Centers for Disease Control and Prevention’s Social Determinants of Health
Public Health Use Case Workgroup for Chronic Disease Prevention
Meeting #2

Clinical and Community Data Initiative (CODI) and the Colorado Health Observation
Regional Data Service (CHORDS) Presentation
Wednesday, May 4, 2022

The presentation slides and recording are available at
https://confluence.hl7.org/display/GRAV/Public+Health+Use+Case+Workgroup+for+Chronic+Disease+Prevention+Home

Questions-and-Answers Log

1. How are CODI@CHORDS ingesting data from CBOs? Is it standardized?
   - The process of ingesting data depends on the community-based organization (CBO).
   - The data is compiled and placed in records for a social determinants of health (SDOH) table based on how each CBO documents session participation.
   - Collected individual information is used to build out a demographics table.
   - Current mapping helps establish different program types and categories.

2. How do individuals with linked data consent to sharing their data?
   - The primary use cases refer to research; CODI followed the typical Institutional Review Board (IRB) process to obtain these data. The IRB consent waiver falls under public health surveillance, but in the future, it will depend on various use cases.
   - Significant efforts are underway to ensure all clients of the organizations are aware of data sharing. For example, Ray’s team worked with lawyers from North Carolina when they formulated the work with YMCA.
   - Governance resources on this topic include:
     - [https://journals.lww.com/jphmp/Fulltext/2022/03000/A_Governance_Framework_to_Integrate_Longitudinal.32.aspx](https://journals.lww.com/jphmp/Fulltext/2022/03000/A_Governance_Framework_to_Integrate_Longitudinal.32.aspx)
     - [https://www.coloradohealthinstitute.org/research/CHORDS](https://www.coloradohealthinstitute.org/research/CHORDS)
   - For further resources, contact Emily Kraus (emily@kraushold.com) and Nina Bastian (bastiann@coloradohealthinstitute.org).

3. What is the data platform/API to synthesize data? Where do the tables live? Where is the data being synthesized?
   - Each community uses the common data model but house the tables and data in their respective data warehouse. With the creation of any new table or update, a query goes out to ensure that each data partner has total autonomy over their data.
   - CHORDS and CODI function as a clinical community-distributed data network.
     - They query the data with the vocabulary of the standard data model across their organizations

4. What value sets represent the backend in these SDOH concepts and data?
   - Gravity Project
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● Gravity Project Terminology can be found here: https://confluence.hl7.org/display/GRAV/SDoH+Data+Elements+And+Status
● The current codes available for Diagnoses, Goals, and Interventions are in the Value Set Authority Center (VSAC).

5. What was the protocol?
● The protocol appears in the PPRL Implementation Guide.
  ○ https://github.com/mitre/data-owner-tools

6. How are SDOH concepts and value sets represented in the CODI data model?
● Ray responded, regarding SDOH on the clinical side, his organization follows Gravity. On the CBO side, one of informatics fellows, Pat Zhang, will focus on how to map CBO screeners and leverage Gravity data, where possible. Pat will begin with screeners and intake.

7. Was this a one-way data transport to enhance the electronic health record or were referral activities returned to Girls On The Run as well?
● To date, CODI in Colorado has not built out the referral table to capture formal referrals. Right now, we can identify children who have participated in Girls on the Run and have been seen by one of the three large healthcare providers through privacy preserving record linkage (PPRL). But we do not know whether there were formal referrals from one organization to the other.
● When we build out the referral table in the data model, the goal is to track bilateral referrals so that we could see bidirectional impacts of participation in different community and health care settings. That being said, we anticipate that formal referrals do not make up the majority of overlap between health care and community partners, so it is important to track participation through PPRL in addition to formal referrals.

8. What was the most significant positive outcome for each of the different stakeholders in this project? Health Systems, CBOs and - ultimately and importantly - patients/clients?
● The positive outcomes vary from partnership to partnership as each stakeholder has different needs. With public health upstream from these local partners, it can be difficult to know how this work affects the public good and how public health addresses and participates in this work.
● Early feedback included a broader sense of community and contribution.

9. Do national level CBOs, such as the Area Agencies on Aging, support social needs identification and service delivery more broadly?
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CODI in Colorado has had preliminary discussions with the area agency on aging (housed by DRCOG in Colorado) to discuss partnerships. DRCOG has done a considerable amount of work regarding SDOH. The issue we ran into was data compatibility. DRCOG did not collect data with enough personally identifiable information (PII) to use in record linkage, and even had some cases where they were carrying out SDOH data collection on paper and hadn’t transferred records to an electronic format. We also found that some data they collected were part of specific grant efforts, so they were collected over a short period (e.g., one year), rather than longitudinally. For this reason, data like attendance records or call logs ended up being a better source of longitudinal data from community partners.

CODI in Colorado has also explored partnering with government-provided social services such as WIC/SNAP and a local group that’s creating a distributed data network across multiple large social service providers. We found that there are additional barriers to linking with some government-provided services, particularly involving data use agreements and privacy preserving record linkage (PPRL). These are not insurmountable but led us to select community data partners that did not have these barriers.

CODI in North Carolina is in the early stages of partnering with WIC in NC.

10. Does the workgroup work with partners where English is not the first language?

As Ray responded in the chat, the workgroup does not now engage an organization where English is not the primary language. The workgroup attempted such a partnership in NC but COVID-19 responsibilities prevented the organization’s participation.

11. Do current applications include groups working specifically with community health workers (CHW), and, if so, any current application of CHW Common Indicators Project? Is there any case of linking health departments, Public Health Institute, CBOs, and federally qualified health centers (FQHCs)? How inclusive can or should this table be, thinking in terms of how a common collaboration is HUD and HHS, with the intention of recreating that type of collaboration in a US territory government context?

- CODI@CHORDS engages at least seven FQHCs and will work on links to PH, CBO, and FQHC data. In the NC pilot, FQHCs didn’t have the bandwidth due to COVID.
- HUD and HHS collaboration offers an effective option to explore at higher levels. The workgroup, with NC Coalition to End Homelessness in NC CODI, at least will use HUD data elements.

12. Do templates exist, either as an example or precedent, for agreements between project partners to facilitate such an agreement?

- Please email Ray about agreements to share on governance using the contact information found below.
  - Raymond J King, PhD, MSc
    Senior Advisor for Informatics
    Division of Nutrition, Physical Activity, and Obesity
Related Feedback Request:

Workgroup members discussed the importance of inclusive definitions and creation of SDOH measures. Data aggregation and use does not arbitrarily determine which communities require more intervention. Instead, community needs-based involvement should determine the SDOH to address.

Ray and Emily totally agree with this. And they think that clinical-community partnerships provide an avenue to gain local knowledge about what works best for a community. These partnerships foster collaboration and decision-making across diverse groups and inherently broaden our definitions of SDOH.

We have also learned through CODI that facilitating the clinical and community interoperability/data sharing to produce the aggregated data we all want requires that we address the information needs of the data owners. For example, CBOs and WIC in NC want aggregated clinical and community to target services to areas of greatest need.