

Connecting for Better Health

Issue Brief:

Collection and Use of Social Determinants of Health Data in California

Social determinants of health (SDOH) are environmental conditions that impact an individual's health, functioning, and quality of life. These include financial instability, food insecurity, housing, access to transportation, trauma, discrimination, and other factors. There is broad agreement that medical care accounts for about 10-20% of health outcomes, with the remaining 80% of contributors being SDOH.¹ Because of the profound role SDOH play in health care and the shift towards value-based care, states and health care organizations have begun to advocate for the collection of SDOH data. These data can be useful both at the community level to address population health needs, and at the individual level to address social needs.² This brief focuses on SDOH data in the context of both community-level needs and individual-level social needs.

With this push to incorporate SDOH in health care comes an opportunity to develop and implement a robust data integration and sharing plan so that information collected can be used to understand individual and community needs. Often, even when SDOH data are collected, interoperability between organizations is lacking; for example, when data are entered as unstructured free text, it is difficult for other organizations or providers to correctly extract these data.³ Standardized data structures can facilitate this collection and sharing.

One system for electronic data sharing is through health information exchanges (HIEs). HIEs allow for providers across different practices and specializations to access and send patient data appropriately and securely. Through incorporating physical health, behavioral health, and social data into a statewide HIE, providers can more quickly gather a comprehensive understanding of their patient's needs. Additionally, mandated use of an HIE prevents business interests (often centered around data) from negatively impacting patient care.⁴

This brief outlines national and state efforts to better collect and share SDOH data, what California can learn from other states' efforts, and big picture policy recommendations to support state initiatives like CalAIM in implementing system, program, and payment reform efforts.

What has California already done and what have we learned?

California's first serious investment in SDOH began with its Medi-Cal Whole Person Care Pilot (WPC) from 2016 to 2020. Twenty-five pilot programs began WPC in partnership with Medi-Cal managed care plans, health departments, specialty mental health agencies, community-based providers, and other public agencies. The goal was to coordinate medical health, behavioral health, and social service needs using a patient-centered approach for the most vulnerable Medi-Cal beneficiaries'. To use resources effectively, WPC Pilots identified target populations, assessed health and housing needs, shared data between systems, coordinated real-time care, and evaluated progress and outcomes.⁵

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Highlights from WPC:

- **Insight into health care utilization:** Counties are able to see how clients interact with different services and systems – a first step in improving efficiency and addressing unmet needs.
- **Development and expansion of HIE:** While one frequently cited challenge in the pilots was centered on data sharing (e.g., inconsistencies in data reporting across different organizations, skepticism around new tools, concerns around risks), pilots reported success in using data sharing systems over time and found the data useful in understanding their clients' health.⁶
- **Universal consent:** To address regulatory barriers across programs regarding consent, pilots developed universal consent forms or segmented consent forms that allowed for the release of records to all WPC partners, providing California a basis to work with moving forward.⁷
- **Cross-sector partnerships:** The efforts by WPC pilots have provided California with a stronger understanding of pain points and opportunities. The program also created meaningful partnerships and provided concrete workflow tools to aid in future initiatives.⁶

Opportunities uncovered by WPC⁸:

- **Identity management:** Providers and counties alike require automated identity management for sustainability and scalability.
- **Referral tools:** Community-based providers increasingly need technology that proactively suggests referrals based on patient data.
- **Continued communication and trust building:** State leaders must continue to provide leadership and guidelines to help partners use systems consistently, leading to improved efficiency and thus patient outcomes.

What have we learned from other states?

Other states have made large strides in integrating SDOH data into health care at the state level, creating data sharing networks and implementing community resource referral platforms. Below is a brief overview of three states' approaches and their notable facilitators.

Indiana

The Indiana Health Information Exchange (IHIE) is a statewide HIE with 117 hospital connections representing 38 health systems and with over 50,000 providers able to send or retrieve data through the network.⁹ Because of health system partners' desire for population health and SDOH information, Indiana launched an extension of its research database, the Indiana Network for Patient Care to the Indiana Network for Population Health (INPH). To avoid the time-burden of requiring clinicians to collect information, Indiana's goal is to extract this data into the INPC from existing sources. Researchers working with multiple partners are developing a system to automatically pull data from the census, the state department, and the CDC, and to then link patient data to geographical data.¹⁰

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Key takeaways:

- A robust technical architecture aids in the integration of data across multiple platforms and sources.
- Standards for data collected in the EHR or by community-based organizations exist (e.g., LOINC, SNOMED, CPT and FIPS codes), and a statewide HIE can take advantage of this standardization when extracting data.

Colorado

Colorado's Office of eHealth Innovation (OeHI), established to "promote and advance the secure, efficient, and effective use of health information, and to help inform, incentivize, and influence future health IT initiatives", as well as the eHealth Commission, which provides guidance and recommendations to OeHI, together provide a strong foundation for Colorado's HIE systems and ability to integrate SDOH data into health care.¹¹ These bodies have shaped Colorado's rapid progress in health information technology (health IT) by broadly deploying electronic health records (EHRs) systems and establishing two sustainable, linked HIEs: the Colorado Regional Health Information Exchange (CORHIO) and the Quality Health Network (QHN). Between these two HIEs, around 90 hospitals and over 7,500 providers are connected.

With stakeholders across the state, OeHI and the eHealth Commission developed the Colorado Health IT Roadmap in 2019, which "provides a framework outlining the state's health IT efforts to achieve reliable health data." Notably, the roadmap has an emphasis on social services, explicitly guiding state agencies and stakeholders to include data relating to social determinants of health when identifying uses for health information and data use policies surrounding health information sharing.¹¹

Key takeaways:

- Separate regional HIEs can connect and aid in statewide coverage.
- Large, collaborative community of health care leaders and stakeholders ensures mission momentum and development of actionable goals.

Nebraska

CyncHealth (formerly NEHII) is a statewide HIE connecting over 70% of the state's providers. The HIE recently partnered with Unite Us, creating Unite Nebraska, to build and integrate a system incorporating behavioral health and SDOH into CyncHealth. Recognizing that patients often receive care in multiple states, CyncHealth is expanding the platform to include Iowa, Kansas, Minnesota, Missouri, North Dakota, and South Dakota.¹² Lastly, to invest in interoperability for partnered health systems, CyncHealth is working with NextGate to allow the integration of millions of patient records.¹³

Key takeaways:

- Collaborative technology partnerships can result in a holistic and integrated system. This is true even when there already exists an HIE that would benefit from additional capability/infrastructure.

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- Strong leadership sets up partnerships for success by creating a shared mission of improving patient care.

Policy recommendations for SDOH data collection and use in California

1. Secure ongoing funding specifically for the development and sustainability of data exchange systems with a focus on whole person care, and incentivize continued efforts.
2. Ensure that data collection and sharing is not the end goal by mandating plans for data analysis at a population level and assessment of whether individual client needs are met.
3. Continue to develop a statewide universal consent form to remove risks associated with data sharing.

National Projects and Resources

- [Gravity Project](#): A national public collaborative with over 800 participating organizations that develops guidance on data standards around SDOH. To date, 830 data elements have been identified. The Gravity Project is putting together an FHIR implementation guide and reference implementation for real-world pilots to begin this summer.
- [Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences \(PRAPARE\)](#): A national effort to help health care systems and providers collect SDOH data in order to better serve their patients. The PRAPARE assessment is an evidence-based, standardized patient social risk assessment tool that includes 16 core measures such as race, ethnicity, housing status, employment, insurance, etc. PRAPARE templates are available in 7 EHRs and the assessment has been translated into 26 languages.
- [The Accountable Communities for Health \(ACH\) Initiative's Data-Sharing Toolkit](#): The ACH brings together institutions across different sectors (e.g., health plans, health care systems, providers, community-based organizations, schools) with an overall aim of promoting prevention, community well-being, and health equity. This toolkit provides resources and guidelines to engage in data-sharing across sectors.
- [Accelerating and Aligning Population-Based Payment Models - Data Sharing](#): This white paper was developed by the Health Care Payment Learning & Action Network, a group focused on accelerating the U.S. health care system's adoption of alternative payment models. It offers guidance on data sharing arrangements in population-based payment models, and examples of existing and potential arrangements.

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