

Distributed Research Networks: Opportunities for PCORI

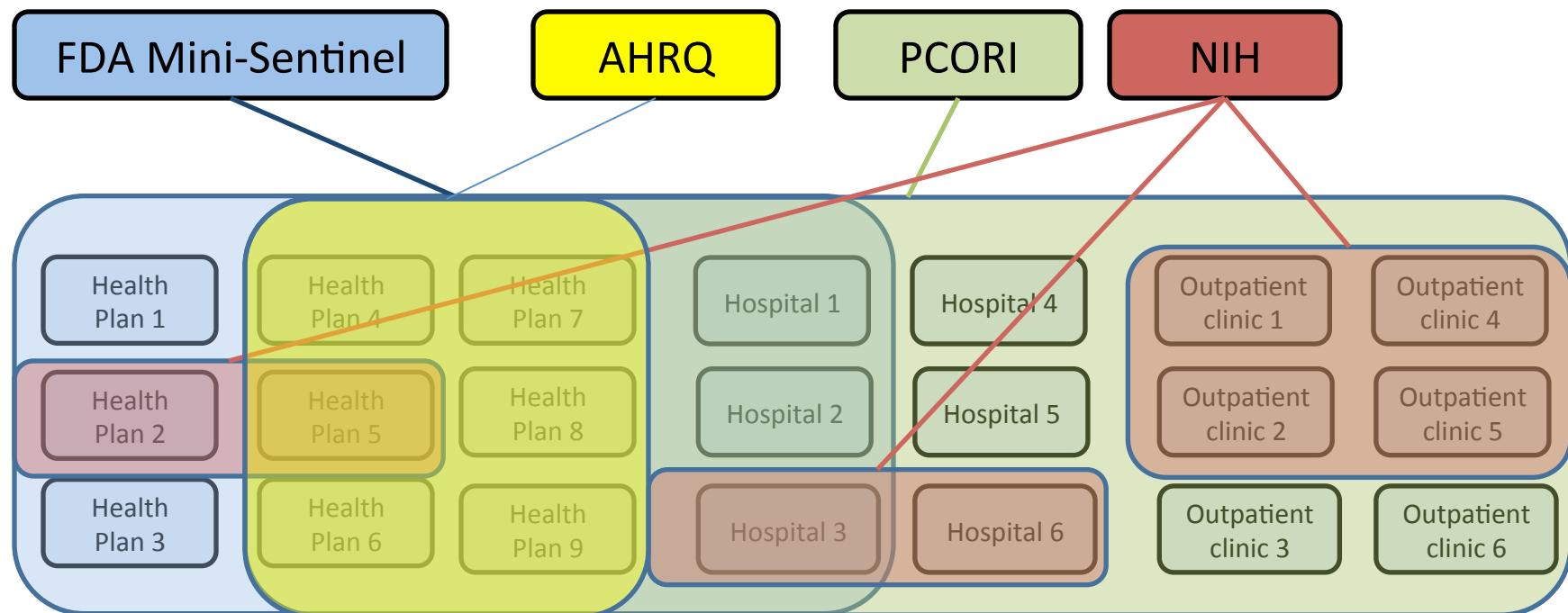
Jeffrey Brown, PhD

Richard Platt, MD, MS

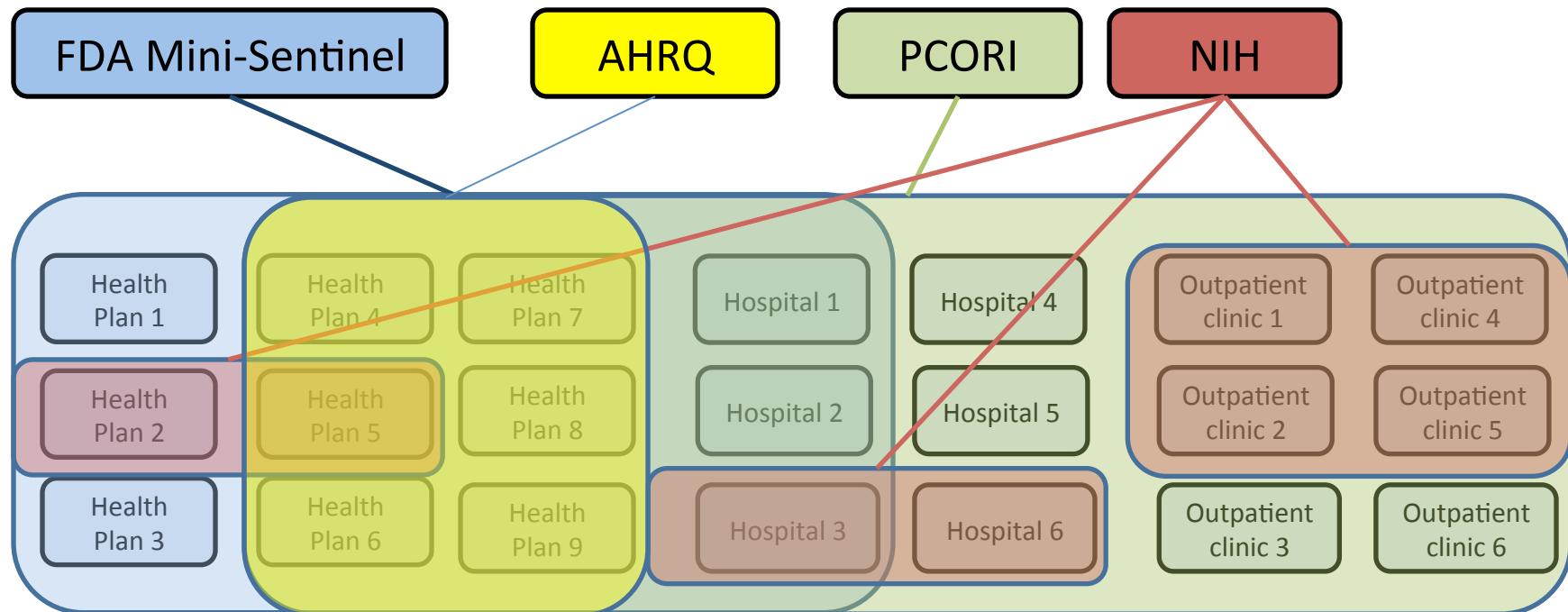
Department of Population Medicine

Harvard Pilgrim Health Care Institute/ Harvard Medical School

Multiple Networks Sharing Infrastructure



Multiple Networks Sharing Infrastructure



- Each organization can choose to participate in multiple networks
- Each network controls its governance and coordination
- **Networks share infrastructure, data curation, analytics, lessons, security, software development**

PCORI Distributed Research Network

Portal control
Executable programs
Menu-driven queries

Coordinating
Center

Investigators

Executable programs
Menu-driven queries

Secure Portal

Mini-
Sentinel
Dataset

SPAN

PEAL

MDPHnet

Any dataset
Any site

Data Partners can participate in specific
PCORI studies if they choose to.

Extant Linkable Distributed Networks

- **SPAN**: Scalable PArtnering Network for CER (AHRQ HMORN)
 - **ADHD** and **Obesity** cohorts
- **PEAL**: Population-Based Effectiveness in Asthma and Lung Diseases Network (AHRQ HMORN+)
 - **Asthma** cohort
- **Mini-Sentinel** (FDA)
 - Utilization / enrollment data for **126 million covered lives**
 - Extensible data model includes selected laboratory tests, linkage to state registries
- **MDPHnet** (ONC): MA Department of Public Health
 - **EHR** data from group practices, currently >1 million pts
 - Current focus on **diabetes** and influenza-like illness

Take home messages

- PCORI can benefit from leveraging existing distributed networks
- Several existing networks use the same distributed approach and software – PopMedNet – enabling any of them to participate in another's activity
- Adding data sources to networks is feasible
 - Patient-reported outcomes
 - Reuse of stand-alone prospective datasets
- Using existing networks and software allows sharing of infrastructure and development costs
 - Open-source model of network development

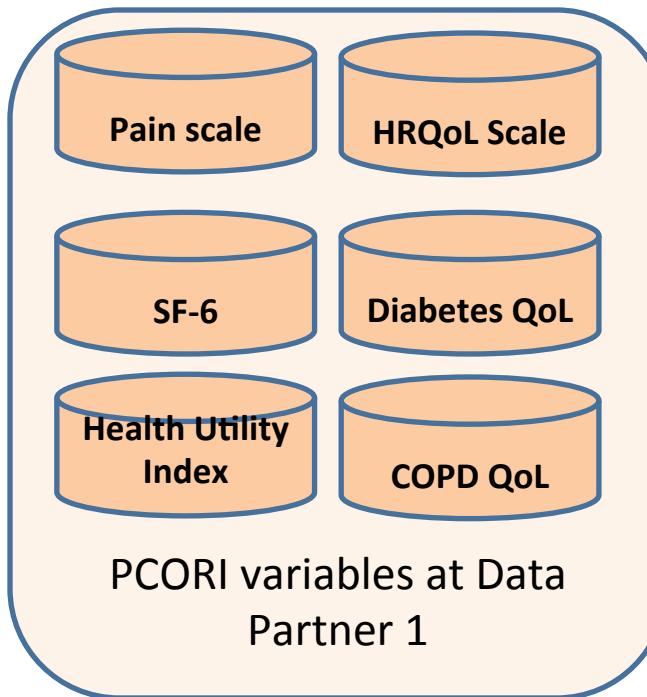
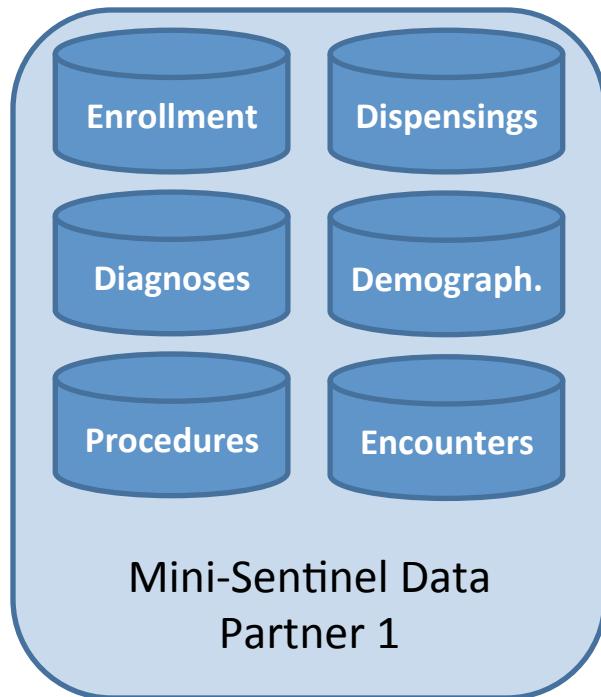
Additional information

PopMedNet Overview

- Open source software that facilitates creation and operation of distributed networks
- Used in several networks and planned for others
- National Standard: PMN is a key component of the ONC's QueryHealth Initiative:
 - Endorsed by the ONC community as a distributed querying platform for policy and governance
 - Included in each QueryHealth Pilot project
 - PMN design meetings national standards for distributed querying
 - Standards & Interoperability (S&I) Framework:
<http://wiki.siframework.org/Home>
 - Technical work group:
<http://wiki.siframework.org/Query+Health+Technical+Approach>

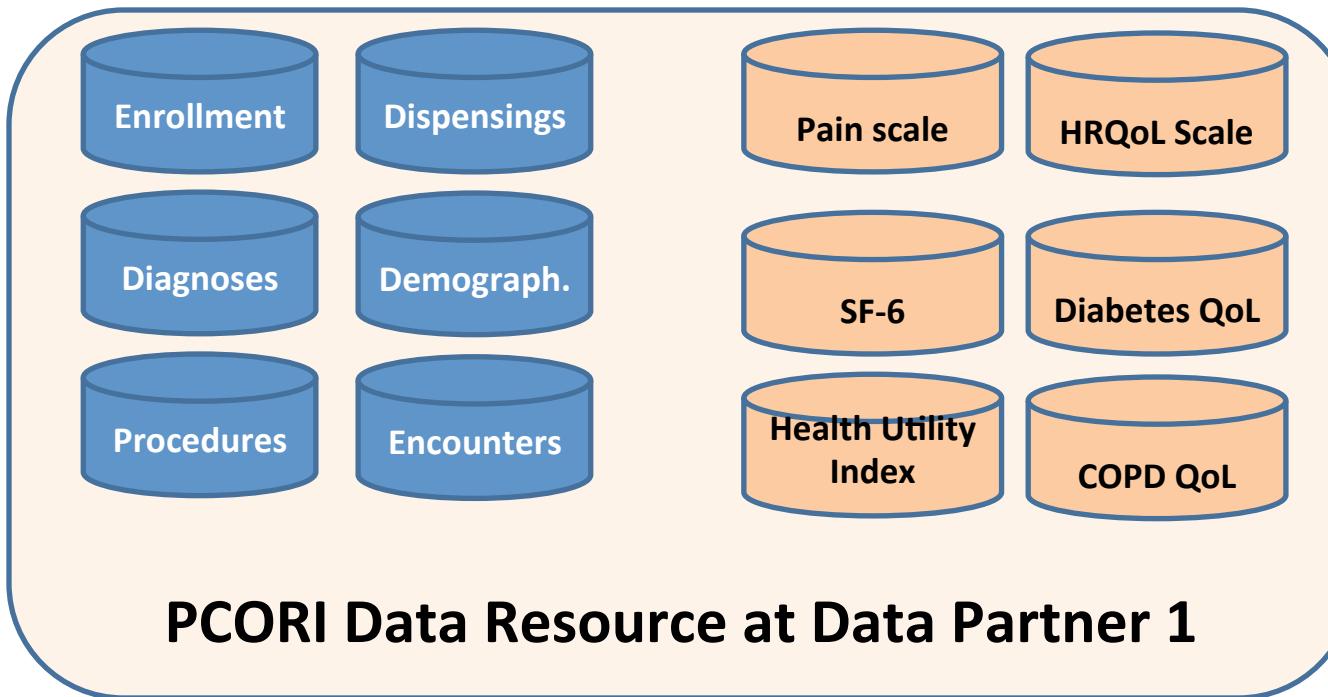
Enhancing Existing Resources (1)

Add patient reported outcomes to existing data resources



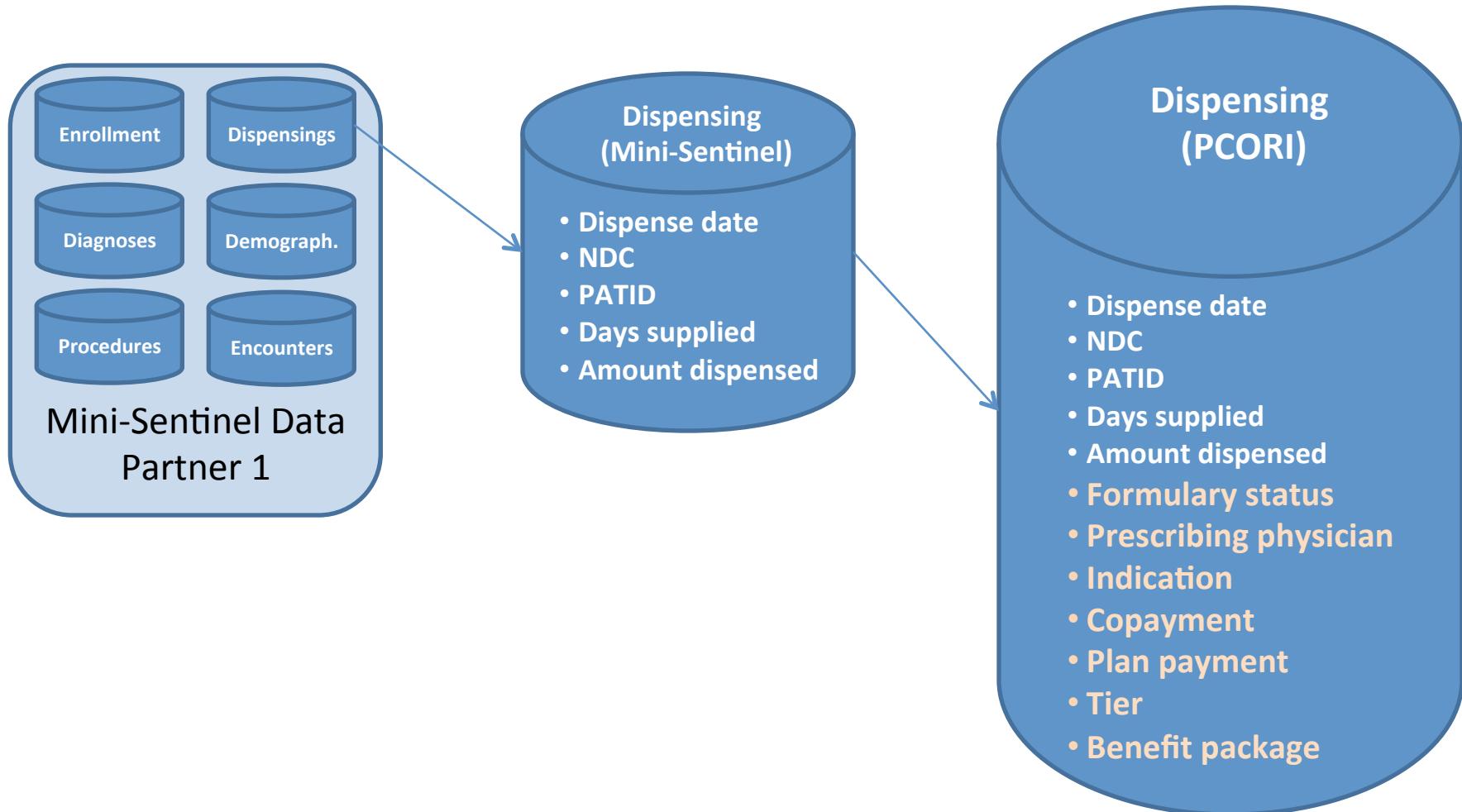
Enhancing Existing Resources (1)

Add patient reported outcomes to existing data resources



Enhancing Existing Resources (2)

Add data to existing data resources (within a table)



Enhancing Existing Resources (3)

- Add new partners to network
- Create additional sub-networks of unique resources
- Enable reuse of project-specific data collection efforts
 - No more “one and done” datasets