

# Infrastructuring a Node on a Federated Research Network

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*SciTS*

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# Acknowledgements

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### PCORI

*PCORI CDRN-1501-26638-1*

*PCORnet/LHSNet*

### MIDAS

*Michigan Institute for Data  
Science*

## Thanks to the Teams!

### Node Teams

Steering Committee

Core Leadership Team

Technology & Informatics Team

Evaluation Team

Health Information & Technology  
Services

Data Office & Research Data  
Warehouse

Compliance & IRB Offices

### LHSNet Teams

### PCORnetTeams



# Background

- New models of research collaboration & infrastructure in healthcare
- Federated research networks are one such model (FRN)
  - Data networks
  - Smaller independent units conforming to the purpose and values of the federation
  - Researchers and teams accessing the federation and the data network
- All hospitals will belong to one or more networks in the near future?
- Emerging literature in healthcare explores infrastructure at the FRN network level although largely atheoretical
- Studies of developing and sustaining infrastructure at local participating institutions (node level) is nascent



# Background

- **PCORI:** the Patient-Centered Outcomes Research Institute
  - Funded by ACA - 2010
  - Goal of improving the quality and relevance of evidence available to help inform health decisions
- **PCORnet:** the National Patient-Centered Clinical Research Network
  - Funded by PCORI - 2013
  - Designed to support research by leveraging large volumes of health data (esp. EHRs)
  - Goal of enabling research to be conducted faster, less expensively, and on a larger scale than possible previously
- **U-M and LHSNet**
  - Funded by PCORI and PCORnet – 2015
  - Goal of establishing UM as a node on one PCORnet Clinical Data Research Networks (LHSNet)



# PCORnet: A Federated Research Network (FRN)

PCORnet is a collaborative national resource for better research



- Federation: **balance of central governance with independence in local affairs**
  - Network: **a group or system of interconnected people, data, & technology**
- Funded in 2013 by PCORI
  - National scope: > 100 m records
  - Faster, more efficient research
    - Pragmatic clinical trials
    - Comparative effectiveness studies
    - Rare disease research
    - Health systems research
    - Post marketing surveillance
    - Biospecimens and clinical data?

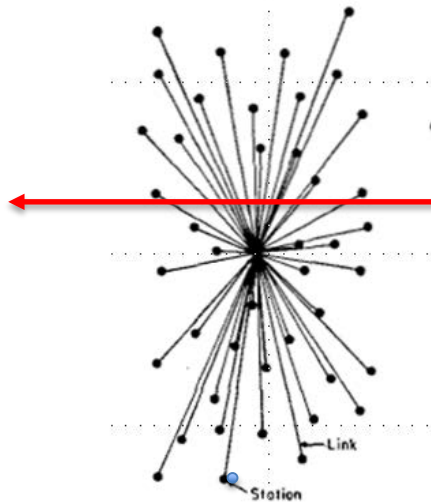
<https://www.pcori.org/sites/default/files/PCORI-PCORnet-Fact-Sheet.pdf>

# Nodes Must Align Across Multiple Network Configurations & *a priori* Agreements on Governance

Centralized

PopMedNet Technical Platform

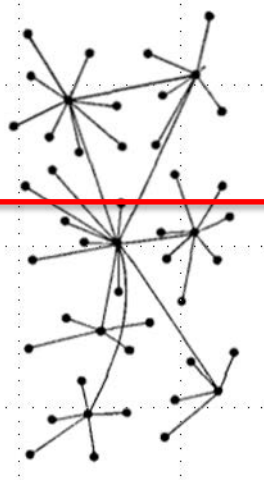
60-80 data marts



Decentralized

Clinical Data Research Network

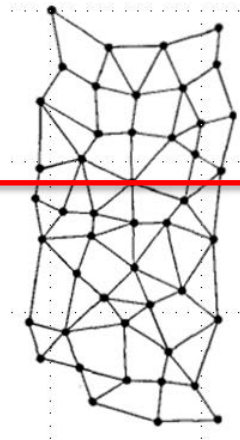
PCORnet & 9-13 CDRNs



Distributed

Study-Specific Collaborations

Many Studies



# Problem: How to design and deploy a node?

- 6 months to get node up and running
- Very limited literature
  - One journal issue - challenges setting up national network PCORnet
    - Capturing longitudinal clinical data from electronic health records
    - Data harmonization across multiple institutions and patient provided data
    - Ethical & regulatory oversight
    - Rapid development of a national resource with heterogeneous groups

*(JAMIA, 2014)*
  - A few reflective papers on federation and ‘federalist principles’

*(Weber 2015, Mandl & Kohane 2015)*



# This Study:

## Applied a Theoretical Perspective to Analyze the Experience

### Socio-technical analytic perspective of “Infrastructuring”

- Contextualized relations among people, organizations, and technologies for scientific collaboration in large systems; A continuing process, not a one-time event *(Star and Ruhleder 1994, 1996)*

### Scales of Infrastructure

- Enabling technology: work to shift from experimental technologies to functioning and stable availability for everyday use
- Organizing work: knowledge management and sustaining work over time
- Institutionalizing: persistent institutional arrangements important to a collective and linked to the goal of a public good

*(Ribes and Finholt, 2009, Ribes 2017, 2018)*





## Overarching Research Question

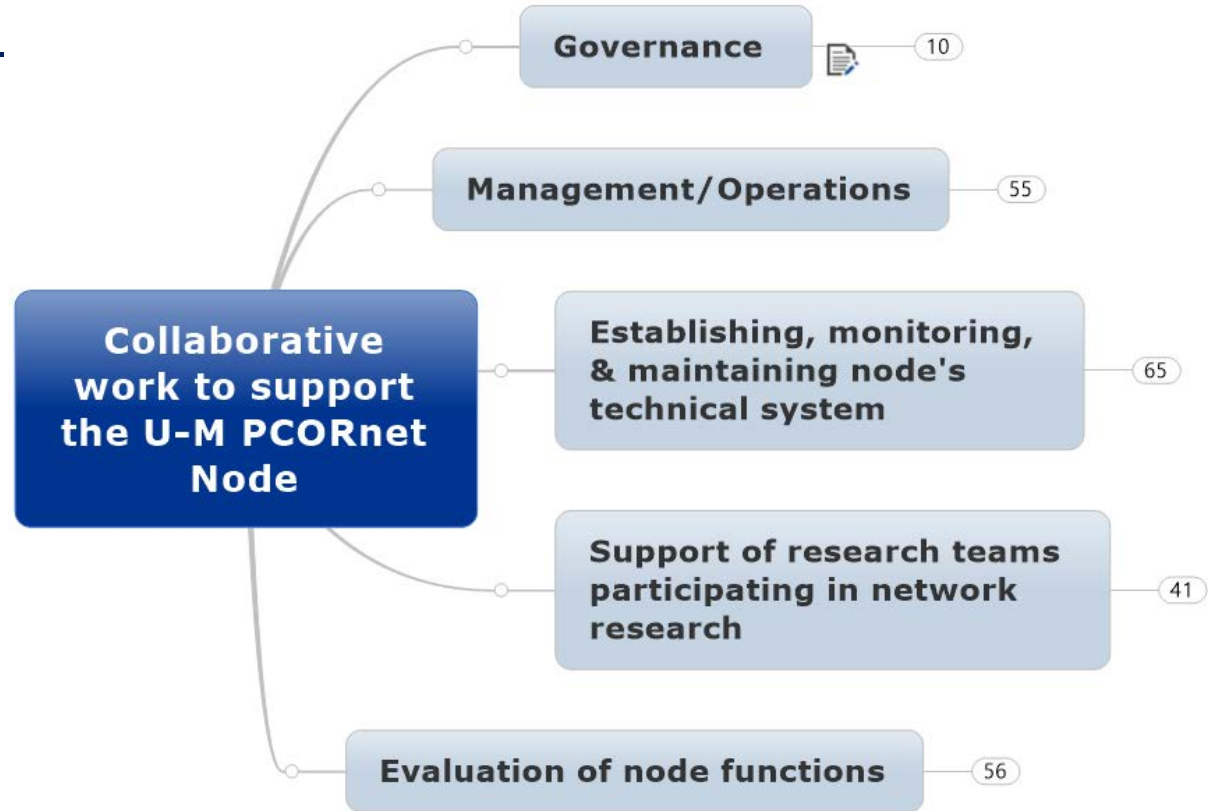
- What infrastructuring is required within an institution to support sustained participation in one or more federated research networks?

## Methods

- Participant observation of one healthcare institution/node on PCORnet
- Reviewed of experiences, notes, minutes, artifacts
- Categorized work efforts using a mind mapping tool
- Mapped work efforts along theoretical dimensions of infrastructuring
- Iteratively refined our analysis based on broad stakeholder feedback
- Validated findings through interviews with three other institutions/nodes in the same hub of PCORnet

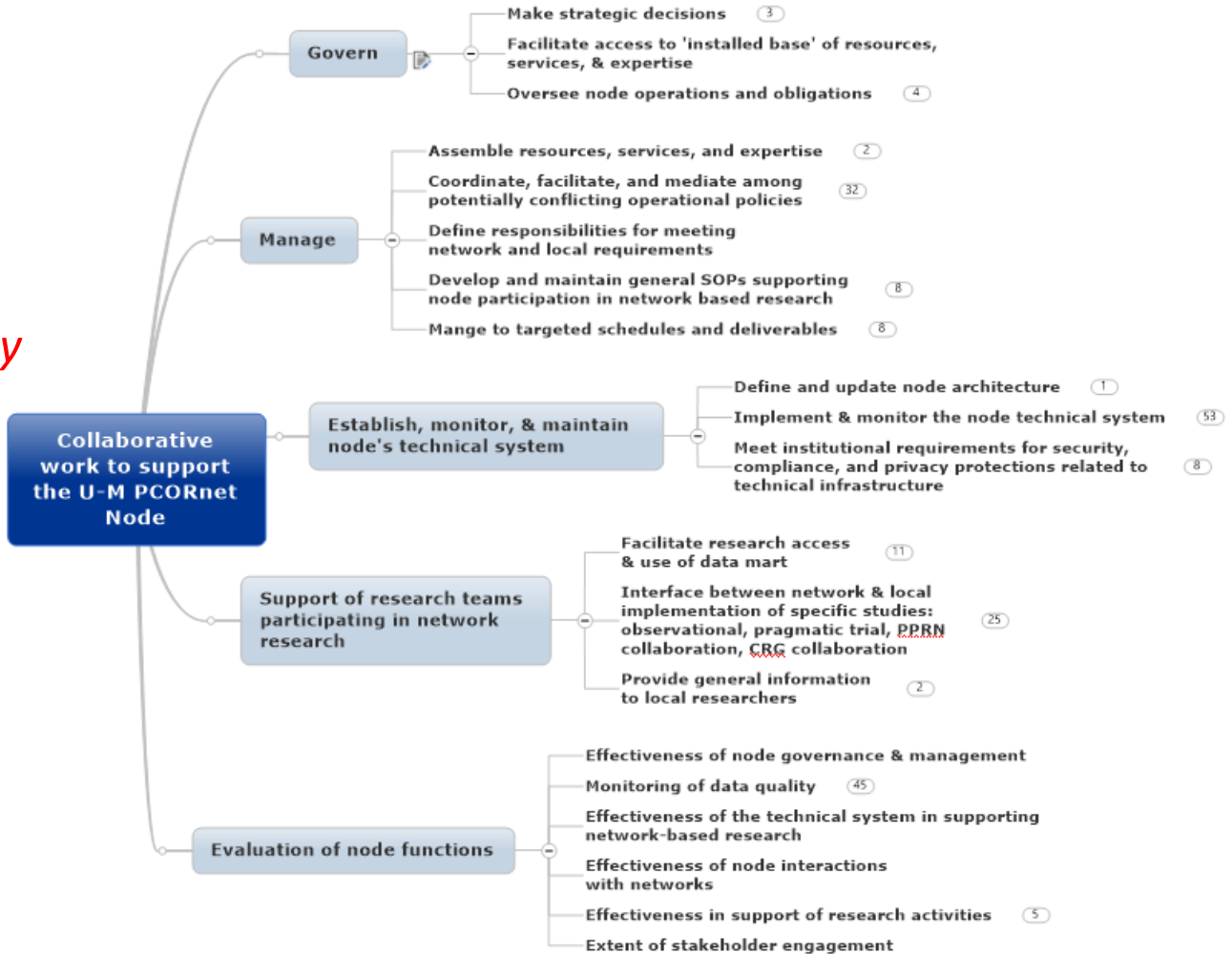


## Categories of node-level work



The work in more detail

*This is all largely invisible work!*



# Framework: Infrastructuring for Work

## Infrastructuring for the “Long Now”

| Work Efforts              | Enacting Technology & Informatics   | Organizing the Work   | Institutionalizing the Node Infrastructure  |
|---------------------------|---|---|---|
|                           | <ul style="list-style-type: none"> <li>*Secure connection from datamart to PopMedNet (PMN)</li> <li>*Develop and maintain a datamart conformant with the common data model</li> </ul> | <ul style="list-style-type: none"> <li>*Meet coordinating committee policies &amp; expectations</li> <li>*Align, Leverage, Develop, Mediate, Reconcile local work &amp; policy with network requirements</li> </ul> | <ul style="list-style-type: none"> <li>*Embed node infrastructure into institutional infrastructure</li> <li>*Embed network research processes in local research processes</li> </ul> |
| Governance                |   |   |   |
| Management                |   |   |   |
| Technology & Informatics  |   |   |   |
| Support of Research Teams |   |   |   |
| Evaluation                |   |   |   |



# Our Contribution

- Identified a classification of node level work efforts that generalized to other nodes on this FRN
- Mapped work efforts and team configurations to an established theoretical perspective, currently missing in health care FRN literature
- The framework we generated may guide others in strategic planning; infrastructuring as design and sustainability
- We demonstrated the importance of infrastructuring from sociotechnical perspective, thereby surfacing the "invisible" work of aligning, leveraging, developing and mediating



- Thanks for your attention
- Comments welcome
- Feel free to contact us
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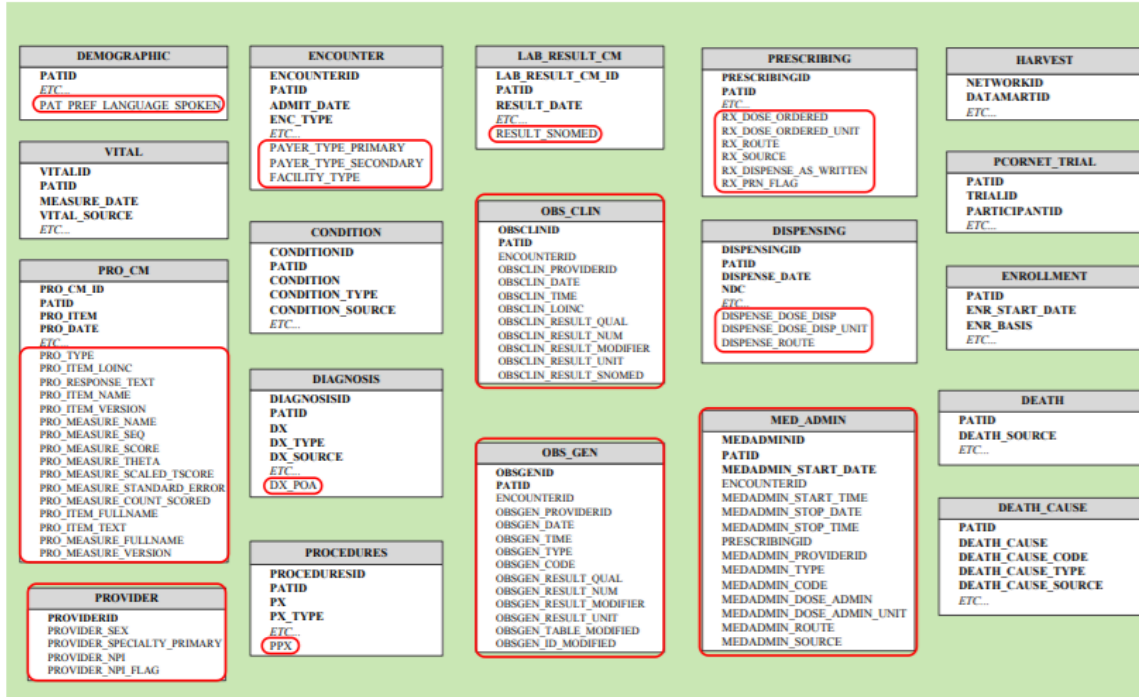




# Centralized Technical Network

## PCORnet Common Data Model v4.0

New to v4.0



**Bold font** indicates fields that cannot be null due to primary key definitions or record-level constraints.



# Example: Infrastructuring for Data Sharing

Data sharing infrastructure for the 'long now'

- Technical system connection with local system
- Use and sharing of PHI data
  - Federally regulated e.g., DHHS and FDA
  - State regulations vary
  - Local node policies vary
- Required extensive work with security, compliance, IRB, legal departments within and across node and network level
- We generated reusable artifacts now in use for other networks



# Example: Infrastructuring to Support Research Teams

- Teams are dynamic
- Those doing the IT and informatics work are not typically identified as research team members, yet they share enormous responsibility for the integrity of the research
- The work is invisible to researchers (“Isn’t it just IT?”)
- Infrastructuring for research network participation and sustainability is not written into grants

