For example, one project included an EHR-based CDS tool aimed at reducing barriers to addressing intimate partner violence (IPV).<sup>45</sup> The intervention included self-reported questionnaires embedded in the EHR, clinical decision support for IPV screening and detection, telehealth referrals to national IPV counseling services, and EHR modifications to support billing for IPV services. The three-part EHR-based intervention appeared to be effective in both increasing the frequency of screening and the number of patients identified as at risk for significant future physical IPV-related injuries.<sup>45</sup>

Another AHRQ-funded CDS project integrated contextual factors into CDS to improve outcomes, including social risk factor information.<sup>46</sup> The project team incorporated contextual information into the CDS knowledge base to help clinicians pick up on contextual red flags and prevent contextual errors. In addition to eliciting contextual information directly from the patient via a questionnaire, contextualized CDS could also cull data from the patient's medical record utilizing a set of rules designed to identify common contextual red flags that link to social risk factors. For example, recent worsening of asthma symptoms due to medication non-adherence could be related to job loss or loss of health insurance. In this case, the clinician can switch the patient to a less costly medication.

**The COHERE (Contextualized Care in Community Health Centers' Electronic Health Records) developed CDS tools that provide alerts to care team members of patients' known social risks and recommends relevant care plan adaptations for hypertension and diabetes control.**<sup>47</sup> COHERE uses existing data in the EHR to identify patients with potential social risks. When a social risk is detected, a CDS alert pops up in the EHR, notifying care team members like doctors and nurses. The CDS tool does not just inform, it also suggests changes to the patient's care plan to address the social risk. For instance, for a diabetic patient with food insecurity, the tool might recommend discussing meal planning strategies or providing referrals to food banks.

## 2.3.2 Challenges

While some initiatives have demonstrated success in routine SDOH data capture, there continues to be some challenges to scale and expand these efforts.

**Patients may be reluctant to share and/or document social risk factor and health-related social needs data due to stigma and concerns about healthcare organization trustworthiness.** Evidence suggests that patients with social risks often do not want assistance from the healthcare system.<sup>48,49</sup> Most informants raised the issue that patients are often hesitant to share social risk factor information primarily because they are unclear about how information will be used by health systems and clinicians.

A few informants also raised that even when patients understand the value of sharing SDOH information with clinicians, they may be concerned about disclosing temporary situations they do not want in their permanent record, fearing bias or profiling. Additionally, they may not want to be asked these questions if there is no direct benefit to them. One informant emphasized that sensitive topics like immigration status or child protective services-related questions can lead to increased reluctance in sharing such data.

Informants also discussed that patients often express hesitation about having social risk factor data stored in their EHR and are concerned about data privacy and security. Moreover, displaying such sensitive information without proper consent or privacy safeguards may raise ethical concerns and potentially violate patient privacy or autonomy. A few informants also suggested that while it is critical to share data back to the patient, displaying and discussing health-related social needs can introduce bias or stigma and perpetuate stereotypes for certain patient populations.

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*“I worry that sometimes when we do it that we put it into a place where it ends up just being a check the box. It’s like, you know, when they screen you for psychosocial needs. When you go into your doctor. It’s just like...half the time the nurse or the doctor doesn’t even look you in the eye when they’re asking you these questions. They just do it because it’s part of what they have to do.”*

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**Clinicians have limited bandwidth to collect social risk factor data and adjust care plans to accommodate health-related social needs.** Incorporating comprehensive social risk factor screening into clinical practice requires determining how and who will bear the additional workload burden not just for data collection but also for making these data actionable and useful in terms of PC CDS recommendations.

The literature<sup>30,50</sup> suggests multidisciplinary staff members (such as clinicians, medical assistants, social workers, case managers) universally reported a few barriers to integrating screening into clinical workflows across care settings, such as logistical burdens, staff turnover, billing for additional time spent, and adequate staff training.<sup>44,51</sup> For instance, in a mixed methods evaluation study<sup>37</sup> of an SDOH screening intervention, the screening team members encountered challenges such as active interference or perceived frustration from clinicians and patients due to increased waiting times as a result of screening. Although staff members acknowledged the importance of SDOH screening, they highlighted a lack of positive feedback and perceived constraints in capacity for routinely screening all patients.

Several informants highlighted that social risk screening tools and discussions in inpatient and outpatient settings are often completed by social workers, case managers, and/or patient navigators. This often means that there are no clear workflows to hand off such information relevant to clinical decision making.

Finally, if clinicians identify a social need during a clinical encounter, they are often unsure of how to appropriately respond to the patient, document the interaction, and help address the social need. Specifically, clinicians are frequently unaware of community resources and/or unable to directly access referral resources during the clinical encounter and adjust treatment decisions accordingly. For example, if a diabetic patient does not have access to a refrigerator to store their insulin and an appropriate referral has been made, the clinician may not be able to track the status of the referral and make a timely treatment decision.

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*“Another big tension around actually doing the documentation is that people are like, well, I don’t want to screen them if I can’t refer them somewhere, and we are absolutely struggling to figure out how to make it easy for folks to do that.”*

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The lack of closed-loop referral systems and the need to collate community resources to address social needs is discussed in more detail under Section 3. Additional Considerations.

### 2.3.3 Opportunities

In order to meet the need for routine screening of social risk factors and establish PC CDS workflows to support social risk-informed care, three opportunities can be considered.



**Opportunity 5: Ensure transparent practices in the collection of and use of SDOH data for PC CDS.** One of the first steps to address the challenge of patients’ reluctance to share social risk factor data on a routine basis is to ensure transparency in how the social risk and needs data are collected and used for PC CDS. In order to ensure transparency, healthcare systems should clearly outline how such data will be used, stored, and protected. This includes providing information on who will have access to these data and for what purposes.

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*“[Patients ask,] ‘Why are you asking me these things? What do you want to know? Is it just data that you’re going to put into this giant database? Or is this something that’s going to help me and my family and my community?’... If you’re taking somebody’s data, you have to tell them what you’re using it for, and you also have to kind of return the results of that data.”*

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**Opportunity 6: Use patient-centered and user-centric approaches<sup>50</sup> to develop optimal PC CDS implementation workflows for documentation of social risk factors and health-related social needs.** A patient-centered approach prioritizes the unique needs, preferences, and values of the patient. It involves active patient engagement and ensures that healthcare decisions respect patients’ individual circumstances. A user-centric

approach focuses on designing systems and tools that are intuitive and convenient for all users, including patients and clinicians, facilitating ease of use and accessibility.

From the patient perspective, screening tools should be carefully chosen based on the patient population and their needs. Before implementing screening tools, health systems can engage patient representatives in the process to build acceptability and consensus around its value and utility.<sup>52</sup> This includes involving patients in discussions about health-related social needs and potential interventions, offering choices, and respecting patient preferences regarding data-sharing.

In order to reduce clinical staff burden, health systems and health information technology (IT) developers must establish data collection processes to ensure that end-users' needs and workflow considerations are optimized.<sup>53</sup> Social risk screening data can be integrated directly into the EHR by prompting patients to complete social screening questionnaires prior to the visit through patient portals or via text. At the clinical encounter, patients can complete questionnaires on computer tablets in clinic waiting and exam rooms. Collected data can then be integrated into the EHR with minimal or no staff effort. Data entry can be further optimized through use of NLP techniques or automatic data capture from other data sources. Multidisciplinary care team members such as clinicians, social workers, case managers, and patient navigators should have access to training and support on using the new workflows, data interpretation, and effectively navigating SDOH resources to inform PC CDS interventions. One informant underscored that access to training and resources could help motivate clinicians to move beyond merely “checking the box” for social risk factor screening and support them with using the data for PC CDS.



**Opportunity 7: Engage PC CDS stakeholders to support the design, development, and implementation of PC CDS that can support social risk-informed care.**

Based on our literature review and interviews, there are limited PC CDS tools available to address social needs in the context of healthcare decision making and care planning. Engaging a diverse range of stakeholders with representation from different communities is critical to ensure that the design and development of PC CDS facilitates social risk-informed care. A collaborative approach will foster user adoption, enhance functionality, strengthen community partnerships, and promote sustainable implementation of social risk-informed care through PC CDS.

PC CDS developers should partner with patient advocacy groups representing the at-risk population in the design phase. By employing engagement methods like focus groups, surveys, or co-design methodologies, patient preferences can be incorporated as part of the design. Informants emphasized the need to integrate social risk factor data collection into existing workflows rather than creating a standalone process. Developers should include clinicians in pilot testing of PC CDS prototypes to ensure these tools are user-friendly and seamlessly integrated. This integration should minimize additional clicks or steps required to access social risk factor information and recommendations.

Additionally, PC CDS tools should be developed in a manner that the PC CDS recommendations are specific and actionable. The guidance should provide clear steps for addressing identified social needs, like pre-populated referral forms, links to relevant community resources, or automated hand-offs to care team members such as social workers or case managers. Healthcare systems need to establish partnerships with community public health experts and social community-based organizations to ensure that PC CDS tools are providing recommendations and referral resources in alignment with what is available in the community.

## 2.4 Standardize Representation of SDOH Data to Support Data Integration and Sharing for PC CDS Development



Incorporating SDOH data into PC CDS requires using standard code systems for structured, interoperable representation to enable seamless integration and social risk alerts and recommendations. Therefore, standardization of SDOH data capture and exchange relevant for PC CDS is essential to develop PC CDS incorporating SDOH data effectively. Healthcare organizations have recently focused on collecting data related to transportation, financial strain, and food insecurity due to their relevance for healthcare decision making.<sup>54</sup> However, there are inconsistencies in how data are captured across different care settings and in different fields within the EHR.<sup>31,55</sup>

Key informants noted that SDOH data that might be important for PC CDS interventions are often not available. Moreover, even if SDOH data are collected, the lack of standardized representation across care settings may hinder integration into PC CDS tools. For example, if a patient is screened each time they are hospitalized and they go to different hospitals, it will be difficult to reconcile that data if interoperability standards are not used consistently. It is crucial to standardize collection and presentation of SDOH data in EHRs to help developers of PC CDS tools integrate high-quality SDOH data and support care teams incorporating such data into clinical decision making and more actively adapting care plans through the use of such tools.

### 2.4.1. Current Efforts and Initiatives

The importance of standardized representation of SDOH data has resulted in several efforts and initiatives which are highlighted below.

**Standardized capture of SDOH data is available in the major medical vocabularies/ terminology standards used in health information and technology.** International Classification of Diseases, Tenth Revision, Clinical Modification (ICD-10-CM) includes social diagnostic codes (Z codes) found within ICD-10-CM categories Z55-Z65, which can be utilized to record SDOH data like housing conditions, food insecurity, or transportation limitations. For instance, Kaiser Permanente Northwest created an EHR tool to aid in documenting SDOH using ICD-10-CM Z codes. However, studies indicate that clinicians seldom utilize Z codes in clinical documentation.<sup>56</sup>

Logical Observation Identifiers Names and Codes (LOINC) provides standardized codes for representing screening assessments and measures of SDOH, including questions, answers, and forms. These codes cover factors like housing stability, food security, transportation, education, employment, and social connections.<sup>57</sup> Similarly, the Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT), as part of their strategic plan for 2020-2025, initiated a project to enhance SDOH content within SNOMED CT.<sup>58</sup>

**Gravity Project activities and outputs are advancing both terminology and data exchange standards for SDOH.** The Gravity Project's<sup>59</sup> terminology and technical workstreams are focused on developing consensus-driven SDOH data standards to represent and exchange SDOH that are relevant for PC CDS.

As part of the terminology workstream, the Gravity Project identifies and codes data elements for SDOH across screening, diagnoses, goals, and interventions. It also focuses on developing national standards for electronic capture and exchange of SDOH data across various care settings. Submissions have been made to coding stewards for ICD-10-CM, LOINC, and SNOMED CT to address concept gaps. Additionally, it has and continues to develop value sets for several social risk domains relevant to PC CDS such as food insecurity, housing instability, homelessness, inadequate housing, transportation insecurity, financial insecurity, material hardship, educational attainment, social connection, stress, and interpersonal violence.

As part of its technical workstream, the Gravity Project developed the SDOH Health Level Seven (HL7) Fast Healthcare Interoperability Resources (FHIR®) Implementation Guide, which supports several clinical activities such as assessments, goals development, interventions, referrals, data aggregation, and exchange with patient and clinician facing applications such as PC CDS tools.<sup>60</sup>

**ASTP/ONC leads efforts to advance the standardized electronic exchange and use of SDOH data relevant for PC CDS.** ASTP/ONC supports and advances the use of interoperable SDOH data that can be electronically captured, used, and exchanged through resources and programs.<sup>61</sup> ASTP/ONC's Health IT Certification Program requires the use of USCDI that includes standardized SDOH data elements described above in this action plan.<sup>62</sup> ASTP/ONC's Interoperability Standards Advisory (ISA) is a listing of health information standards that includes vocabulary, code set, terminology, content, and structure standards to support SDOH data interoperability. Under the Standards Version Advancement Process (SVAP), health IT developers can voluntarily update certified health IT products to newer versions of adopted SDOH standards under the 21st Century Cures Act.<sup>63</sup>

## 2.4.2 Challenges

While there are several initiatives that are focusing on developing standards and promoting their use, there are specific challenges that need to be addressed to increase the adoption of standards that ensure the design and development of quality PC CDS tools.

**Lack of uniform standards adoption across healthcare makes it difficult to share and integrate SDOH data in PC CDS.** Most informants highlighted that while many health systems nationwide are increasingly capturing SDOH data, these data are not captured in a consistent and meaningful way. There is a consensus among informants regarding the imperative for a concerted effort to promote and adopt standards-based SDOH data through use of standardized assessment tools, terminology standards, and interoperability standards.

This lack of uniformity makes it challenging for EHRs to effectively integrate, aggregate, store, visualize, and share SDOH data in a manner that is meaningful or actionable for PC CDS, especially when spanning multiple organizations.<sup>64</sup> For example, one system might record food insecurity as a binary yes/no, while another might use a more detailed scale. This lack of standardization leads to fragmented and incomplete data, preventing clinicians from having a comprehensive understanding of a patient's food needs, which is crucial for holistic care.



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*“I think the first challenge that we have in informatics.... let's focus on food. There are 10 different ways that clinics ask questions about food insecurity, [need] for food, or help for food. And so, the standardization of SDOH data then becomes a real challenge, because every clinic wants to use their own.”*

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Although numerous EHRs have the capability to capture SDOH data in a structured way, these are not typically mapped to terminology and data exchange standards, which presents a significant challenge to using this information for PC CDS.<sup>65</sup> For example, housing instability data may be captured through checkboxes or dropdown menus, but without standard coding like LOINC or SNOMED CT, this information remains siloed within EHRs. This inconsistency poses challenges for integrating housing instability data into CDS systems, impacting the ability to generate accurate alerts and recommendations for patient care. Additionally, most informants alluded to the poor adoption of SDOH data standards, likely because healthcare organizations often struggle with how to adopt them effectively. This can stem from a lack of resources, insufficient training, or uncertainty about implementation processes. The complexity of integrating new standards into existing systems can further hinder the widespread adoption necessary for consistent SDOH data use.

**The use of standardized SDOH data may limit the ability to document nuances related in a meaningful way.** The key challenge lies in devising standards that are adaptable enough to accommodate diverse needs, social complexities, and practices. The effort to standardize SDOH data in EHRs faces challenges similar to other standardization efforts. Studies reveal discrepancies between EHR data and how patients described SDOH, indicating that current standards may not adequately capture patients' social needs and often do not match with how SDOH are described narratively. One informant noted that standardization can remove human diversity. While standards are needed, it is important to consider what is lost when categorizing SDOH.

Some informants highlighted that standardized SDOH data capture is often limited to discrete responses, hindering the identification and resolution of detailed social needs. For example, one informant shared how patient navigators were not able to fully document how financial struggles affect patients, such as affording copays, rent, or transportation using the standardized SDOH screening tool in the EHR. EHR prompts may focus on missed appointments due to transportation issues, overlooking those who attend their appointments despite challenges, leading to incomplete assessments and potential misinterpretation by the care team.

One study that compared EHR data with ethnographic observations of clinical encounters summarized how nuanced SDOH relevant to the clinical diagnosis is either captured in clinical notes using “signal phrases” or often excluded or underrepresented despite the detailed discussion on social needs.<sup>66</sup> For example, one diabetic patient’s job as a baggage handler impacted his ability to manage his diabetes. However, the clinical notes mentioned “[patient] is busy working...not a lot of time to manage his diabetes.” Another patient shared how their eating habits, stress levels, and lack of social support due to their caregiving responsibilities impacted their ability to self-manage their diabetes, but this information was minimally captured in notes as “trouble caring for father.”

### 2.4.3 Opportunities

The literature review and discussions with key informants identified a few recommendations related to standardized representation of SDOH data to support data capture and integration for PC CDS development.



**Opportunity 8: Develop training programs and resources to assist healthcare organizations in adopting available SDOH standards to support PC CDS.**

By providing comprehensive training programs and readily available resources, healthcare organizations can overcome implementation barriers and successfully adopt SDOH data standardization practices, enabling smoother SDOH data integration in PC CDS and leading to better social risk-informed care.

Training programs can educate healthcare organizations on the "why" and "how" of SDOH standardization, including using HL7 FHIR® for data exchange and integrating standardized data into EHRs and PC CDS. Training could also cover consistent data collection and secure sharing protocols. Supportive resources like online toolkits, reference guides, and ongoing technical support through webinars, question and answer sessions, and dedicated personnel should be developed, especially to support smaller healthcare organizations and/or rural settings with fewer resources.

Collaboration with standardization bodies such as HL7, industry efforts like the Gravity Project, and professional associations such as The Joint Commission and the National Quality Forum (NQF) ensures training aligns with best practices and equips healthcare professionals across disciplines.

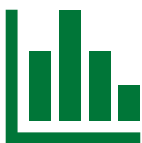


**Opportunity 9: Design flexible data collection processes that allow for the documentation of nuanced SDOH data while maintaining standardization.**

While standardization aims to improve care and promote health equity, it must strike a balance between providing guidance and allowing flexibility for individual adaptation. In the realm of PC CDS, incorporation of standardized SDOH data requires careful trade-off considerations.<sup>66</sup> If PC CDS interventions only incorporate standardized discrete or coded data, there is a risk of excluding valuable contextual insights that could be important for decision making.

Individual healthcare systems can work with their EHR vendors to tailor standardized SDOH screening tools to include some custom fields that are in line with their clinicians' preferences and the population's needs. This approach should include the selection of a core set of SDOH data elements that are standards-based and then incorporating open-ended fields or additional questions to capture nuanced and in-depth information.

## 2.5 Measure the Effectiveness of PC CDS Tools That Incorporate SDOH



Research has highlighted that evidence is needed to demonstrate that addressing specific social needs will lead to better health outcomes.<sup>67</sup> Similarly, when an SDOH-based PC CDS tool is built, it is necessary to understand its effectiveness in improving health outcomes, as well as if the tool supports the clinical team with developing care plans that accommodate patients' health-related social needs.

One informant emphasized that evidence demonstrating the benefits of integrating SDOH in PC CDS is especially critical for driving health and payment systems to support the collection and use of SDOH data. This includes testing emerging PC CDS technology that incorporates SDOH and integrates these

data in the EHR in different healthcare and community settings. Additionally, an informant noted that it is necessary to evaluate potential unintended consequences that may result from the collection and use of SDOH for PC CDS, as well validating the collection process, instruments, and timing with patients to support trust and patient-centeredness.

### 2.5.1 Current Efforts and Initiatives

Initiatives to support the evaluation of the integration of SDOH in healthcare may be adapted to measure the effectiveness of PC CDS tools that incorporate SDOH.

**ASTP/ONC's Social Determinants of Health Information Exchange Toolkit offers guidance on the planning, design, implementation, and evaluation of SDOH information exchange.**<sup>68</sup> The toolkit features a framework for monitoring and evaluating performance metrics for SDOH information exchange. It identifies evaluation frameworks and approaches to consider, such as the Centers for Disease Control and Prevention (CDC) Framework for Program Evaluation, system-oriented evaluation, theory of change, and logic models. It also includes strategies for leveraging different data and stakeholders to measure SDOH information exchange related to process, utilization, quality, and finance.

The toolkit describes key challenges related to monitoring and evaluating SDOH information exchange services and activities, including access to standardized metrics, data privacy, and the time needed to observe outcomes in SDOH interventions. Opportunities suggested by the toolkit for supporting measurement and evaluation in SDOH information exchange include aligning performance outcome metrics across sectors, engaging with stakeholders throughout the evaluation process, and identifying realistic evaluation goals. PC CDS researchers may leverage the monitoring and evaluation framework, as well as opportunities suggested by the toolkit to measure and evaluate the effectiveness of SDOH-based PC CDS tools.

**The Social Interventions Research and Evaluation Network (SIREN) is working collaboratively to develop a conceptual framework that defines the boundaries, inputs, and outcomes of interventions to address SDOH within the healthcare setting.**<sup>69</sup> Building on a previously developed framework that provided infrastructure for tracking patient-reported and publicly-available community SDOH data through the clinical workflow, SIREN's subsequent work aims to inform future research on interventions that identify and address SDOH in healthcare settings.<sup>69</sup>

To promote shared understanding and assessment of the impact of these interventions and their utility for advancing health equity, SIREN's framework will support evaluation of individual and population health outcomes and contribute to the evidence base used to support healthcare interventions that address SDOH-related needs. CDS researchers may adapt this framework to evaluate PC CDS interventions that incorporate SDOH data to tailor treatment plans based on patients' health-related social needs.

### 2.5.2 Challenges and Barriers

Evaluation is an integral part of the CDS lifecycle; however, the incorporation of SDOH is a relatively new direction for CDS, resulting in an additional challenge for the field.

**There are no common measures and metrics specific to evaluating SDOH-based PC CDS tools.** While measures exist for assessing the effectiveness of PC CDS related to process and clinical outcomes,<sup>70</sup> additional outcomes that are specific to SDOH may be needed to assess the effectiveness of PC CDS tools that incorporate these factors.

Though process and clinical outcomes will likely remain important, key challenges with evaluating PC CDS tools that use SDOH data and tailor treatment recommendations based on specific health-related social needs are the potential gaps in relevant measures and metrics that are needed to determine their effectiveness in improving healthcare decision making. With the emergence of SDOH-based PC CDS technologies, additional consideration is needed for measuring the impact of PC CDS when incorporating SDOH data and health-related social needs.

### 2.5.3 Opportunities

With the development of PC CDS tools that incorporate SDOH factors, the CDS community must also undertake initiatives to facilitate the measurement and evaluation of these tools to ensure they are effective.



**Opportunity 10: Identify measures and metrics to evaluate the impact of PC CDS tools that incorporate SDOH data.**

The first step in evaluating the effectiveness of PC CDS tools that integrate SDOH factors is knowing which measures and metrics are important. CMS, the National Committee on Quality Assurance, and NQF are key actors who may support the establishment of standard outcome measures and metrics to assess the use of SDOH in clinical care.<sup>71</sup>

From these measures, CDS researchers and evaluators can identify those that should be applied to PC CDS to assess the effectiveness of tools incorporating SDOH factors. Similar to the opportunities described in the ASTP/ONC toolkit,<sup>68</sup> CDS researchers can also align performance outcome metrics across sectors, so there is shared understanding and established benchmarks for determining success.



**Opportunity 11: Develop reliable methods to evaluate PC CDS interventions that address identified health-related social needs.**<sup>37</sup>

Feasibility and acceptability studies are needed to understand the performance of PC CDS tools in real-world settings to meet specific health-related social needs. All informants highlighted the importance of understanding the benefits and utility of collecting SDOH data to inform PC CDS and provide considerations for patients' health-related social needs.

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*“This is one of the things that I really worry. You know, we don't really know all the answers right now. But the only way that we're going to get there is if we create systems and then have processes to continuously evaluate.”*

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Approaches used to evaluate these tools should account for the many sociotechnical factors (e.g., personnel; workflow; communication; and organizational policies, procedures, and culture)<sup>72</sup> that influence the success of a PC CDS intervention. PC CDS researchers should prioritize investigations of SDOH-related PC CDS interventions or tools and their implementation in healthcare and community settings to expand research in this area and provide evidence that supports their adoption.

### 3. Additional Considerations

In addition to the five key needs related to the incorporation and use of SDOH data in PC CDS documented in this report, we have identified two overarching considerations that impact efforts in this area.

#### 3.1 Mitigate Bias and Improve Accuracy of Artificial Intelligence Algorithms Underlying PC CDS Tools That Incorporate SDOH

Artificial intelligence (AI) holds great potential to improve healthcare delivery and is currently used to support a range of healthcare systems and tools, including CDS. CDS can leverage AI algorithms to help inform patient care decisions and analyze patient data across systems to aid diagnostic processes.<sup>73</sup>

However, the outputs of AI tools can be inherently biased due to multiple factors, such as unrepresentative training datasets or insufficient demographic information in training models.<sup>74</sup> While this can produce a range of biases, biases related to racial, ethnic, and gender biases have received significant attention due to their potential to exacerbate health inequities and contribute to disparities in clinical care.<sup>75,76</sup> These biases can specifically impact PC CDS. For instance, predictive models in CDS tools can unintentionally assign inaccurate weights for SDOH data.<sup>77,78</sup> For example, algorithms using race as a variable to calculate estimated glomerular filtration rates (eGFR) in kidney disease have led to the underdiagnosis of Black patients, leading to implications for their transplant eligibility and treatment decisions.<sup>77,78</sup> Additionally, emerging AI methodologies such as large language models (generative artificial intelligence) have the potential to limit the accuracy of the decision support.<sup>79</sup> While inclusion of SDOH in PC CDS can promote healthcare decision making that is better tailored to patients' unique social risk factors and social needs, the potential to introduce bias in underlying algorithms is a barrier to developing PC CDS tools. Another problem specific to large language models and generative AI specifically is the possibility that they will create highly plausible but wrong answers to questions, a phenomenon sometimes called "hallucination" or "confabulation."<sup>79,80</sup> If these hallucinations occur in a biased fashion (for example, more often for certain patient groups whose data are underrepresented in research), or if they affect patients in an inequitable way (e.g., if patients with low health literacy are more likely to believe a hallucinated answer than patients with high health literacy), they could worsen equity gaps. Therefore, proactive approaches to mitigate bias and promote accuracy of algorithms employed by PC CDS tools are critical when incorporating SDOH.

Due to the growing recognition of the potential for healthcare algorithms to exacerbate health disparities, several national efforts are working to mitigate underlying bias and enhance the accuracy of healthcare algorithms. In October 2023, the White House issued an Executive Order on Safe, Secure, and Trustworthy AI. The Executive Order emphasized aligning action on AI around the "FAVES" principles: that "AI should lead to healthcare outcomes that are Fair, Appropriate, Valid, Effective, and Safe (FAVES)."<sup>81</sup> ASTP/ONC followed by issuing a Final Rule in December 2023 to advance health IT that included transparency requirements for AI and other algorithms used in predictive decision support intervention.<sup>82</sup> A predictive decision support intervention (DSI) is "technology intended to support decision making based on algorithms or models that derive relationships from training or example data and then are used to produce an output or outputs related to, but not limited to, prediction, classification, recommendation, evaluation, or analysis."<sup>83</sup> The Final Rule shares a number of strategies for achieving the FAVES principles, including improving transparency in how predictive DSIs are designed, developed, evaluated, and used; enhancing trustworthiness by sharing how IT developers

manage risks and govern predictive DSIs; supporting consistency by providing information on predictive DSIs to users; and advancing health equity by addressing bias and health disparities.<sup>83</sup>

As PC CDS technology evolves and focuses on the identification and use of SDOH data to inform decision making and improve patient outcomes, these FAVES principles outline potential opportunities to ensure that reduces bias in PC CDS and the potential to exacerbate health disparities.

### 3.2 Cross-Sector Data-Sharing of SDOH Data Relevant for PC CDS and Closed-Loop Referrals

To support the creation of PC CDS tools that promote social risk-informed healthcare, there is an ongoing need for partnerships between health and social care systems that facilitate the development of an integrated, cross-sector data infrastructure.<sup>84</sup> Key informants noted that patient-specific SDOH and social risk data are more often collected outside of healthcare settings by organizations such as social service providers, public health agencies, and community organizations. These diverse data can provide a more holistic understanding of patients' lives beyond their medical conditions. It is especially useful for PC CDS tools to leverage these data to produce tailored risk stratifications and target patient-specific interventions and referrals. However, this relevant data may not be readily captured in an EHR, limiting their use by PC CDS tools. Efforts to integrate these data have been limited by the fact that leveraging SDOH data outside of the EHR is costly, time-consuming, and requires access to protected data across different systems.<sup>85</sup> As a result, promoting cross-sector data-sharing between health and social care systems would make these data more accessible to care teams, and help them act upon it within a closed-loop referral system.

To develop a robust infrastructure for cross-sector data-sharing for PC CDS at scale, state- or community-level PC CDS pilots that leverage a cross-sector data-sharing approach are needed. At these levels, resources can be pooled to create robust SDOH information exchange ecosystems that enable the seamless sharing of data across healthcare and social service organizations relevant for PC CDS. A multi-sector approach will be needed to build the necessary technological infrastructure to support the exchange of SDOH data and protect patient privacy. This includes deploying secure information systems, such as health information exchanges, data warehouses, and interoperability platforms, to facilitate seamless standardized data exchange among clinicians, social service agencies, and other relevant entities.<sup>86</sup> To encourage community-based organizations to participate in data-sharing initiatives, healthcare organizations should establish reciprocal relationships by sharing health outcomes data back to them.<sup>87</sup>

As a shorter-term opportunity, key informants also recognized the importance of creating a closed-loop referral system that would more seamlessly connect patients with community resources to help address their health-related social needs. Key informants shared that the process of completing referrals is often time-consuming and labor-intensive, with members of the care team unaware of the full extent of the resources and services available for patients. In response, it would be useful for health systems and community resources to collaborate on the development of a resource database. The database would make resource information available in a single place, supporting care teams to complete the closed-loop referrals necessary to provide risk-informed care.

## 4. Conclusion

Contextualizing clinical recommendations based on individual social risk factors and health-related social needs is vital for patient-centered care. PC CDS tools that integrate these data can provide individualized and holistic care recommendations that can positively impact clinical and quality of care outcomes. While PC CDS tools are not the only solution to addressing health inequities, they can facilitate progress towards that overarching goal by including social risk factor data and promoting social risk-informed care.

This action plan identifies five key needs that must be fulfilled to effectively integrate social risk factor data into PC CDS tools. While efforts such as the ASTP/ONC Health IT certification program and the Gravity Project have advanced SDOH data standards, and recent CMS regulations will promote data collection and use within healthcare, the evidence base around effectively using social risk factor data for PC CDS and implementing them in practice is still limited. By uncovering and articulating outstanding barriers that need to be overcome to elevate PC CDS capabilities to address social needs, this action plan distills some recommendations that can be implemented through coordinated efforts between clinicians, researchers, health IT developers, public health experts and Federal agencies, and community organizations.

It is important to acknowledge that the implementation and recommendations within this action plan are focused on the PC CDS community. While the healthcare system plays an important role in improving patient outcomes by identifying and addressing social risk factors and health-related social needs, there are several other cross-sector approaches needed at the community-level to fully address patients' health-related social needs and impact SDOH. Meanwhile, PC CDS can be advanced using an iterative process and can be leveraged to make care delivery more equitable, impactful, and tailored to the holistic needs of diverse patient populations.

## Appendix A: Methods

We conducted a literature and key informant interviews to identify challenges, current efforts, and opportunities to inform our action plan for incorporating SDOH in PC CDS.

### A1. Literature Review

The literature review included PubMed searches for peer-reviewed articles (see **Table 1**) related to the use of SDOH data in PC CDS.

**Table 1.** PubMed Search Terms for Literature Review

Search Topic	PubMed Search Strategy
Social determinants of health or health equity and clinical decision support	("social determinants of health"[MeSH Terms] OR ("social"[Title/Abstract] AND "determinants"[Title/Abstract] AND "health"[Title/Abstract]) OR "social determinants of health"[Title/Abstract]) AND ("decision support systems, clinical"[MeSH Terms] OR ("decision"[Title/Abstract] AND "support"[Title/Abstract] AND "systems"[Title/Abstract] AND "clinical"[Title/Abstract]) OR "clinical decision support systems"[Title/Abstract] OR ("clinical"[Title/Abstract] AND "decision"[Title/Abstract] AND "support"[Title/Abstract]) OR "clinical decision support"[Title/Abstract])

Three team members conducted a title and abstract screening of 86 identified articles. Articles were deemed “eligible,” “ineligible,” or “tentative” based on inclusion/exclusion criteria (see **Table 2**). A total of 48 articles from the PubMed search that were deemed “eligible” or “tentative” were included for full-text review to confirm eligibility.

**Table 2.** Literature Search Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
<ul style="list-style-type: none"> <li>Published in the past 10 years (2014-2024)</li> <li>Published in English</li> </ul>	<ul style="list-style-type: none"> <li>Does not include human patients (e.g., veterinary studies; algorithms or clinician-focused tools that do not involve some patient-specific)</li> <li>Epidemiological or observational studies assessing the relationship of SDOH with health outcomes for research purposes</li> </ul>

To augment our review, we also conducted targeted hand-searches of grey literature and included additional peer-reviewed literature recommended by Workgroup members and CDSiC project team members. Using these methods, we identified 30 additional pieces of peer-reviewed and grey literature to include in our full-text review for a total of 78 articles.



## A2. Key Informant Interviews

We conducted five individual key informant interviews with an occupational therapist, a clinical informaticist, a nurse researcher, a patient advocate, and a health services researcher. A small group interview was also conducted with one patient educator and one patient navigator. In total there were seven key informants. Using synthesized findings from our literature review, we developed a semi structured interview guide to elicit feedback on the challenges related to the use of SDOH data in PC CDS, existing real-world efforts that address the barriers to incorporating SDOH data into PC CDS and support actionable decision making, and opportunities to advance the use of SDOH for PC CDS. Interviews were approximately 60 minutes long and conducted via Zoom with audio- and video-recording. An experienced CDSiC team member served as a lead facilitator during the discussion, while a designated notetaker recorded detailed notes.

## A3. Analysis and Synthesis

Data were abstracted from the final list of articles deemed eligible after both stages of review. Findings were synthesized to identify needs related to incorporating and using SDOH data and mapped to stages of the PC CDS lifecycle framework. For each of the identified needs, we synthesized findings related to the challenges or barriers associated with integrating SDOH data for PC CDS, as well as current efforts and future opportunities to address these needs. We used rapid qualitative content analysis of detailed notes to identify common themes and insights described by the key informants.<sup>88</sup> Themes were analyzed using inductive and deductive coding to identify overarching needs and key challenges, current efforts and initiatives, and possible opportunities for each of the identified needs.

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