Incorporating Social Determinants of Health Data from Health Care Partners and Community-Based Organizations into a Common Data Architecture

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CHORDS
Harmonizing Information for a Healthier Colorado

CODI
CLINICAL AND COMMUNITY DATA INITIATIVE

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Executive Summary

Integrating social determinants of health (SDoH) data across health systems and community-based organizations is essential to understand social needs and their relationship to health outcomes. In 2018, the Clinical and Community Data Initiative (CODI) was funded by the Centers for Disease Control and Prevention (CDC) to explore the feasibility of linking patient-level longitudinal data across programs, settings, and systems in Colorado through the Colorado Health Observation Regional Data Service (CHORDS). CHORDS is a distributed data network in Colorado that has developed flexible infrastructure to house SDoH data using a common data model. Through CODI, CHORDS effectively links SDoH data from health care and community data partners using privacy-preserving record linkage. This report describes a series of modifications implemented by CHORDS and its network participants to accurately capture and utilize SDoH data, including steps taken to conform disparate data from health care and community-based organizations into a common data model.

Introduction

Efforts are underway in Colorado to link data across health care and community settings to improve understanding of the social determinants of health (SDoH). Over multiple decades researchers have characterized the deep and abiding connections between SDoH, health behaviors, and health outcomes.[1] These connections are increasingly recognized by health systems, legislators, and the public at large. SDoH relate broadly to "conditions where people live, learn, work, and play".[2] SDoH include factors such as access to adequate food, housing, transportation, health care services, and resources to cover other basic needs. Many organizations are involved in assessing, delivering, and evaluating social needs and services, but assessments of SDoH often do not integrate data across multiple types of organizations. This report provides a detailed assessment of the challenges and opportunities of building data systems to understand SDoH both within and across health care and community-based organizations.

One of the most promising opportunities to address SDoH in health care settings is the ability to use information systems to collect, track, and evaluate the social needs of patients in conjunction with their health care. Health care organizations are uniquely positioned to screen and assist patients with social needs because of trusted relationships and frequent contact between health care providers and patients. Social needs also appear in general trends in health care including quality improvement, value-based care, and population health management. On a federal level, the Centers for Medicare and Medicaid Services (CMS) issued guidance in 2021 on addressing SDoH.[3] This was the first time CMS has provided states with formal direction on how Medicaid programs implement programs and services related to social needs.[4] Specifically, electronic health records (EHRs) and their systems provide an opportunity to link and track social data in conjunction with other health data. Health care organizations across the country are developing systems that, at a minimum, can document the extent of their patients' social needs. Some organizations are also building capacity to address patients' social needs by providing enhanced services internally (e.g., social work) or by sending electronic referrals to external organizations.[5,6]

Community-based organizations are central to delivering social services that address SDoH, and increasingly are playing a role in assessment and evaluation of social needs as they relate to health outcomes.[7] While extensive resources have been invested to incorporate and standardize SDoH into existing health care metrics (e.g., ICD/SNOMED codes and patient reported outcomes)[8], this has not happened across community-based organizations. Community-based organizations that address social needs often do not share standard definitions, data, or assessment strategies. Specifically, data systems for community-based organizations are often built to capture data about daily operations and social service delivery, and may not include information about underlying needs, referrals from other organizations, or the effectiveness of specific programs. By linking data related to SDoH between health care and community-based organizations, there are new opportunities to improve patient and population health and fill in some of the data gaps at each type of organization.

These linkage opportunities are bolstered by new technology-based approaches to better integrate disparate data systems. For example, various "record linkage" tools and techniques provide ways to connect data in an individual's EHR with data collected by a food bank to address that same individual's food needs. In addition to integrating social needs, there is substantial value in linking data across health care and community-based organizations—systems which are often disconnected. This record linkage improves patient and population health in multiple ways.

On a population level, screenings for social needs happen across multiple health care and social service organization contexts that serve the same geographic population. By linking social needs screenings across organizations, it's possible to understand which social needs occur most often in a community and among specific subgroups (e.g., by race/ethnicity, age, neighborhood, or insurance status).

On a patient level, data linkage can help identify how often individuals are (a) screened for social needs, (b) referred to a social resource, (c) engaged with a given community-based organization that offers a relevant social program, and (d) impacted by participation. These social programs provide diverse services, leveraging a variety of business models. Some programs are administered within a health care organization (e.g., a pediatric weight management program at a clinic), some by government agencies (e.g., Supplemental Nutrition Assistance Program (SNAP)), and some are offered through community-based organizations (e.g. homeless shelters, food banks, after-school programs). Referrals can be tracked from the initial screening to each specific program, whether internal or external to the health system. Additionally, data linkage can help merge data on social program participation (e.g., the "dose" of the program) with health outcomes data. This process consists of linking data from social programs back to health care organizations to assess outcomes. While aggregated data may be sufficient for some population health metrics, the most dramatic improvements to patient care require longitudinal linkage of individual patient records.

Despite the promise and necessity of integrating social needs across organizations, informatics challenges abound. Historically, screenings for social needs in health care systems have often been implemented by individual providers or clinics, for a defined purpose, typically in the absence of organization-wide planning. Screenings may be tied to specific populations (e.g. pediatric or high risk) or time-limited funding streams, making broader population-based assessments or longitudinal linkage challenging. Health care and community-based organizations may use different screening tools and customized screening questions, making direct comparison of linked responses impossible. Community-based organizations may not have capacity to collect, protect, or otherwise manage client-level data in a way that can be effectively and safely linked to EHRs at health care organizations. Although national efforts, such as the Gravity Project[8], are underway to capture and standardize SDoH data, health care organizations may not have systems for managing, standardizing, and reporting on the multiple stages of data, including screenings, referrals, and outcomes.

One current effort—CODI in Colorado—is addressing these informatics challenges by developing a process of linking data from a regional distributed data network (DDN) of health care providers—the CHORDS Network—to community data partners that address SDoH. The goal of CODI is to create longitudinal, patient-level datasets to understand the comprehensive process of patient participation in community programs and associated health outcomes. This report describes a series of modifications implemented by a DDN to capture and utilize SDoH data. It showcases how CODI and the broader CHORDS Network have developed data infrastructure to address many of the challenges of data storage, standardization, and linkage within and across systems. The report describes the SDoH data tables that have been built as part of the CHORDS common data model (CDM); provides examples of how data are shared between health care and community partners; and outlines next steps to further enhance the process of collecting and sharing SDoH data.

The CHORDS Network and CODI

CHORDS is a regional distributed data network along the Front Range of Colorado that uses EHR data to support research and public health evaluation and monitoring efforts. CHORDS, which began in 2011, consists of 14 health care and behavioral health partners that share a common data model in federated virtual data warehouses (VDWs) and two community data partners.[9]

In 2018, CODI was funded by the Centers for Disease Control and Prevention (CDC) to explore the feasibility of linking patient-level longitudinal data across programs, settings, and systems in Colorado. CODI brings health care and community data partners together to understand how well medical and non-medical interventions are serving patients' social, health and wellness needs.[10] CODI was initially developed as a pilot of CHORDS and has since been more fully integrated into network operations. CODI onboarded the two community partners that now participate in the CHORDS network.

The CHORDS CDM includes 21 tables to store and standardize EHR data. The CDM is based on leading DDN models, including the Health Care Services Research Network (HCSRN, formally the HMORN) VDW and the Patient Centered Outcomes Research Network (PCORnet) CDM. The CHORDS CDM is structured based on relational database best practices to ensure that patient data can be connected across tables by primary and foreign keys. Each CHORDS data partner conforms their data to these standards through their own virtual data warehouse (VDW). Most of the CHORDS health care data partners also participate in the CODI extension of CHORDS, which provides approved data users enhanced functionality, including privacy-preserving record linkage (PPRL) (described in more detail later in the report) and record-level data sharing, among other benefits. CODI enhances EHRs with data from community partners that provide social, health, and wellness programs. Each community data partner has its own VDW (supported by a technical partner) and retains control of its use. CODI has also expanded the CHORDS data model to include new data tables that house information about non-clinical intervention programs offered by health care and community data partners, as well as individual-level program participation. Eventually, CODI will also build out data tables to house referral and asset delivery data.

CHORDS Tables for SDoH Data

In spring 2018, the CHORDS team surveyed health care data partners to understand which types of social needs screenings they were doing. CHORDS decided to focus on food and housing-related social needs screenings as a proof of concept. As of 2021, seven of the 14 CHORDS health care data partners contributed social screening data to their VDWs; all seven participate in CODI. Because organizations screen patients for social needs in distinct ways, it's essential that tables housing screening data can be flexible. The two most common screening tools were the Accountable Health Communities (AHC) Health-Related Social Needs (HRSN) tool and the Protocol for Responding to and Assessing Patient's Assets, Risks, and Experiences (PRAPARE) tool.[11,12] Two data partners also included screening questions that were similar to AHC or PRAPARE questions, but not the same. The goal was to design tables for the CDM that could incorporate these standard screening tools as well as custom questions. CHORDS developed three tables to meet these needs, called the PRO_SURVEYS, PRO_QUESTIONS, and PRO_RESPONSES tables. CODI has leveraged and expanded on the initial CHORDS SDoH tables by adding direct service, asset delivery, and referral tables, in addition to linking health care and community data partners.

Table 1: SDoH Data Tables in the CHORDS Common Data Model

Type of SDoH Data	Table Name	Description	Example Fields
Screening Data	PRO_SURVEYS	Static table providing details about each screening survey	Survey description, type, LOINC code
	PRO_QUESTIONS	Static table providing details about each screening question in each screening survey	Question text, wording, LOINC code
	PRO_RESPONSES	Contains details about responses to each screening question for each survey	Response value, date/time, source
Direct Service and Asset Delivery Data	PROGRAM	Contains one record for each type of program offered by a data partner	Program description, setting, frequency, duration, location
	SESSION	Contains one record for each interaction between a patient and a program	Session date, mode, type of intervention, dose
	ASSET_DELIVERY	Contains one record for each contiguous period of time during which a person consistently receives assets.	Asset type, purpose, date, frequency
Referral Data	REFERRAL	contains one record for each outgoing or incoming referral to internal or external programs or resources.	Referral date, organization initiating referral, organization receiving referral

Screening Data Tables

The PRO_SURVEYS table contains information about which screening questionnaires and surveys are used by an organization to assess and screen their patients for behavioral health and SDoH. It is a static table, similar to a table of contents, that provides details for each survey in the CDM such as the survey name, type, full description, notes, and a LOINC code if applicable. Each survey has a unique identifier (PRO_ID) that identifies a survey and survey type combination. The PRO_ID links each survey to the associated survey in the other screening tables. PRO_ID is assigned for the two most common social needs screening tools (AHC-HRSN and PRAPARE). If data partners used a custom screening tool, then a new PRO_ID was generated. **Appendix A** provides a data dictionary for PRO_SURVEYS, PRO_QUESTIONS, and PRO_RESPONSES tables and includes data element provenance. **Appendix B** shows the SDoH surveys in the CHORDS PRO_SURVEYs table as of 2021.

The PRO_QUESTIONS table is also a static table that contains the screening questions used for each screening survey. The PRO_QUESTIONS table is particularly useful to see and compare question wording for each survey. Some data partners have used questions that are similar but not the same. The PRO_QUESTIONS table allows users to understand differences in question wording. A QUESTION_ID field is a unique identifier for each question and allows for differentiation in wording. The PRO_QUESTIONS table also conveys supplementary information about each question, similar to the PRO_SURVEYS table. This information includes question versions, LOINC codes associated with questions, and the question domain (which currently include food insecurity, housing instability, or behavioral health). **Appendix C** shows the questions for the SDoH surveys in the CHORDS PRO_QUESTIONS table as of 2021.

The PRO_RESPONSES table is used to capture patient responses to survey questions associated with standard and custom screening and assessment surveys. This table includes all responses to questions listed in the PRO_QUESTIONS table including "Total Score" values if applicable. Each row in the PRO_RESPONSES table corresponds to a response to a specific survey question. Many patients have multiple responses per encounter if they were administered a survey with multiple questions. The PRO_RESPONSES table is uniquely identified by a RESPONSE_ID field, and also contains the PRO_ID and QUESTION_ID fields to link it to the PRO_SURVEYS and PRO_QUESTIONS tables, respectively. PRO_RESPONSES also contains an encounter ID (ENC_ID) and PERSON_ID field to link it to other CHORDS tables, including the ENCOUNTER table that contains all patient encounters. Finally, the PRO_RESPONSES table contains information about how and when the survey was administered.

Direct Service and Asset Delivery Data Tables

CODI added two tables to the CHORDS CDM to house direct services, called the PROGRAM and SESSION tables.[14] **Appendix D** provides a data dictionary for each of the tables. CODI also developed a table to house asset (e.g., food, money) distribution called the ASSET_DELIVERY table. The ASSET_DELIVERY table has not yet been built in the CHORDS partner VDWs.

The PROGRAM table is structured flexibly to accommodate a wide variety of program types. The programs initially piloted through CODI included comprehensive pediatric weight management interventions, a program promoting positive youth development through physical activity, and a food assistance navigation service. Each of these programs addressed SDoH in different ways.

The PROGRAM table contains one record for each distinct program. The fields with the PRESCRIBED_ prefix only apply to those programs with a predefined frequency of interaction, such as a program that lasts for ten weeks and meets twice a week for two hours each time. This regularity allows researchers to know the intended dose and intensity (i.e., frequency of interaction) for the program.

The AFFILIATED_PROGRAM field provides a way to document that a given program is affiliated with an encompassing parent program. For example, consider a weight-related program with two component programs (a cooking class and a physical activity program); this configuration includes three programs. Participation in each is based on each participant's needs. The affiliated programs (i.e., cooking class, physical activity program) include prescribed doses and have specific aims, while the parent program has no set dose, and its aims are broad. The AFFILIATED_PROGRAM field allows the affiliated programs to indicate the parent program with which they are affiliated. For example, if a program is offered at multiple locations, the location-specific programs can be tied back to the overall parent program.

There are no dates of enrollment or completion associated with a program. The PROGRAM table describes how the program is administered irrespective of any patient's participation in the program. Enrollment and completion dates would need to be stored in a separate program participation table. Such a table does not exist because initial analyses determined that enrollment is often hard to distinguish from attendance. Completion date was almost never available. A researcher interested in program completion might compare the cumulative dose received with the prescribed total dose for that program.

The SESSION table contains one record for each interaction between a patient and a program. When a patient has multiple interactions with a program, the SESSION table will have multiple records, or sessions.

The DOSE field in the SESSION table indicates the amount of time in hours spent interacting with the patient during a given session. This field should only be populated based on what is documented in the EHR or other IT system. If the duration of the session is not documented, the DOSE field should remain empty. The DOSE field is not populated if the duration of the session is not documented, such as interventions conducted by mail or online.

The SESSION table includes several process-related fields (SCREENING, COUNSELING, and those with the INTERVENTION_ prefixes). In some cases, the values of these fields need to be established based on local program knowledge as opposed to what is present in the EHR. For example, if a program stipulates that every session includes physical activity, the INTERVENTION_ fields can be set solely based on attendance information because the EHR or IT system may not track whether physical activity happened—it always happens.

The ASSET_DELIVERY table is one of the tables that CODI partners will populate in the future. An asset is a resource, such as food or money, transferred by a program to an individual. The ASSET_DELIVERY table contains one record for each contiguous period of time during which a person consistently receives assets. The intention is that each record represents a series of asset deliveries that regularly transpires. In situations where each delivery is ad hoc, the expectation is that a separate record appears for each such delivery. Otherwise, CODI assumes the deliveries occur on a recurring basis as described by the record. DELIVERY_FREQ indicates the number of deliveries within each unit of time. DELIVERY_FREQ_UNIT establishes the corresponding unit of time. Data partners that participate in asset delivery are encouraged to populate the ASSET_PURPOSE at a minimum because it provides researchers with insight into the circumstances surrounding the delivery of assets.

Referral Data Table

A final table that CODI is recommending should be added to the CHORDS CDM is the REFERRAL table. The REFERRAL table tracks patient referrals to and from different organizations.

The REFERRAL table is another upcoming table that CODI partners will populate. It contains one record for each outgoing or incoming referral. The REFERRAL table provides a more complete picture of how social needs are communicated between health care and community organizations. The DIRECTION field indicates if the record represents a data partner initiating a referral (outgoing) or receiving a referral (incoming). Internal referrals should still result in two records in the REFERRAL table: one outgoing referral and a second incoming referral. The purpose of the source and destination organization fields is to link outgoing referrals with incoming referrals so researchers can see whether a referral successfully connected a patient to a program.

Privacy-Preserving Record Linkage

Because individuals may have data at multiple organizations, it is critical to be able to link information on the same individual together from multiple data sources. This process is known as record linkage (RL). Traditional RL methods, also known as clear-text record linkage, use personally identifiable information like name, date of birth, gender, and address to identify the same individual and de-duplicate individuals across organizations. Newer RL methods, called privacy-preserving record linkage (PPRL), use a variety of techniques to encrypt personal identifiers before the RL process. By encrypting personal identifiers the PPRL process can protect individual’s privacy while also enabling data to be integrated at the individual-level across systems. Three CHORDS health care data partners and two community data partners are using PPRL to gather an individual’s information across clinical and community organizations to create a longitudinal record for researchers to work with.[13] In the context of SDoH, PPRL is essential to understand how individuals are screened, referred, offered, and benefiting from social needs services.

Applications of the CODI Tables for SDoH

As of mid-2021, CHORDS data partners have implemented all of the tables except ASSET_DELIVERY and REFERRAL. This section provides examples of how the CODI tables have been applied to specific health care and community settings. Because of the diversity of CHORDS health care and community data partners, it is valuable to examine case studies of how partners have mapped their data to each of the current tables as well as opportunities and challenges moving forward.

Health Care Data Partners

As of 2021, there are nine CHORDS health care data partners that participate in CODI Project. Health care data partners represent diverse providers in the Denver Metro region, including a children's hospital, independent federally qualified health centers (FQHCs), a large safety-net health system, and a Health Maintenance Organization (HMO) where all patients are members. Table 2 shows the social needs screenings carried out by the health care data partners. Seven of the nine health care data partners screened patients for social needs in 2021. Five partners used the PRAPARE screening tool and one partner used the AHC-HRSN screening tool. Three partners used custom social needs screenings that are either similar to the established tools or developed uniquely for their organization, and two partners did not do any social needs screening. As of 2021, two partners offered social or wellness programs or interventions.

Table 2: Types of Social Needs Screenings at Health Care Data Partners

Data Partner	PRAPARE	AHC-HRSN	Custom Screen	No Screen
HCDP-1		☑	☑	
HCDP-2			☑	
HCDP-3				☑
HCDP-4	☑			
HCDP-5	☑			
HCDP-6	☑		☑	
HCDP-7	☑			
HCDP-8	☑			
HCDP-9				☑

Case Study: ***Denver Health and Hospital Authority***

Taking a deeper dive into one CHORDS health care data partner's experience with integrating SDoH tables provides insight into some of the nuances and challenges of working with SDoH data. Denver Health and Hospital Authority (Denver Health) is an urban, safety-net health care system that includes a hospital, 6 FQHC clinics, school-based health centers, and other specialty clinics and services. Denver Health has a long history of screening specific groups of patients (e.g., pediatric patients) for social needs and connecting patients to social services. However, screening tools have changed over time as have the locations within Denver Health where they have been administered. Although Denver Health uses the standard AHC-HRSN tool in some locations, it also uses and has used custom questions regarding food and housing needs.

When loading SDoH data into the CODI PRO_SURVEYS, PRO_QUESTIONS, and PRO_RESPONSES tables, Denver Health used the pre-defined survey and question IDs for their AHC-HRSN data. For the 12 questions related to food and housing that were different from the AHC-HRSN or PRAPARE tools, Denver Health created custom questions. All custom questions were given the same survey name "DH-1." Some custom questions were very similar to the AHC-HRSN questions. For example, AHC-HRSN asks, "Within the past 12 months, were you worried that your food would run out before you got money to buy more?” Respondents can answer “Never true,” “Sometimes true,” or “Often true.” One of the custom questions asked at some health care system locations is similar, but states, “Within the past 3 months, did you ever worry that your food would run out before you got money to buy more?” Respondents can answer “Yes,” or “No.” The content of the questions are the same, but the timeframes and response options are different. The screening data tables in the VDW provide space for each of these question and response variations within the same environment, which makes it easier for a researcher to combine questions if necessary.

Denver Health also provides weight management interventions, which are currently loaded into the PROGRAM table. As of July 2021, DH loaded 15 programs into the PROGRAM table and had 10,174 associated program sessions in the SESSION table.

Denver Health is implementing system-wide screening and referrals. The health care system has close connections with many community-based organizations across the Denver Metro region to whom they can refer patients, including the two community data partners that are part of CHORDS. Colorado is also implementing a social-health information exchange (S-HIE) to capture process of SDoH screening, referrals, utilization, and connection to health outcomes.

There are a handful of data, systems, and governance challenges in effectively capturing SDoH referral data and standardizing it in the REFERRAL table. Currently there is no place in Denver Health’s EHR to record a referral from a health care provider or care navigator to a community-based organization. The closest approximation is tracing referrals from providers to specialty health care services (e.g., to an endocrinologist or oncologist). The S-HIE is facilitating implementation of infrastructure to capture referrals electronically, either through vendor-based referral platforms or other e-referral mechanisms. Some of these platforms may not directly interact with EHRs, further complicating longitudinal linkage to referrals for an individual patient. There are also few other models of capturing referrals beyond e-referral platforms (e.g., faxes) that may contribute to future referral data. As the discovery process around capturing and linking referral data continues, the goal of the REFERRAL table is to be flexible enough to house and normalize the myriad types and sources of referral data.

Once analysts are able to more clearly capture referral data, Denver Health can pilot the process of extracting, transforming, and loading referral data into the REFERRAL table in the CHORDS VDW. This will be instrumental in providing a full capture of SDoH screenings, referrals, and programs and interventions. The ability to link individuals across these processes and organizations will provide valuable information about the connection between social needs and physical health, and researchers will be able to track these interconnected processes over time.

Community Data Partners

Community-based organizations offer a unique perspective on SDoH as they are often organizations that provide direct services and evidence-based programs to address the social needs of individuals. As of 2021, the CHORDS Network included two community data partners: Girls on the Run of the Rockies and Hunger Free Colorado. Although both organizations address SDoH in distinct ways, the same CHORDS data tables can be used to record information about these different programs and how individuals interacted with them.

Many community-based organizations do not have the resources and experience to build, store, and analyze data tables that could conform to those at health care organizations. To bridge this gap, CODI piloted the use of a data coordinating center that could facilitate the technical and analytic components of project participation for community partners. In CHORDS, Denver Health acted as a technical partner for the two community data partners. In other words, Denver Health provided the technical expertise to transform community partner raw data to the CHORDS CDM. In cases where data model conformance challenges arose—either because these data were not collected or significant logistical or because of governance issues—Denver Health provided analytic support to find workarounds. For community data partners, the CODI team geocoded address data and only retained census tract geocodes, dropping the exact address data to maintain participant privacy.

Both community data partners, Girls on the Run and Hunger Free Colorado, were able to populate the PROGRAM and SESSION direct service tables from the CHORDS CDM from vastly different types of intervention programs. The next two case studies examine the processes of understanding opportunities and challenges of each community data partner's unique data and modifications that were made to conform the data to the CHORDS CDM.

Case Study: ***Girls on the Run of the Rockies***

Girls on the Run is an organization offering after-school positive youth development programs that promote physical activity and well-being among girls in grades 3-8. Running is integrated with life skills lessons lead by trained coaches. Girls on the Run addresses SDoH needs by developing participants' social and emotional health and increasing opportunities for physical activity.

Girls on the Run populated the PROGRAM table with each geographic location of their two main programs: Girls on the Run (for grades 3-5) and Heart & Sole (for grades 6-8). Within the two types of programs, there were 510 specific school programs throughout Colorado. A record was logged into the SESSION table when a participant attended a program session, and when a coach documented attendance. Between September 2017 and April 2020, there were 104,961 sessions documented by coaches and 18,464 individual participants.

There were a few components of Girls on the Run data that had to be changed or transformed to be incorporated into the PROGRAM and SESSION tables in the CHORDS CDM. First, the data did not have a unique identifier for each participant. Instead, Girls on the Run structured their data according to season. For example, the same student participating in one fall session and one spring session would have two unique records. Multiple records over multiple seasons had to be reconciled and deduplicated, and new unique IDs had to be created before linking identities through PPRL across CHORDS data partners.

The way that Girls on the Run stored location data was different than the way the CHORDS tables stored location data. Programs are typically offered at neighborhood schools. Schools were identified by their name and address, but the exact school name or address sometimes changed between seasons depending on who was creating the records. To create unique records for schools, the CODI team reconciled addresses and school names across all records.

The CODI team also considered the completeness of the data. Girls on the Run did not expect to capture 100% of the individual sessions. In 2017 they started using a system called RacePlanner for attendance data, and there was an adoption curve for this system. By 2020, the organization estimated that they were capturing 40-50% of their attendance, which has implications for data quality.

Finally, just as EHRs were not initially developed for population health research or monitoring, most community-based organizations do not collect data with research use cases in mind. The highest quality data from health care and community-based organizations come from the data that are most essential for direct operations and those that are tied to financial resources. For example, billing diagnoses are often thoroughly populated in health care organizations' EHRs because they are directly tied to reimbursement for services. For Girls on the Run, participant registration data was tied to payments and grant funding and to parental consent, so it was accurate and complete. Attendance data was not tied to either of these components, so it was not collected as systematically.

Geocoding was important not only for research use cases, but it was valuable for Girls on the Run to have a map of their participants. They have used this map in their communication materials and in grant applications. Girls on the Run also found the broader quality assurance checks on attendance and specific data fields to be useful for internal operations.

Case Study: ***Hunger Free Colorado***

Hunger Free Colorado connects families and individuals to food resources and fuels change in systems, policies, and social views so no Coloradan goes hungry. Their pediatric referrals are the only records that contain sufficient identifiable data at the individual level to support record linkage, and so these were the records included in the Hunger Free

Colorado VDW. 4,994 pediatric patients were referred from CHORDS health care data partners to Hunger Free Colorado between February 2018 and July 2020.

One of the primary ways that Hunger Free Colorado responds to pediatric referrals is by calling patients on their hotline phone service. The organization populated the PROGRAM table with one record for their main hotline service. Each pediatric referral that resulted in a connected hotline call was logged in the SESSION table, for a total of 1,303 sessions.

Similar to Girls on the Run, Hunger Free Colorado had certain data components that had to be changed or taken into consideration when being incorporated into the PROGRAM and SESSION tables. Hunger Free Colorado collects data at the household rather than the individual level, primarily because the food assistance program, SNAP, is administered at the household level. More broadly, food is often consumed at the household rather than individual level, and thus food insecurity is often understood in a family or household context. When linking Hunger Free Colorado sessions to individual EHR records, there was no way to link a specific pediatric patient to a Hunger Free Colorado hotline call. It was possible to link a pediatric patient's address to the address of a person calling in to the hotline service, but there was a risk of misclassifying siblings or other people living in the same household.

For the first phase of CODI, it was only feasible to link referrals from pediatric providers to Hunger Free Colorado. However, Hunger Free Colorado interacts with a great many more families than those referred by pediatric providers. Because there is insufficient identifying information to link other Hunger Free Colorado participants, it would be challenging to expand linkage to other groups outside of pediatric referrals.

Like Girls on the Run, the quality of certain Hunger Free Colorado data depends on its utility for operational, programmatic, or financial purposes. For example, certain demographic information, such as race/ethnicity, are not well populated in the partner's data. Because race/ethnicity do not impact program participation, they are not currently systematically collected. Other demographic information, such as primary language, is well populated in the Hunger Free Colorado data because it influences which food resources participants can be referred to.

Conclusion and Next Steps

Health care and community-based organizations have long collaborated to address patients' physical and social needs, with the understanding that the two are strongly interdependent. Quality data systems are essential to capture the complex nature of social and health care services. New advances in technical solutions, such as PPRL, create opportunities for the important work that's being done in clinical and community settings to be standardized and synthesized for improved patient care, research, public health monitoring, and systems quality improvement. CHORDS is a distributed data network in Colorado that has effectively linked SDoH data from health care and community data partners. It has developed flexible infrastructure to house SDoH data using a common data model. CODI has added new tables to the CHORDS CDM to further enhance the types of SDoH data that are collected and has implemented a PPRL method to link individuals across health care and community settings.

While CHORDS has made great strides, there are important next steps to continue to standardize and integrate SDoH data within and across systems. Implementing the asset delivery and referral tables requires continued investment in the process of transforming and standardizing these complex data within and across systems. Once achieved, these data allow the network to begin understanding the closed-loop referral process, from screening to referrals to programs or interventions to health outcomes. Data at each step of the process are complex and require thoughtful mapping and standardization. It will also be important to consider how CHORDS data partners may link or interact with local health information exchanges (HIEs) and commercial vendors that provide referral services.

CHORDS, through support from CODI, is also working on extending community partnerships to include more types of community-based organizations and coverage of social services. For example, the network is exploring the best way to link government programs such as the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) and SNAP to EHRs. Along those lines, the governance structures that were developed to share health record data must be modified to incorporate comingled SDoH and EHR data from health care and community-based organizations. More on the CHORDS and CODI governance structures can be found at www.CHORDSnetwork.org. These challenges are particularly apparent when linking to government programs like WIC and SNAP, which are governed by state and federal regulations.

Finally, linking data across diverse organizations and data types requires robust data quality standards. CHORDS has implemented data quality assessment tools for health care data partners. However, future work must examine the expectations and reasonable changes that can be made to community partner data. This requires developing a framework for analyzing data quality in the context of SDoH, and creating unique thresholds for community data quality standards that may be different from those used across health care organizations.

The success of the SDoH data integration into CHORDS has been built on immense trust across participating organizations. As CHORDS continues to dive into complex challenges and opportunities for linking SDoH data, maintaining trusted relationships and thoughtful governance are essential.

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Appendix A: Data Dictionary for Screening Tables (PRO_SURVEYS, PRO_QUESTIONS, and PRO_RESPONSES)

PRO_SURVEYS Table Fields

Name	Description	Definition	Data Element Provenance	Field-Level Implementation Guidance
PRO_ID	Unique identifier to a survey and survey type combination.	NVARCHAR(15) NOT NULL	KP CESR Data Dictionary	**Only** for custom additions to this table: Assign a PRO_ID number using the two (2) letter code assigned to your organization concatenated with a number corresponding to the survey. Leading the PRO_ID with the assigned code ensures that the PRO_ID will be unique across data partners.
PRO_SURVEY	Short name of questionnaire type Sample values include: PHQ GAD EPDS AHC-HRSN PRAPARE NI=No information UN=Unknown OT=Other	NVARCHAR(15) NOT NULL DEFAULT= OT	KP CESR Data Dictionary	Please adhere to the values provided unless you are adding a custom screening tool to the PRO_SURVEYS table. If you are adding a custom screening tool, you may create your own PRO_SURVEY value or use the OT default value.

PRO_ SURVEY_ DESCRIPTION	Description of the survey Valid values include: Patient Health Questionnaire Generalized Anxiety Disorder Edinburgh Postnatal Depression Scale Accountable Health Communities Health-Related Social Needs Protocol for Responding and Assessing Patient Assets, Risks, and Experiences	NVARCHAR(80) NULL	KP CESR Data Dictionary	Please adhere to the values provided unless you are adding a custom screening tool to the PRO_SURVEYS table. If you are adding a custom screening tool, you may create your own DESCRIPTION value, or leave the field NULL.
PRO_SURVEY_ TYPE	Survey type Sample values include: PHQ-2 PHQ-4 PHQ-9 PHQ-A GAD-2 GAD-7 EPDS AHC-HRSN PRAPARE NI=No information UN=Unknown OT=Other	NVARCHAR(15) NOT NULL DEFAULT= OT	KP CESR Data Dictionary	Please adhere to the values provided unless you are adding a custom screening tool to the PRO_SURVEYS table. If you are adding a custom screening tool, you may repeat the value from PRO_SURVEY, or use the OT default value.

PRO_SURVEY_ TYPE_ DESCRIPTION	Description of survey type Sample values include: Patient Health Questionnaire-2 (PHQ-2) Patient Health Questionnaire-4 (PHQ-4) Patient Health Questionnaire-9 (PHQ-9) Patient Health Questionnaire Modified for Adolescents - A (PHQ-A) Generalized Anxiety Disorder-2 (GAD-2) Generalized Anxiety Disorder-7 (GAD-7) Edinburgh Postnatal Depression Scale Accountable Health Communities Health-Related Social Needs Protocol for Responding and Assessing Patient Assets, Risks, and Experiences	NVARCHAR(80) NULL	KP CESR Data Dictionary	Please adhere to the values provided unless you are adding a custom screening tool to the PRO_SURVEYS table. If you are adding a custom screening tool, describe the survey type in PRO_SURVEY_TYPE_DESCRIPTION if needed (or leave blank or repeat the PRO_SURVEY_DESCRIPTION).
PRO_SURVEY_ TYPE_NOTES	Additional notes for the survey type	NVARCHAR(255) NULL	KP CESR Data Dictionary	

PRO_SURVEY_TYPE_LOINC	LOINC code for survey type Logical Observation Identifiers, Names, and Codes (LOINC) from the Regenstrief Institute.	NVARCHAR(18) NULL	PCORnet CDM v4.1 - PRO_CM table	Custom surveys will not have a Logical Observation Identifiers, Names, and Codes (LOINC) code and therefore PRO_SURVEY_TYPE_LOINC will be NULL. From PCORnet: Current LOINC codes are from 3-7 characters long but Regenstrief suggests a length of 10 for future growth. The last digit of the LOINC code is a check digit and is always preceded by a hyphen. All parts of the LOINC code, including the hyphen, must be included. Do not pad the LOINC code with leading zeros.

PRO_QUESTIONS Table Fields

Name	Description	Definition	Data Element Provenance	Field-Level Implementation Guidance
PRO_ID	Unique identifier to a survey and survey type combination.	NVARCHAR(15) NOT NULL	KP CESR Data Dictionary	
QUESTION_ID	Unique identifier for a question	INT NOT NULL	KP CESR Data Dictionary	
QUESTION_VER	Sequence number of available versions of each question	INT NOT NULL DEFAULT = 1	KP CESR Data Dictionary	
QUESTION_DATE	Date the question was published	DATE NULL Recommended format MMDDYYYY	KP CESR Data Dictionary	This is the date associated with the survey version. Questions may be added to surveys at different times. If the date a question was added to a survey is unknown, leave the field NULL. If only the year is known, use format 01/01/YYYY.
QUESTION_TEXT	Text of the question as published	NVARCHAR(255) NOT NULL	KP CESR Data Dictionary	

QUESTION_LOINC	LOINC code for survey question including total score. Logical Observation Identifiers, Names, and Codes (LOINC) from the Regenstrief Institute.	NVARCHAR(18) NULL	PCORnet CDM v4.1 - PRO_CM table	From PCORnet: Current LOINC codes are from 3-7 characters long but Regenstrief suggests a length of 10 for future growth. The last digit of the LOINC code is a check digit and is always preceded by a hyphen. All parts of the LOINC code, including the hyphen, must be included. Do not pad the LOINC code with leading zeros.
QUESTION_DOMAIN	Domain related to the question Valid values include: FOOD_INSECURITY HOUSING_INSTABILITY BEHAVIORAL_HEALTH	NVARCHAR(36) NULL	Added to table for SDoH grouping	All other domains should be NULL.

PRO_RESPONSES Table Fields

Name	Description	Definition	Data Element Provenance	Field-Level Implementation Guidance
RESPONSE_ID	Unique identifier for each response recorded. This is an identity column.	INT NOT NULL	CHORDS VDW	
PRO_ID	Unique identifier to a survey and survey type combination.	NVARCHAR(15) NOT NULL	KP CESR Data Dictionary	
QUESTION_ID	Unique identifier for a question	INT NOT NULL	KP CESR Data Dictionary	
QUESTION_VER	Sequence number of available versions of each question	INT NOT NULL DEFAULT = 1	KP CESR Data Dictionary	
PERSON_ID	An arbitrary identifier unique to an individual within a data partner's VDW. See Primary Keys section.	NVARCHAR(36) NOT NULL	Based on PCORNET description for PATID and HCSRN 'MRN' field.	
RESPONSE_DATE	Date associated with the entered response	DATE NOT NULL Recommended format MMDDYYYY	KP CESR Data Dictionary	

RESPONSE_TIME	Time associated with the entered response	TIME(7) NOT NULL	KP CESR Data Dictionary	
RESPONSE_TEXT	Full text of entered response.	NVARCHAR(255) NULL	KP CESR Data Dictionary	
RESPONSE_NUM	Numeric value associated with entered response or numeric score for an item or total score.	NUMERIC(8) NULL	PCORnet CDM v4.1 - PRO_CM table (PRO_RESPONSE_NUM)	
ENC_ID	Unique identifier used for linking table to the VDW Encounter tables	NVARCHAR(36) NULL	KP CESR Data Dictionary	
RESPONSE_ SOURCE	Person (e.g., patient, legal guardian) who provided the response. Valid values include: PT = Patient PR = Parent PX = Proxy LG = Legal Guardian NI=No information UN=Unknown OT=Other	NVARCHAR(2) NULL	CHORDS	This information may not be available.

SURVEY_ ADMINISTERED_ BY	The person administering the survey or asking the survey questions Valid values include: MD = Physician PA = Physician Assistant RN = Nurse MA = Medical Assistant HC = Health Care Partner PN = Patient Navigator CM = Case Manager NI=No information UN=Unknown OT=Other	NVARCHAR(2) NULL	CHORDS	This information may not be available.

SURVEY_ MEDIUM	How the survey was administered Valid values include: PA=Paper EC=Electronic (includes personal or tablet computer, web kiosks, smartphone) PH=Telephonic IV=Telephonic with interactive voice response (IVR) technology NI= No information UN=Unknown OT=Other	NVARCHAR(2) NULL	PCORnet CDM v4.1 PRO_CM table (PRO_METHOD)	This information may not be available.

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Appendix B: PRO_SURVEYS Table Screening Tools Related to SDoH

This table shows the SDoH surveys that have been loaded into the VDW. It is a static table and does not show the responses to the surveys.

PRO_ID	PRO_ SURVEY	PRO_ SURVEY_ DESCRIPTION	PRO_ SURVEY_ TYPE	PRO_ SURVEY_ TYPE_ DESCRIPTION	PRO_ SURVEY_ TYPE_NOTES	PRO_SURVEY_ TYPE_LOINC
CHORDS-7	PRAPARE	Protocol for Responding and Assessing Patient Assets, Risks, and Experiences	PRAPARE	Protocol for Responding and Assessing Patient Assets, Risks, and Experiences	NA	NA
CHORDS-8	AHC-HRSN	Accountable Health Communities Health-Related Social Needs	AHC-HRSN	Accountable Health Communities Health-Related Social Needs	NA	NA
DH-1	DH-FH	Denver Health Food and Housing Questions	DH-FH	Denver Health Food and Housing Questions	DH food and housing questions related to different workflows and combined into 1 custom survey	NA

Appendix C: PRO_QUESTIONS Table Screening Tools Related to SDoH

This table shows the SDoH survey questions that have been loaded into the VDW. It is a static table and does not show the responses to the surveys.

PRO_ ID	QUESTION_ ID	QUESTION_ VER	QUESTION_ DATE	QUESTION_ TEXT	QUESTION_ LOINC	QUESTION_ DOMAIN
CHORDS-7	7	1	2016-09-02	What is your housing situation today?	NA	HOUSING_ INSTABILITY
CHORDS-7	8	1	2016-09-02	Are you worried about losing your housing?	NA	HOUSING_ INSTABILITY
CHORDS-7	14	1	2016-09-02	During the past year, have you or any family members you live with been unable to get any of the following when it was really needed? Check all that apply (food).	NA	FOOD_ INSECURITY
CHORDS-8	1	1	2017-01-01	What is your living situation today?	NA	HOUSING_ INSTABILITY
CHORDS-8	3	1	2010-01-01	Within the past 12 months, you worried that your food would run out before you got money to buy more.	NA	FOOD_ INSECURITY
CHORDS-8	4	1	2010-01-01	Within the past 12 months, the food you bought just didn’t last and you didn’t have money to get more.	NA	FOOD_ INSECURITY

Appendix D: Data Dictionary for Direct Services and Asset Delivery Tables (PROGRAM, SESSION, and ASSET_DELIVERY)

PROGRAM Table Fields

Name	Description	Definition	Data Element Provenance
PROGRAMID	Identifying unique row ID	INT NOTNULL	CODI
PROGRAM_NAME	A name of the program (e.g., Girls on the Run).	NCHAR(50) NOTNULL	CODI
PROGRAM_DESCRIPTION	A description of the program.	NCHAR(250) NOTNULL	CODI
PROGRAM_SETTING	A setting in which the program is offered (clinical or community).	NCHAR(15) NOTNULL	CODI
AFFILIATED_PROGRAMID	A parent program of which this program is a component.	INT NULL	CODI
AIM_NUTRITION	True if the aim of the program includes improving nutrition. 1=True 0=False	NUMERIC(1) NOTNULL	CODI
AIM_ACTIVITY	True if the aim of the program includes improving physical activity. 1=True 0=False	NUMERIC(1) NOTNULL	CODI
AIM_WEIGHT	True if the aim of the program includes improving weight status. 1=True 0=False	NUMERIC(1) NOTNULL	CODI
PRESCRIBED_TOTAL_DOSE	A total amount of time (in hours) a child should spend in the program. This field should equal DURATION x FREQUENCY x LENGTH (weeks x sessions/week x hours/session).	NUMERIC(4) NOTNULL	CODI
PRESCRIBED_PROGRAM_DURATION	A measure of the time (in weeks) from start to finish.	NUMERIC(3) NOTNULL	CODI
PRESCRIBED_SESSION_FREQUENCY	A number of sessions delivered each week.	NUMERIC(1) NOTNULL	CODI

PRESCRIBED_SESSION_LENGTH	A number of hours delivered each session.	NUMERIC(2) NOTNULL	CODI
LOCATION_ADDRESS	A primary location at which this program's sessions are administered, expressed as an address.	NCHAR(50) NULL	CODI
LOCATION_LATITUDE	A latitude of the corresponding address location.	NUMERIC(8) NULL	CODI
LOCATION_LONGITUDE	A latitude of the corresponding address location.	NUMERIC(8) NULL	CODI
LOCATION_GEOCODE	A primary location at which this program's sessions are administered, expressed as a geocode.	NVARCHAR(15) NULL	CODI
LOCATION_BOUNDARY_YEAR	A census year for which the corresponding geocode location applies.	NUMERIC(8) NULL	CODI
LOCATION_GEOLEVEL	A specificity of the geocode location. This can be assessed using logic that considers the length of the GEOCODE value (2 characters for state; 5 characters for county; 11 characters for census tract).	NVARCHAR(15) NULL	CODI
SESSION_OMISSION_PERCENT	A numeric estimate of the percentage of all sessions missing from the SESSION table (based on intended dose) for this program; 0% indicates a belief that the session information is fully populated.	NUMERIC(3) NULL	CODI
SESSION_OMISSION_DESCRIPTION	A description of the circumstances under which session information for this program is missing; this field is required when the omission percent is greater than 0%.	NVARCHAR(200) NULL	CODI

SESSION_OMISSION_SYSTEMATIC	True if session information for this program is systematically missing (e.g., because only half of the sessions are documented in an EHR). 1=True 0=False	NUMERIC(1) NULL	CODI

SESSION Table Fields

Name	Description	Definition	Data Element Provenance
SESSIONID	Unique identifying ID	INT NOTNULL	CODI
PERSON_ID	A link back to the demographics table.	NVARCHAR(36) NOT NULL	CODI
ENC_ID	A link back to the encounter this session corresponds to (if any).	NVARCHAR(36) NOT NULL	CODI
PROVIDER	A provider primarily responsible for this session.	NVARCHAR(36) NOT NULL	CODI
PROGRAMID	A link back to the program this session belongs to (if any).	INT NOT NULL	CODI
SESSION_DATE	A date on which the session was conducted.	DATE NOTNULL Recommended format MMDDYYYY	CODI
SESSION_MODE	An indication of the way the session was delivered (e.g., individual, group, phone).	NVARCHAR(15) NULL	CODI
SCREENING	True if the session included any assessment of lifestyle behaviors related to obesity, such as physical activity, nutrition, screen time, or sleep. 0=False 1=True	NUMERIC(1) NULL	CODI
COUNSELING	True if the session included any advice or direction regarding lifestyle related to obesity, such as physical activity, nutrition, screen time, or sleep.	NUMERIC(1) NULL	CODI

	0=False 1=True		
INTERVENTION_ACTIVITY	True if the session included performing at least moderate physical activity; moderate activity requires a moderate amount of effort (5-6 on a scale of 0 to 10) and noticeably accelerates the heart rate and breathing. 0=False 1=True	NUMERIC(1) NULL	CODI
INTERVENTION_NUTRITION	True if the session included an activity designed to improve nutrition. 0=False 1=True	NUMERIC(1) NULL	CODI
INTERVENTION_NAVIGATION	True if the session included a navigational service to access benefits or to overcome barriers to care. 0=False 1=True	NUMERIC(1) NULL	CODI
DOSE	A measure of the amount of time in hours spent on this encounter. Researchers can compare the total dose to the prescribed total dose to assess the extent to which a child completed a program.	NUMERIC(3) NULL	CODI

ASSET_DELIVERY Table Fields

Name	Description	Data Element Provenance
ASSET_DELIVERY_ID	Unique identifying ID	CODI
PATID	A link back to the demographic table.	CODI
PROGRAMID	A link back to the program table.	CODI
ASSET_PURPOSE	An intended purpose for the use of a monetary asset (e.g., health insurance or food).	CODI
DELIVERY_START_DATE	A date the asset delivery began.	CODI
DELIVERY_END_DATE	A date the asset delivery ended.	CODI
DELIVERY_FREQ	A number of times an asset is delivered each unit of time.	CODI

Name	Description	Data Element Provenance
DELIVERY_FREQ_UNIT	A unit of time used to describe how often an asset is delivered. For example, an asset delivered twice a week has a frequency of 2 and a unit of Weekly. An asset delivered every other week has a frequency of 0.5 and a unit of Weekly.	CODI

Appendix E: REFERRAL Table Fields

Field	Definition	Data Element Provenance
REFERRALID	Unique identifying ID	CODI
PATID	A link back to the demographic table.	CODI
ENCOUNTERID	A link back to the encounter table, if the referral can be unambiguously associated with an encounter.	CODI
DIRECTION	An indication of whether the referral was incoming or outgoing.	CODI
REFERRAL_DATE	A date the referral was made.	CODI
REFERRAL_STATUS	A final disposition of the referral.	CODI
REFERRAL_PRIOR_AUTH	An indication of whether prior authorization was required for the referral.	CODI
SOURCE_PROVIDERID	A provider responsible for initiating this referral.	CODI
SOURCE_ORGANIZATION	An organization that initiated the referral.	CODI
DESTINATION_ORGANIZATION	An organization to which the referral was sent.	CODI
DESTINATION_SPECIALTY	A clinical specialty for which the patient is being referred.	CODI