

PCORnet PPRN Partner Meeting



Welcome!

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PCORnet Data Infrastructure and PPRN Needs

Jeff Brown and Lesley Curtis

***Data Standards, Security, and Network
Infrastructure Task Force***



PCORnet Distributed Research Network Aims

- Create a research-ready PCORnet Distributed Research Network (DRN)
 - 11 Clinical Data Research Networks
 - 18 Patient-Powered Research Networks
 - Other interested participants
- Leverage evolving resources and capabilities of HHS existing multipurpose clinically embedded networks, electronic data, and clinical research initiatives

Data Standards, Security & Network Infrastructure Task Force

Key responsibilities

- Create a distributed research network capable of supporting rapid, efficient, and reproducible multi-network research
- Ensure that CDRNs/PPRs maintain physical and operational control over their data
- Use distributed analysis methods that minimize the need to share patient level data

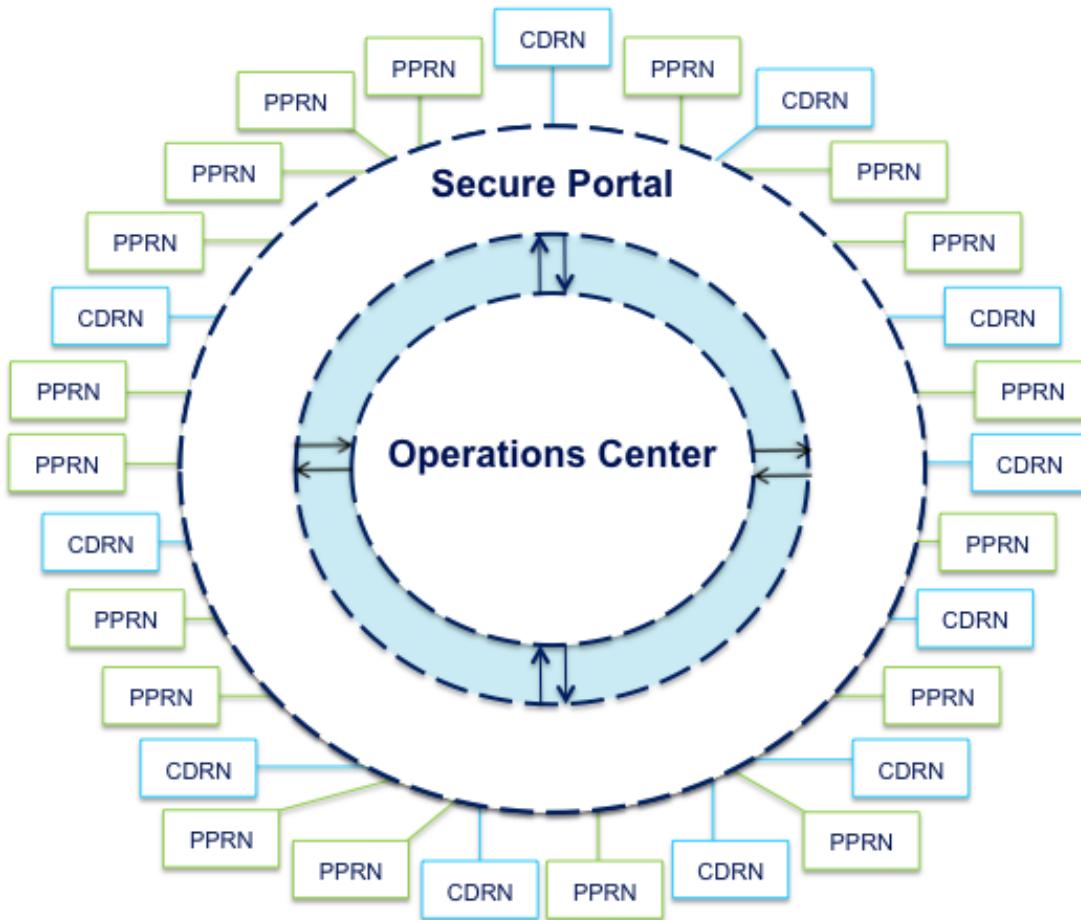
Topics for today

What is a distributed research network?

- What does it mean to be part of a distributed research network?
- What does it mean to “query” a distributed research network?

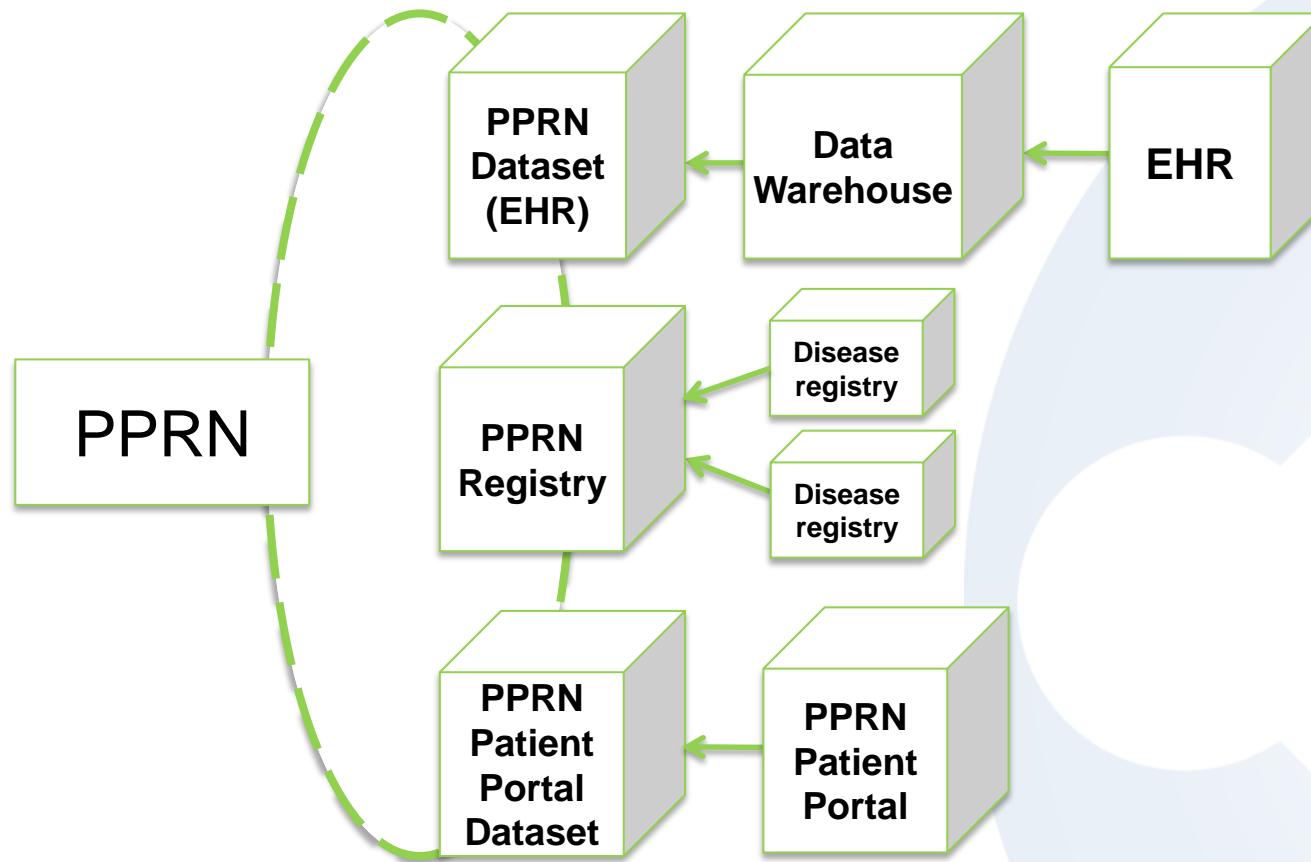
How will we standardize data across PPRNs?

What is a distributed research network?

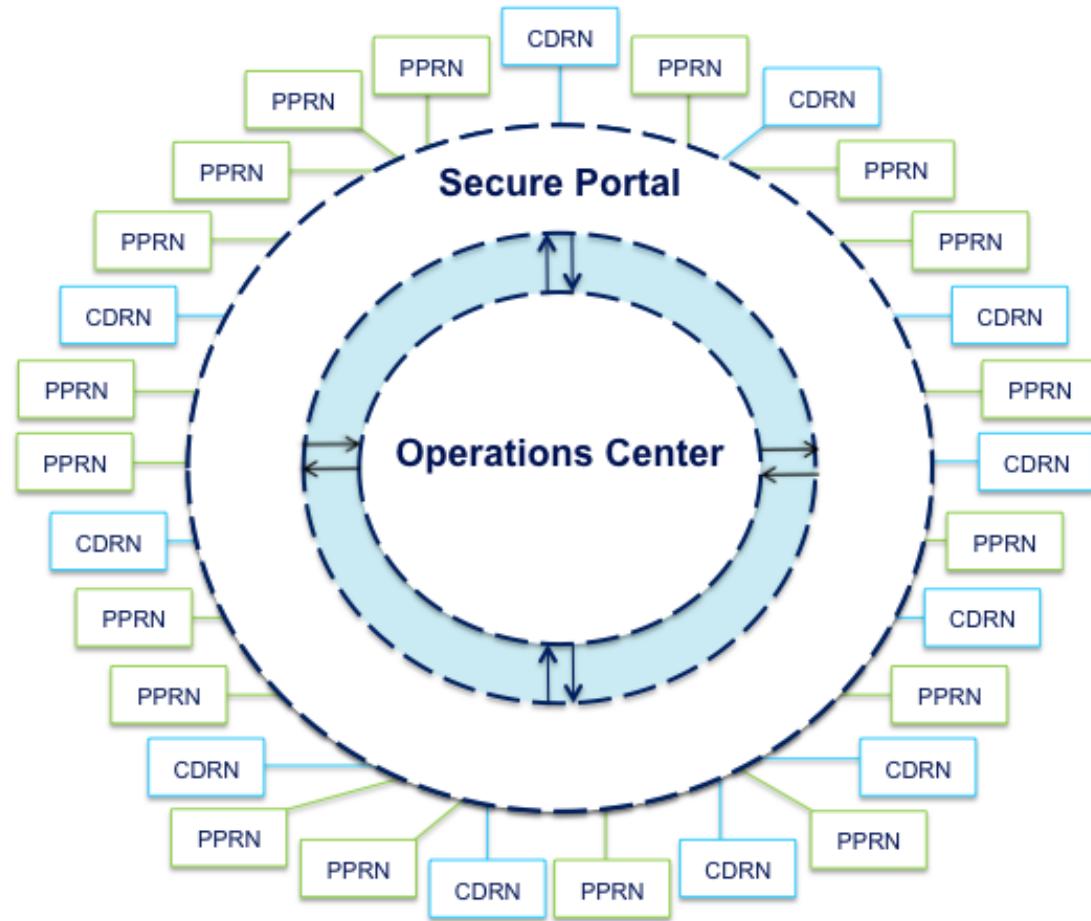


- CDRNs
- PPRNs
- Guiding principles
- Standardized data
- Secure portal
- Operations Center with querying capability

PPRNs bring different kinds of data to PCORnet



What does it mean to query the PCORnet DRN?

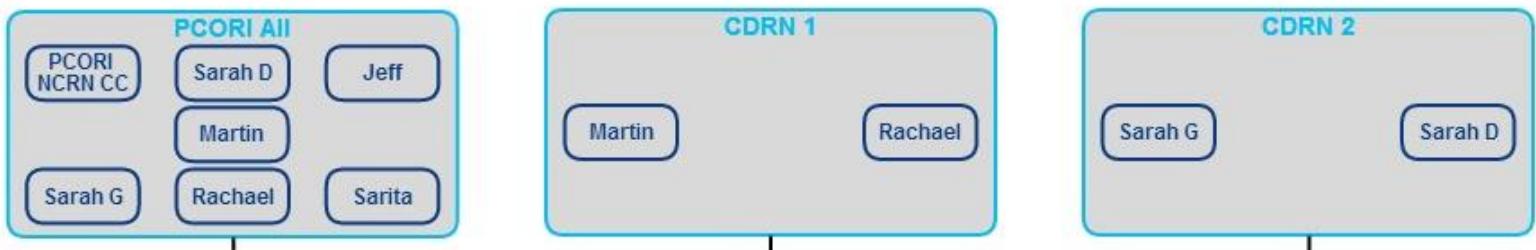


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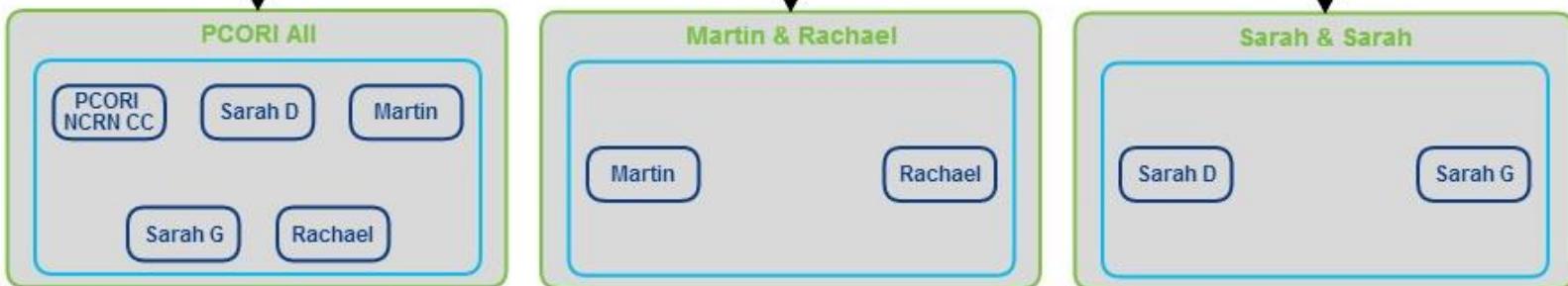
Organizations



Groups



Projects



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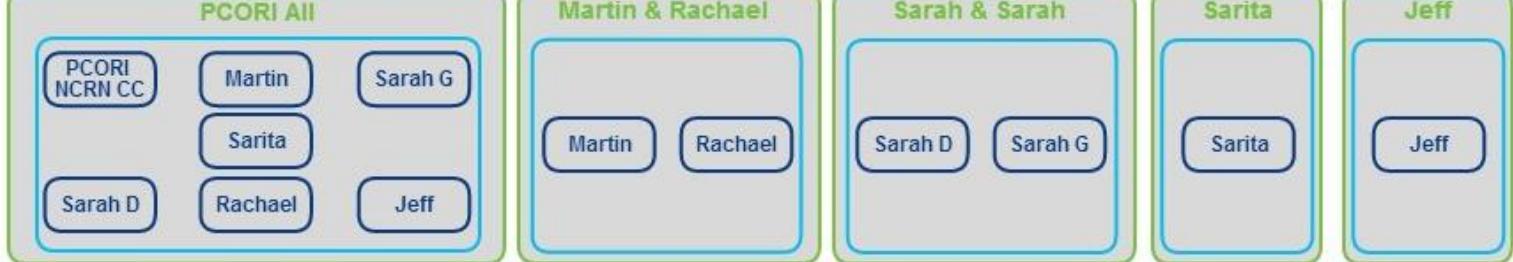
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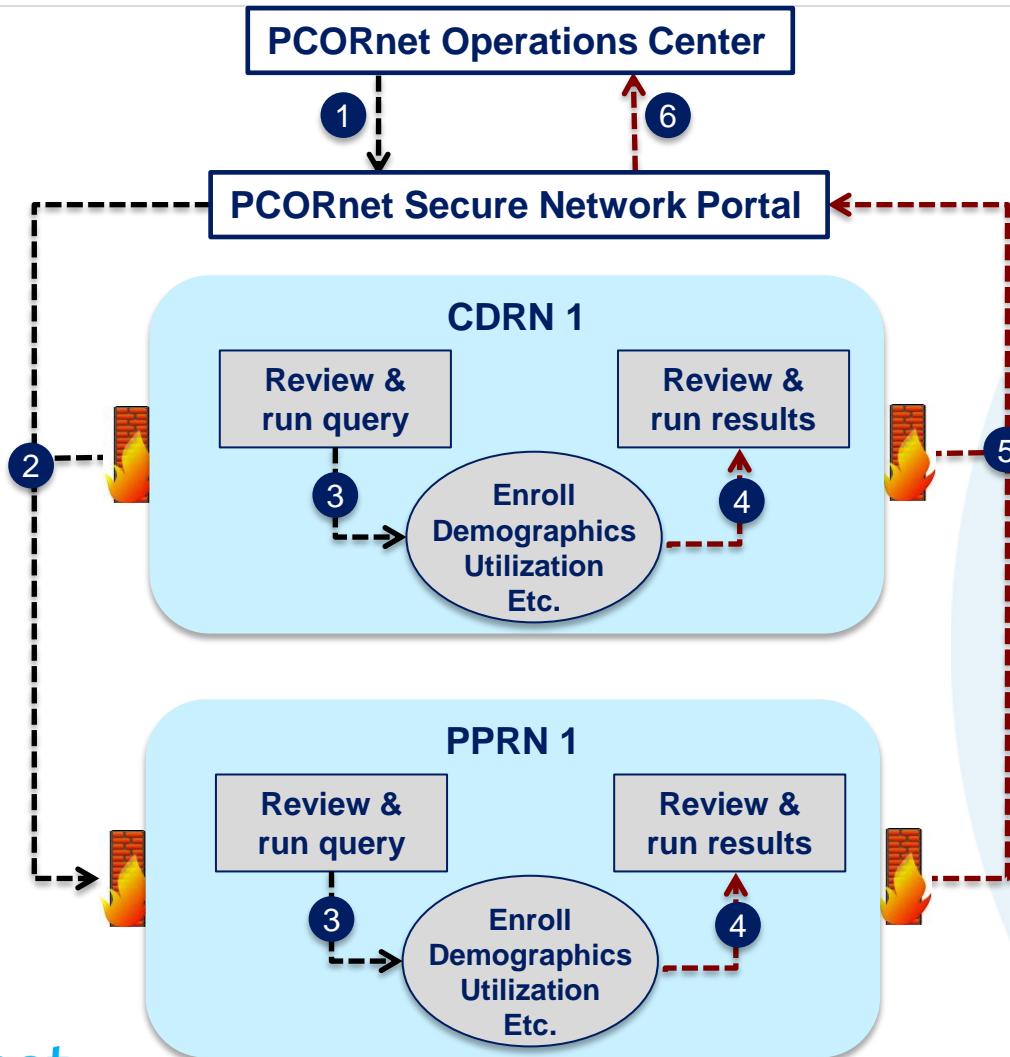
Groups



Projects



PCORnet Distributed Analysis



- 1- User creates and submits query (a computer program)
- 2- Data partners retrieve query
- 3- Data partners review and run query against their local data
- 4- Data partners review results
- 5- Data partners return results via secure network
- 6 Results are aggregated

CDRN and PPRNs maintain physical and operational control over their data

- Distributed approach allows partners to maintain control of their data and all uses
- Partners have option to review requests before execution and review results before release
- No need to change local workflow related to release of information
- All activities secure and audited

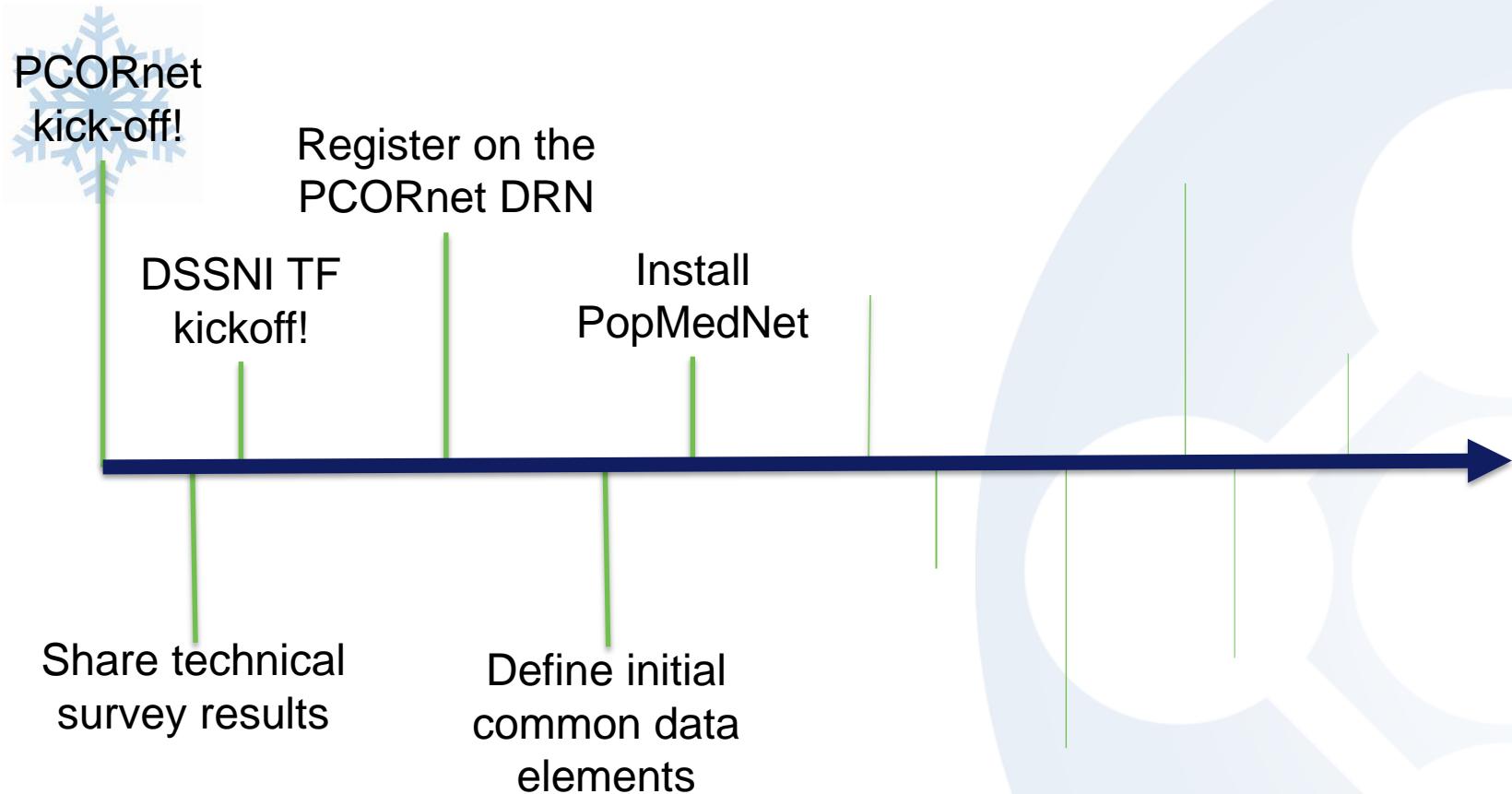
A few things to keep in mind when selecting an approach to data capture

- ➊ Whatever you choose should **support your needs** and produce a database that can be **analyzed using non-proprietary software**.
- ➋ Consider open source platforms
- ➌ Learn from each other!

How will we standardize data across the PPRNs?

- ➊ Learn about the kinds of data that PPRNs are bringing to PCORnet
- ➋ Begin with data that are common to many PPRNs
 - Demographics
 - Vital signs
 - Diagnoses/conditions
 - Others?
- ➌ Develop standardized definitions of common data elements
 - Use existing standards whenever possible

What's next?



Thank you!



Adjourn and Picking Up Tomorrow

- 🕒 Tomorrow's webinar will begin at 8am
- 🕒 Separate registration is required for those listening in online, please do so on pcori.org in the Meetings & Events section. You will receive a separate link.
- 🕒 See you tomorrow!