



Frequently Asked Questions about Colorado Health Observation Regional Data Service (CHORDS)

Contents

Overview

1. What is CHORDS?
2. What is the purpose of CHORDS?
3. Who are the current partners?
4. What kinds of health data are available?
5. Can my site contribute data to the CHORDS network?
6. What will CHORDS look like in the future?
7. What are CHORDS' governance principles?
8. What governance policies ensure data are safely and securely accessed and shared?

Public Health Monitoring

9. Who has access to CHORDS data?
10. How does CHORDS access health data for public health monitoring?
11. What are the current public health monitoring topics?

Health Research

12. How can CHORDS provide data to researchers?
13. What research initiatives are currently using CHORDS?
14. Can I use CHORDS to find/recruit patients to enroll in my clinical study?
15. What is the IRB process for studies using CHORDS?
16. Are there materials available to help me describe CHORDS in my grant application?
17. What is the authorship model for publishing studies that use CHORDS data?

Technical Infrastructure

18. How are data shared in CHORDS?
19. How does a site contribute data to CHORDS?

Overview

1. What is CHORDS?

Colorado Health Observation Regional Data Service (CHORDS) is a regional collaborative partnership between Colorado health providers, public health departments, and the University of Colorado Denver to share health data. CHORDS collects, analyzes and presents data from participating partner electronic health records (EHRs) into one registry that can be used to monitor population health and conduct research. All data is securely exchanged by removing personally identifiable information.

CHORDS refers to both the technology platform and a virtual organization of partners. The partners agree to share patient health data which provides insight on local health needs and issues. CHORDS is funded by several federal and state grants/contracts and non-profit foundations.

2. What is the purpose of CHORDS?

CHORDS facilitates access to local health data for communities throughout Colorado to monitor population health trends, study populations or diseases, and evaluate interventions. EHR data provide a level of accuracy, statistical power, and geographic detail unavailable through established health surveys, the traditional local public health information source. New community- and clinic-based interventions, outreach programs, and preventive services, informed by local EHR data, may be more successful because granular data can identify specific communities or populations, measure factors affecting health, and target interventions. EHR data can answer many health questions that surveys or claims data typically cannot (e.g., which neighborhood has the highest level of hypertension and lowest level of hypertension control?).

CHORDS is broadening its scope and reach to provide

data for research and recruit additional health care and behavioral health providers.

3. Who are the current partners?

CHORDS partners include both organizations that contribute health data (i.e., healthcare providers), and authorized partners that may query health data (i.e., local public health agencies and researchers). Healthcare provider's currently contributing data to CHORDS include:

- [Children's Hospital of Colorado](#)
- [Clinica Campesina](#)
- [Clinica Tepeyac](#)
- [Colorado Alliance for Health Equity and Practice](#)
- [Colorado Coalition for the Homeless](#)
- [Denver Health and Hospital Authority](#)
- [High Plains Health Center](#)
- [Kaiser Permanente of Colorado](#)
- [Metro Community Providers Network](#)
- [Salud Family Health Center](#)

CHORDS initially provided data to one local public health agency (Denver Public Health). CHORDS is expanding to include local public health users in the Denver Metropolitan area (Boulder County Public Health, Broomfield Public Health and Environmental Health, Jefferson County Public Health, Tri-County Public Health Department) and other researchers across Colorado.

4. What kinds of health data are available?

In accordance with HIPAA and local Institutional Review Board (IRB) regulations, CHORDS provides aggregate and/or record-level health data for population health monitoring. In the future, CHORDS will provide aggregate and/or record-level data to local researchers as well. CHORDS can provide information on a number of individual health, socio-demographic, and environmental factors including:

- Diagnoses (e.g., ICD-9/10 diagnosis code and date of diagnosis)

- Encounters (e.g., date of encounter and site)
- Health behaviors (e.g., tobacco, alcohol, and/or drug use)
- Laboratory results (e.g., test type, date of test and result)
- Patient demographics (e.g., age, gender, race)
- Patient residence and community factors (e.g., census tract of residence, American Community Survey measured level of poverty and education)
- Pharmacy (e.g., outpatient pharmacy medication dispenses)
- Procedures (e.g., procedure type and date)
- Vital signs (e.g., height, weight, and blood pressure)

Each data-contributing partner stores data from their EHR in a **virtual data warehouse** or VDW. This is referred to as a 'datamart' where health data can be accessed for population health monitoring or research.

Please contact us for a complete description of the fields currently available through CHORDS. With every research project, CHORDS assesses additional needs and the feasibility of expanding the fields in the VDW and incorporating other data models. CHORDS is interested in building links to a variety of new data sources to aid researchers.

5. Can my site contribute data to the CHORDS network?

Yes, CHORDS is in a constant state of growth, adding healthcare providers and their data. To contribute data, a site must have an EHR and capacity to build a VDW. The process for contributing data includes completing governance and technology activities and often takes approximately one year to complete. To ensure appropriate data sharing, a governance agreement must be completed between the site and the CHORDS network.

After appropriate data sharing agreements are executed, sites will develop a VDW and populate their VDW datamart with EHR data. To make data accessible through the CHORDS network, CHORDS administrators will grant and configure permissions needed for the site

to download the necessary software. See [“How does a site contribute data to CHORDS”](#) for additional details.

6. What will CHORDS look like in the future?

We anticipate significant growth for CHORDS in the coming years. New data-contributing sites will be added, additional monitoring topics will be developed, and the current platform will be adapted for researchers to access CHORDS data. CHORDS will continue to update its existing data model and consider accessing data from alternative data models such as OMOP.¹

7. What are CHORDS’ governance principles?

Governance, or how the data-contributing partners and data users make shared decisions, is central to the success and sustainability of the CHORDS network. The CHORDS Governance Guiding Principles are provided below.

CHORDS public health monitoring and research activities will:

- Be based on transparent and shared decision-making
- Enhance evidence-based personal and public health care
- Foster an innovative information network infrastructure and methods
- Assess population measures and share knowledge in the public domain
- Include diverse perspectives (patients, populations, providers, and delivery systems)
- Establish clear priorities that balance project goals with available resources

Data contributing organizations will:

- Retain autonomy (e.g., authority to give access to their data)
- Ensure appropriate use through stewardship of data resources

¹ Overhage JM, Ryan PB, Reich CG, Hartzema AG, Stang PE. (2012) Validation of a common data model for active safety monitoring research. *JAMIA* 2012;19:54e60. doi:10.1136/amiajnl-2011-000376.

- Participate as collaborative citizens and leaders within the distributed network
- Ensure compliance with site-specific, local, state, and federal policies and regulations

Public health and research end users will:

- Orient partners to high priority monitoring or research activities
- Rapidly disseminate findings to the public
- Be vigilant in protecting patient confidentiality and privacy
- Engage stakeholders regarding data, infrastructure, and value of findings

8. What governance policies ensure data are safely and securely accessed and shared?

Principles and policies fostering data sharing have been established through goodwill and trust of participating organizations. Participating organization agree to value and honor collaborator sites’ autonomy and recognizes the benefit and responsibility of sharing health information. Essential to this trust is active stewardship of protected and confidential health data which furthers goodwill among the public, patients, and participating healthcare organizations.

The following principles guide CHORDS activities and ensure the safety and security of data sharing:

- Requestors should ask for the minimum data necessary to answer a question of interest.
- Queries yielding identifiable results are not permitted.
- CHORDS will release only aggregated data and will not identify partner-specific information.
- All partners are responsible for ensuring compliance with federal and state laws and regulations, including HIPAA.
- Data partners are responsible for compliance with institutional data use/sharing policies.

CHORDS is a distributed database; data partners retain

full control over their data and decide which data are available for querying, which queries are approved and executed, whether results are returned to requestors, and who is permitted to submit queries. CHORDS submits proposed activities for investigational review board (IRB) review and adheres to HIPAA regulations; data are exchanged in accordance with those protocols and regulations (e.g., protected health information/ personally identifiable information is typically removed).

Furthermore, each research study using CHORDS must obtain its own IRB approval. Data safety and management procedures must be clearly described and approved by an IRB and any other relevant regulatory boards before data queries begin for a given study. In addition, all CHORDS users, data contributing partners and any business associates must execute the necessary Data Use Agreements, Business Associate Agreements, and/or other contracts or legal documents required in advance of data sharing.

Public Health Monitoring

9. Who has access to CHORDS data?

Local public health department representatives in the Denver metropolitan area have access to CHORDS monitoring data. Community partners may request CHORDS data through their local public health department.

10. How does CHORDS access health data for public health monitoring?

CHORDS provides information for public health monitoring, also referred to as population health, through topic-specific queries. For each population health topic area, CHORDS uses a query to gather

relevant health data from data-contributing sites and assembles that data into a registry. The registry is then used to provide information about the health of a population in the form of indicators specific to that topic.

Parameters can be used to customize the query for a specific time period or geographic or demographic population. For instance, for monitoring tobacco use, CHORDS includes a tobacco 'adapter' (query) that collects tobacco registry data (e.g., demographic, tobacco use status and geographic information) for each patient. Not every healthcare provider participates in every registry (e.g., a children's hospital could not provide adult indicator data).

11. What are the current public health monitoring topics?

Current public health monitoring topics include:

Topic Area	Example Indicators and Related Population Health Questions	Example of Relevant Data Fields
Obesity	<ul style="list-style-type: none"> Adult prevalence of obesity: What percent of adults are at an obese weight? 	<ul style="list-style-type: none"> Height Weight BMI
Tobacco Use and Exposure	<ul style="list-style-type: none"> Adult prevalence of tobacco use: What percent of adults use tobacco? Pediatric prevalence of second hand smoke exposure: What percent of children are exposed to tobacco? 	<ul style="list-style-type: none"> Self-reported tobacco use Self-reported second hand smoke exposure
Diabetes	<ul style="list-style-type: none"> Adult prevalence of diabetes: What percent of adults have been diagnosed with diabetes? Adult prevalence of pre-diabetes: What percent of adults have been diagnosed for pre-diabetes? Adult diabetes control: What percent of diagnosed diabetics are currently in control 	<ul style="list-style-type: none"> Diabetes diagnosis codes Hemoglobin A1C lab test results
Cardiovascular Disease	<ul style="list-style-type: none"> Adult rate of hypertension screening: What percent of adults are screened for high blood pressure? Adult prevalence of hypertension: What percent of adults have been diagnosed with high blood pressure (known as hypertension)? 	<ul style="list-style-type: none"> Systolic and diastolic blood pressure levels Diagnosis of hypertension
Mental Health	<ul style="list-style-type: none"> Adult prevalence of depression: What percent of adults have been diagnosed with depression? 	<ul style="list-style-type: none"> Depression diagnosis codes

In the future, CHORDS hopes to expand to include the following public health topics.

Future Topic Area	Example Indicators and Related Population Health Questions	Example of Relevant Data Fields
Future: Asthma	<ul style="list-style-type: none"> What percent of children are screened for asthma? What percent of asthmatic children are under control? 	<ul style="list-style-type: none"> Diagnosis of asthma Asthma control questionnaire
Future: Hepatitis C	<ul style="list-style-type: none"> What percent of Denver residents have tested positive for Hepatitis C Virus? What percent of Denver adults have been tested for Hepatitis C Virus? 	<ul style="list-style-type: none"> Hepatitis C diagnosis codes Screening test
Future: Congenital Heart Disease (CHD)	<ul style="list-style-type: none"> What is the prevalence of CHD among Colorado residents? Do CHD patients effectively transition from pediatric to adult care settings? 	<ul style="list-style-type: none"> CHD diagnosis codes Cardiac procedure codes

Health Research

12. How can CHORDS provide data to researchers?

CHORDS is currently expanding to provide aggregate-, individual-, and encounter-level data to researchers. With every research project, CHORDS assesses additional needs and the feasibility of expanding the fields in the VDW. CHORDS will build links to a variety of new data sources to aid researchers (e.g. nursing clinical notes and patient report outcomes).

13. What research initiatives are currently using CHORDS?

A handful of research projects will pilot the use of the CHORDS network to identify eligible patients and follow study participants over time. Current research initiatives include:

- Congenital Heart Defects: creating a repository of patient records for adolescents and adults with congenital heart defects.
- Traumatic Brain Injuries: following a cohort of pediatric patients with traumatic brain injuries longitudinally and assessing a variety of health outcomes.
- Hepatitis C: identifying a cohort of Hepatitis C patients to study pharmacotherapy trends, characterize treatment variation, and compare disease progression between treatment groups.

14. Can I use CHORDS to find/recruit patients to enroll in my clinical study?

Though CHORDS is not currently able to find and recruit patients (i.e., for a clinical trial), CHORDS could be used in the future to estimate the size of a study cohort, identify and match controls, and longitudinally monitor patients over time.

15. What is the IRB process for studies using CHORDS?

CHORDS has completed and received IRB approval (i.e., non-human subject research) for its basic “infrastructure”. That review described the overall infrastructure of the database system and the security measures in place to ensure data remain private and confidential. This infrastructure IRB requires each research study using CHORDS to apply for its own IRB approval (e.g., describing study’s procedures, data handling, and intended use of the data) which would reference the CHORDS prior approval.

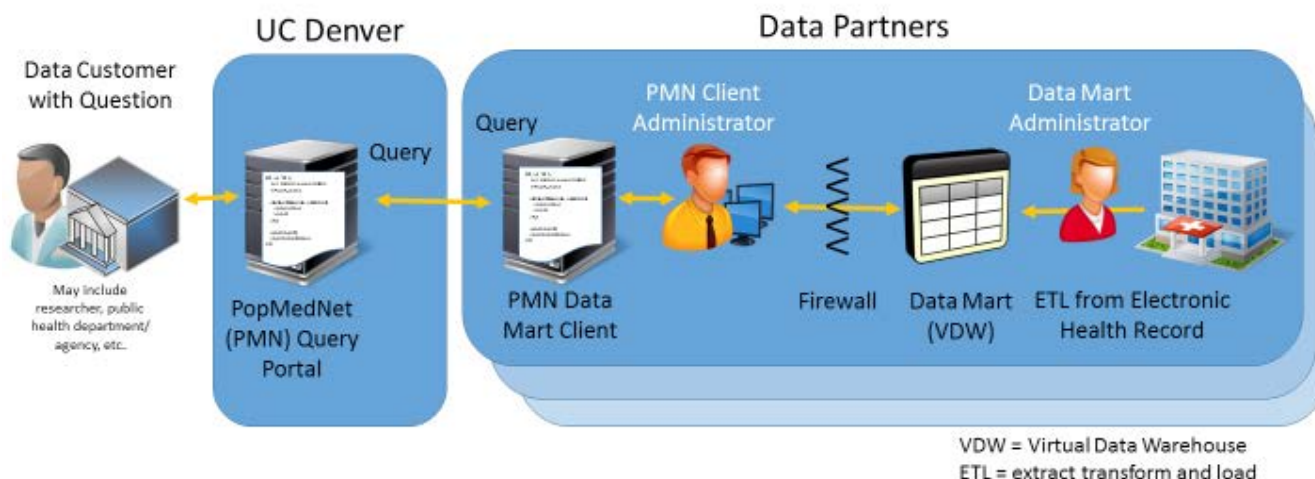
16. Are there materials available to help me describe CHORDS in my grant application?

CHORDS has template documents and language prepared to assist researchers applying for grant funding or submitting an IRB application where CHORDS would be utilized. Examples include data use agreement templates, business associate agreement templates, and CHORDS’ IRB approval. CHORDS team members can provide additional assistance during the grant application process.

17. What is the authorship model for publishing studies that use CHORDS data?

A presentation or publication including data from multiple CHORDS sites will generally have at least one actively involved co-author from each site. This is not an honorary position or a reward for contribution of data; each co-author is responsible for the quality and integrity of data from her/his site as well as for engagement with health system leadership regarding interpretation.

For detailed guidelines on authorship, please refer to CHORDS’ Research Policies and Procedures.

Figure 1. CHORDS Federated Query Overview

Technical Infrastructure

18. How are data shared in CHORDS?

CHORDS data sharing is powered by **PopMedNet™**, a software application that creates and enables simple, efficient use of distributed data networks. The system provides secure, customized private portals and query tools. Data partners exercise full control over which data are available for querying, what queries are approved and executed, whether results are returned to requestors, and who is permitted to submit queries. The Department of Population Medicine at the Harvard Pilgrim Health Care Institute (HPHCI) led development of the system in collaboration with Lincoln Peak Partners (LPP).

The CHORDS instance of PopMedNet is hosted and supported by the University of Colorado's Adult and Child Consortium for Health Outcomes Research and Delivery Science with blended funding from a variety of grants from non-profit foundations, state and national funders.

19. How does a site contribute data to CHORDS?

The first step in contributing data is completing all appropriate data sharing agreements (e.g., Data Use and/or Business Associates Agreements). After the data

sharing agreements are executed, as required by the site and by CHORDS, new partner sites will develop a VDW and populate their VDW datamart with EHR data. Finally, sites will request and receive permission to download a PopMedNet "client" that connects their datamart to the CHORDS network.

CHORDS securely exchanges data using the client through a federated query, removing all personally identifiable information before data are shared. A federated query requires each site to opt in to a specific query, ensuring that no data are shared with CHORDS end-users without a site's permission. The system provides secure query tools for public health practitioners and researchers to send data requests to all or selected sites simultaneously.

When a health care provider receives a data request through PopMedNet, those providers exercise full control over who is permitted to submit queries, which data are available for querying, what queries are executed, and whether results are returned to requestors. This distributed database allows data sharing to take place while allowing health care providers to retain full control over their data. Datamart administrators can also query their own local data at any time.

