WHITE PAPER

MAY 2022

Expanding Social Determinants of Health Data across PCORnet® Clinical Research Networks

Presented by:

NORC at the University
of Chicago

Presented to:

Patient-Centered Outcomes
Research Institute

NORC at the University of Chicago

Authors

Prashila Dullabh, MD

Lauren Hovey, MA

Desirae Leaphart, MPH

Andrew B. Chiao, MPH

Krysta Heaney-Huls, MPH

NORC at the University of Chicago
4350 East-West Highway, 8th Floor
Bethesda, MD 20814

Acknowledgments

NORC at the University of Chicago would like to express its gratitude to the Clinical Research Networks participating in PCORnet® and the Coordinating Center for PCORnet and subject matter experts that generously offered their expertise and time. Additionally, we would like to thank the attendees of the "Expanding Social Determinants of Health across PCORnet" webinar. Their contributions helped us develop an on-the-ground understanding of the current progress, successes, challenges, and opportunities for increasing social determinants of health (SDOH) data availability and accessibility across PCORnet. We would also like to acknowledge the guidance provided by Claudia Grossmann, Nik Koscielniak, Julianna Paris, and Penny Mohr on this project.

Suggested Citation

Dullabh, P., Hovey, L., Leaphart, D., Chiao, A.B., & Heaney-Huls, K. Expanding Social Determinants of Health Data across PCORnet® Clinical Research Networks. Patient Centered Outcomes Research Institute; May 2022. Prepared by NORC at the University of Chicago under Contract No. IDIQ-TO#27-NORC-SCI-AOSEPP-05-24-2021

Disclaimer

All statements, findings, and conclusions in this publication are solely those of the authors and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute (PCORI) or its Board of Governors. This publication was developed through a contract to support PCORI's work. Questions or comments may be sent to PCORI at info@pcori.org or by mail to Suite 900, 1828 L Street, NW, Washington, DC 20036.

Table of Contents

Executive Summary

The Patient-Centered Outcomes Research Institute (PCORI®) is undertaking a multi-step assessment process as it considers data infrastructure enhancements to PCORnet®, the National Patient-Centered Clinical Research Network. PCORnet® is a large, nationally representative "network of networks" funded by PCORI® to improve the nation's capacity to efficiently conduct definitive health research, particularly comparative effectiveness research (CER).

PCORI plans to prioritize investments in PCORnet infrastructure enhancements that build on the unique capabilities of the PCORnet data structures and align with PCORI's five National Priorities for Health.[1] PCORI's five National Priorities for Health, adopted by PCORI's Board of Governors in October 2021, are:

1) Increase Evidence for Existing Interventions and Emerging Innovations in Health
2) Enhance Infrastructure to Accelerate PCOR
3) Advance the Science of Dissemination, Implementation, and Health Communication
4) Achieve Health Equity
5) Accelerate Progress Toward an Integrated Learning Health System

In alignment with these priorities, PCORI identified three areas of interest for data infrastructure enhancements:1) social determinants of health (SDOH); 2) patient-reported outcomes (PROs) and other patient-generated health data (PGHD); and 3) Centers for Medicare and Medicaid Services (CMS) claims data. All three opportunities for data infrastructure enhancement have potential to increase data capture, availability, and use across PCORnet® Clinical Research Networks (CRNs)[2] for the purpose of conducting definitive national studies that advance evidence-based approaches to improve health outcomes and health equity by informing healthcare decisions and care delivery.

Under contract from PCORI, NORC at the University of Chicago is assessing opportunities in these three areas, beginning with SDOH, to inform PCORI's planned

---

[1] In 2021, the PCORI Board of Governors also approved a set of Prioritizing Principles for Infrastructure Funding Relating to PCORnet to guide decision-making about PCORI infrastructure funding for the next stages of PCORnet. These Priorities include: "IV. Build on the unique capabilities of the PCORnet data structures, prioritizing investments that will align with the PCORI Strategic Research Priorities." And " Recognize, enable, and promote the value of PCORnet to contribute to a learning health care system through effective partnerships with all stakeholders."

[2] Clinical Research Networks (CRNs) consist of two or more health systems (e.g., hospitals, integrated delivery systems, federally qualified health centers) who have formed a network. The CRN facilitates data capture, standardization, and data sharing within its own network and has also chosen to join the "network of networks" known as PCORnet.

data infrastructure enhancements. For the purposes of this White Paper, NORC used the Department of Health and Human Services (HHS) Office of Disease Prevention and Health Promotion's definition of SDOH, which is "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." This definition encompasses all the HHS Healthy People 2030 SDOH domains: economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context.[1]

This White Paper articulates NORC's findings on the current state of SDOH data collection across PCORnet® CRNs, challenges for expanding PCORnet infrastructure to increase SDOH data availability and accessibility within the networks, and opportunities for data infrastructure expansion. The SDOH data considered include both individual level domains (e.g., housing instability) as well as geographic-level measures derived through linkage of address/geocode to publicly available indices.

These findings are based on a survey of health systems participating in PCORnet; a literature review; key informant interviews (KIIs) with stakeholders associated with PCORI and PCORnet, SDOH researchers, data infrastructure experts; and a public webinar held on November 4, 2021.

Current State. The survey assessed SDOH data collection and use among 55 of the 75 health systems participating in PCORnet.

- Nearly all health systems that completed the survey reported they are collecting and using individual-level SDOH data. However, respondents vary with regard to SDOH domains collected, use of standardized terminology to capture SDOH in electronic health records (EHRs), and the data available for querying.
- Most health systems report collecting detailed address data consisting of street address and 5-digit zip code, but few collect 9-digit zip code.
- More than half the health systems that completed the survey report plans for future SDOH data collection and use, including collecting more SDOH data elements, improving existing screening tools, and implementing new screening tools.
- Several CRNs already use the available data within their networks for robust health disparities research. Their efforts highlight the potential for SDOH research across CRNs, as well as potential data infrastructure improvements that would increase Network-wide capacity.

Opportunities. Based on the current state of the PCORnet data infrastructure and existing SDOH data within participating CRNs, we identified challenges and opportunities for expansion and investment in three areas:

- *Opportunities for Leveraging Existing SDOH Data across PCORnet® CRNs*
  - **Expanding the data stored in the PCORnet® Common Data Model (CDM) to include SDOH data elements that can be coded electronically with approved, interoperable standards**: Currently, CRNs can load demographic information and a limited set of other SDOH-related variables (e.g., language preference) into PCORnet® CDM tables. Data elements could be added to new or existing tables in the PCORnet® CDM to reflect priority SDOH-specific domains that would expand the network's capacity for SDOH research. In addition to prioritizing data elements with existing standards (e.g., food insecurity, housing instability, and transportation), the changes should reflect SDOH data elements health systems already collect, such as financial hardship, employment status, and intimate partner violence. Webinar speakers agreed that the indicators health systems already collect present the best short-term opportunity for standardization and inclusion in the PCORnet® CDM. In addition to the domains already widely available across the CRNs, there are opportunities to capture specific types of SDOH data within a subset of federally qualified health centers (FQHCs), that collect data for the Health Resources and Services Administration (HRSA) Uniform Data System (UDS) (Short-term)
  - **Leveraging natural language processing to expand SDOH availability**: Historically, social needs data are often recorded in unstructured fields rather than discretely captured in structured formats using standards terminologies. Techniques like natural language processing (NLP) could allow researchers to access SDOH data present in unstructured clinical notes without placing additional data collection burden on the health systems and their staff. Webinar speakers and audience members noted that the significant challenges to using NLP militate against a Network-wide roll-out. Instead, webinar participants recommended NLP pilot studies designed to be both site- and research-specific as more feasible, and therefore more effective. (Mid-term)
- *Optimizing Individual-Level and Population-Level Analysis*
  - **Supporting address verification and geocoding**: The survey found that 91 percent of the health systems collect patient street address with 5-digit zip code, but many addresses are unverified. Multiple solutions exist to verify addresses, generate zip codes up to 9 digits, and geocode them. Improving the quality of existing address data across the CRN participants and geocoding these data

  would expand the information available to researchers for individual and population-level analysis of health outcomes and disparities. Webinar speakers noted that aggregate-level data should not replace other individual-level data; it should be used in combination with them. The speakers suggested that PCORnet participants make it a priority to centrally coordinate geocoding across the CRNs. (Short-term)

  - **Enhancing access to research-ready data through linkages to other data sources**: Use of aggregate data alone assumes the structural and neighborhood-level experiences apply across all individuals in a given neighborhood, which introduces biases. Geocoding and then linking to community-level data (i.e., data at the county level and smaller) can overcome these biases. Geocoding enables linkages to publicly available surveys (e.g., the American Community Survey [ACS]) and other data sources rich in SDOH and social risk data. During the webinar, speakers suggested tailoring tools to specific resources to create efficiencies. For example, environmental data sets and micro data sets can be linked to access patient contextual-level data. Most audience members indicated that supporting linkages between CRN data resources and publicly available data sources should be the top priority for PCORI of the options presented (Short-term)

- *Incorporating Other Sources of Social Sector Data across PCORnet® CRNs*
  - **Establishing relationships is critical to engaging with the social sector**: Research data access is one piece of a puzzle that must also include benefits to patient health and care, and referrals to social services. Through relationship building, the health and social sectors can identify shared goals for SDOH data use and the right mechanisms for accomplishing those goals. (Short-term)
  - **Seeking technical solutions to connect to social sector data**: At present, there is limited but rapidly developing infrastructure to connect health systems to community-based organizations (CBOs) and other sources of social sector data (e.g., community resource referral platforms). As health systems consider strategies to understand and mitigate the negative effects of social risk on health outcomes, emergent efforts are developing the standards and data infrastructure to connect social sector and health data in an interoperable, low-burden, and mutually beneficially way. A growing set of infrastructure components is being leveraged for SDOH referrals, data collection, and data sharing—with notable solutions from both health sector market leaders, as well as rapidly expanding community resource referral platforms. Webinar speakers noted it would be helpful for referral platforms and other systems serving CBOs to adopt standardized vocabularies and value sets. (Long-term)

Conclusions. There are a number of potential opportunities for enhancing SDOH data infrastructure within PCORnet. Expanding PCORnet data resources to include SDOH concepts is critical to achieve PCORI's Phase 3 goal of using PCORnet to conduct definitive national studies that advance PCORI's National Priorities for Health, including efforts to accelerate progress towards a learning health system. This multi-dimensional assessment of the SDOH landscape—with sources from the literature and through direct engagement with experts and interested stakeholders—suggests opportunities PCORI could pursue within three thematic areas and areas of inquiry to be undertaken in the short-, mid-, and long-term.

1. Introduction

The Patient-Centered Outcomes Research Institute (PCORI®) is undertaking a series of data convenings for PCORnet®, the National Patient Centered Clinical Research Network. The convenings comprise a multi-step process to identify potential enhancements to PCORnet® data infrastructure, including the PCORnet® Common Data Model (CDM). As part of this process, PCORI® contracted with NORC at the University of Chicago (NORC) to explore opportunities to advance PCORnet data infrastructure in three areas: 1) social determinants of health (SDOH); 2) patient-reported outcomes (PROs) and other patient generated health data (PGHD); and 3) access to Centers for Medicare & Medicaid Services (CMS) claims data.

This White Paper focuses on the first of the three—opportunities related to SDOH. For the purposes of this White Paper, NORC used the Department of Health and Human Services (HHS) Office of Disease Prevention and Health Promotion's definition of SDOH which is "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." This definition encompasses all the HHS Healthy People 2030 SDOH domains: economic stability, education access and quality, health care access and quality, neighborhood and built environment, and social and community context.[2]

1.1 Background

PCORnet®, the National Patient-Centered Clinical Research Network, is a large, nationally representative "network of networks" funded by PCORI® to improve the nation's capacity to efficiently conduct definitive health research, particularly comparative clinical effectiveness research (CER).

In 2021, PCORI's Board of Governors adopted a new set of strategic priorities to guide the organization's future work. These five National Priorities for Health,[3] which are at the center of PCORI's Strategic Plan, are:

1) Increase Evidence for Existing Interventions and Emerging Innovations in Health
2) Enhance Infrastructure to Accelerate PCOR
3) Advance the Science of Dissemination, Implementation, and Health Communication
4) Achieve Health Equity
5) Accelerate Progress Toward an Integrated Learning Health System

---

[3] PCORI's National Priorities for Health

PCORI plans to prioritize investments in PCORnet infrastructure enhancements that build on the unique capabilities of the PCORnet data structures and align with PCORI's National Priorities for Health.[4]

The work described in this White Paper aims to inform and advance these National Priorities, with a focus on two in particular: *Enhance Infrastructure to Accelerate PCOR* and *Achieving Health Equity*. Enhancing PCORnet data infrastructure by increasing the collection of SDOH data concepts in PCORnet data resources is critical to improve availability and use of these data across PCORnet® Clinical Research Networks (CRNs) and will support PCORI's Phase 3 goal of using PCORnet to conduct definitive national studies that advance PCORI's National Priorities for Health, including efforts to accelerate progress towards a learning health system.

NORC reviewed the SDOH data resources available through the CRNs participating in PCORnet and suggested mechanisms for their enhancement. PCORnet is an initiative and program funded by PCORI and consist of multiple CRNs, patient partners, and a Coordinating Center that work together to improve data access for patient-centered outcomes research. Each CRN encompasses multiple health systems, such as hospitals, integrated delivery systems, and federally qualified health centers (FQHCs) (see Figure 1 and Appendix B). The Coordinating Center for PCORnet supports the maintenance of data and research infrastructure to facilitate research. PCORnet also includes patient partners, who participate in all Network governance, provide input on research design and implementation, and advise on approaches to ensure patient engagement and patient-centeredness.

As a patient-centered initiative, patient engagement and the protection of individual privacy are core values for PCORnet. The PCORnet infrastructure complies with applicable laws, regulations, and legal requirements, including but not limited to those governing privacy, security, data, research, and human subjects; a statement on the PCORnet privacy-protection infrastructure is available here.

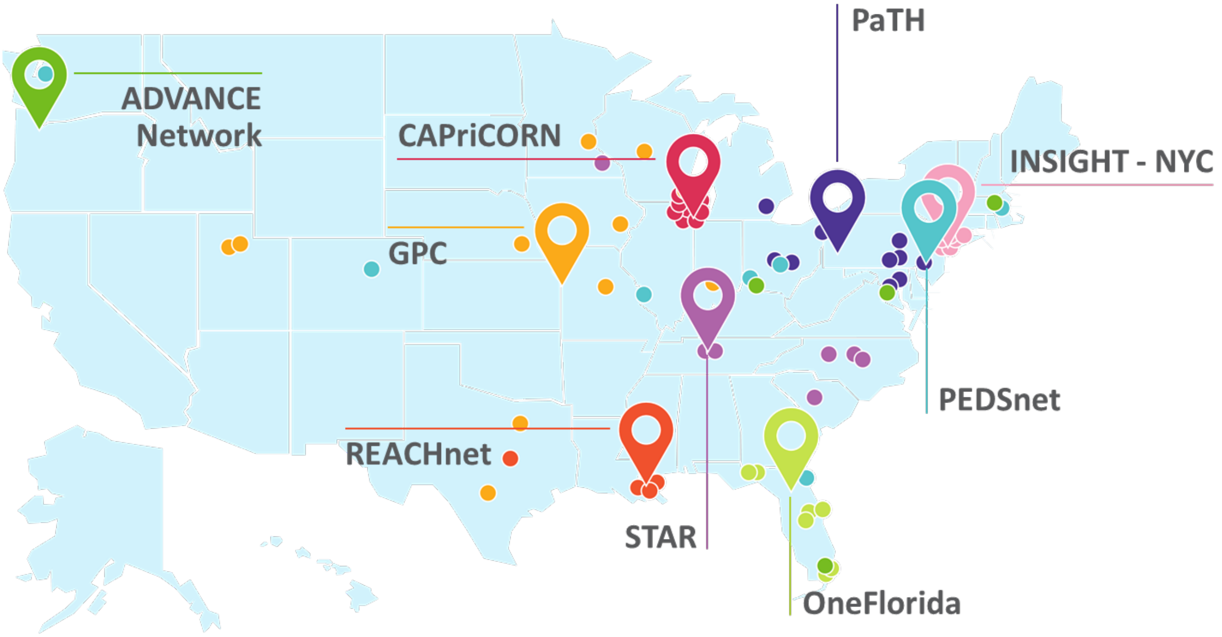
The PCORnet infrastructure uses a distributed research network model, which includes standardized data and multiple health systems and data marts. A key security feature of the PCORnet infrastructure is that the data stay with each network partner behind its

---

[4] In 2021, the PCORI Board of Governors also approved a set of Prioritizing Principles for Infrastructure Funding Relating to PCORnet to guide decision-making about PCORI infrastructure funding for the next stages of PCORnet. These Priorities include: "IV. Build on the unique capabilities of the PCORnet data structures, prioritizing investments that will align with the PCORI Strategic Research Priorities." And "Recognize, enable, and promote the value of PCORnet to contribute to a learning health care system through effective partnerships with all stakeholders."

firewall, protected under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and are not amassed into a single data pool or data warehouse.

Figure 1. Clinical Research Networks (CRNs) participating in PCORnet, December 2021



Source: Developed by the Duke Clinical Research Institute (DCRI) with PCORI funding (Award CC2-Duke-2016-TO12). Used with permission from PCORI.

The PCORnet® CDM is one of the resources PCORnet participants use to enhance the consistency, usability, and "research readiness" of data available through the CRNs. Data are collected by health systems participating in PCORnet through a variety of processes and are transformed into the PCORnet® CDM, which is conducted at either the health system level or by the CRN. Once in the PCORnet® CDM, deidentified data are sent to the Coordinating Center for PCORnet and where they undergo a data curation process and quarterly quality control checks, and if approved, are considered research ready. Currently, the SDOH data in the PCORnet® CDM include demographics and other variables needed for SDOH-related analysis (see text box); however, several domains of social risk (e.g., food, housing, financial insecurity) have not yet been included.[3]

Prior efforts explored defining a standard set of SDOH elements CRNs would be asked to load into the PCORnet® CDM. In 2018, for example, PCORI funded the Health Disparities Collaborative Research Group (CRG) to recommend enhancements to the PCORnet® CDM to make it more complete, comprehensive, and research-ready for studies on health disparities. The CRG's recommendations included: 1) individual-level SDOH data based on National Academy of Medicine (NAM) recommendations; 2) additional domains, including food security and housing stability; and 3) geocoded community-level data from sources such as the American Community Survey (ACS) and U.S. Census data.[4]

PCORnet Network Partners also convened an SDOH workgroup to identify barriers and opportunities for SDOH data collection among PCORnet participants and incorporation of SDOH data into the PCORnet® CDM. The workgroup made four major recommendations for incorporating SDOH data into the PCORnet® CDM:[5]

- Integrate patient address for geocoding (street address and/or zip code), with a preference for 9-digit over 5-digit zip codes.
- Integrate alcohol and depression into the PCORnet® CDM—given that these data are prioritized by NAM, already routinely collected, and available in many local research data warehouses (RDWs).
- Integrate NAM and the CMS Accountable Health Communities (AHC) screening tool domains, given that many are increasingly collected.
- Create data fields in the PCORnet® CDM so that SDOH data elements can be included in PCORnet data resources, beginning with a few key data elements that are routinely collected and/or high priority for health systems.

The SDOH data currently represented in the PCORnet CDM:

- Age
- Sex
- Sexual orientation
- Gender identity
- Race
- Ethnicity
- Preferred language spoken
- Insurance status
- Patient address
- Facility location
- Substance use

NORC has taken these recommendations into account in our assessment of the current state of SDOH data collection among Network participants, and their priorities for increasing SDOH research capacity.

1.2 Roadmap of Paper

The intended audience for this paper includes PCORI staff, the PCORI Board of Governors, the Coordinating Center for PCORnet, participating CRNs, and the broader research and stakeholder community. It begins with a brief overview of our methods, followed by a discussion of the current state of individual-level SDOH data collected across participating CRNs, based on the results of a Network-wide survey fielded in July 2021. The paper then identifies salient challenges and opportunities to improve PCORnet data infrastructure—as articulated by key informant stakeholders and technical experts—to improve the accessibility of SDOH data for research across the participating

CRNs. These findings will assist PCORI in assessing and prioritizing short-, mid-, and long-term opportunities to enhance the PCORnet infrastructure, in alignment with the PCORI Board of Governors approved *Prioritizing Principles for Infrastructure Funding Relating to PCORnet*.[6]

2. Methods

We undertook four data collection activities in preparing this White Paper:

1. A survey of the health systems within the participating CRNs about the current state of SDOH data collection and use
2. A targeted literature review focused on the current state of SDOH data collection and use—including challenges and opportunities, supplemented with technical research on emerging opportunities
3. Key informant interviews (KIIs)
    a. Initial stakeholder interviews to gather the perspectives of CRN and Coordinating Center principal investigators and other investigators, representatives from PCORI's Board of Governors, and external SDOH experts
    b. Supplemental interviews with technical experts to provide additional information on topics raised during the stakeholder KIIs
4. A 90-minute public webinar on the White Paper findings to gather a broad set of perspectives from presenters and attendees on opportunities to enhance SDOH data infrastructure within participating CRNs.

2.1 Analytic Approach and Research Questions

Three overarching goals guided our inquiry—assessing the current state of SDOH availability, identifying challenges to SDOH data accessibility, and eliciting future-facing opportunities to enhance SDOH data infrastructure to support health equity research using PCORnet data resources. Table 1 summarizes our main goals and research questions.

Table 1. Goals and Research Questions

Goals	Research Questions
1. Current Landscape of SDOH Data Collection and Use within PCORnet® CRNs	1. What is the current state of SDOH data collection (for routine care and research purposes) in PCORnet® CRNs and their participating health systems? 2. To what extent are SDOH data integrated into the health system electronic health records (EHRs) or CRN research data warehouse/DataMart? 3. What standards are being used for SDOH data collection?
2. Barriers to SDOH Use for Research Purposes	4. What are the challenges associated with accessing or using available SDOH data within PCORnet® CRNs? 5. What data quality issues (e.g., data completeness, availability of structured data) hamper the use of SDOH data for research?
3. Opportunities to Enhance PCORnet Data Infrastructure to Expand SDOH Data Availability	6. What tools, resources, or other data infrastructure are needed to enhance the availability of SDOH data within the networks? 7. What modifications or enhancements to the PCORnet® CDM are needed to facilitate SDOH data availability? 8. What priorities for SDOH data collection would enhance the PCORnet data infrastructure? 9. What other efforts can inform SDOH data collection within the networks and/or enhancements to the PCORnet data infrastructure?

2.2 Survey of PCORnet® CRN Participating Sites

To identify the SDOH data elements currently collected across the participating sites, we fielded an online survey using the Qualtrics platform, over three weeks in July and August 2021. The Coordinating Center for PCORnet emailed the survey to each CRN with a request to distribute the survey among their participating health systems (see Appendix A). Of the 75 sites participating in PCORnet, 55 sites completed the survey (see Appendix B for descriptions of the CRNs and participating sites).

The PCORnet Network Partners' SDOH workgroup 2018 survey of PCORnet® CRNs informed the latest survey questions. The SDOH data elements probed in both surveys were derived from NAM recommendations, CMS AHCs, and Uniform Data System (UDS) measures. The 2021 survey asked about such factors as economic stability (e.g., food security, household income, employment status, financial resource strain, housing security/stability, homeless status, seasonal/immigrant farmworker); education access and quality (e.g., education); neighborhood and built environment (e.g., transportation, neighborhood/built environment); social and community context (e.g., physical activity, interpersonal violence, stress, social isolation, discrimination); and other demographics (e.g., language, household size). This White Paper includes self-reported SDOH data elements, such as social and community factors, and derived from other types of data collection, such as zip code.

2.3 Literature Review

We conducted a targeted search of peer-reviewed and grey literature from the past five years. For published literature, we searched PubMed. For the grey literature, we searched Google; professional organization websites (e.g., Healthcare Information and Management Systems Society [HIMSS], American Medical Informatics Association [AMIA], research and policy organizations [e.g., SIREN]); and government websites (e.g., Office of the National Coordinator for Health Information Technology [ONC], Agency for Healthcare Research and Quality [AHRQ], and Office of the Assistant Secretary for Planning and Evaluation [ASPE]) (see Appendix C, Figure C-1). Additionally, we reviewed resources that the CRNs and their affiliated health systems provided in response to NORC's survey.

2.4 Key Informant Interviews

We conducted 11 stakeholder KIIs to inform our assessment of current activities, challenges, and opportunities within the participating networks. Key informants, who represented a range of perspectives on SDOH research and data infrastructure, were both internal and external to PCORI: one expert from the Coordinating Center for PCORnet; two PCORI Board members; three representatives from CRNs actively engaged in SDOH research (ADVANCE, INSIGHT, and OneFlorida); three experts on health systems research and SDOH data infrastructure; and two federal informants engaged in SDOH-related initiatives (see Appendix C, Figure C-2). Based on these initial interviews, we conducted supplementary KIIs with three experts in natural language processing, geocoding, and data linkages.

2.5 Webinar

On November 4, 2021, the NORC team convened a 90-minute webinar to discuss the White Paper findings. In total,189 individuals attended the webinar, including representatives from PCORnet Network Partners, the Coordinating Center for PCORnet, government entities, NORC, and PCORI, as well as attendees from industry and institutions not participating in PCORnet. The webinar consisted of presentations by the internal team providing background on PCORnet and the initial survey effort, followed by three expert-led sections on each of three major themes: leveraging existing SDOH data, individual- and population-level analysis, and social sector data. Audience input was solicited on each theme in the form of questions posed directly to them via the speakers, polls that asked them to prioritize opportunities within each theme, Q&A between speakers and audience, and a live chat conversation. NORC incorporated input from the speakers and audience into this White Paper.

3. Key Findings

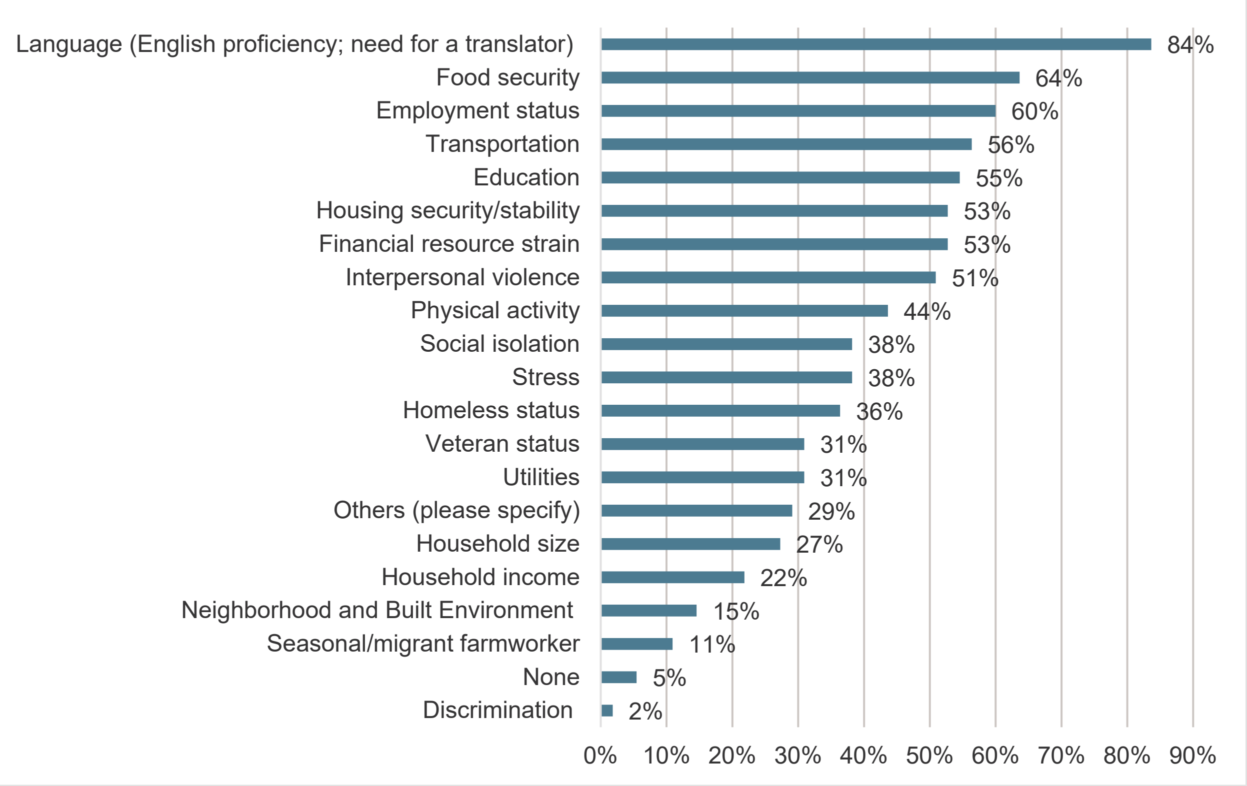
We present the results of our research in three sections: 1) current state of SDOH data collection and use within health systems participating in PCORnet, 2) challenges and opportunities for SDOH use in research, and 3) relevant initiatives furthering SDOH-related data infrastructure.

3.1 Current Landscape of SDOH Data Collection and Use Across Health Systems participating in PCORnet

The survey provided insights into the current landscape of SDOH data collection and use among survey respondents from 55 of the 75 sites participating in PCORnet (see Appendix B for descriptions of the CRNs and participating sites). The goal was to determine which SDOH domains are collected at the health system level, the extent to which health systems are collecting SDOH in their EHRs and RDWs, and their priorities for SDOH collection and use. The results informed both the literature review and the KIIs.

Nearly all health systems that completed the survey collect and use individual-level SDOH data. The survey asked health systems to select which individual-level SDOH data elements they use and collect from among a list of SDOH data elements (Figure 2). Ninety-five percent (n = 52) collect and use individual-level SDOH data elements. Eighty-four percent collect and use English proficiency data from patients. More than half collect and use data on interpersonal violence, housing security/stability, financial resource strain, education, transportation, employment, and food security.

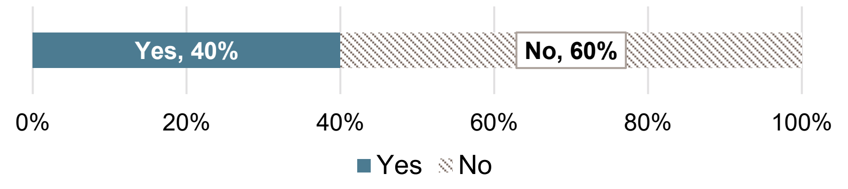
Figure 2. Individual-level SDOH Data Elements Health Systems Use and Collect*



* Multiple 'other' responses included patient need for social supports, health literacy, alcohol use, and depression.

More than half of health systems participating in PCORnet do not use standard terminologies to collect SDOH data. The survey asked if health systems collect any SDOH data elements using standard terminology (i.e., use of a controlled medical vocabulary for clinical terms).[7] Forty percent (n = 22) use standard terminology, ICD-10 and LOINC, where available; 60 percent (n = 33) do not (Figure 3).

Exhibit 3. Health Systems Participating in PCORnet Using Standard Terminology to Collect SDOH Data



Almost half do not use a framework to inform SDOH data capture. About 47 percent of health systems do not use any of the named frameworks. The rest use one or more SDOH frameworks for data collection. When asked to specify which other frameworks are used, if any, responses included Epic's SDOH tool (SDOH Wheel), Iowa Healthcare Collaborative (IHC) domains, or a combination of frameworks (Table 2).

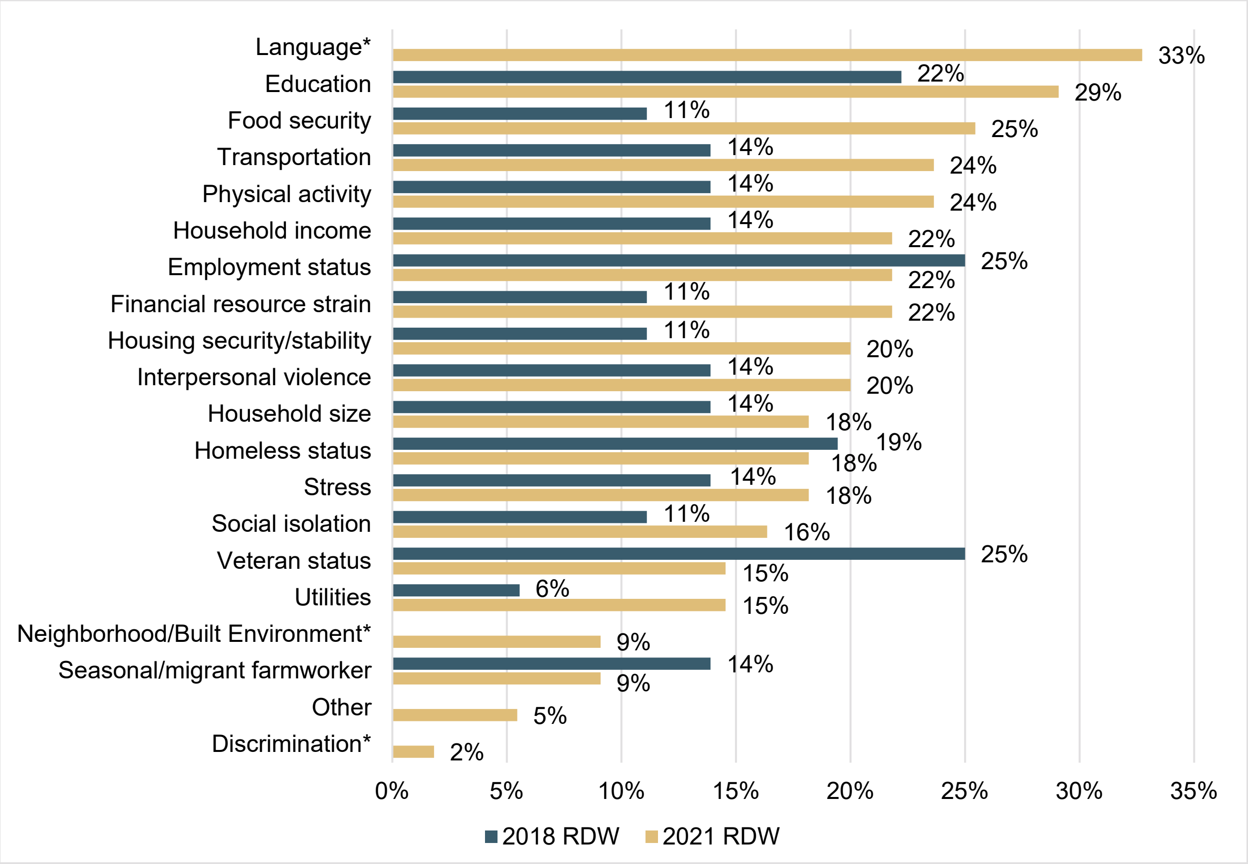
Table 2. SDOH Frameworks Currently Used by Participating Health Systems

SDOH Framework*	Health Systems Indicating Use n (%)
None of the above	26 (47%)
Others (please specify)	19 (35%)
CMS AHC Core Domains	12 (22%)
Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE)	6 (11%)
UDS measures	5 (9%)
Healthy People	5 (9%)
NAM Domains	4 (7%)
CMS AHC Supplemental Domains	3 (5%)
Health Leads	1 (2%)

*Respondents could select more than one framework.

Participating health systems have more SDOH data stored in their RDWs compared to 2018. More health systems participating in PCORnet are storing SDOH information across most data domains surveyed compared to 2018, except seasonal/migrant farmworker status, homeless status, veteran status, and employment status (Figure 4).

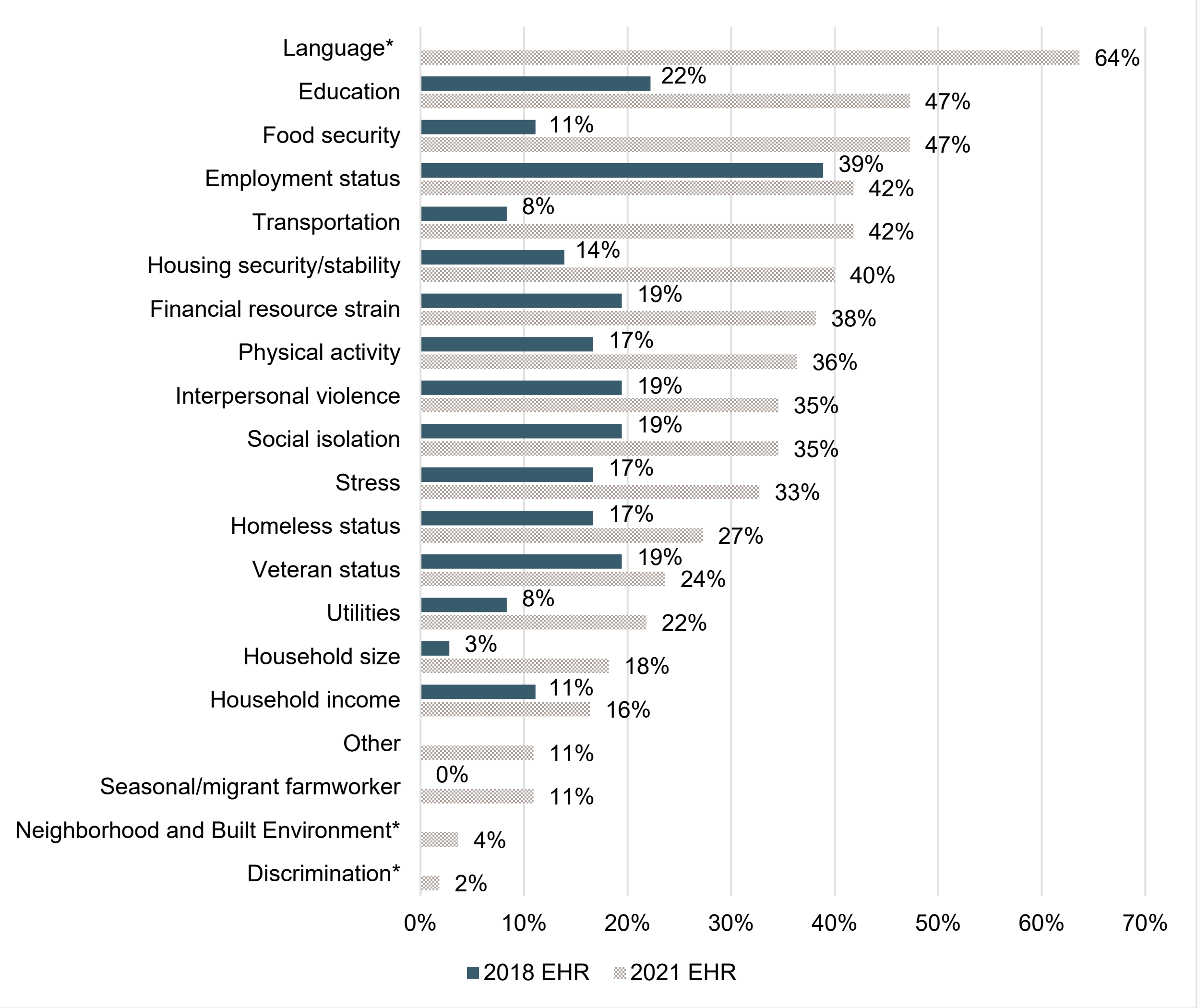
Figure 4. SDOH Data Collection in Research Data Warehouses (2018 vs 2021)



*Language, Neighborhood/Built Environment, Perceived Discrimination, and Other were added to the survey in 2021. There is no 2018 baseline for these domains.

Health systems participating in PCORnet integrated additional SDOH data elements into their EHRs between 2018 and 2021. Compared to 2018 survey results, health systems expanded their collection of SDOH data elements into more domains, and more health systems collect data elements within these domains (Figure 5).

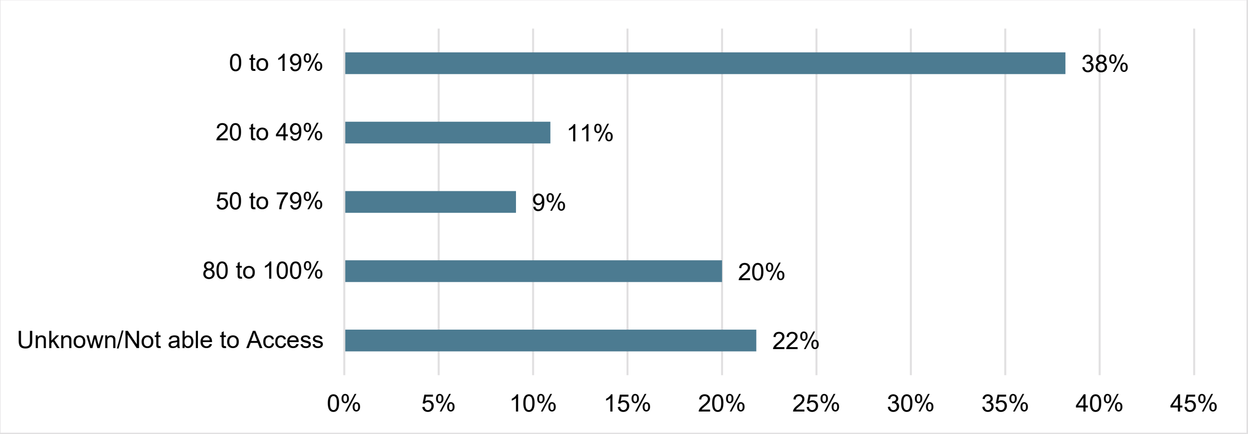
Figure 5. SDOH Data Collection in Electronic Health Records (2018 vs 2021)



* Because Language, Neighborhood/Built Environment, Perceived Discrimination, and Other were added to the survey in 2021, they have no 2018 baseline.

Almost 40 percent of health systems report low percentages of patient SDOH data in the EHR. When asked to report the percentage of patients with one or more SDOH data elements present in the EHR, health systems' responses varied widely. The largest share (38 percent) of health system respondents document SDOH data in the EHR for 0-19 percent of their patients. Twenty percent have documented SDOH data in the EHR for 80-100 percent of patients. Nearly one-quarter (22 percent) do not know this information or are unable to access it (Figure 6).

Figure 6. Health Systems Reported Percent of Patients with SDOH Data in the EHR



Most health systems participating in PCORnet have address data but few have patients' 9-digit zip codes. The survey asked health systems to indicate at which level they collect patient address information. Only nine percent collect 9-digit zip codes; 91 percent collect some combination of street address and/or 5-digit zip code. The Coordinating Center's further analyses of the address information available across the health systems found that the average missingness of 9-digit zip code was 73 percent (median =96.905).

Many health systems have plans for future SDOH data collection and use. An optional question in the survey asked health systems to describe their plans for collecting and using SDOH data in the next two to four years. Just over half (53 percent, n = 29) of the health systems that participated in the survey responded to this question. Many of the 29 systems have plans for SDOH data collection and use, including integrating and using community-level SDOH information, expanding SDOH data collection for more patients, and implementing or creating a new SDOH screening tool.

Future Plans of Health Systems participating in PCORnet (2 to 4 Years) for SDOH Data Collection

- Integrating and Using Community-Level SDOH Information
- Expanding SDOH Data Collection for more Patients
- Implementing or Creating a New SDOH Screening Tool
- Improving or Adding Questions to an Existing SDOH Screening Tool
- Enhancing Data Quality
- Improving Technology for Data Collection and Extraction
- Aligning SDOH Data Collection with Relevant Policy Initiatives

In conclusion, we identified four salient groups of issues across survey responses:

- Collection and use of patient-level SDOH data present a clear priority for health systems participating in PCORnet. Since 2018, more health systems reported increases in the number of SDOH data elements collected in their EHRs and available in their RDWs.

- The percentage of patients with one or more SDOH measures completed in the EHR varies across health systems. More than one-third of health systems reported less than 20 percent of their patients have SDOH information in the EHR; another 20 percent reported that 80-100 percent of patients have at least some SDOH data documented in the EHR.
- Most health systems are collecting address data at the street number plus 5-digit zip code level; few collect zip codes at the 9-digit level needed for geocoding.
- Many health systems have plans to expand and enhance their collection of SDOH through actions such as collecting more SDOH data elements, improving existing screening tools, and implementing new screening tools.

3.2 Challenges and Opportunities for SDOH Use for Research

We draw from the literature, KIIs, and the webinar to discuss salient challenges and opportunities for increasing the availability and accessibility of SDOH data available within PCORnet® CRNs through data infrastructure enhancements. We focus on three areas:

- Leveraging Existing SDOH Data to Expand the PCORnet® CDM
- Optimizing Individual- and Population-Level Analysis
- Incorporating SDOH Data from Other Sources into the PCORnet® CDM

We discuss the challenges within each area and suggest opportunities to expand PCORnet data infrastructure to overcome them. Appendix E, Figure E-1 provides additional technical detail for these challenges and opportunities, when applicable.

Challenges and Opportunities for Expanding the PCORnet® CDM Based on Existing SDOH Data

In considering an expansion of the SDOH data included in the PCORnet® CDM, key informants suggested prioritizing data elements that are nearer to being ready for standardized data collection, as well as those health systems already collect. Informants also suggested using natural language processing (NLP) to capture SDOH information collected in unstructured forms (e.g., clinical notes).

Challenge 1: Prioritizing SDOH domains and data elements to be added to the PCORnet® CDM, given immature SDOH standards. SDOH-related data elements included in the PCORnet® CDM are currently limited to demographic information and a limited set of other variables. As PCORI considers opportunities to expand the PCORnet® CDM with prioritized SDOH data elements, two issues must be addressed:1) ensuring that SDOH data elements align with standardization in the broader health care ecosystem, and 2) leveraging SDOH data that participating health systems already capture as part of their clinical workflows.

The Gravity Project is in the process of developing consensus-based standards for coding SDOH data, specifically identifying coded data elements and associated value sets to represent SDOH data in the EHR.[8,5] The codes associated with three domains—food insecurity, housing instability, and transportation—received approval for inclusion in ICD-10-CM as "Z codes" as of October 1, 2021.[9] This will enable data in these domains to be coded in the EHR in a standard, structured way that makes them available for research and clinical use. These codes are now also included in the United States Core for Data Interoperability (USCDI),[10] which provides a framework for collecting and exchanging structured, patient-level data (see Appendix D, Figure D-3 for more information on these initiatives).[11]

NORC's 2021 survey found that the domains Gravity has or nearly completed are collected by a majority of the responding health systems—food insecurity (64%), housing instability (53%), transportation access (56%), financial hardship (53%), employment status (60%), and intimate partner violence (51%).[12] Most key informants identified three of these SDOH domains—housing instability, food insecurity, and transportation access—as top priorities.

Opportunity 1: Prioritize a set of SDOH-related data elements for inclusion in the PCORnet® CDM. (Short-term)

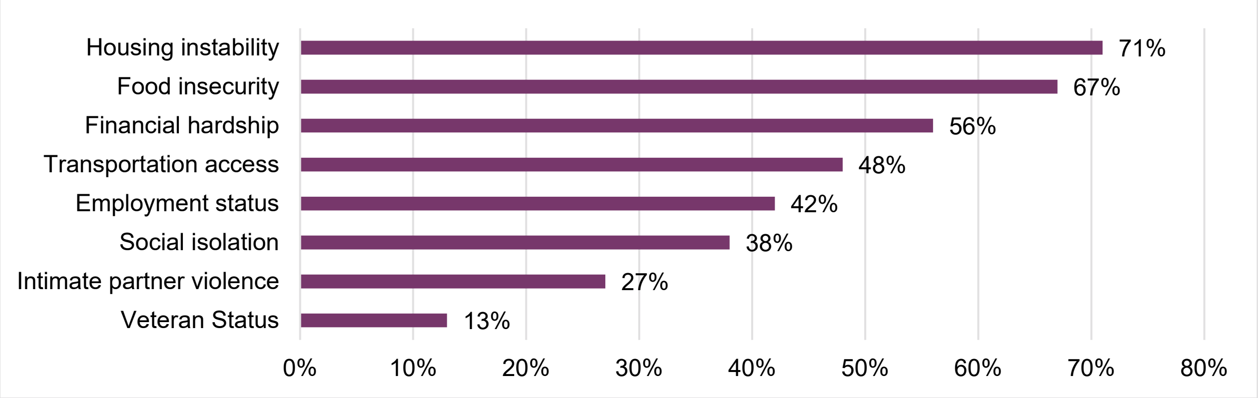
Key informants with expertise in the PCORnet CDM® emphasized the larger task is prioritizing domains for inclusion in the PCORnet CDM® so that corresponding data elements can be identified and included in PCORnet® CDM tables. Prioritization decisions should be guided by domains and data elements PCORnet® CRNs currently collect and for which data standards already exist. The 2021 survey found alignment between Gravity and CRN priorities, suggesting CRNs can soon leverage these standards to improve the quality of the SDOH data across the captured through health systems participating in PCORnet and can also leverage Gravity's common data elements for enhancing the PCORnet® CDM. During the webinar, speakers agreed that the indicators health systems already collect (i.e., language, education, food security, employment status, transportation, housing security, and financial resource strain)

---

[5] At present, Gravity has developed codes for food, housing insecurity, transportation, financial hardship, employment status, and Veteran status; two domains (intimate partner violence and social isolation) are being finalized; and codes for material hardship and elder abuse will be finalized in the near future. Additional codes will be developed in the winter of 2021–2022 for unemployment, education, and stress, plus additional consideration of veterans' social risk.

present the best short-term opportunity for standardization and inclusion in the PCORnet® CDM. We also polled the webinar audience with the following question: "Incorporating SDOH elements into the PCORnet® CDM would increase the availability of SDOH data to researchers using network infrastructure. Which domains would you prioritize for inclusion?" The results of the poll are in Figure 7, with housing instability the most frequently selected SDOH domain for prioritization.

Figure 7. SDOH Webinar Audience Vote for SDOH Domains Prioritization into the PCORnet® CDM (n=86) *



*Audience members could select multiple options.

In addition to the domains already widely available across the CRNs, there are opportunities to capture specific types of SDOH data within a subset of the participating health systems. For example, ADVANCE represents many sites that collect robust data on social isolation and stress. ADVANCE also includes many FQHCs, who are required to collect data for the Health Resources and Services Administration (HRSA) UDS, including federal poverty level, migrant seasonal status, homeless status, and Veteran status, among others (see Appendix D, Figure D-1). Even within this small sub-domain of clinics, there could be rich data for certain studies. Although these FQHCs cover a small proportion of patients, the data for SDOH are more likely to be complete.

Challenge 2: Identifying SDOH data elements for inclusion in the PCORnet® CDM, given the heterogeneous SDOH data across PCORnet® CRNs. The SDOH data collected by survey respondents, which represent 19 domains (Figure 2, above), arise from a myriad of social risk screening tools and assessments used at point of care for different purposes (e.g., general risk screening, condition-specific or social risk–specific screening, person-specific screening) and collected at different points in a visit (e.g., pre-visit screening, in-person assessment).[13] Even among commonly used screening tools, the SDOH domains screened and the questions asked vary (e.g., the NAM social and behavioral measures; the PRAPARE tool; and the CMS AHC tool). Health systems may modify assessment tools to address the specific needs of their patient populations, which is valuable at the clinical level but adds variability when aggregating data (see Appendix D, Figure D-1).[14] EHR vendor-specific tools and mapping adds to this complexity.[15,16] Some domains (such as transportation) lack gold standard screening tools, meaning a wide variety of tools (including ad hoc questionnaires) are used. There is additional variability to the extent the data are entered into an electronic form (e.g., Epic Healthy Planet, Health Wheel) using existing coding standards (e.g., ICD-10-CM codes).

Opportunity 2a: Crosswalk SDOH domains of interest for the PCORnet® CDM with the data elements in use across the networks. (Short-term)

Once priorities are set for expanding the data stored in the PCORnet® CDM to cover certain SDOH domains, understanding where the data come from becomes essential (i.e., data provenance). The electronic data platforms used to collect (and code) this information need to be identified to develop the corresponding PCORnet® CDM value set. Webinar speakers agreed that the more variability in how SDOH data elements are collected, the more difficult it will be to harmonize the data. Mapping data to one common standard terminology will take time and consideration.

> **"The goal is not perfect standardization, but the more data gets used, the more collaborations happen."**
>
> -Key Informant, Member of PCORI Board of Governors

Opportunity 2b: Create new data curation processes to load new SDOH data elements into the PCORnet® CDM and harmonizing it to PCORnet® CDM standards. (Short-term)

Bringing SDOH data into the PCORnet® CDM and making it available across CRN sites rely on several key decisions and processes. Webinar speakers discussed the importance of setting SDOH priorities before standardizing the SDOH domains selected for inclusion in the PCORnet® CDM. Changes to the PCORnet® CDM would then necessitate changes to extract, transform, and load (ETL) processes associated with transmitting and quality checking any new SDOH data. ETL is a process programmers use to extract data from network data sources (e.g., health care systems participating in PCORnet), transform the data to fit a standardized data model specification (e.g., the PCORnet® CDM), and then load the data into a data warehouse for future query.

The PCORnet data infrastructure includes mechanisms to assess the data quality of CRNs and health systems participating in PCORnet. During quarterly data refreshes, new data are added to the CRN data warehouses from the previous quarter. Before these data can be made available for queries, they must be checked to ensure they conform to the PCORnet® CDM and meet quality standards—including completeness, persistence, use of standard terminologies (e.g., ICD-10, LOINC, SNOMED), and sufficient metadata for analysis. The Coordinating Center for PCORnet estimates performing 1500+ assessments during the data curation process. For any SDOH data elements added to the PCORnet® CDM, these assessments must be revisited, and new quality benchmarks established.[17]

Updates to these processes will allow new SDOH data elements to be made available for querying. They will also establish clear guidelines for data quality for any new elements to ensure all contributed data is in research-ready format, so the data can be made available for use in a timely manner. Key informants made clear that as more consensus measures are developed for SDOH, guidance from the Coordinating Center will be necessary to implement any changes to the PCORnet® CDM.

Challenge 3: Collecting and standardizing patient-reported SDOH data. Webinar audience members noted the potential for collecting the SDOH data from patients as part of virtual visits or in pre-visit questionnaires. Building data infrastructure on the clinical side for patient-reported SDOH data is a promising strategy to gather more complete data, but these data sources are heterogeneous and not collected consistently. For example, one audience member's clinic routinely collects SDOH data in Epic for the pediatric population but not routinely for adults.

Opportunity 3: Collecting and standardizing patient-reported SDOH data directly from patients for a more complete view of patient health. (Mid-term)

Audience members noted that additional SDOH data entry forms could be developed to collect SDOH from patients as part of the clinical workflow, during clinical visits or pre-visit screenings in health systems participating in PCORnet. For Epic users, this would require the Epic MyChart team to build the workflows and standardize definitions. Those without MyChart would need to develop new clinical workflows to ensure collection of comprehensive patient-reported SDOH data. Speakers referenced OCHIN's work building infrastructure and providing training to support clinicians in collecting SDOH data.

Challenge 4: Untapped SDOH data in unstructured fields of the EHR. Health systems' limited use of existing standard terminologies for documenting SDOH data in the EHR is a barrier to having robust SDOH data for research.[18] Historically, studies have found that social needs data are often recorded in the EHR—but in unstructured fields rather than in structured formats using standard terminologies.[19] For example, a recent housing study that analyzed the SDOH documentation rate across a large academic health care system found low rates of structured SDOH data for multiple SDOH domains. When structured data were combined with unstructured data and then further combined the Area Deprivation Index (ADI), however, a more comprehensive picture of patient housing needs emerged.[20]

To access SDOH data not captured in structured form but nonetheless available from health systems, NLP could be a useful mechanism for extracting such data in a consistent manner across a network. NLP is distinct from keyword indexing in that it can distinguish between specific text and more complex word patterns and it can also recognize detailed discussions.[21] Although NLP algorithms can be more effective at identifying and extracting relevant data than keyword indexing, informants explained that: 1) the necessary algorithms require training on large amounts of text, and 2) privacy concerns related to health information further complicate the process.[22] Seven challenges are notable:

- SDOH data collection varies by site. On a site-by-site basis, there will be differences in what SDOH information is collected in structured forms, what is recorded as a clinical note and is therefore extractable via NLP, and what is missing altogether.
- Forms are rarely encoded using LOINC or SNOMED codes when they are available; but they are often not available, even for commonly used instruments.
- Analysis requires harmonization of concepts due to discrepancies in how SDOH elements are collected (e.g., "Discharge to a homeless shelter" vs. "Have you been homeless in the past 12 months?" have different time periods associated with the same concept).
- While improvements are in progress, the forms ("flow sheets") in EHRs are not typically collected in research data warehouses.
- Data stewards do not always have visibility of, or control over, provenance that could improve data quality. For example, research data can lose information and change encoding as it goes through different ETL steps. Protected/personal health information (PHI) is contained in note fields, which cannot be shared outside the clinical environment. Health systems would need to remove all PHI if they were to send data to the CRNs or another site for NLP.
- NLP takes time and resources to build, test, and implement.

Opportunity 4: Support pilot studies using NLP to mine unstructured individual-level SDOH data. (Mid-term)

Given that health systems participating in PCORnet collect unstructured data and PCORI wants to minimize provider burden and make the best use of available data, NLP may be a viable solution for CRNs to extract large volumes of unstructured SDOH from the EHR data.[23] But webinar speakers and audience members noted that the significant challenges to using NLP—including heterogeneity in how and where sites collect this information, missing data, and the substantial resources needed to develop and implement NLP—militate against a Network-wide roll-out. Instead, webinar participants recommended NLP pilot studies designed to be both site- and research-specific as more feasible, and therefore more effective.

Building infrastructure to support NLP (e.g., tables for storing and querying extracted data, processes for deidentifying extracted data) and developing the NLP algorithms (e.g., identifying and extracting appropriate data) would be required for such an effort. A recent meta-analysis of SDOH data extraction through NLP identified two tools and processes that could inform such a CRN or PCORnet Network Partner led effort: 1) gather SDOH keywords to create a lexicon for every domain that will be extracted, and 2) develop a rule-based system to locate the clinical notes associated with the desired concepts for extraction. The same analysis also discusses different methods of extraction (e.g., rule-based, supervised), and cites articles detailing such methods that could potentially serve as a useful guide for NLP processes that might be appropriate for PCORnet® CRNs.[24] Other resources and research in the field could also be leveraged.[25,26 ,27 ,28]

Challenges and Opportunities Optimizing Individual- and Population-Level Analysis

Key informants discussed the utility of geocoding individual-level data at the address level to support population-level analysis. Informants also reflected on the wide range of publicly available data at the area level that are relevant for SDOH research. Geocoding address data and linking data to aggregate sources could enhance PCORnet Network Partners' abilities to support research from micro- to macro-geographic scales, as long as individual-level privacy is maintained.

Challenge 5: Lack of geocoded address data available for analysis and linkage. Results from the 2021 NORC survey, validated by the Coordinating Center for PCORnet, found that 91 percent of the health systems are collecting patient street address with 5-digit zip code. Key informants estimated that address data, once geocoded, could be linked to approximately 165 other data sources to facilitate area-level and SDOH research.

Also, according to key informants, addresses can be verified and geocoded in a few steps if street address and 5-digit zip code are available. Open-source solutions and commercial products are available into which address data can be loaded and checked against databases (e.g., the U.S. Postal Service database). These databases are used to verify address and generate multiple variables for research—including 9-digit zip code (5-digit zip code and zip4); Census tract; longitude and latitude; a 15-digit block identification number (from which Census block groups, tracts, and counties can be generated); and carrier route, delivery point, and vacancy status (if specialized geocoding mode is enabled). An accuracy indicator is automatically returned as well, indicating the address match type. A log file is also generated at the end of the process to show match rate by match type. If the house number of an address is missing, complex (e.g., multi-unit, two-word street names), or erroneous (e.g., transposed numbers, patients failing to report house numbers, or patients who are homeless), these databases can suggest matches, although they may not return accurate results and/or may default to zip code centroids.[29] The address verification and geocoding process can operate behind a firewall, with access restricted to select PCORnet® CRN staff to provide necessary privacy protections.[30,31] The webinar speakers discussed the utility of open-source solutions for verifying and geocoding addresses, but noted that health systems will likely be charged for open-source solutions after a certain level of use.

Commercial products have the capacity to process batches of three million records with a processing time of seven to eight hours.[32] However, they do not integrate into existing workflows, and require hands-on attention from analysts who load and review the data. Open-source products (Census API,[33] Google API[34]) that run on R or Python can be integrated into existing workflows; but they also require analyst review, and challenges exist relative to capacity, cost, and accuracy. The Census API, for example, can only process 10,000 records at a time. The Google API charges $5/1000 addresses processed (after a free trial of Google Cloud Platform for the first three months). In addition, the data Google returns are not separated by address fields but concatenated by comma—increasing the labor associated with quality checking and data analysis. Finally, use of commercial/cloud products will likely require a business associate agreement (BAA). Geocoding an address against the Google API may be considered a HIPAA breach if such an agreement is not in place.

Opportunity 5: Deploy mechanisms to improve address data quality and geocode addresses to support SDOH research. (Short-term)

Efforts to verify addresses at the street number and 5-digit zip code level would increase researchers' ability to geocode data within health systems participating in PCORnet. Multiple solutions exist to generate zip codes up to 9 digits and to geocode them, which increases readiness for linkage.[35,36] If CRNs or health systems participating in PCORnet were to pursue a solution for address verification and geocoding, they could potentially involve a range of strategies, such as:

- Open-source solutions are plausible, although they warrant a discussion of how to protect PHI and have strict security parameters governing data sharing and use. The most important step would be developing a common protocol for each unique site participating in PCORnet, and then adapting and adopting the approach for verifying and geocoding patient addresses. Sites may wish to use a distributed or federated protocol for verifying their data.
- PCORnet Network Partners could engage with a commercial vendor to generate detailed address data and geocoding. Using an existing platform, with technical support for researchers, health systems, and CRNs, could be an efficient approach compared to building a new solution.
- The PCORnet® CDM currently contains an address table, whose data quality and completeness could potentially be improved to support geocoding. Code could be developed to load address information (street address, city, state) into a publicly available converter tool using compliant security and privacy-protecting solutions to determine 9-digit zip code, latitude, and longitude. One stakeholder suggested that this approach might be more cost effective than funding each site participating in PCORnet to enable this function separately.
- As an alternative to the solutions above, a webinar audience member raised the idea of using latitude and longitude to link data with Geographic Information System (GIS) software. The webinar speakers agreed that latitude and longitude can be extracted from patient address, even in the absence of the 9-digit zip code.

Challenge 6: Expanding SDOH data access by enabling linkages to publicly available data sets. Use of aggregate data alone assumes that structural and neighborhood-level experiences apply across all individuals in a given neighborhood. This problem, known as the ecological fallacy, is particularly evident in dense urban areas where low- and high-income housing exist in close proximity.[37,38] Geocoding and then linking to community-level data (i.e., data at the county level and smaller) can overcome these biases. Webinar speakers noted that aggregate-level data should not replace other individual-level data; it should be used in combination with them. The speakers suggested that geocoding be made a priority across the participating CRNs, with the goal of supporting researchers in using those data to explain structural and systemic factors, including structural or systemic racism exacerbating health disparities.

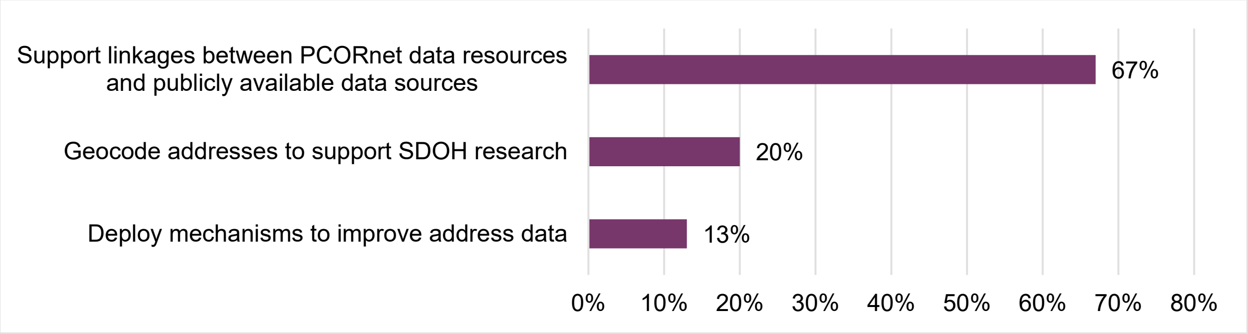
A key issue complicating address-based geocoding and linkages is that sources of aggregate SDOH data vary in their geographical specificity. For example, the ACS, a common source for poverty and income data, is available at the Census block group level.[39] Other data sources code at the Census tract level, which average roughly three times larger than the block group. County-level measures can add other useful data, such as air quality and crime. Depending on the research use case, different levels of geographical specificity may be desired. One informant reported that community-level databases tend to use Census-derived variables, given that the Census geographies are more stable (changing only every 10 years). Census variables also group geographies into neighborhoods. Postal service codes, in contrast, are subject to more frequent changes (e.g., new housing developments necessitate zip code updates), and are based on postal service areas that do not always correspond to neighborhoods. The geocoding solutions described in the previous section generate both postal and Census information, making the resulting data linkable to a variety of data sources.

Opportunity 6: Support linkages between data within the sites participating in PCORnet and publicly available sources of publicly available data. (Short-term)

Key informants identified multiple opportunities and resources to enhance the PCORnet data infrastructure by using geocodes to link PCORnet data resources to other data sources.[40,41,42,43,44] To facilitate linkages from EHR data across the CRNs to other data sources, PCORnet Network Partners could consider a vendor solution or build PCORnet-specific tools. For example:

- Leverage existing linkage efforts being used by individual CRNs. For example, Datavant Switchboard, a patient privacy-preserving record linkage solution, has been implemented across CRNs and can be used to facilitate data linkages.
- Tailor tools to specific sources (e.g., Department of Housing and Urban Development) to create efficiencies.
- Develop probabilistic matching algorithms to correct addresses and update zip codes at the DataMart level; for example, standardize key fields (ST vs. Street), and then match on fields such as house number, house suffix, street prefix, directional prefix, street suffix, directional suffix, apartment number/description, and 5-digit zip code.
- Leverage the Federal Statistical Research Data Centers (Census Bureau) for micro data. There are 18 different federal departments and agencies that share their data with the 31 federal statistical data centers (FSRDs); these, in turn, have their own networks of research organizations. The FSRDs function like ResDAC, allowing individual-level data linkage of SDOH data.
- During the webinar, we asked the audience to prioritize specified options of population-level data sets to enhance SDOH research capacity using PCORnet resources (Figure 8). Most audience members indicated that supporting linkages between PCORnet data resources and publicly available data sources should be the top priority for PCORI of the options presented (Figure 8).

Figure 8. Audience Vote on Opportunities for Prioritization (n=45)



Challenges and Opportunities to Incorporate SDOH data from the Social Sector

> **“There is the fear of creating further health disparities. Social services facilities do not want this data to be used against themselves. There is push back from the social sector because they see that by standardizing and applying medical terminology to this data, the data becomes medicalized, and this is not what these social service organizations stand for.”**
>
> - Key Informant, Health Systems Research and SDOH Data Infrastructure Expert

Data from the social sector could provide much needed information on the environmental and social contexts that is known to affect a patient’s health outcomes.[45] But such integration raises numerous questions: What infrastructure would be necessary? What data would be most valuable? How can data from community-based organizations (CBOs) be meaningfully incorporated to benefit research and patient care?[46]

Challenge 7: Building trust and a value proposition for social sector participants. According to key informants, the patient must be at the core of questions about how the health sector can interact with the social sector. Research data access is one piece of a puzzle that must also include benefits to patient health and care, and referrals to social services. Through this lens, one key informant commented that health systems should be prepared to overcome obstacles to collecting and using such data, including the necessity to build trust between academic research communities and CBOs. This relationship must be mutual—with commensurate benefit to health systems, CBOs, and the communities both organizations serve.

Opportunity 7: Establish mutually beneficial partnerships. (Short-term)

CRNs and other PCORnet Network Partners could invest in an engagement process with CBOs and other social sector organizations to discuss and develop a strategy for connecting PCORnet Networks Partners to sources of social risk data. A recent NORC white paper presents case studies and key considerations for policy makers interested in pursuing collaborations between health systems and CBOs.[47] The Robert Wood Johnson Foundation also published papers that could serve as a framework for engaging CBOs at the CRN-level or health system-level to establish relationships that could eventually make social sector data available to PCORnet Network Partners.[48]

Challenge 8: Fragmented infrastructure to connect health systems to the social sector. Findings from the 2021 NORC survey revealed that many health systems are interested in using and/or improving collection of community-level SDOH data. Similarly, key informants suggested that CBOs may be an untapped source of SDOH data for PCORnet Network Partners (e.g., address, SDOH screening data, social services used, demographics). However, CBOs have little time or capacity for data collection that is easily interoperable with health system needs and data standards. CBOs also have different data models and use different taxonomies for the SDOH concepts collected in health care. CBOs will require considerable infrastructure and funding support to enable researchers using PCORnet data resources to access CBO data: 1) in a form that is standardized and high quality, and 2) via mechanisms that are privacy preserving and low burden for the CBOs.

> **"It is important to learn how to listen to CBOs, condition-specific organizations, affinity, or population-based communities…These grassroots organizations trying to improve health and wellbeing could use the support and would want to be consulted and included."**
>
> - Key Informant, Health Systems Research and SDOH Data Infrastructure Expert

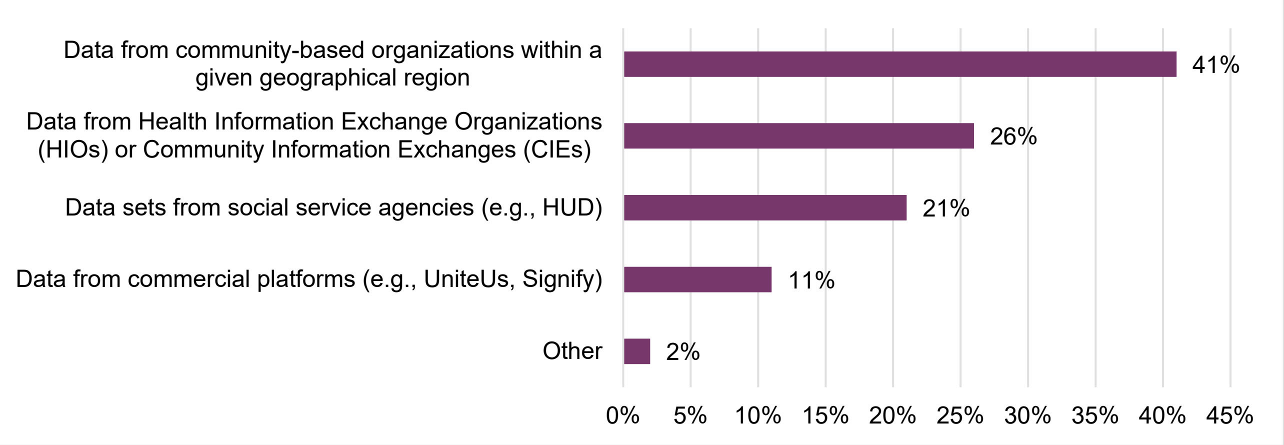
Opportunity 8: Incorporate social sector data into PCORnet® CRNs, align with data standards and platforms already in use. (Long-term)

Opportunities exist to leverage data standards,[49,50] workgroups, funded projects,[51,52,53,54,55] and existing platforms,[56,57] such that researchers affiliated with PCORnet Network Partners or using PCORnet data resources can access and analyze CBOs' data. During the webinar, we asked the audience to select which social sector data they see as having the greatest potential to enhance SDOH research using PCORnet resources. The most frequently selected option was data from CBOs within a given geographical region (Figure 9). A growing set of infrastructure components is being leveraged for SDOH referrals, data collection, and data sharing—with notable solutions from both health sector market leaders (Epic, Allscripts, Cerner, NextGen), as well as rapidly expanding community resource referral platforms (NowPow, UniteUs, Healthify, Aunt Bertha). For example, webinar speakers noted it would be helpful for referral platforms and other systems serving CBOs to standardize—in much the same way that ONC compelled health IT vendors to represent concepts by standardizing around certain vocabularies and value sets. The Gravity Project is the best example of work to standardize SDOH data. If commercial vendors for health and social sector providers adopted the standards being developed under the Gravity Project, data interoperability and secondary use of data for research would be significantly improved.

Within its current infrastructure and processes, CRNs or health systems participating in PCORnet could do the following:

- Pursue data linkages between data from CRNs and social sector data. PCORnet infrastructure can support data linkages and leverage privacy preserving methods, enabling social service organizations to share data on populations relevant to CRNs, while continuing to house the data at the social service organization. This would allow the right data to be matched and linked to the right person while ensuring the preservation of privacy.
- Connect to an existing commercial platform or health information exchange organization (HIO) that allows the CBOs to store their data (e.g., community resource referral platforms) and share data with CRNs or sites participating in PCORnet. These commercial platforms are already scaled and can aggregate data from diverse communities.

Figure 9. Audience Vote for Social Sector Data Prioritization into the PCORnet® CDM (n=66) *



*Participants could select only one choice. Percentages do not add to 100 percent due to rounding.

Conclusions

The findings of our literature review, KIIs, and the webinar revealed eight challenges and eight opportunities that represent areas for PCORI's near-, mid-, and long-term consideration.

These challenges and opportunities fall under three major themes: 1) *Setting priorities for SDOH data across PCORnet® CRNs (short-term)* would include improvements to the quality, breadth, and utility of SDOH data through technical approaches that are proximal to PCORI's sphere of influence (i.e., leveraging existing data, to centrally coordinating the geocoding of CRN address data, and linkages to other data sources such as SDOH-rich surveys, environmental data, and micro data). 2) *Population-level analysis (mid-term)* would leverage untapped sources of SDOH data within the CRNs using NLP pilots to answer site-specific and study-specific research questions. 3) *Connecting to other sources of social risk data (long-term)* would include CBO and other social sector data integration, given nascent efforts to connect and improve interoperability between the health sector and social sector, and the relationship-building involved in doing so. Webinar speakers noted it would be helpful for referral platforms and other systems serving CBOs to adopt standardized vocabularies and value sets.

Enhancing the availability of SDOH data in the PCORnet® CDM and improving the informatics capabilities to capture these data will support PCORI's Phase 3 goal of using PCORnet to conduct definitive national studies that advance PCORI's national priorities for health, including efforts to accelerate progress towards a learning health system. In addition, by augmenting the breadth of SDOH data loaded into the PCORnet® CDM, the Network will advance efforts to achieve PCORI's National Priorities for Health and meet the demands of a changing healthcare research landscape.

Appendix A. SDOH Survey of Health Systems Participating in PCORnet

PCORI is undertaking a series of convenings to explore ways in which the PCORnet® Common Data Model might be enhanced to include additional data elements covering social determinants of health (SDOH) and patient-reported outcomes (PROs)/patient-generated health data (PGHD) and improving access to public claims data. The process is in alignment with the PCORI Board-approved *Prioritizing Principles for Infrastructure Funding Relating to PCORnet* and PCORI's Strategic Research Priorities and will support the conduct of patient-centered comparative effectiveness research (CER) that provides patients, caregivers, and providers with the information they need for shared decision making.

Activities for this process will entail a series of literature reviews, key informant interviews, webinars, and white paper development for each of three topics: 1) opportunities for collecting and integrating SDOH data in PCORnet® CRNs, 2) enhancing opportunities for the collection of PROs/PGHD in PCORnet® CRNs, and 3) improving access to Medicare and Medicaid claims data. PCORI has contracted with NORC at the University of Chicago to conduct this work.

The purpose of this survey is to understand the current landscape across the CRNs regarding collecting and integrating SDOH data. This information will be used to inform qualitative data collection for the SDOH white paper and webinar which will ultimately inform the strategic planning process. **This is a 14-question survey that will take less than 10 minutes to complete.** Your individual responses will be kept confidential, and all personal identifiers removed. Please circulate this survey to representatives from each of your CRN-associated health systems as we would like responses from each individual health system.

The results of the survey will be shared with PCORI for the purpose of understanding the landscape of SDOH activities within the CRNs.

1. Name

2. Role

3. Email Address

4. Name of Affiliated Health System

5. Name of Affiliated CRN

6. In terms of SDOH data, what specific individual-level SDOH data elements is your health system using and collecting? *Select all that apply.*

a. Education
b. Financial resource strain
c. Stress
d. Physical activity
e. Social isolation
f. Interpersonal violence
g. Food security
h. Housing security/stability
i. Utilities
j. Transportation
k. Employment status
l. Veteran status
m. Homeless status
n. Seasonal/migrant farmworker
o. Household size
p. Household income
q. Neighborhood and Built Environment (neighborhood cohesion; neighborhood safety/disorder; built environment walkability)
r. Discrimination (perceived discrimination; health care discrimination)
s. Language (English proficiency; need for a translator)
t. Others (please specify)
u. None

7. Are you collecting any of these data elements described in question 6 using standard terminology?

a. Yes (If you selected yes, please specify coding terminology, functional assessment, or another framework being used)
b. No

8. Please indicate which frameworks you use to collect SDOH data. *Select all that apply.*

Additional information on each framework is available here: NAM Domains, CMS AHC Core Domains, CMS AHC Supplemental Domains, UDS Measures, PRAPARE, Health Leads, Healthy People.

a. NAM Domains

b. CMS AHC Core Domains
c. CMS AHC Supplemental Domains
d. UDS measures
e. PRAPARE
f. Health Leads
g. Healthy People
h. Others (please specify)
i. None of the above

9. Please indicate which SDOH data is integrated into your EHR from assessments or outside data sources, and which are in your local research data warehouse (RDW). *Select all that apply.*

a. Education
b. Financial resource strain
c. Stress
d. Physical activity
e. Social isolation
f. Interpersonal violence
g. Food security
h. Housing security/stability
i. Utilities
j. Transportation
k. Employment status
l. Veteran status
m. Homeless status
n. Seasonal/migrant farmworker
o. Household size
p. Household income
q. Neighborhood and Built Environment (neighborhood cohesion; neighborhood safety/disorder; built environment walkability)
r. Discrimination (perceived discrimination; health care discrimination)
s. Language (English proficiency; need for a translator)
t. Others (please specify)

10. Please indicate which five SDOH data elements are highest priority to your health system. *Select only five.*

a. Education
b. Financial resource strain

c. Stress
d. Physical activity
e. Social isolation
f. Interpersonal violence
g. Food security
h. Housing security/stability
i. Utilities
j. Transportation
k. Employment status
l. Veteran status
m. Homeless status
n. Seasonal/migrant farmworker
o. Household size
p. Household income
q. Neighborhood and Built Environment (neighborhood cohesion; neighborhood safety/disorder; built environment walkability)
r. Discrimination (perceived discrimination; health care discrimination)
s. Language (English proficiency; need for a translator)
t. Others (please specify)

11. Approximately what percentage of patients have SDOH data (one or more elements completed) in EHR?

12. Please indicate at what level you collect patient address information.

a. Patient Street Address
b. 9-digit zip code
c. 5-digit zip code

13. What are your health system's plans for collecting and using SDOH data in the next 2-4 years? *This question is optional.*

14. Please include links to any publications or presentations you would like to share regarding your SDOH work within your health system, network, and/or PCORnet. *This question is optional.*

Appendix B. CRN Summary

The table below summarizes the CRNs participating in PCORnet at the time of the data collection and analysis, July to December 2021.

Clinical Research Network	Network Composition	Partner Organizations
Accelerating Data Value Across a National Community Health Center Network (ADVANCE)	Led by OCHIN, Inc., ADVANCE represents more than 5 million patients at community health centers (CHCs) nationwide. Partners contribute ambulatory patient and community-level data from more than 44.6 million clinic encounters for more than 5 million patients.	OCHIN, Inc. (Lead) Fenway Health Health Choice Network HealthLandscape Oregon Health & Science University Robert Graham Center
Chicago Area Patient-Centered Outcomes Research Network (CAPriCORN)*	CAPriCORN maintains data for 10 million patients from private and public health systems across the Chicago area. Led by Northwestern University, CAPriCORN receives data for patients who received care at partner-affiliated sites in the region, including community-based organizations, outpatient care sites, federally qualified health centers, primary and specialty care practices, and academic medical centers.	Alliance Chicago Cook County Health and Hospitals System Edward Hines Jr. VA Hospital and Jesse Brown Medical Center Loyola University Health System Lurie Children's Hospital of Chicago Northshore University HealthSystem Rush University Medical Center University of Chicago University of Illinois Hospital and Health Sciences System
Greater Plains Collaborative (GPC)	The GPC collected data for more than 20 million patients. Led by the University of Kansas Medical Center Research Institute, the network used its data to focus on three disease cohorts: amyotrophic lateral sclerosis (ALS), breast cancer, and obesity. The network's de-identified database gathered data primarily from electronic health record and billing systems and merged these data with claims from the Centers for Medicare & Medicaid Services to increase data completeness.	University of Kansas Medical Center (Lead) Allina Health, Intermountain Healthcare Marshfield Clinic Research Institute Medical College of Wisconsin University of Iowa Healthcare University of Missouri University of Nebraska Medical Center University of Texas Health Science Center at San Antonio University of Texas Health Science Center at Houston University of Texas Southwestern Medical Center University of Utah Washington University in St. Louis

Clinical Research Network	Network Composition	Partner Organizations
INSIGHT	INSIGHT brought together seven health systems in and around New York City to collect data on 12 million unique patients. Led by Weill Medical College of Cornell University, INSIGHT has six additional partners in the New York area and collects data from electronic health records and Medicare, Medicaid, and commercial insurance claims.	Weill Cornell Medicine (Lead) Albert Einstein College of Medicine Columbia University Irving Medical Center Icahn School of Medicine at Mount Sinai New York-Presbyterian Hospital New York University School of Medicine
OneFlorida	Led by the University of Florida, the network included 11 additional partners populating a database containing information on more than 5 million Florida residents. Data are available since 2012. Data come from patients who consented to release their health information as well as electronic health records from partner organizations, Medicaid and Medicare claims, the Florida Cancer registry, and state vital statistics.	University of Florida – UFHealth (Lead) AdventHealth Bond Community Health Center, Inc. Emory University Florida State University Nicklaus Children’s Hospital Orlando Health System Tallahassee Memorial Healthcare Tampa General Hospital University of Alabama at Birmingham University of Miami and UHealth University of South Florida and USFHealth
Path Towards a Learning Health System (PaTH)	Led by the University of Pittsburgh, PaTH comprises seven health systems in the Mid-Atlantic and midwestern regions. The network had data on more than 13 million patients as of July 30, 2019. Data sources included Medicare and Medicaid claims, EHRs, relevant laboratory results, and patient-reported surveys	University of Pittsburgh (Lead) Geisinger Health System Johns Hopkins Institute for Clinical & Translational Research Johns Hopkins Medicine Penn State College of Medicine Penn State Health Medical Center Temple University School of Medicine The Ohio State University The Ohio State University Medical Center University of Michigan Institute for Clinical & Health Research UPMC

Clinical Research Network	Network Composition	Partner Organizations
PEDSnet	PEDSnet is a national pediatric learning health system. Led by Children's Hospital of Philadelphia, PEDSnet was made up of eight pediatric medical centers, whose primary markets were located in 12 states, with data on more than six million children, adolescents, and young adults. PEDSnet's data encompasses all pediatric diseases and specialties. The main data sources are electronic health records. Additional data were collected by individual studies from health insurance and medication claims, birth records, and child and parent surveys.	Children's Hospital of Philadelphia (Lead) Ann & Robert H. Lurie Children's Hospital of Chicago Boston Children's Hospital Children's Hospital Colorado Cincinnati Children's Hospital Medical Center Nationwide Children's Hospital Nemours Children's Health System St. Louis Children's Hospital Seattle Children's Research Institute Stanford Children's Health
Research Action for Health (REACHnet)	Led by the Louisiana Public Health Institute (LPHI), REACHnet is a CRN that represented almost 6.4 million patients at four healthcare systems in Louisiana and Texas.	Louisiana Public Health Institute (Lead) Baylor Scott & White Health Research Institute Ochsner Health System Tulane Medical Center University Medical Center New Orleans
Stakeholder, Technology and Research (STAR)	Led by Vanderbilt University Medical Center, the STAR Network had collected electronic health record data for more than 20 million patients as of August 2018. The network collected data from academic health centers; community hospitals; and a variety of outpatient practices including primary care, specialty practices, and safety net facilities serving diverse populations.	Vanderbilt University Medical Center (Lead) Duke University Health Sciences South Carolina Mayo Clinic Meharry Medical College The University of North Carolina at Chapel Hill Vanderbilt Health Affiliated Network Wake Forest Baptist Health

*CAPriCORN is no longer participating in PCORnet

Appendix C. Expanded Methods

Figure C-1. Search Terms for Grey and Published Literature and Illustrative Resources

Area	Search Terms
Data Infrastructure	Medical Informatics [Mesh], Data Collection [Mesh]; "Electronic Health Records [Mesh] ; Research Data Warehouse
Integrating SDOH	Social Determinants of Health [Mesh], "social determinants of health", "social risk factors"
Illustrative Resources	
Integrating Data On Social Determinants Of Health Into Electronic Health Records[58] • Developing a Social Determinants of Health Common Data Model for PRAPARE (Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences)[59] • Using Health Information Technology to Bring Social Determinants of Health into Primary Care: A Conceptual Framework to Guide Research[60] • PCORnet® 2.0 Steering Committee Notes • Data Science Recommendations to PCORnet® Data Committee on the Study of Health Disparities • Social Determinants of Health Working Group Presentation • SDOH Data Availability: Collated Responses	

Figure C-2. Key Informants by Stakeholder Type

Stakeholder Type	Key Informant Name and Organization
PCORnet and CRN Leadership	▪ Keith Marsolo, Duke University, Coordinating Center for PCORnet ▪ Erika Cottrell, ADVANCE ▪ Rainu Kaushal, INSIGHT ▪ Elizabeth Shenkman, OneFlorida
PCORI Board of Governors	▪ Danny Van Leeuwen, Health Hats ▪ Eboni Price-Haywood, Ochsner Xavier Institute for Health Equity and Research
SDOH Data Infrastructure	▪ Laura Gottlieb, University of California San Francisco/SIREN ▪ Evelyn Gallego, EMI Advisors/Gravity ▪ Andrew Hamilton, AllianceChicago
Federal Informants	▪ Christine Hunter, NIH/Office of Behavioral and Social Sciences Research (OBSSR) ▪ Meagan Khau, CMS Office of Minority Health, Data and Policy Analytics Group (DPAG)
Technical Experts	▪ Quentin Brummet, NORC at the University of Chicago ▪ Daniella Meeker, University of Southern California ▪ Chang Zhao, NORC at the University of Chicago

Appendix D. Supporting Figures

Figure D-1. SDOH Screening Tool Domains

Social & Economic Risk Screening Tool	Recommended Social and Behavioral Domains and measures for Electronic Health Records* National Academy of Medicine (formerly Institute of Medicine)[61]	PRAPARE: Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences National Association of Community Health Centers (NACHC)[62]	Accountable Health Communities Screening Tool Centers for Medicare & Medicaid Services[63]
Total # of Questions	24	21	10
Residential address	X	X	
Race/ethnicity	X	X	
Alcohol use	X		
Tobacco use & exposure	X		
Depression	X		
Education	X	X	
Financial resource strain – overall	X		
Household income		X	
Household size		X	
Housing		X	X
Food		X	X
Clothing		X	
Utilities (phone, gas, electric)		X	X
Medicine / health care		X	
Childcare		X	
Transportation		X	X
Neighborhood safety		X	
Interpersonal violence / safety	X	X	X
Physical Activity	X		
Social connections / isolation	X	X	

Social & Economic Risk Screening Tool	Recommended Social and Behavioral Domains and measures for Electronic Health Records* National Academy of Medicine (formerly Institute of Medicine)[61]	PRAPARE: Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences National Association of Community Health Centers (NACHC)[62]	Accountable Health Communities Screening Tool Centers for Medicare & Medicaid Services[63]
Stress	X	X	
Migrant / seasonal farmworker		X	
Veteran status		X	
Primary language		X	
Incarceration history		X	
Refugee status		X	
Insurance status		X	

Figure D-2. Examples of CRNs Conducting Health Equity Research using SDOH

To demonstrate the possibilities of research with the SDOH data currently existing within PCORnet® CRNs, we highlight several CRNs that have made significant investments in collecting and incorporating SDOH: ADVANCE, INSIGHT, and OneFlorida. We identified these CRNs through our literature review and key informant interviews as example case studies demonstrating advanced use of SDOH data for research.

These CRNs are using individual-level SDOH data from their health systems' data warehouses or linking patient data to community-level SDOH measures for PCOR and CER.

PCORnet® CRN	Research and Infrastructure
ADVANCE[64]	■ **Research Example:** ADVANCE incorporated community-level SDOH into patients' EHRs using HealthLandscape's geospatial technology and data library to create a Community Vital Signs Geocoding Application Programming Interface (API) to assign geographic identifiers and insert into EHRs of Federally Qualified Health Centers (FQHCs).[65] ■ **SDOH Data Element(s):** Community-level SDOH linked to geographic identifiers included built environment, environmental exposures, neighborhood race/ethnic composition/economic conditions/resources/socioeconomic composition, and the Social Deprivation Index.[66] ■ **Infrastructure:** geocoding, linkages
INSIGHT[67]	■ **Research Example:** INSIGHT conducted research on the association between residential neighborhood social conditions and health care utilization and costs. Medicare claims data was linked with SDOH, measured by the Area Deprivation Index, at the Census block level. ■ **SDOH Data Element(s):** address, Area Deprivation Index[68] ■ **Infrastructure:** geocoding, linkages
OneFlorida[69]	■ **Research Example:** OneFlorida, University of Florida, and a technology partner developed an NLP model to review nurses' and social workers' notes while removing personally identifiable information (PII). The informant highlighted that a key challenge to scaling their model to PCORnet or other CRNs is whether networks prefer to train the model on their own text versus adapting the workflows and processes of a trained model to their own network. ■ SDOH Data Element(s): social risk factors ■ **Infrastructure:** natural language processing
OneFlorida[70]	■ **Research Example:** OneFlorida characterized the prevalence of obesity among children from diverse geographic regions and racial/ethnic backgrounds in Florida using EHR data.[71] Data was sourced from their data trust comes from Medicaid claims records which contain 5-digit zip codes. ■ **SDOH Data Element(s):** Race/ethnicity, geographic location, urbanicity[72] ■ **Infrastructure:** geocoding, linkages

Figure D-3. Relevant National Policies and Initiatives Focused on SDOH Data Collection and Implications for PCORnet Participants

Entity	Initiative	Description	Implications for PCORnet
Administration for Community Living (ACL)	Innovative Technology Solutions for Social Care Referrals Challenge Competition	ACL launched a Challenge Competition in March 2020 to support the development of interoperable, statewide referral and analytics platforms required to enable partnerships between health care facilities and community-based social services organizations. Stakeholders include aging and disability, and Medicaid programs, CBOs, health IT developers, providers, and health plans.[73]	Several announced awardees, including those in New York and Missouri, formed a Referrals Collaborative and an Aging Services Data Collaborative, respectively. PCORnet Networks would benefit from engaging with the work products of these collaboratives.
Agency for Healthcare Research and Quality (AHRQ)	Creating a National Small-Area SDOH Data Platform	AHRQ is building on previous federal efforts by identifying comprehensive data sets with existing community-level data on SDOH variables to create a publicly available data platform of standardized SDOH data. It will include data sources at the census tract, zip code, and county level.[74]	The beta version of the SDOH database is publicly available, and usable for PCOR and health services researchers.[75]
Centers for Medicare and & Medicaid Services (CMS)	Accountable Health Communities (AHC)	CMS' investment of $157 million in the AHC models intends to support health systems in developing and testing models for identifying and addressing SDOH.	AHC will encourage universal, comprehensive screening of SDOH among Medicare and Medicaid beneficiaries at participating sites with the goal of reducing their health care costs and utilization.[76],[77]
CMS	Improving Medicare Post-Acute Care Transformation Act of 2014 (the IMPACT Act)	A requirement of the IMPACT Act is standardized data of long-term care hospitals, skilled nursing facilities, home health agencies, and inpatient rehabilitation facilities (IRFs). CMS' Long-Term and Post-Acute Care (LTPAC) Data Exchange allows for interoperable exchange of health information to improve care coordination and patient-centered care planning in long-term care and post-acute care facilities.[78]	CMS is currently undergoing efforts to include SDOH data elements for the post-acute care setting in the LTPAC Data Exchange, providing opportunity for PCORnet Network Partners to use these data specifically regarding long-term and post-acute care facilities.

Entity	Initiative	Description	Implications for PCORnet
CMS	ICD-10-CM Official Guidelines for Coding and Reporting – including guidance on Z codes.[79]	The ICD-10-CM includes SDOH-related Z codes intended to provide opportunity for providers and coding professionals to document SDOH data in the EHR. These Z codes range among topic areas such as housing, food insecurity, and transportation.	Z codes provide an opportunity for health systems to collect SDOH data in a standardized way. CMS has developed a journey map detailing the steps of using ICD-10-CM Z codes.[80]
CMS	Opportunities in Medicaid and CHIP to Address Social Determinants of Health (SDOH) – CMS Letter to State Health Officials, dated January 7, 2021	CMS provided guidance to state health officials to identify opportunities for Medicaid and CHIP to address SDOH, including CMS' support to states with designing programs, benefits, and services. States can consider reimbursing rural health clinics and FQHCs "under Medicaid to screen individuals to identify social needs, collect and analyze SDOH data to inform interventions." CMS encourages the leveraging of Medicaid resources to support data integration and data sharing to assist state health systems in identifying individuals with SDOH needs and linking them to medical and social support services.[81]	This guidance encourages states to leverage Medicaid funds to improve the data sharing capabilities of SDOH data across different Medicaid services, which could indicate possibilities for PCORnet Networks to have more robust SDOH data available from other social service sectors.
Department of Health and Human Services (HHS)	SDOH Workgroup	HHS is currently convening an SDOH Workgroup which includes representatives from multiple HHS agencies. Members of the workgroup bring expertise in SDOH, health equity, and health disparities among other topics. The purpose of this workgroup is to inform federal objectives related to SDOH.	The HHS SDOH Workgroup is currently selecting SDOH data elements that would be priorities to collect among patients. The workgroup is exploring other types of SDOH data elements using Medicare Current Beneficiary Survey data. These prioritized SDOH data elements can be further considered by PCORnet Network Partners to include in the PCORnet® CDM.
Federal Government	Executive Order on Ensuring an Equitable Pandemic Response and Recovery, in effect January 21, 2021	In acknowledgement of the disproportionate and severe impact of COVID-19 on underserved populations and communities of color, this executive order was signed into effect to ensure a health equity approach to responding to the COVID-19 pandemic, including establishing a COVID-19 Health Equity Task Force.[82]	This executive order signals a national priority to address health inequities.

Entity	Initiative	Description	Implications for PCORnet
Health Resources and Services Administration (HRSA)	Uniform Data System (UDS) HRSA Health Center Data and Reporting Requirements	HRSA community health center grantees and look-alikes are required to collect and report annually on measures defined in the Uniform Data System (UDS). HRSA funding requires the collection of patient demographic information, income, migrant and seasonal farmworker status, homeless status, race and ethnicity, preferred language, sexual orientation, and gender identity.[83]	FQHCs participating in PCORnet, and look-alikes already collect UDS data as a requirement of HRSA funding. This provides a framework for other health systems participating in PCORnet to collect these data as well.
HRSA	Health Information Technology Training and Technical Assistance (HITEQ) Center	HRSA maintains the HITEQ Center to support health centers in optimizing their EHR/IT systems.	HITEQ Center provides technical assistance for a variety of services, and specifically works with facilities to aggregate patient data from external sources through its Population Health Management (PHM) Service, including how to obtain and use PHM and SDOH data.[84]
National Institutes of Health (NIH)	PhenX SDOH Assessments Collection	The PhenX SDOH Assessments Collection is a collection of protocols that provide a common currency for studying SDOH across public health research studies. Researchers are encouraged to use this collection to develop, disseminate, and use standard data collection measures.	PCORnet studies funded by NIH can capitalize on the CDE Repository to supplement data elements capturing SDOH in the PCORnet® CDM. The CDE Repository also presents a standardized categorization of SDOH indicators.
Office of the National Coordinator of Health IT (ONC)	ONC United States Core Data for Interoperability (USCDI)	The USCDI is a standardized set of domains and elements for nationwide, interoperable health information exchange. Certified EHR vendors will need to support collection, use and exchange of these data elements.[85]	USCDI provides a framework for collecting and sharing patient-level data. USCDI V2 includes SDOH data elements such as homelessness, lack of adequate food, and transportation, which are data elements PCORnet Networks can consider in its expansion of the PCORnet® CDM.

Entity	Initiative	Description	Implications for PCORnet
ONC	Leading Edge Acceleration Projects (LEAP) in Health Information Technology (Health IT) grants	ONC has funded LEAP in Health IT grants, which support projects that promote better health care by encouraging use of health IT. One of ONC's areas of interest include "Referral Management to Address Social Determinants of Health Aligned with Clinical Care."[86] A recently funded ONC LEAP Health IT project titled "Advancing SDOH Health IT Enabled Tools and Data Interoperability: eCDS and Data Tagging Project" aims to advance the interoperability of SDOH data by supporting efforts to tag data by assessing feasibility of developing an electronic clinical decision support that incorporates SDOH data.[87] Another project, "Innovative Technology Solutions for Social Care Referrals," will create and modernize health IT platforms to connect health care systems and community-based organizations.[88]	ONC is funding the development of innovative methods and technologies to advance the interoperability of SDOH data. This will be useful as PCORnet Networks consider leveraging data from community-based organizations.
Robert Wood Johnson Foundation (RWJF)	Data Across Sectors for Health (DASH)	The DASH initiative is intended to foster alignment among public health, health care, and other community sectors to address SDOH and improve health of communities. RWJF is supporting strategies under this initiative to foster multi-sector data and information sharing across the health and human services sectors.[89]	DASH awards projects to foster multi-sector collaborations to share and use data to improve health and equity in communities. Current grantees are developing data sharing tools to connect health and human services sectors. These tools will be helpful to health systems participating in PCORnet as they consider using community-level data to further SDOH research.
SIREN, UCSF, & the Robert Wood Johnson Foundation	The Gravity Project	SIREN runs the Gravity Project, a consensus-based community effort to expand the core SDOH data set that can be exchanged interoperably. Its focus is the expansion of harmonized standards for SDOH using HL7 FHIR.	The FHIR standards and implementation guides being developed will harmonize common SDOH data elements and domains such as food insecurity, housing stability and quality, and transportation access.[90]

Entity	Initiative	Description	Implications for PCORnet
Multiple Entities	Legislation under Development Related to SDOH	Over 100 pieces of legislation related to SDOH are developed or under development. They are being monitored by The Gravity Project and others (see https://aligningforhealth.org/social-determinants-legislation/).	These legislations may have potential impact on incentives for SDOH data collection for providers.

Appendix E. Technical Strategy

Figure E-1. Technical Processes, by Applicable Opportunity

Opportunity	Additional Detail for Associated Technical Processes
Opportunity 2b: Create new data curation processes to load new SDOH data elements into the PCORnet® CDM and harmonizing it to PCORnet® CDM standards	This process would include: ▪ Developing standard value sets ▪ Identifying clinical observation data that the health systems collect in EHRs ▪ Creating processes for loading the SDOH data into the PCORnet® CDM and harmonizing them to the PCORnet® CDM standards ▪ Establishing quality benchmarks for new SDOH data and updating the data curation process to include those quality checks ▪ Developing guidance documents for Network Partners as they work on harmonizing the data.
Opportunity 4: Support pilot studies using NLP to mine unstructured individual-level SDOH data	Options for scaling an effectively trained NLP model: ▪ The approaches and lessons learned from multiple CRNs engaged in NLP projects could be leveraged to scale and deployed across PCORnet. ▪ As part of a community of practice, PCORnet Network Partners could facilitate the sharing of NLP algorithms among researchers. ▪ Specialists participating in PCORnet could develop, train, and disseminate algorithms for deployment across the Network Partners to extract different types of SDOH from clinical notes. NLP tools would likely include processes for data de-identification, de-duplication, and data element extraction; and could include visualization and other tools to monitor the NLP process. ▪ To safeguard PHI, ADVANCE uses a privacy preserving model for NLP in which aggregate data, rather than the full-text clinical notes, are shared with the central site.
Opportunity 5: Deploy mechanisms to improve address data quality and geocode addresses to support SDOH research	▪ CRNs and other Network Partners could potentially make use of Esri, a geocoding commercial software. Some Network Partners who have their own EHR platforms and business enterprise solutions for verifying and geocoding patient data already work with Esri. The University of Florida Health System, for example, uses Esri to accomplish verification and geocoding of patient addresses. ▪ CRNs or Network Partners could build a converter tool to use on data flowing into the CRN DataMarts. The tool would need to connect to a data dictionary or database to verify addresses (e.g., the USPS database), and have the PCORnet® CDM updated to store these data and enable queries across the Network. ▪ As part of the data curation process by which health systems upload reference files to the CRN's research data warehouses, CRNs could offer a tool to autofill addresses and institute additional quality checks and/or requirements for patient address (i.e., with house number and street, and 5-digit zip code as the desired minimum dataset). ▪ PCORnet® CRNs could explore how to incentivize health systems to collect accurate address data with higher specificity, as well as encouraging them to standardize the format in which address data are geocoded and stored. For example, OneFlorida health systems use incentives to ensure address accuracy (for billing purposes), and they make use of EHR-integrated geocoding tools to leverage this data. Similarly, ADVANCE works with FQHCs, which are incentivized to collect patient address data.

Opportunity	Additional Detail for Associated Technical Processes
Opportunity 6: Support linkages between data available via the participating sites and publicly available sources of publicly available data	▪ Address-based linkages can be accomplished by using the U.S. Census Bureau's Master Address File (MAF) and the Census Bureau and Social Security Administration's (SSA's) Numerical Identification (Numident) File. Data sources can also be linked and/or verified by person-level matching. The MAF is a collection of all addresses in the U.S., based on the decennial Census and the USPS Delivery Sequence File. The MAF is updated biannually with data from the USPS, the Census, and other census data collections. The SSA's Numident data contains information tied to an individual's social security number (name, dates of birth and death, parent names). The Census Bureau creates its own Numident file by combining this information with additional data on address and household composition gathered from state and federal administrative records. ▪ The linkage process itself generally involves a four-part process: 1) extracting the target data; 2) cleaning the data and conducting address matching with a probabilistic model (e.g., matching HUD data to the MAF file, then HUD to ACS via a MAF identifier); 3) person-level matching (e.g., HUD data to the Numident file, then ACS to Numident, then HUD and ACS to a shared ID); and 4) final linkage verification. ▪ Build tools to facilitate linkages—which could include establishing a repository where researchers document examples of successful linkages between sources, and their methods. This would create knowledge-sharing efficiencies across the Network Partners. ▪ Tailor tools to specific sources (e.g., Department of Housing and Urban Development) to create efficiencies. For example: • Link to environmental data sets and micro data sets to access patient contextual-level data. Environmental data sets, such as satellite images or Florida's geographic library, can be linked using zip codes or at the Census tract level. • Link patient data to geographic indicators such as ACS data, the United States Department of Agriculture (USDA) Food Atlas, and Dartmouth Atlas of Healthcare, as well as composite indices such as the Social Deprivation Index. An audience member provided a caveat for area-level data, noting that they are less useful in densely populated areas (e.g., New York City) or areas experiencing population growth or change (e.g., due to gentrification or new housing developments).
Opportunity 8: Incorporate social sector data into PCORnet Networks, align with data standards and platforms already in use	▪ Identify and leverage master agreements for data sharing between the social service and clinical organizations. For example, one PCORnet study is using social service data related to obesity programs—looking at how to leverage data from Women, Infants, and Children (WIC) and diabetes prevention programs for specific interventions. ▪ Identify one or more entities equipped to standardize and store the data to serve as the DataMarts with which CBO data are shared. ▪ Develop ETL protocols to allow CBOs to share data. ▪ Establish data quality benchmarks to which CBOs must conform during the data curation process, coupled with health information technology (health IT) and analyst support for checking data and resolving quality issues. Consider supporting CBOs directly or via consulting to help sites produce standardized data that can be leveraged further downstream. ▪ Conduct a PCORnet® CDM update that reflects the data elements CBOs will be asked to contribute, and possibly a new CBO-specific table enabling CBO and health system data to remain separate.

References

---

[1]Office of Disease Prevention and Health Promotion. Social Determinants of Health. [n.d.] https://health.gov/healthypeople/priority-areas/social-determinants-health

[2]Office of Disease Prevention and Health Promotion. Social Determinants of Health. [n.d.] https://health.gov/healthypeople/priority-areas/social-determinants-health

[3] PCORnet Common Data Model Specification v 6.0. [n.d.]. https://pcornet.org/wp-content/uploads/2022/01/PCORnet-Common-Data-Model-v60-2020_10_221.pdf

[4] Block R. G., Puro J., Cottrell E., Lunn, M. R., Dunne, M. J., Quiñones, A. R., Chung, B., Pinnock, W., Reid, G. M., & Heintzman, J. (2020). Recommendations for improving national clinical datasets for health equity research. *Journal of the American Medical Informatics Association, 27*(11), 1802-1807. https://doi.org/10.1093/jamia/ocaa144

[5] PCORI. (2019, January 07). PCORnet SDH Workgroup Final Presentation.

[6] PCORI. (2021, February 08). Prioritizing Principles for Infrastructure Funding Relating to PCORnet. April 19, 2021. https://www.pcori.org/document/prioritizing-principles-infrastructure-funding-relating-pcornet

[7] González Bernaldo de Quirós, F., Otero, C., & Luna, D. (2018). Terminology Services: Standard Terminologies to Control Health Vocabulary. *Yearbook of Medical Informatics, 27*(1), 227-233. https://doi.org/10.1055/s-0038-1641200

[8] The Gravity Project. (2021). Timeline. https://confluence.hl7.org/pages/viewpage.action?pageId=91996855#TheGravityProject-ProjectTimeline(Updated2021.08.20)

[9] The Gravity Project. (2021). ICD-10 Coding Submissions. https://confluence.hl7.org/display/GRAV/ICD-10+Coding+Submissions

[10] The Gravity Project. (2021). Gravity Project USCDI Submission. https://confluence.hl7.org/display/GRAV/Gravity+Project+USCDI+Submission

[11] The Office of the National Coordinator for Health Information Technology (ONC). (2021). USCDI V2. https://www.healthit.gov/isa/taxonomy/term/1806/uscdi-v2#uscdi-proposal-mode-uscdi-data-element-page-display

[12] HL7 International. (2021). The Gravity Project. https://www.hl7.org/gravity/

[13] Hovey, L., Singer, R., Desai, P., Norris, J., Dhopeshwarkar, R., & Dullabh, P. (2021, March). Social Determinants of Health Data Sharing at the Community Level. https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//199726/social-determinants-health-data-sharing.pdf

[14] Freij, M., Dullabh, P., Lewis, S., Smith, S. R., Hovey, L., & Dhopeshwarkar, R. (2019). Incorporating Social Determinants of Health in Electronic Health Records: Qualitative

---

Study of Current Practices Among Top Vendors. *JMIR Medical Informatics, 7*(2), e13849. https://doi.org/10.2196/13849

[15] Olson, D. P., Oldfield, B. J., & Navarro, S. M. (2018, March 18). Standardizing Social Determinants of Health Assessments. Health Affairs Forefront. https://www.healthaffairs.org/do/10.1377/forefront.20190311.823116

[16] Gottlieb, L., Tobey, R., Cantor, J., Hessler, D., & Adler, N. E. (2016). Integrating social and medical data to improve population health: opportunities and barriers. *Health Affairs, 35*(11), 116-2123. https://doi.org/10.1377/hlthaff.2016.0723

[17] Forrest, C. B., McTigue, K. M., Hernandez, A. F., Cohen, L. W., Cruz, H., Haynes, K., Kaushal, R., Kho, A. N., Marsolo, K. A., Nair, V. P., Platt, R., Puro, J, E., Rothman, R. L., Shenkman, E. A., Waitman, L. R., Williams, N. A., & Carton, T. W. (2021). PCORnet® 2020: Current state, accomplishments, and future directions. Journal of Clinical Epidemiology, 129, 60-67. https://doi.org/10.1016/j.jclinepi.2020.09.036

[18] Cantor, M. N., & Thorpe, L. (2018). Integrating data on social determinants of health into electronic health records. *Health Affairs, 37*(4), 585-590. https://doi.org/10.1377/hlthaff.2017.1252

[19] Winden, T. J., Chen, E. S., Monsen, K. A., Wang, Y., & Melton, G. B. (2018). Evaluation of Flowsheet Documentation in the Electronic Health Record for Residence, Living Situation, and Living Conditions. *AMIA Joint Summits on Translational Science proceedings. AMIA Joint Summits on Translational Science*, *2017*, 236–245.

[20] Hatef, E., Ma, X., Rouhizadeh, M., Singh, G., Weiner, J. P., & Kharrazi, H. (2021). Assessing the Impact of Social Needs and Social Determinants of Health on Health Care Utilization: Using Patient- and Community-Level Data. *Population Health Management, 24*(2), 222–230. https://doi.org/10.1089/pop.2020.0043

[21] Demner-Fushman, D., Elhadad, N., Friedman, C. (2021) Natural Language Processing for Health-Related Texts. In E.H. Shortliffe & Cimino J.J. Cimino (Eds.), *Biomedical Informatics*. Springer, Cham. https://doi.org/10.1007/978-3-030-58721-5_8

[22] Li, I., Pan, J., Goldwasser, J., Verma, N., Wong, W. P., Nuzumlalı, M. Y., Rosand, B., Li, Y., Zhang, M., Chang, D., Taylor, R. A., Krumholz, H. M., & Radev, D. (2021). Neural Natural Language Processing for Unstructured Data in Electronic Health Records: a Review. arXiv preprint arXiv:2107.02975.

[23] Hatef, E., Rouhizadeh, M., Tia, I., Lasser, E., Hill-Briggs, F., Masrsteller, J., & Kharrazi, H. (2019). Assessing the Availability of Data on Social and Behavioral Determinants in Structured and Unstructured Electronic Health Records: A Retrospective Analysis of a Multilevel Health Care System. *JMIR Medical Informatics, 7*(3), e13802. https://doi.org/10.2196/13802

[24] Patra, B. G., Sharma, M. M., Vekaria, V., Adekkanattu, P., Patterson. O. V., Glicksberg, B., Lepow, L. A., Ryu, E., Biernacka, J. M., Furmanchuk, A., George, T. J., Hogan, W., Wu, Y., Yang, X., Bian, J., Weissman, M., Wickramaratne, P., Mann, J. J.,

---

Olfson, M., … Pathak, J. (2021). Extracting social determinants of health from electronic health records using natural language processing: a systematic review, *Journal of the American Medical Informatics Association, 28*(12), 2716-2727. https://doi.org/10.1093/jamia/ocab170

[25] Conway M., Keyhani S., Christensen L., South, B. R., Vali, M., Walter, L. C., Mowery, D. L., Adbelrahman, S., & Chapman, W. W. (2019). Moonstone: a novel natural language processing system for inferring social risk from clinical narratives. *Journal of Biomedical Semantics, 10*(1), 6. https://doi.org/10.1186/s13326-019-0198-0

[26] Stanford University. Stanford CoreNLP. https://stanfordnlp.github.io/CoreNLP/

[27] University of Washington BioMedical Natural Language Processing Group. http://depts.washington.edu/bionlp/index.html?projects

[28] Dorr D., Bejan, C. A., Pizzimenti, C., Singh, S., Storer, M., & Quinones, A. (2019). Identifying Patients with Significant Problems Related to Social Determinants of Health with Natural Language Processing. *Studies in Health Technology and Informatics, 264*, 1456-1457. https://doi.org/10.3233/SHTI190482

[29] US Census Bureau. Comparison of Survey, Federal, and Commercial Address Data Quality. CARRA Working Paper Series - Working Paper #2014-06. (2014, June 30). https://www.census.gov/content/dam/Census/library/working-papers/2014/adrm/carra-wp-2014-06.pdf

[30] US Census Bureau. Geocoding Services Web Application Programming Interface (API). (2021, July). https://geocoding.geo.census.gov/geocoder/Geocoding_Services_API.pdf

[31] Google Maps Platform. Web Services: Geocoding API. https://developers.google.com/maps/documentation/geocoding/overview

[32] Pitney Bowes. MapMarker USA User Guide. (2019, January 30). https://www.manualslib.com/manual/1804690/Pitney-Bowes-Epic-V3-1.html#product-Epic%20v3.1

[33] US Census Bureau. Geocoding API. https://geocoding.geo.census.gov/

[34] Google Maps Platform. Web Services: Geocoding API. https://developers.google.com/maps/documentation/geocoding/overview

[35] Bazemore, A. W., Cottrell, E. K., Gold, R., Hughes, L. S., Phillips, R. L., Angier, H., Burdick, T. E., Carrozza, M. A., & DeVoe, J. E. (2016). "Community vital signs": incorporating geocoded social determinants into electronic records to promote patient and population health. *Journal of the American Medical Informatics Association, 23*(2), 407–412. https://doi.org/10.1093/jamia/ocv088

[36] ESRI. ArcGIS. https://www.esri.com/en-us/arcgis/about-arcgis/overview

---

[37] Gottlieb, L. M., Francis, D. E., Beck, A. F. (2018). Uses and misuses of patient- and neighborhood-level social determinants of health data. *The Permanente Journal, 22*, 18-078. https://doi.org/10.7812/TPP/18-078

[38] Cottrell E. K., Hendricks M., Dambrun K., Cowburn, S., Pantell, M., Gold, R., & Gottlieb, L. M. (2020). Comparison of Community-Level and Patient-Level Social Risk Data in a Network of Community Health Centers. *JAMA Network Open, 3*(10), e2016852. https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2772337

[39] Schaeffer C., Teter C., Finch E. A., Hurt C, Keeter M. K., Liss D.T, Rogers A, Sheth A, Ackermann R, A pragmatic randomized comparative effectiveness trial of transitional care for a socioeconomically diverse population: Design, rationale and baseline characteristics, Contemporary Clinical Trials, Volume 65,2018, Pages 53-60. https://doi.org/10.1016/j.cct.2017.12.003.

[40] Centers for Disease Control and Prevention. CDC/ATSDR Social Vulnerability Index. https://www.atsdr.cdc.gov/placeandhealth/svi/index.html

[41] Hatef, E., Ma, X., Rouhizadeh, M., Singh, G., Weiner, J. P., & Kharrazi, H. (2021). Assessing the Impact of Social Needs and Social Determinants of Health on Health Care Utilization: Using Patient- and Community-Level Data. *Population Health Management, 24*(2), 222–230. https://doi.org/10.1089/pop.2020.0043

[42] Health Disparities Collaborative Research Group. Data Science Recommendations to the PCORnet Data Committee on the Study of Health Disparities. [n.d.] [link]

[43] AHRQ. (2021). Social Determinants of Health Database (Beta Version). https://www.ahrq.gov/sdoh/data-analytics/sdoh-data.html

[44] Cantor, M. N., & Thorpe, L. (2018). Integrating data on social determinants of health into electronic health records. Health Affairs, 37(4), 585-590. doi: http://dx.doi.org.mutex.gmu.edu/10.1377/hlthaff.2017.1252

[45] Bazemore, A. W., Cottrell, E. K., Gold, R., Hughes, L. S., Phillips, R. L., Angier, H., Burdick, T. E., Carrozza, M. A., & DeVoe, J. E. (2016). "Community vital signs": incorporating geocoded social determinants into electronic records to promote patient and population health. Journal of the American Medical Informatics Association : JAMIA, 23(2), 407–412. https://doi.org/10.1093/jamia/ocv088

[46] Hatef, E., Ma, X., Rouhizadeh, M., Singh, G., Weiner, J. P., & Kharrazi, H. (2021). Assessing the Impact of Social Needs and Social Determinants of Health on Health Care Utilization: Using Patient- and Community-Level Data. Population health management, 24(2), 222–230. https://doi.org/10.1089/pop.2020.0043

[47] Hovey L, Singer R, Desai P, Norris J, Dhopeshwarkar R, Dullabh P. Social Determinants of Health Data Sharing at the Community Level. March 2021. https://aspe.hhs.gov/sites/default/files/migrated_legacy_files//199726/social-determinants-health-data-sharing.pdf

---

[48] Flatley J. Aligning Health Care and Social Services. Robert Wood Johnson Foundation. August 2019. https://www.rwjf.org/en/library/research/2019/08/aligning-health-care-and-social-services.html

[49] The Gravity Project. (2021). ICD-10 Coding Submissions. https://confluence.hl7.org/display/GRAV/ICD-10+Coding+Submissions

[50] The Gravity Project. (2021). Gravity Project USCDI Submission. https://confluence.hl7.org/display/GRAV/Gravity+Project+USCDI+Submission

[51] DirectTrust. Launch of Information Exchange for Human Services (IX4HS) Consensus Body. September 10, 2021. https://directtrust.org/blog/launch-of-information-exchange-for-human-services/%E2%80%8B

[52] National Interoperability Collaborative. Project Unify/Consent. https://hub.nic-us.org/groups/project-unify

[53] Office of the National Coordinator of Health IT. Interoperability Proving Ground (IPV): 360X. https://www.healthit.gov/techlab/ipg/node/4/submission/276

[54] DASH Connect. (2021). Data Across Sectors for Health: DASH CIC Awardees. https://dashconnect.org/awardees/cic-awardees/

[55] Office of the National Coordinator of Health IT. Leading Edge Acceleration Projects (LEAP) in Health Information Technology (Health IT) Notice of Funding Opportunity (NOFO); FY 2021 Special Emphasis Notice (SEN). https://www.healthit.gov/topic/onc-funding-opportunities/leading-edge-acceleration-projects-leap-health-information

[56] Cartier Y, Fichtenberg C, and Gottlieb L. Community Resource Referral Platforms: A Guide for Health Care Organizations. April 16, 2019. https://sirenetwork.ucsf.edu/sites/default/files/wysiwyg/Community-Resource-Referral-Platforms-Guide.pdf

[57] Datavant. https://datavant.com/

[58] Cantor, M. N., & Thorpe, L. (2018). Integrating data on social determinants of health into electronic health records. Health Affairs, 37(4), 585-590. doi:10.1377/hlthaff.2017.1252

[59] Hamilton, A., & Weir, R. (2019, February 14). Developing a Social Determinants of Health Common Data Model for PRAPARE (Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences). https://365.himss.org/sites/himss365/files/365/handouts/552577270/handout-213-Final.pdf

[60] Cottrell EK, Gold R, Likumahuwa S, Angier H, Huguet N, Cohen DJ, Clark KD, Gottlieb LM, DeVoe JE. (2018). *Journal of Healthcare for the Poor and Underserved*, 29(3), 949-963. doi: 10.1353/hpu.2018.0071

---

[61] Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records; Board on Population Health and Public Health Practice; Institute of Medicine. Capturing Social and Behavioral Domains and Measures in Electronic Health Records: Phase 2. Washington (DC): National Academies Press (US); 2015 Jan 8. https://www.ncbi.nlm.nih.gov/books/NBK268995/ doi: 10.17226/18951

[62] NACHC. (2016). PRAPARE®: Protocol for Responding to and Assessing Patient Assets, Risks, and Experiences Paper Version of PRAPARE® for Implementation as of September 2, 2016 http://www.nachc.org/wp-content/uploads/2016/09/PRAPARE_One_Pager_Sept_2016.pdf

[63] Billioux, A., K. Verlander, S. Anthony, and D. Alley. 2017. Standardized Screening for Health-Related Social Needs in Clinical Settings: The Accountable Health Communities Screening Tool. NAM Perspectives. Discussion Paper, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/201705b

[64] ADVANCE Collaborative. http://advancecollaborative.org/?page_id=147

[65] Bazemore, A. W., Cottrell, E. K., Gold, R., Hughes, L. S., Phillips, R. L., Angier, H., Burdick, T. E., Carrozza, M. A., & DeVoe, J. E. (2016). "Community vital signs": incorporating geocoded social determinants into electronic records to promote patient and population health. Journal of the American Medical Informatics Association: JAMIA, 23(2), 407–412. https://doi.org/10.1093/jamia/ocv088

[66] Andrew W Bazemore, Erika K Cottrell, Rachel Gold, Lauren S Hughes, Robert L Phillips, Heather Angier, Timothy E Burdick, Mark A Carrozza, Jennifer E DeVoe, “Community vital signs” : incorporating geocoded social determinants into electronic records to promote patient and population health , Journal of the American Medical Informatics Association, Volume 23, Issue 2, March 2016, Pages 407–412, https://doi.org/10.1093/jamia/ocv088.

[67] INSIGHT Clinical Research Network. (n.d.). About Us. https://insightcrn.org

[68] Zhang Y, Ancker JS, Hall J, Khullar D, Wu Y, Kaushal R. Association Between Residential Neighborhood Social Conditions and Health Care Utilization and Costs. *Med Care*. 2020;58(7):586-593. doi:10.1097/MLR.0000000000001337

[69] University of Florida Health. University of Florida Health, NVIDIA develop artificial intelligence model to hasten clinical trials, boost medical decision-making. April 8, 2021. https://ufhealth.org/news/2021/university-florida-health-nvidia-develop-artificial-intelligence-model-hasten-clinical

[70] OneFlorida Research Consortium. (n.d.). Our Mission: Improving Health Care. https://onefloridaconsortium.org/

[71] Lemas, D. J., Cardel, M. I., Filipp, S. L., Hall, J., Essner, R. Z., Smith, S. R., ... & Janicke, D. M. (2019). Objectively measured pediatric obesity prevalence using the

---

OneFlorida Clinical Research Consortium. *Obesity research & clinical practice*, *13*(1), 12-15.

[72] Lemas, D. J., Cardel, M. I., Filipp, S. L., Hall, J., Essner, R. Z., Smith, S. R., Nadglowski, J., Donahoo, W. T., Cooper-DeHoff, R. M., Nelson, D. R., Hogan, W. R., Shenkman, E. A., Gurka, M. J., & Janicke, D. M. (2019). Objectively measured pediatric obesity prevalence using the OneFlorida Clinical Research Consortium. *Obesity research & clinical practice*, *13*(1), 12–15. https://doi.org/10.1016/j.orcp.2018.10.002

[73] Administration for Community Living (ACL). (2021). Challenge: Innovative Technology Solutions for Social Care Referrals. https://acl.gov/socialcarereferrals

[74] ASPE. (n.d.). Enhancing Patient-Centered Outcomes Research (PCOR): Creating a National Small-Area Social Determinants of Health Data Platform. https://aspe.hhs.gov/enhancing-patient-centered-outcomes-research-pcor-creating-national-small-area-social-determinants

[75] AHRQ. (2021). Social Determinants of Health Database (Beta Version). https://www.ahrq.gov/sdoh/data-analytics/sdoh-data.html

[76] Alley DE, Asomugha CN, Conway PH, Sanghavi DM. Accountable Health Communities — Addressing Social Needs through Medicare and Medicaid. *N Engl J Med*. 2016;374(1):8-11.doi:10.1056/NEJMp1512532

[77] Garg A, Boynton-Jarrett R, Dworkin PH. Avoiding the Unintended Consequences of Screening for Social Determinants of Health. *Jama*. 2016;316(8):813. doi:10.1001/jama.2016.9282

[78] The Office of the National Coordinator for Health Information Technology (ONC). (2018). Long-Term and Post-Acute Care. https://www.healthit.gov/topic/health-it-health-care-settings/long-term-and-post-acute-care

[79] Centers for Medicare & Medicaid Services (CMS). (2021). ICD-10-CM Official Guidelines for Coding and Reporting FY 2022 https://www.cms.gov/files/document/fy-2022-icd-10-cm-coding-guidelines.pdf

[80] Centers for Medicare & Medicaid Services (CMS). (2021). Using Z Codes: The Social Determinants of Health (SDOH) Data Journey to Better Outcomes. https://www.cms.gov/files/document/zcodes-infographic.pdf

[81] Centers for Medicare & Medicaid Services (CMS). (2021). Opportunities in Medicaid and CHIP to Address Social Determinants of Health. https://www.medicaid.gov/federal-policy-guidance/downloads/sho21001.pdf

[82] The White House. (2021). Executive Order on Ensuring an Equitable Pandemic Response and Recovery. https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/21/executive-order-ensuring-an-equitable-pandemic-response-and-recovery/

---

[83] Uniform Data System. (2021). 2021 Health Center Data Reporting Tables. https://bphc.hrsa.gov/sites/default/files/bphc/datareporting/pdf/2021-uds-manual-tables.pdf

[84] HITEQ Center. (2021). HITEQ Center: Resource Overview. http://hiteqcenter.org/Resources/Population-Health/Getting-and-Using-Data

[85] The Office of the National Coordinator for Health Information Technology (ONC). (2021). USCDI V2. https://www.healthit.gov/isa/taxonomy/term/1806/uscdi-v2#uscdi-proposal-mode-uscdi-data-element-page-display

[86] The Office of the National Coordinator for Health Information Technology (ONC). (2021). ONC Funding Opportunities. https://www.healthit.gov/topic/onc-funding-opportunities/onc-funding-opportunities

[87] Advancing SDoH Health IT Enabled Tools and Data Interoperability Home. (2021). Advancing SDoH Health IT Enabled Tools and Data Interoperability Home https://oncprojectracking.healthit.gov/wiki/display/ASHIETDI/Advancing+SDoH+Health+IT+Enabled+Tools+and+Data+Interoperability+Home

[88] Department of Health and Human Services. (2021). Innovative Technology Solutions for Social Care Referrals. https://www.challenge.gov/challenge/innovative-technology-solutions-for-social-care-referrals/

[89] Data Across Sectors for Health. (2021). Background. https://dashconnect.org/background/

[90] The Gravity Project. (2019). Gravity Project FHIR IG. https://confluence.hl7.org/display/PC/Gravity+Project+FHIR+IG