

# Distributed Research Networks: Opportunities for PCORI

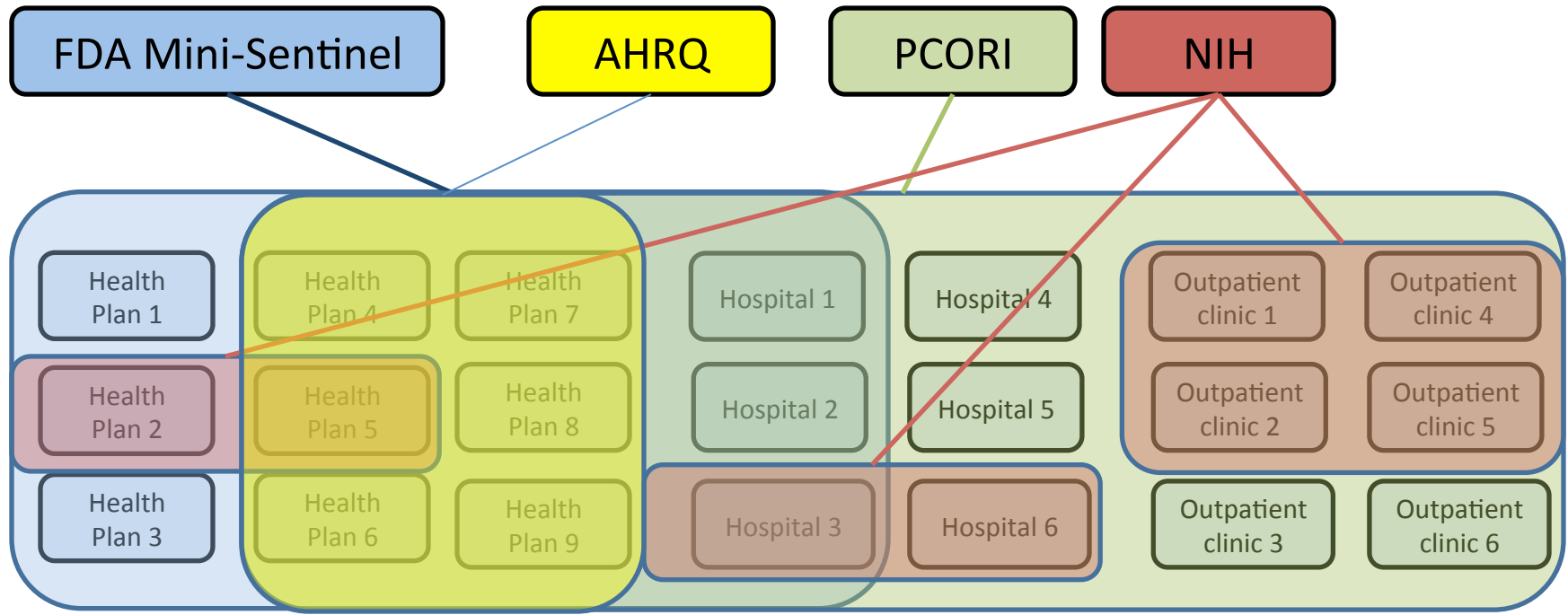
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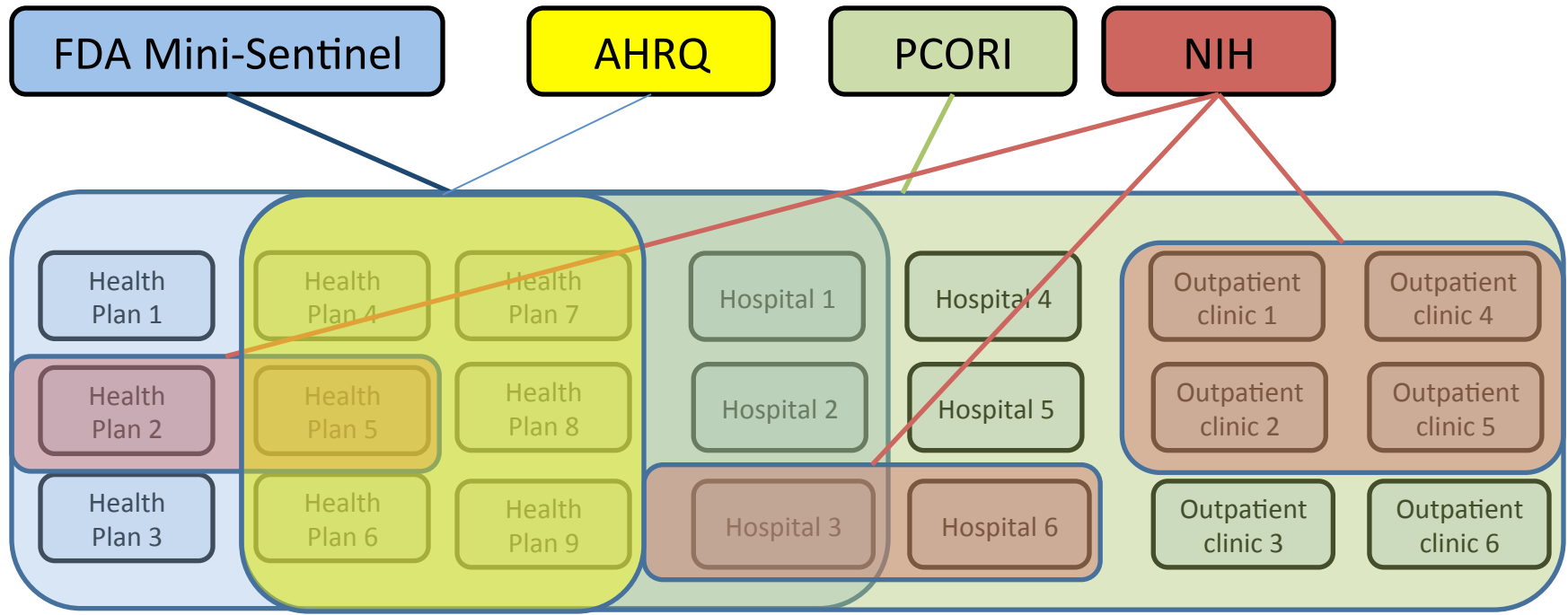
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# Multiple Networks Sharing Infrastructure



# 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

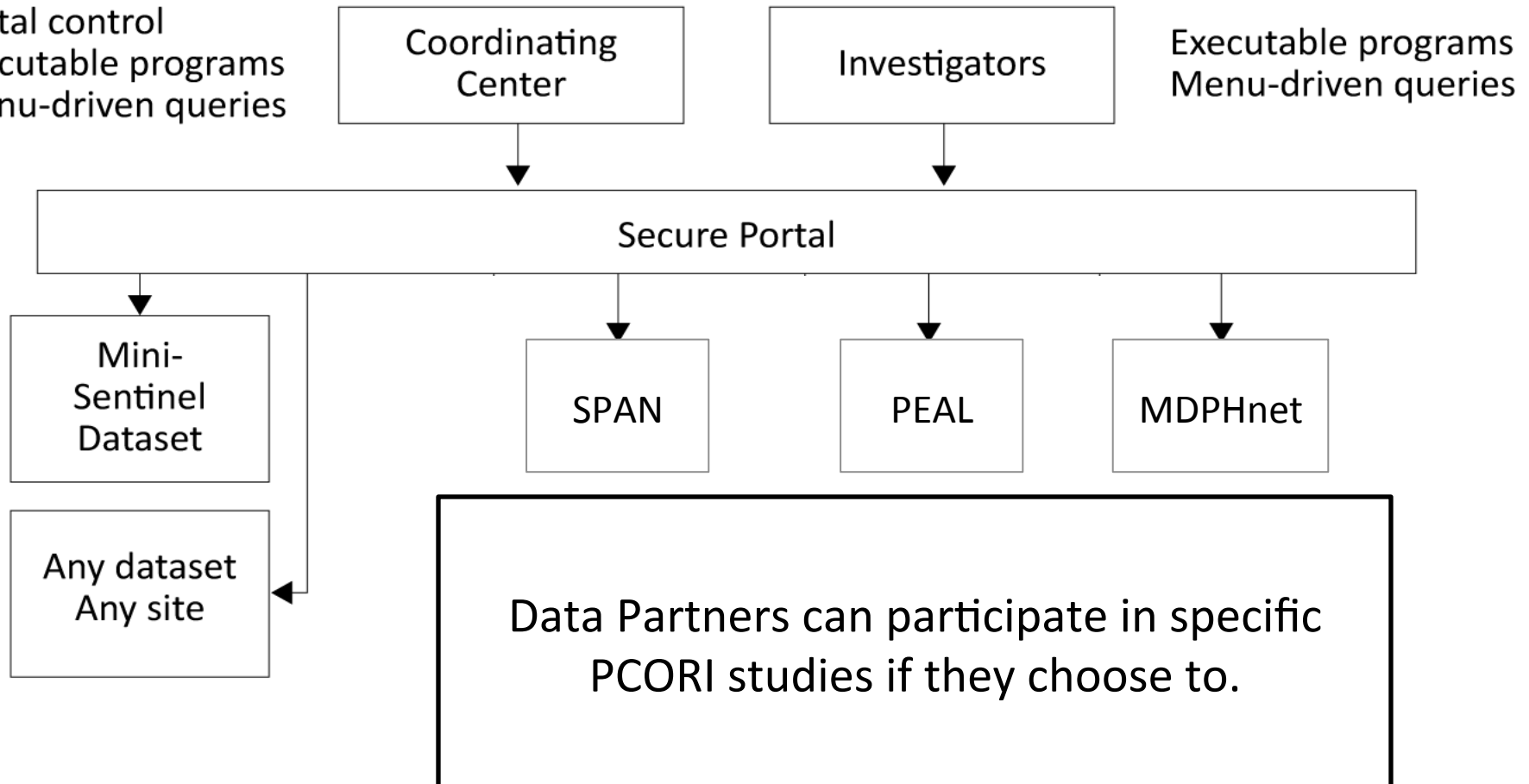
SPAN

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

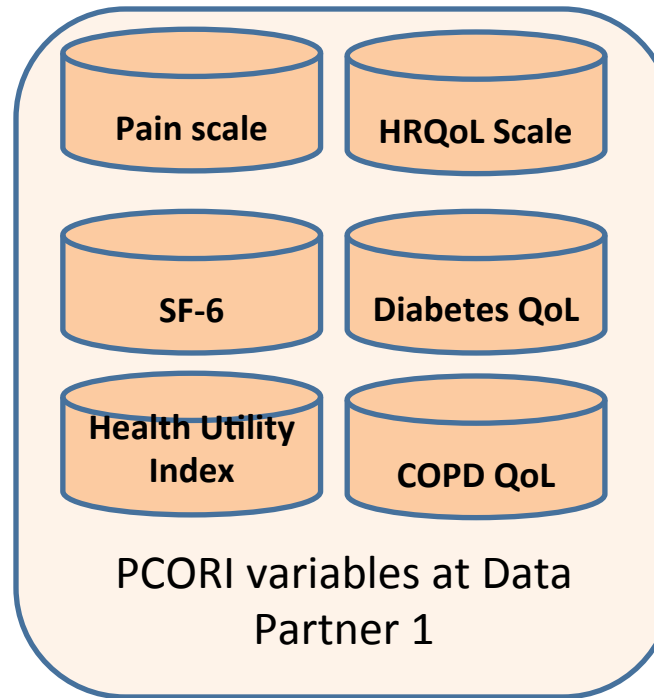
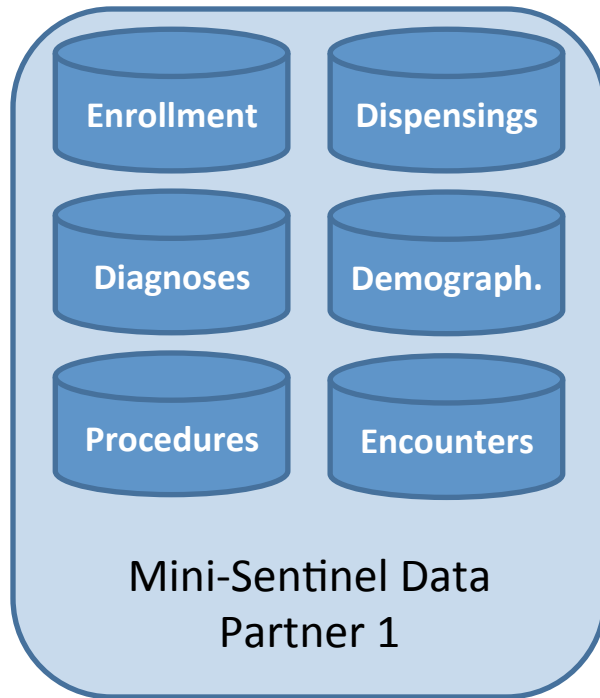
# PopMedNet Overview

- 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>



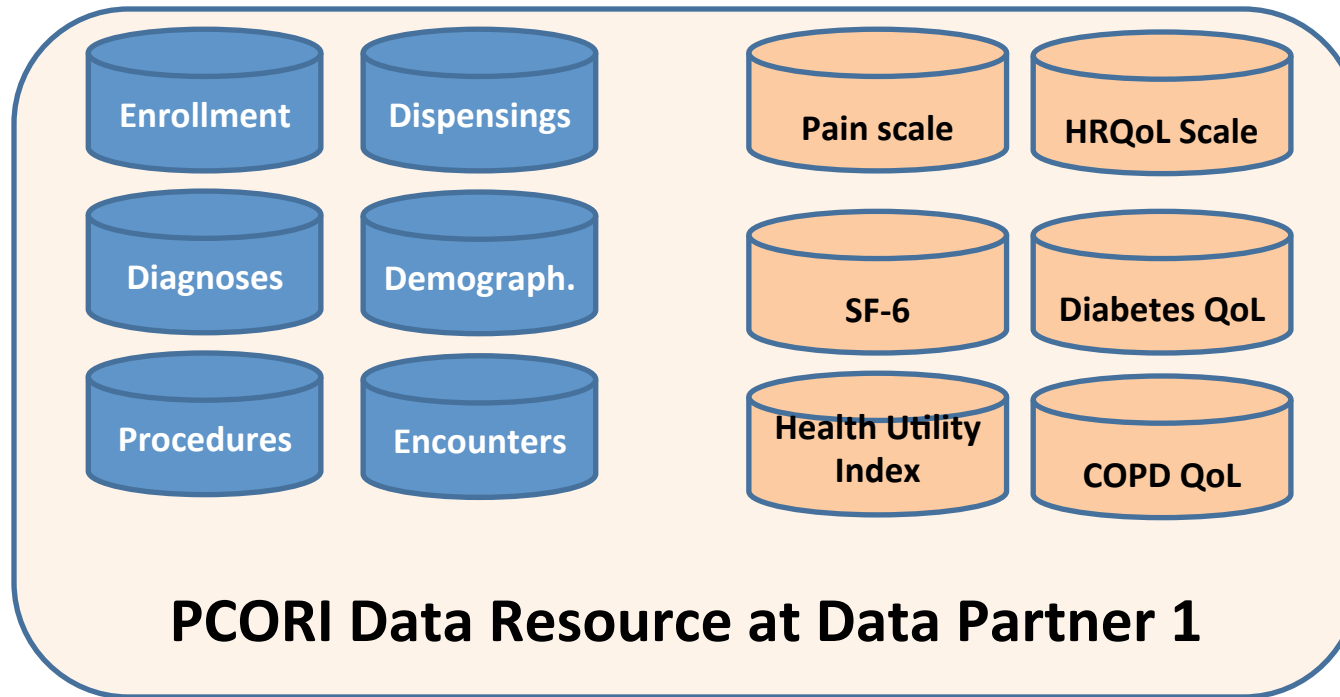
# Enhancing Existing Resources (1)

**Add patient reported outcomes to existing data resources**



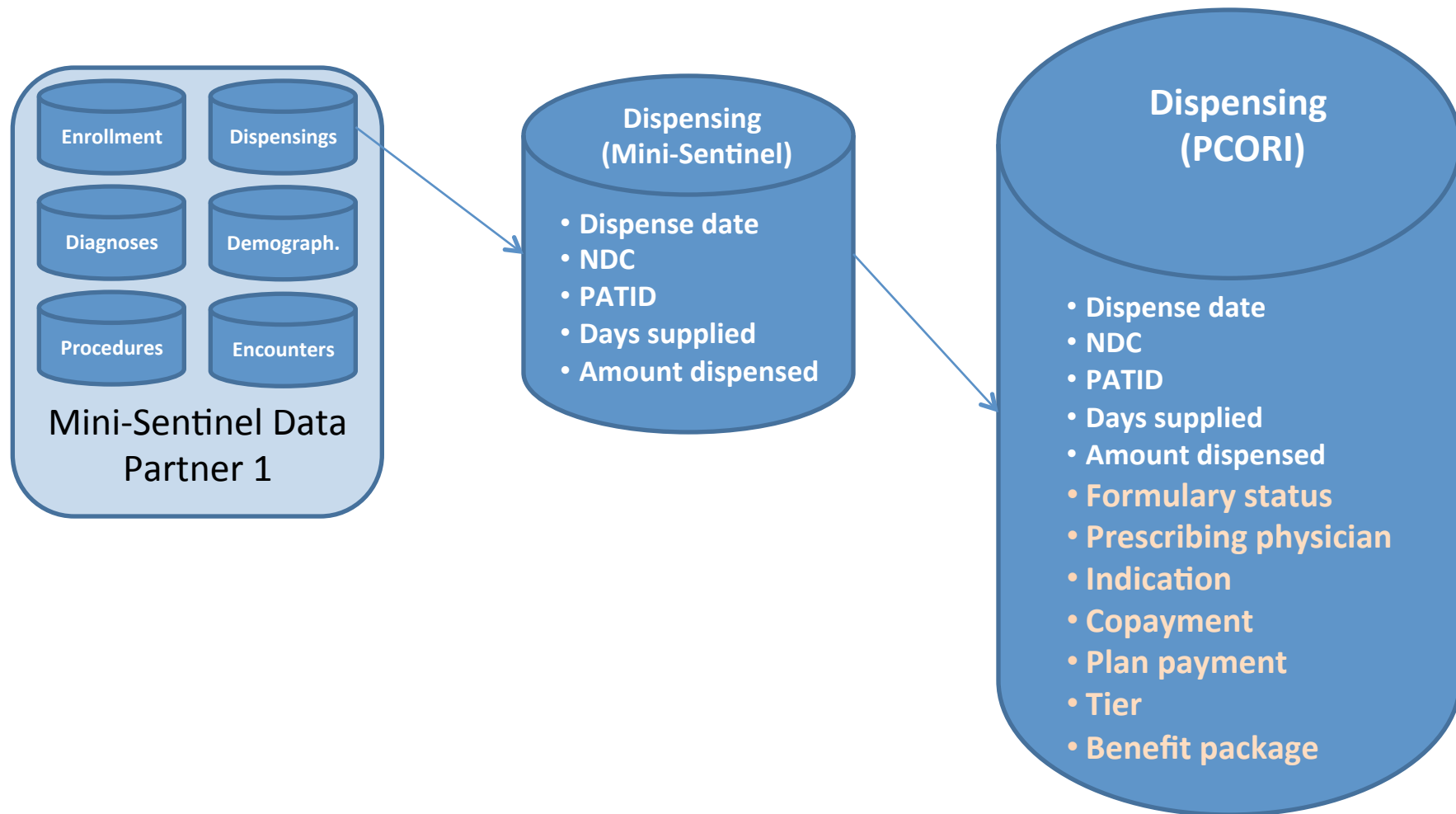
# Enhancing Existing Resources (1)

**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