Outline

- Why a Cross-Network Directory Service
- Design: Flexible and Extensible Architecture
- CNDS Pilot
- Key Features and Functionality
- What’s Next
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Why Create a Cross-Network Directory Service (CNDS)?

- Distributed health data research and surveillance networks are proliferating

- It is challenging to find the right data resources and collaborators
CNDS Purpose

CNDS aims to facilitate collaboration across the networks by enabling users to . . .
Find Collaborators

I KNOW A GUY
WHO KNOWS A GUY
WHO KNOWS
ANOTHER GUY
My study requires inpatient medication and transfusion data for at least 200,000 inpatient visits in the past 3 years.

~

Where can I find data?
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Design: Flexible and Extensible

- PopMedNet™ (PMN) is an open-source software platform used by Sentinel, PCORNet, HCSRN, and other health data networks.

- CNDS, built lightly on PMN uses a modular design that minimizes the impact on existing networks.

- The CNDS metadata data model enables changes to metadata elements without software redesign or programming.
CNDS is a web service with a database and an Application Programming Interface (API)
Architecture

- APIs enable communication between web applications
- Implementing CNDS using API calls between PMN and CNDS:
  - Makes CNDS feel like part of PMN while insulating PMN and CNDS from each other
  - Enables changes to either system without affecting the other
Existing PopMedNet Architecture

PCORnet PMN API

PCORnet PMN Operational Database

Sentinel PMN API

Sentinel PMN Operational Database

PCORnet PMN Web App

Sentinel PMN Web App
CNDS Purpose

CNDS aims to facilitate collaboration across the networks by enabling users to find collaborators and discover and query data sources.
Design: Flexible and Extensible Architecture

- CNDS connects distinct research networks
- The data model captures information about expertise, data sources, and technology resources
- Users can explore the data and connect to others
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CNDS Pilot

- Workgroup convened (representatives from Harvard Pilgrim Health Care Institute, FDA, a Sentinel data partner – Humana, a PCORnet data partner – University of Michigan, and the software developer)
- Larger stakeholder meetings held
- Create demonstration versions of PMN for Sentinel and PCORnet with new CNDS interfaces and functionality
- Populated user, organization, and data source information into CNDS database
- We did not focus on what to collect; instead we built a system that can collect nearly anything
- Tested, tested, tested
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Metadata

- At the core of CNDS is metadata
- Metadata about organizations and their data sources are captured in a “Profiles” screen
Data Model and User Interface

- The metadata inventory will change and grow over time
- The data model and software were built to accommodate change
  - The **data model** can be quickly updated with minimal training (no programming)
  - The **software user interface** ("profile" and "discovery" pages) are generated automatically from the metadata to simplify expansion and modifications
  - CNDS services include a robust metadata model that is extensible to **accommodate a virtually unlimited inventory of metadata fields**, without requiring further software development, and user interfaces that are programmatically generated based on the contents of the metadata model.
Key Features and Functionality

- The CNDS software application is made up of four components:
  - Governance
  - Registration
  - Discovery
  - Communication
Governance

- Governance is central to CNDS
- All access controls currently available in PMN are supported in CNDS, for example:
  - Create, edit, delete networks, data sources, organizations, users
  - Respond to or reject requests
  - See Request Queue
- Governance is also incorporated into all CNDS components
Much of governance is encoded in “Registration” metadata

- Users can indicate “What” data they collect and “Who” they will share information with
Registration – What is collected

Profile page where data source owners indicate data collected

Note that these are examples only, the system can capture anything deemed important to stakeholders
### Registration – Who its Visible to

<table>
<thead>
<tr>
<th>Data Domains</th>
<th>DataMart Permissions</th>
<th>Request Type Permissions</th>
<th>Installed Models</th>
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<tbody>
<tr>
<td>CNDS Visibility</td>
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<table>
<thead>
<tr>
<th>Domain</th>
<th>No One</th>
<th>My Network Members</th>
<th>All PMN Members</th>
<th>All PMN and CNDS Members</th>
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<tbody>
<tr>
<td>Types of Data Collected</td>
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<td>Inpatient Encounters</td>
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<td>Inpatient Diagnosis Codes</td>
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- Data source owners indicate what information is visible and discoverable
- Currently, there are 4 levels of visibility
- Visibility can be can set per metadata element or by group
On the discovery page, the user selects metadata elements to search, sees a summary of the search . . .
.. and gets a result set with data sources whose owners have indicated they collect the data of interest and want this to be discoverable
Communication

- After finding data sources in Discovery, a user can:
  - Send an information or data request (query) to the data sources in a secure environment
    - Data request handling builds on standard PMN functionality
  - Track all requests and responses within the system
Outline

- Why a Cross-Network Directory Service
- Design: Flexible and Extensible
- Software Components
- What’s next
5 Factors Keeping Networks Disconnected

1. Networks have **different governance policies** and different requirements for participation.

2. There is **no mechanism for broadcasting research capabilities** — the types of data available and the research and clinical expertise of their staffs — in a way that facilitates discovering common research interests and gives network participants control over who sees what.

3. Between networks there is **no secure and reliable means of making data requests** and tracking response activity.

4. There are no **operational standards or metrics for describing data** at a level that enables researchers to judge fitness-for-use of others’ data sources.

5. There is **no reliable mechanism for sending queries** that will execute correctly across networks with different common data models.

CNDS addresses factors 1-3 through its Registration, Discovery, Communication, and Governance capabilities.
Project Highlights

- Diversity of electronic health data sources creates challenges to identify data resources and potential collaborators.
- We implemented an open source web services system that enables:
  - Extensible metadata data model
  - Discovery of data sources
  - Governance rules
  - Cross-network communication
- Future work includes engaging with stakeholders to promote metadata curation, establishing governance rules, and implementing the service in a production environment.
What’s Next

- The CNDS project has demonstrated the feasibility of:
  - Discovering potential research collaborators and new data sources and seamlessly querying them across independent distributed research networks.
  - This was demonstrated in Sentinel and PCORnet
What’s Next

▪ To fully unify these networks — and pave the way for others to join — we recommend establishing a cross-network coordinating center to:
  ▪ Develop and implement governance rules between networks
  ▪ Promote and manage network engagement with CNDS
  ▪ Operate the CNDS infrastructure
  ▪ Future work includes: software development to integrate CNDS into the main line of the PopMedNet software code; enhancing the Discovery functionality; implementing in production; engaging with stakeholders to promote metadata curation; establishing a CNDS coordinating center and governance rules.
▪ The web service uses standard APIs and could be integrated with other software applications in addition to PopMedNet.
▪ Despite considerable overlap between their common data models (CDMs), PCORnet and Sentinel data partners cannot send requests to each other. CNDS delivers a framework that enables such cross-network communication.
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  - Principal Investigator: Charles Friedman

- **Sentinel Partner – Humana**
  - Principal Investigator: Vinit Nair

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