

PCORnet PPRN Partner Meeting



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The National Patient-Centered Clinical Research Network

Welcome!

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PCORnet Data Infrastructure and PPRN Needs

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Data Standards, Security, and Network Infrastructure Task Force



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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

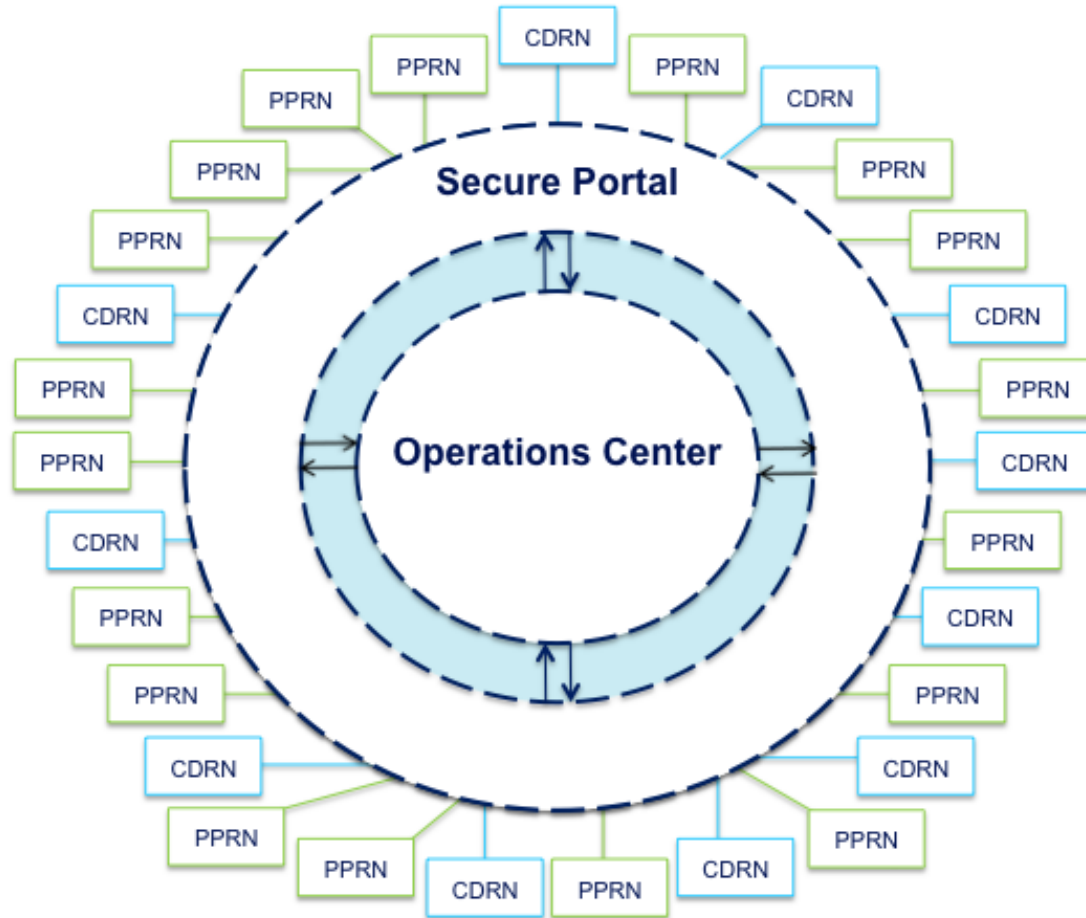
Key responsibilities

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

Topics for today

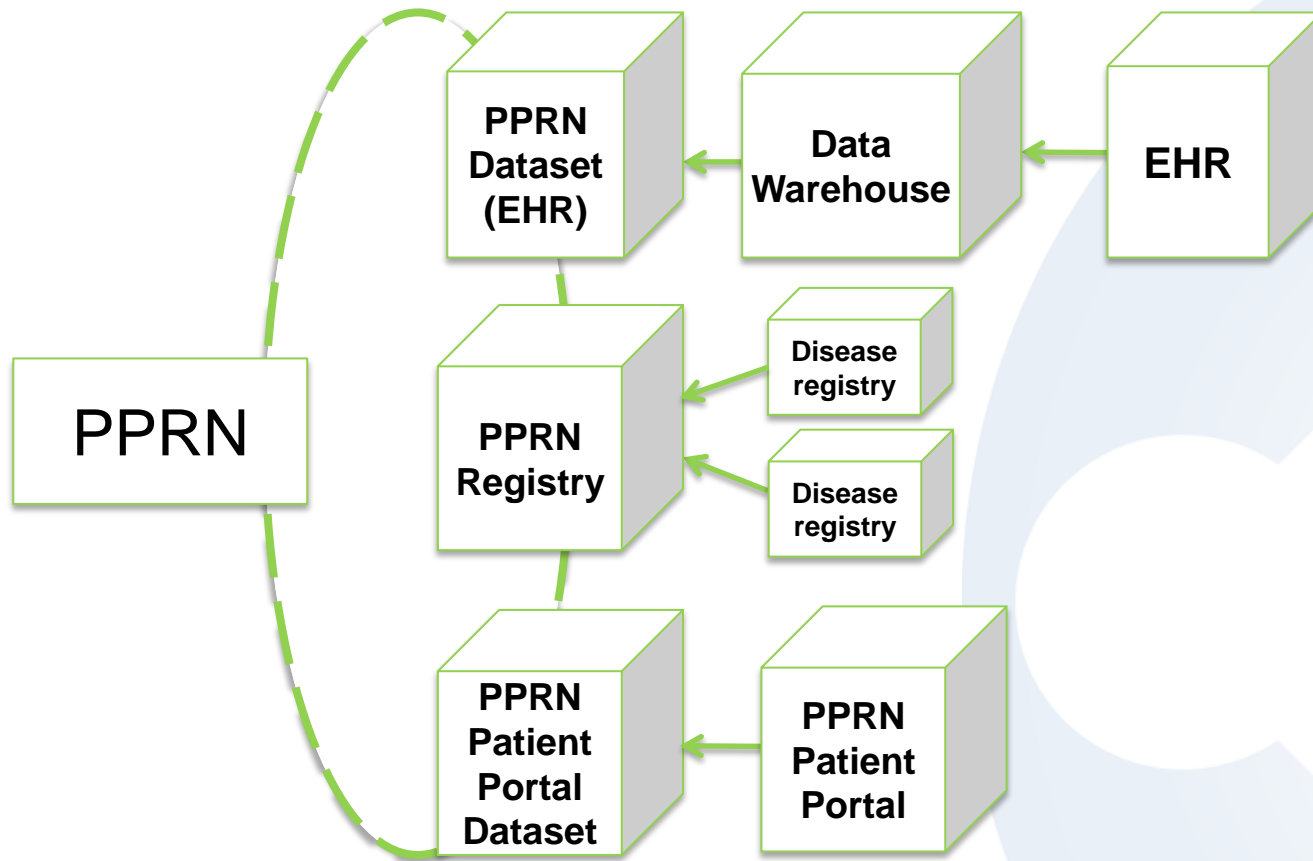
- ⦿ What is a distributed research network?
 - What does it mean to be part of a distributed research network?
 - What does it mean to “query” a distributed research network?
- ⦿ How will we standardize data across PPRNs?

What is a distributed research network?

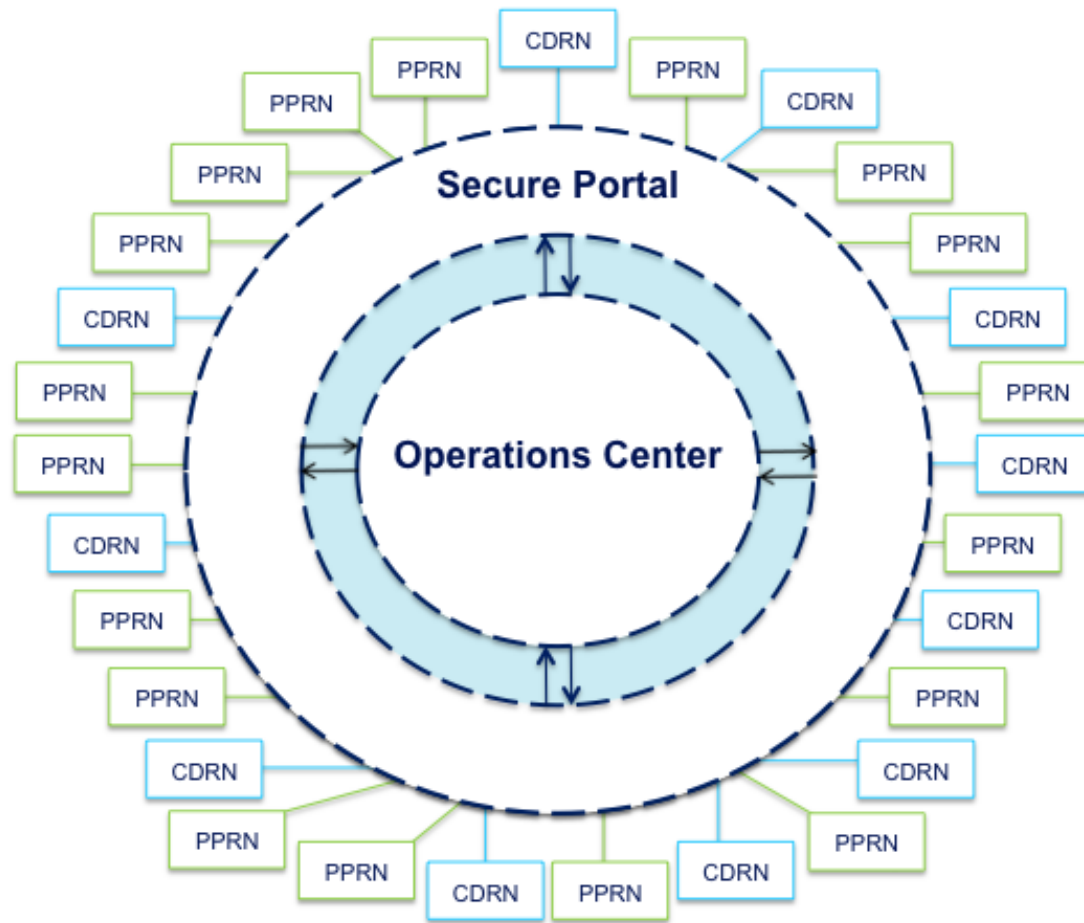


- CDRNs
- PPRNs
- Guiding principles
- Standardized data
- Secure portal
- Operations Center with querying capability

PPRNs bring different kinds of data to PCORnet



What does it mean to query the PCORnet DRN?

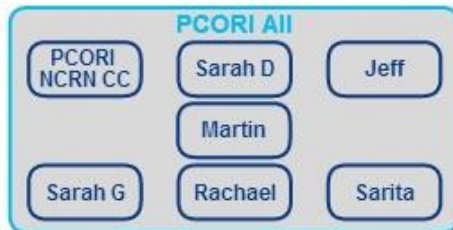


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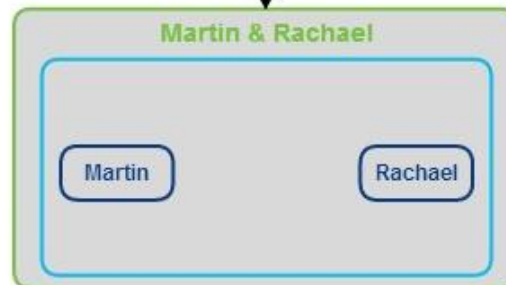
Organizations



Groups



Projects



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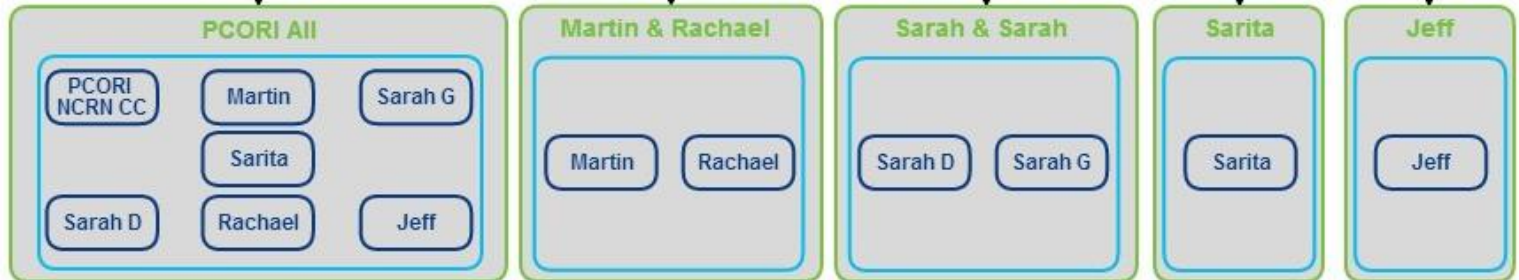
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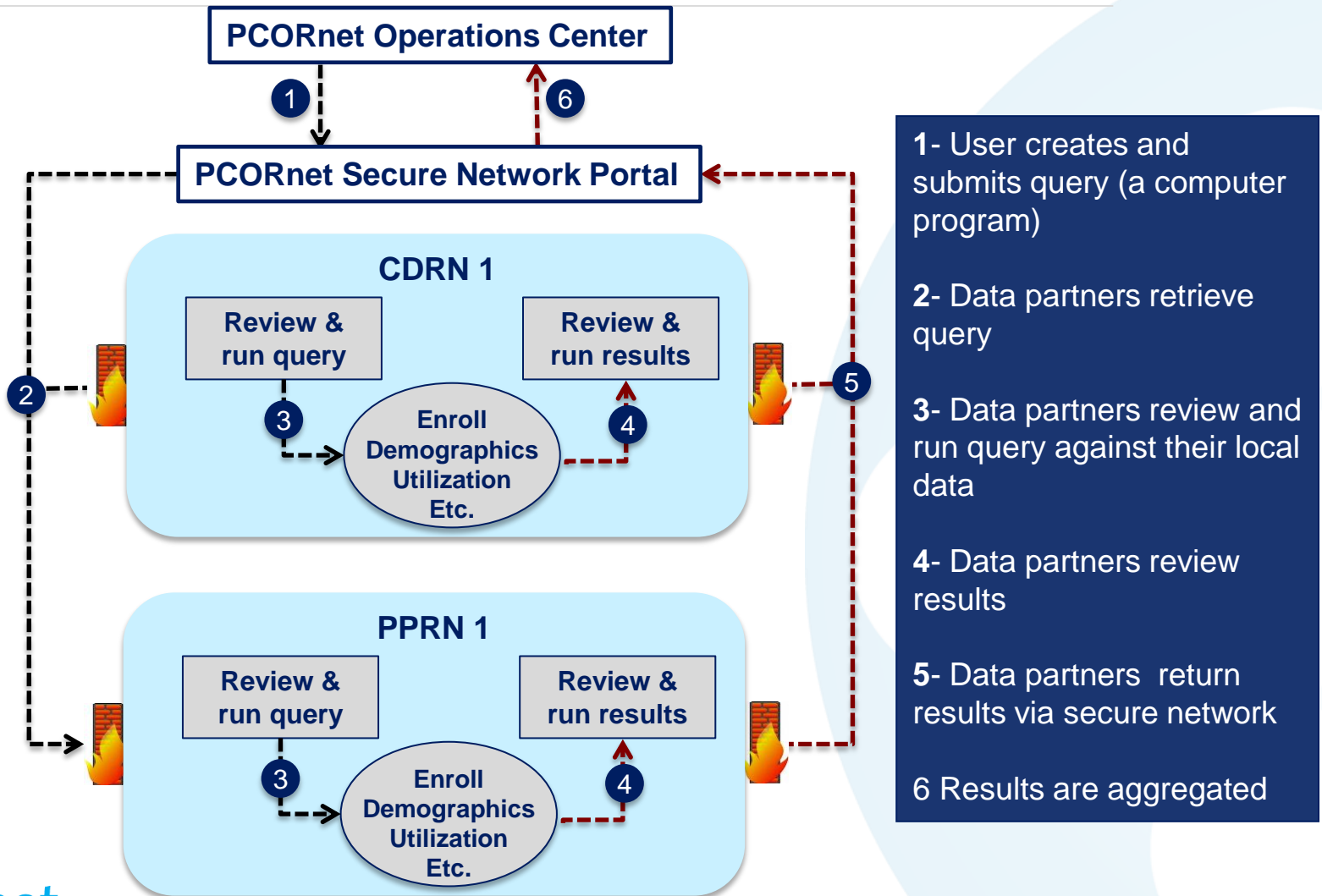
Groups



Projects



PCORnet Distributed Analysis



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

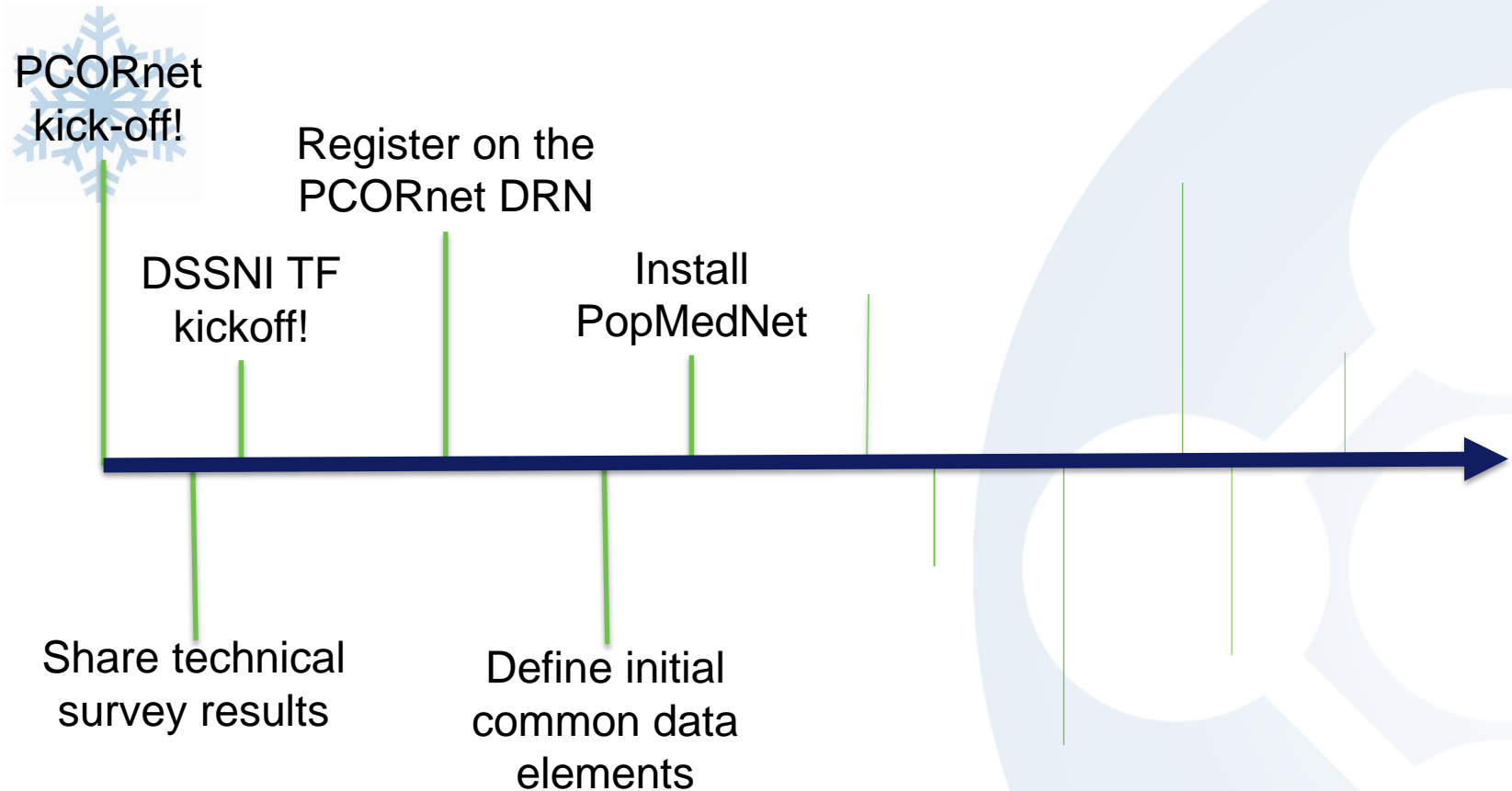
A few things to keep in mind when selecting an approach to data capture

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

How will we standardize data across the PPRNs?

- 🌐 Learn about the kinds of data that PPRNs are bringing to PCORnet
- 🌐 Begin with data that are common to many PPRNs
 - Demographics
 - Vital signs
 - Diagnoses/conditions
 - Others?
- 🌐 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!