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SOCIETY FOR CLINICAL TRIALS

# Taking the Next Steps with PCORnet®: A Deep Dive into the PCORnet® Network, Common Data Model, and Engagement Resources

Moderator: Gustavo Jimenez-Maggiora

Presenters: Adrian Hernandez, Lauren Cohen, Keith Marsolo, Rowena Dolor

# Today's Faculty



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# On Today's Webinar

- Our presenters will cover:
  - Ways that PCORnet® Supports Research
  - A Deeper Dive into the Components of the PCORnet® Common Data Model
  - Resources for Stakeholder Engagement

# Before We Begin Our Presentations...

- We will hold a Q&A session after today's presentations.
- We encourage all webinar attendees to submit questions via the Question Box.
- If we don't get to your questions today, we will follow up with you after the webinar via email.
- Today's webinar is being recorded and will be available to SCT members in the Members-Only Area of the SCT website.

# Taking the Next Steps with PCORnet®: A Deep Dive into the PCORnet® Network, Common Data Model, and Engagement Resources



January 15, 2025

*PCORnet® is intended to improve the nation's capacity to efficiently conduct patient-centered health research, particularly comparative clinical effectiveness research (CER), by providing a large, highly representative network of health data, research expertise, and patient insights. PCORnet has been developed with funding from the Patient-Centered Outcomes Research Institute® (PCORI®).*

# Disclosures

- Lauren Cohen – Nothing to Disclose
- Rowena Dolor – Nothing to Disclose
- Adrian Hernandez – Research and consulting with Boehringer Ingelheim, Boston Scientific Corporation, Bristol Myers Squibb, Cytokinetics, Inc., Eidos Therapeutics, GlaxoSmithKline, Intellia, Intercept, MyoKardia, Novartis, Novo Nordisk, Prolaio, TikkunLev Therapeutics, Inc
- Keith Marsolo – Nothing to Disclose

# Supporting Research in PCORnet®



Lauren Cohen, MA

Associate Director  
Duke Clinical Research Institute  
Duke University School of Medicine



# Unite data and communities for faster, more targeted research

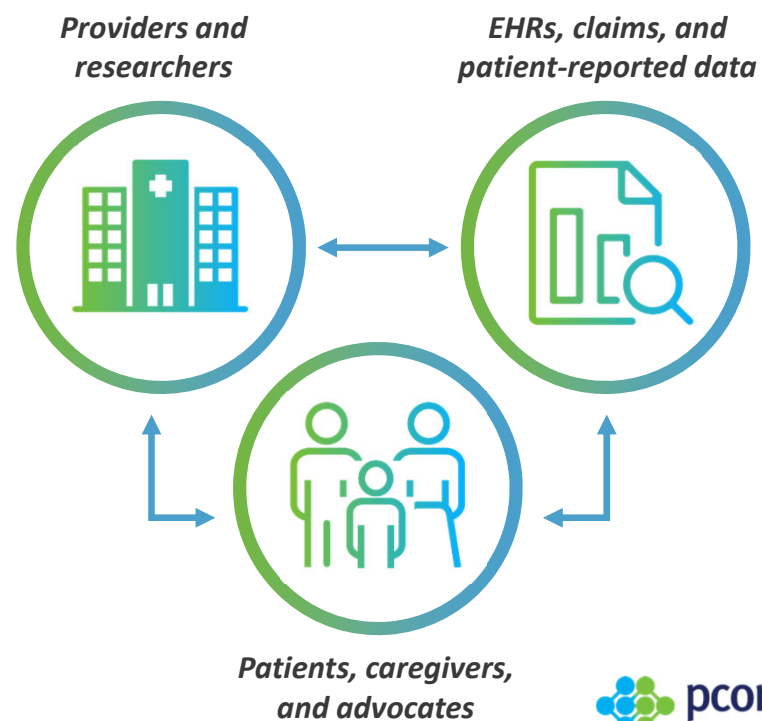
## One PCORnet, Many Possibilities

PCORnet is a national resource where high quality health data, patient partnership, and research expertise deliver fast, trustworthy answers that advance health outcomes.

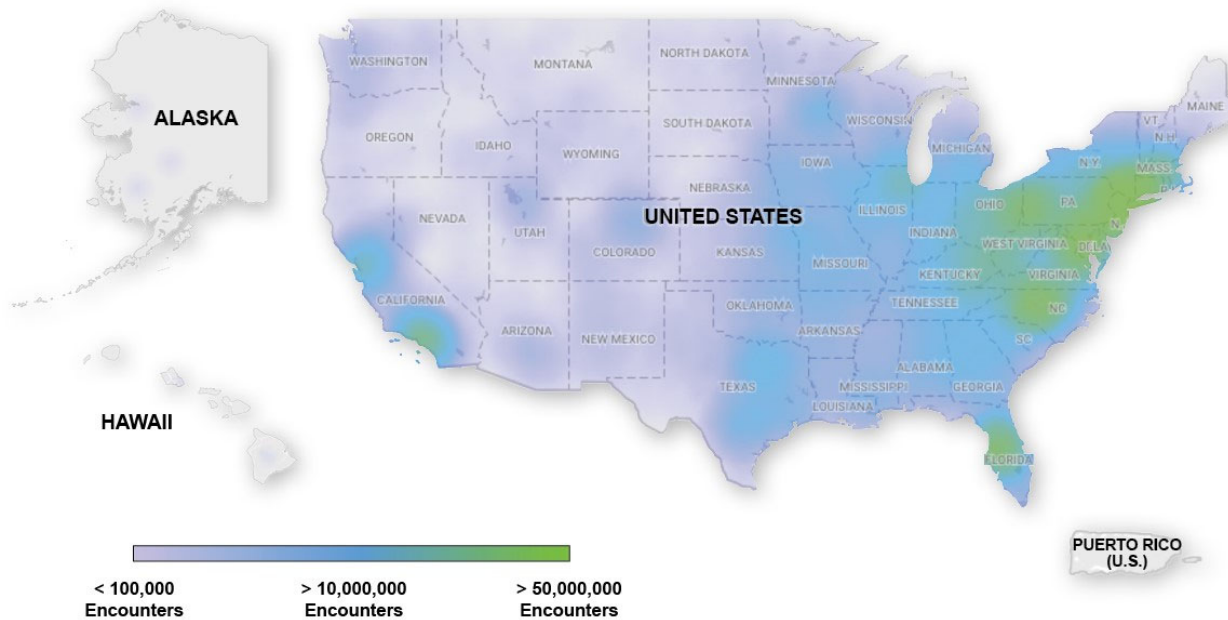
- **Real-world evidence studies**
- **Comparative effectiveness research**
- **Population health research**
- **Pragmatic research**
- **Health systems research**
- **And more**

## More Than a Data Network

Access to **patient insights** and **thousands of clinicians** with expert knowledge of PCORnet-enabled data = meaningful research targets and faster answers.



# PCORnet is connected to data from everyday health care encounters with more than 47 million people across the U.S. each year



## PCORnet Population (2023)

### Number of Unique Patients

- 47,658,522

### Race

- 1% American Indian or Alaska Native
- 4% Asian
- 15% Black or African American
- <1% Native Hawaiian or Other Pacific Islander
- 62% White
- 1% Multiple Race
- 2% Refuse to answer
- 10% Other/Missing/Unknown

### Ethnicity

- 69% Non-Hispanic
- 15% Hispanic
- 1% Refuse to answer
- 8% Other/Missing/Unknown

### Socioeconomic Status by 5-digit Zip Code\*

- 33% Quartile 1
- 18% Quartile 2
- 20% Quartile 3
- 16% Quartile 4
- 13% Address missing

# Research in PCORnet®

PCORnet is a national resource where high-quality health data, patient partnership, and research expertise delivers fast, trustworthy answers that advance health outcomes.



Morbidity and Mortality Weekly Report (MMWR)

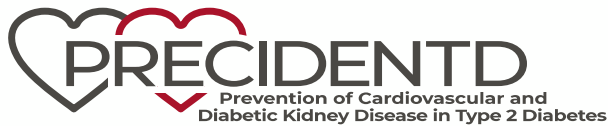
Cardiac Complications After SARS-CoV-2 Infection and mRNA COVID-19 Vaccination — PCORnet, United States, January 2021–January 2022

Research

Completed; PCORI Public and Professional Abstracts, and Final Research Report Posted

Has Results

Comparing Three Types of Weight Loss Surgery -- The PCORnet® Bariatric Study



PREVENTABLE

PRagmatic EVAluation of evENTs And Benefits of Lipid-lowering in oldEr adults



Healthcare Worker Exposure Response & Outcomes



# PCORnet<sup>®</sup> Research Designs

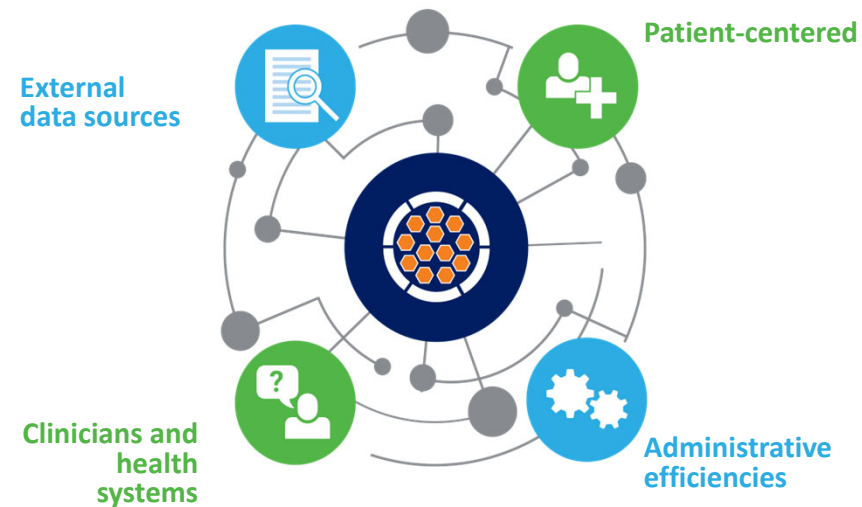
- Prospective, interventional pragmatic randomized clinical trials
- Data-only (retrospective or prospective)
- Surveillance studies

- Characteristics of PCORnet<sup>®</sup> research:

- Patient-centered
- Leverage real-world data
- Engaged clinicians and health systems
- Administrative efficiencies and rapid study start-up

- **Anyone can access PCORnet and the PCORnet<sup>®</sup> Front Door – it's a national resource**

- You don't have to be a member to utilize the Network as either a funder or a researcher who is developing a proposal
- PCORnet<sup>®</sup> projects often include a mix of sites that are part of PCORnet, as well as sites that are not



# The PCORnet® Front Door

## The Front Door is the Access Point for PCORnet Resources & Services

A “knock” on the Front Door can also support:

### Study Design

- Preliminary data for proposals, effect sizes and potential study power

### Connections to Network Collaborators

- Partners to co-design research
- People with specific expertise

### PCORnet® Study Support

- Deeper partnership with PCORnet provides access to best practice sharing, patient engagement, and transparent quality improvement initiatives



[Learn More About the Front Door](#)

# Connecting with PCORnet®

## Network Collaborator Request

- The Front Door connects requestors with collaborators within the Network. Requestors can seek sites for funded studies, partners to co-design research leveraging PCORnet, or find people with specific expertise.
  - The Front Door team shares information about the opportunity with the Network
  - We support you to host an informational webinar to the Network
  - You present and answer questions
  - Interested sites and parties respond to us and we share the list with you
- Sites decide on a study-by-study basis if they want to participate or not
- Can be helpful to have a PCORnet 'champion' if you/your institution is not familiar with the Network

# Connecting with PCORnet®

## Study Feasibility Data

- For imminent funding opportunities, PCORnet can provide preliminary data to
  - Determine study feasibility
  - Provide data for proposals
  - Identify eligible sites
- Queries generally take ~8 weeks to return data

**Table 1.** Demographic characteristics of the intellectual and developmental disabilities cohort across data-contributing partners participating in PCORnet (October 2019 – October 2022).

|   | ADHD <sup>1</sup> | Autism Spectrum Disorder | Inborn Metabolic Disorders presenting with ID <sup>1</sup> | Intellectual Disability, Coded | Cerebral Palsy | Congenital Malformations of the Brain | Down Syndrome | Other Conditions presenting with ID <sup>1</sup> | Spina Bifida  | Fetal Alcohol Syndrome | Fragile X Syndrome |
|---|-------------------|--------------------------|--|--------------------------------|----------------|---------------------------------------|---------------|--|---------------|------------------------|--------------------|
| <b>Number of unique patient records<sup>2</sup></b> | 1,074,213         | 321,700                  | 126,235  | 118,631                        | 98,716         | 77,534                                | 51,373        | 49,813   | 44,563        | 4,561                  | 2,844              |
| <b>Mean Age (SD)</b>                                | 24.65 (14.04)     | 15.17 (10.09)            | 46.44 (21.91)  | 32.88 (16.77)                  | 25.03 (16.16)  | 18.56 (16.90)                         | 18.75 (14.46) | 19.45 (15.93)                                    | 28.75 (17.97) | 18.59 (10.30)          | 25.80 (16.50)      |
| <b>Female</b>                                       | 42%               | 24%                      | 56%  | 42%                            | 45%            | 50%                                   | 47%           | 50%  | 60%           | 46%                    | 28%                |
| <b>Race</b>   |                   |                          |  |                                |                |                                       |               |  |               |                        |                    |
| White   | 75%               | 64%                      | 74%  | 64%                            | 64%            | 62%                                   | 67%           | 69%  | 71%           | 64%                    | 73%                |
| Black or African American                           | 12%               | 14%                      | 10%  | 20%                            | 17%            | 16%                                   | 11%           | 9%   | 11%           | 19%                    | 10%                |
| American Indian or Alaska Native                    | 1%                | 1%                       | 0%   | 1%                             | 0%             | 1%                                    | 0%            | 0%   | 1%            | 4%                     | 0%                 |
| Asian   | 1%                | 4%                       | 2%   | 2%                             | 2%             | 3%                                    | 3%            | 3%   | 3%            | 1%                     | 1%                 |
| Native Hawaiian or Other Pacific Islander           | 0%                | 0%                       | 0%   | 0%                             | 0%             | 0%                                    | 0%            | 0%   | 0%            | 0%                     | 0%                 |
| Multiple Races <sup>3</sup>                         | NA                | NA                       | NA   | NA                             | NA             | NA                                    | NA            | NA   | NA            | NA                     | NA                 |
| Other <sup>3</sup>                                  | 11%               | 18%                      | 13%  | 13%                            | 15%            | 18%                                   | 19%           | 17%  | 15%           | 12%                    | 16%                |
| <b>Hispanic</b>                                     |                   |                          |  |                                |                |                                       |               |  |               |                        |                    |
| Yes   | 10%               | 17%                      | 11%  | 14%                            | 15%            | 18%                                   | 20%           | 16%  | 15%           | 10%                    | 14%                |
| No  | 81%               | 74%                      | 77%  | 80%                            | 79%            | 76%                                   | 72%           | 78%  | 78%           | 85%                    | 76%                |
| Other   | 9%                | 9%                       | 12%  | 7%                             | 7%             | 6%                                    | 7%            | 7%   | 7%            | 5%                     | 10%                |
| <b>Area Deprivation Index (ADI)<sup>4</sup></b>     |                   |                          |  |                                |                |                                       |               |  |               |                        |                    |
| SES Q1  | 34%               | 30%                      | 33%  | 23%                            | 26%            | 27%                                   | 31%           | 34%  | 28%           | 29%                    | 31%                |
| SES Q2  | 19%               | 17%                      | 19%  | 18%                            | 17%            | 17%                                   | 17%           | 17%  | 19%           | 19%                    | 18%                |
| SES Q3  | 19%               | 19%                      | 21%  | 24%                            | 22%            | 21%                                   | 19%           | 19%  | 23%           | 20%                    | 18%                |
| SES Q4  | 13%               | 14%                      | 13%  | 19%                            | 16%            | 16%                                   | 14%           | 13%  | 15%           | 12%                    | 12%                |
| Missing   | 16%               | 20%                      | 14%  | 16%                            | 18%            | 18%                                   | 19%           | 17%  | 15%           | 20%                    | 20%                |
| <b>Healthcare Utilization in the Past 3 Years</b>   |                   |                          |  |                                |                |                                       |               |  |               |                        |                    |
| Ambulatory  | 95%               | 94%                      | 97%  | 95%                            | 95%            | 95%                                   | 94%           | 96%  | 95%           | 94%                    | 94%                |
| Emergency Department                                | 27%               | 26%                      | 29%  | 34%                            | 31%            | 34%                                   | 22%           | 28%  | 31%           | 35%                    | 19%                |
| Inpatient   | 8%                | 10%                      | 19%  | 19%                            | 23%            | 31%                                   | 18%           | 25%  | 27%           | 15%                    | 11%                |
| Telehealth  | 47%               | 47%                      | 45%  | 49%                            | 45%            | 47%                                   | 33%           | 47%  | 42%           | 46%                    | 47%                |

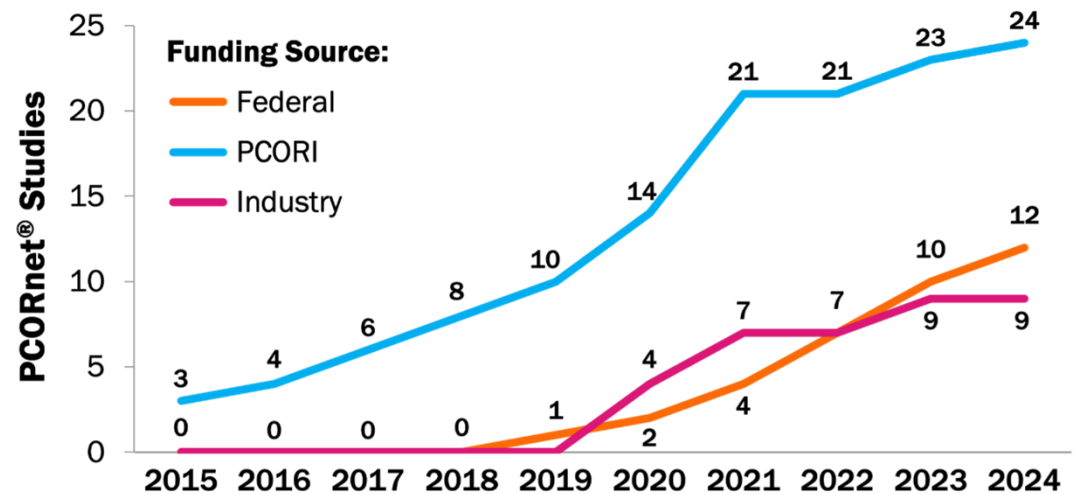


# PCORnet® Studies by Funding Source

Total PCORnet® Studies as of December 1, 2024 = 51

## ○ PCORnet® Studies are committed to the following:

1. Using two or more PCORnet® Clinical Research Networks, or “CRNs”
2. Ensure that participants and patients are engaged throughout the project lifecycle
3. Are committed to broad dissemination of findings and returning study results to participants
4. Agree to share study progress, performance metrics, and best practices with the Network regularly
5. Leverage the PCORnet® Common Data Model as appropriate



PCORnet® Studies are attributed to the year they are funded.  
Data as of August 1, 2024.

The PCORnet® Front Door facilitates the application process

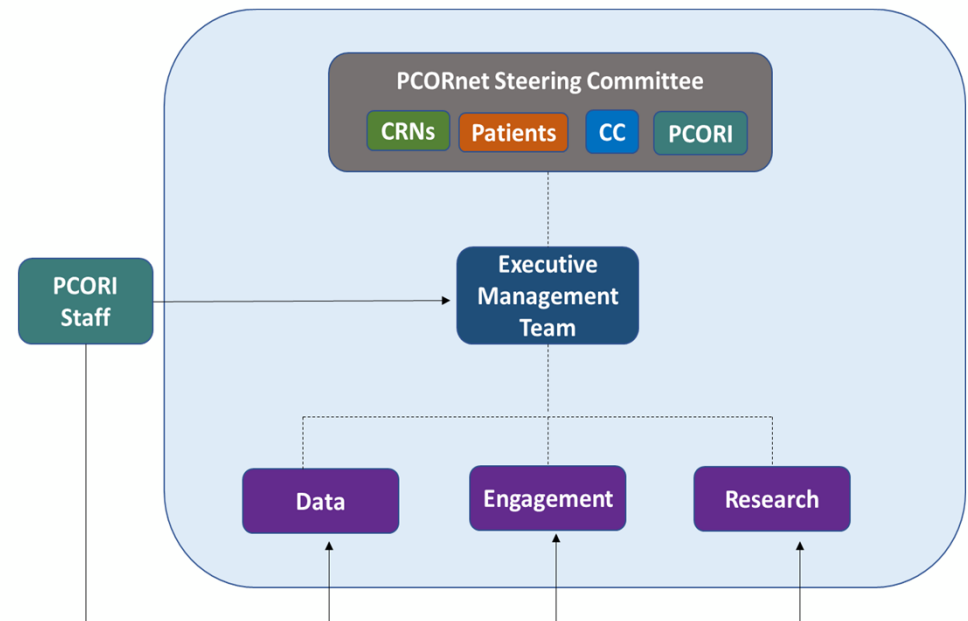




# Other Ways PCORnet<sup>®</sup> Supports Research

Engaged Community with Administrative Efficiencies and Benefit of Experience

- Master Data Sharing Agreement and pre-negotiated study-specific Data Sharing Agreement
- Agreement to use NIH SMART (Single) IRB
- Master clinical trials template
- Governing bodies support all components of PCORnet<sup>®</sup> Studies



# One Example: PREVENTABLE

(PRagmatic EVALuation of evENTs And Benefits of Lipid-lowering in oldEr adults)

## The Question

*Can taking a commonly used heart medication prevent dementia in adults over the age of 75?*

## Strength of PCORnet®

A “one stop shop” for capturing 3 complementary sources of data (Medicare, EHR, & survey)

## Study Snapshot

- **Pragmatic trial**
- **20,000 patients** aged 75 and older
- **100 U.S. sites** partnered with PCORnet & the National Veterans Affairs Network
- **Pragmatic design** used existing EHR/Medicare data plus phone surveys. Medications shipped directly to patients

## The PCORnet® History

2017: NHLBI requests and works with the Front Door on a **feasibility query** to inform possible RFA

2018: RFA released. Front Door works with investigator responding to the RFA on a **feasibility query**, a **Network collaborator request** to identify interested sites, and proposal development. **Patient partner** panel organized.

2019: Proposal submitted and awarded. Study becomes a **PCORnet® Study**

2020: Enrollment begins

2023: **Over 9,000** participants enrolled, representing **largest NIA-funded study of older adults** to date!



# A Deeper Dive into the PCORnet<sup>®</sup> Common Data Model



Keith Marsolo, PhD

Professor

Department of Population Health Sciences  
Duke Clinical Research Institute  
Duke University School of Medicine

# PCORnet Data Strategy

- Standardize data into a common data model
- Focus on data quality through data curation
- Operate a secure distributed query infrastructure
  - Develop re-useable tools to generate aggregate counts (prep-to-research queries)
  - Governance to support creation of study-specific extracts of patient-level data
  - Capabilities to link across datasets to obtain more complete outcomes & identify potential overlap
- Learn by doing and repeat

# The PCORnet<sup>®</sup> Common Data Model

For data to be useful, it has to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet<sup>®</sup> Common Data Model deliver fast insights.

## Ready for Research

## Available, But Still Evolving

|                                     |           |                       |                               |  |                 |
|-------------------------------------|-----------|-----------------------|-------------------------------|--|-----------------|
| Demographics                        | Diagnoses | Procedures            | Immunizations                 | Tumor Registry                               | Biosamples      |
| Vital Signs                         | Labs      | Clinical Observations | Social Determinants of Health | Patient-Generated Data                       | Genomic Results |
| Medication Orders & Administrations |           |                       | Patient- Reported Outcomes    | Natural Language Processing Derived Concepts |                 |

Data available from Clinical Research Networks, in the PCORnet<sup>®</sup> Common Data Model and ready for use in research

Data available at some Clinical Research Networks, may or may not be in the PCORnet<sup>®</sup> Common Data Model and require additional work for use in research

# The PCORnet<sup>®</sup> Common Data Model

For data to be useful, it has to be standardized across systems. Frequent data curation and a single language enabled by the PCORnet<sup>®</sup> Common Data Model deliver fast insights.

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Data available from Clinical Research Networks, in the PCORnet<sup>®</sup> Common Data Model and ready for use in research

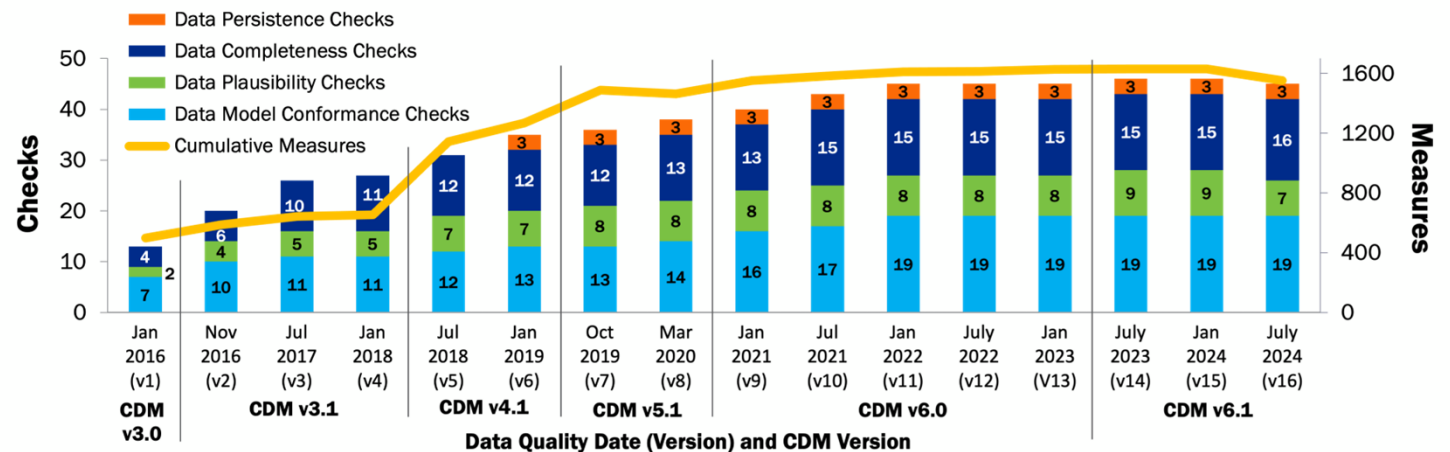
Data available at some Clinical Research Networks, may or may not be in the PCORnet<sup>®</sup> Common Data Model and require additional work for use in research

# Updates as part of PCORnet® CDM v7.0

- Patient-reported outcomes
  - Sites working to load PROMIS measures captured clinically within their health systems
- Social Determinants of health (SDOH)
  - Loading results of patient-level SDOH questionnaires captured within health systems (e.g., food security, housing stability)
  - Implementation of reference files of area-level SDOH measures (e.g., AHRQ SDOH database)
  - Geocoding to support linkage at the zip code and county level (prep-to-research queries), and census tract (studies)
- Patient-generated health data
  - Loading patient-generated health data utilized within health systems (e.g., blood pressure, weight, glucose readings)
- Other changes
  - Inclusion of new fields to capture individual responses for race and ethnicity, aligning with updated guidance from the US Office of Management and Budget (OMB) and allowing more granular summaries of patients with multiple responses
  - Creation of table to denote relationships between patients (e.g., birth mother-child)
  - New table to support patient-reported medications and medications records from other health systems

# Dimensions of Data Quality in PCORnet®

- **Conformance** — Data adhere to the format of the PCORnet® Common Data Model
  - Fields do not contain values outside of the PCORnet® Common Data Model specification
- **Completeness** — Values appear where we expect them
  - Diagnosis codes have an associated diagnosis type (e.g., ICD-9, ICD-10, SNOMED)
- **Plausibility** — Values that appear make sense
  - Less than 5% of records are associated with a future date
- **Persistence** — Patients / records do not disappear between refreshes
  - Less than a 5% decrease in the number of patients or records in a PCORnet® Common Data Model table between refreshes

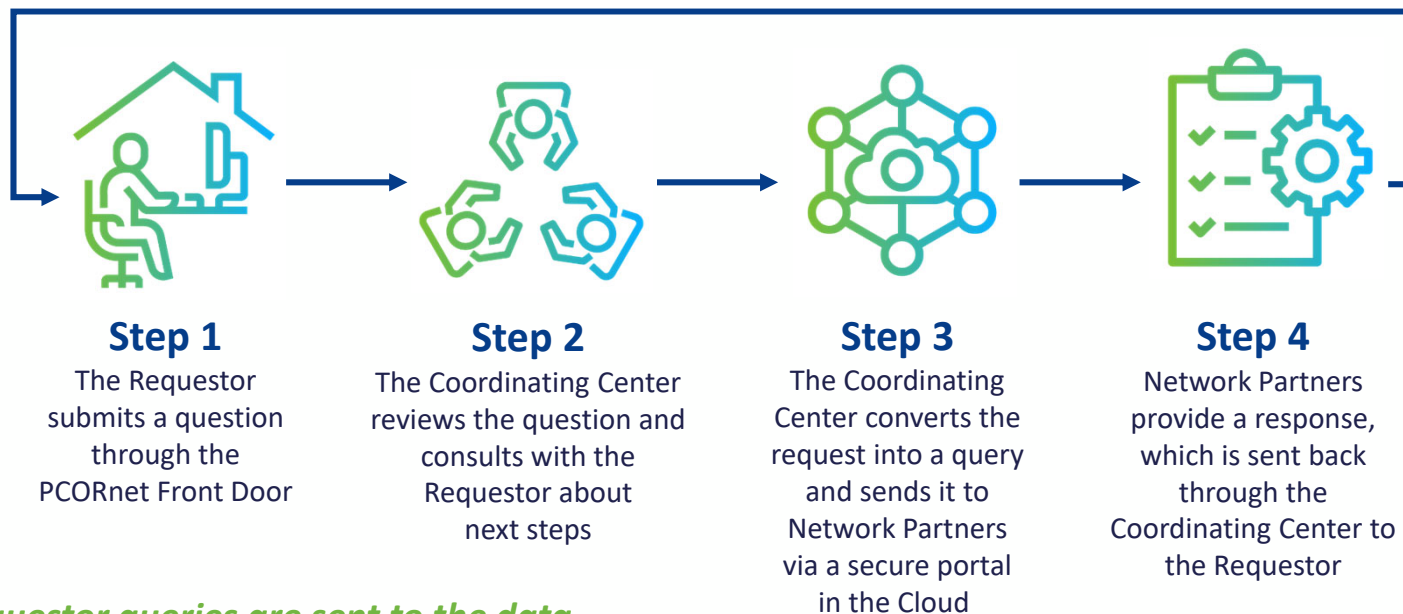


Growth in foundational data quality checks over time. Checks: Rules such as “Values must conform to PCORnet® CDM specifications.”  
 Measures: The number of PCORnet® CDM tables and/or fields affected by the checks. Data as of July 30, 2024.





## Distributed query infrastructure (prep-to-research example)



*Requestor queries are sent to the data — and answers, not data, are sent back to requestors.*

[Read the PCORnet® Privacy Statement](#)

# PCORnet<sup>®</sup> query types

- Univariate statistics from data curation
  - The Coordinating Center for PCORnet<sup>®</sup> has access to hundreds of univariate statistics about data within each Network Partner's PCORnet<sup>®</sup> CDM
  - These results can be used answer simple questions and provide a basic overview of data availability for the aggregate PCORnet population (note: a more sophisticated self-service query platform is being deployed as part of PCORnet<sup>®</sup> Phase 4)
- Prep-to-research queries (i.e., PCORnet<sup>®</sup> Front Door Queries)
  - Generate aggregate counts for patient cohorts based on a set of inclusion / exclusion criteria (typically related to an index event)
  - Results can be aggregated at the Network or DataMart-level, depending on use case
- Study-specific data extracts
  - Extracts of patient-level data for defined cohorts
  - Can be based on inclusion/exclusion criteria (e.g., observational study) or for a specified set of participants (e.g., pragmatic trial)

## Record linkage within PCORnet®

- Through strategic collaboration, PCORnet Network Partners established a **secure** and **standardized** privacy-preserving record linkage (PPRL) infrastructure that is **reusable** and **scalable**
- Each PCORnet network site uses software that converts identifiers into **de-identified tokens** that can be securely shared with the Coordinating Center for PCORnet®
- These tokens can be used to link with:
  - Administrative claims
  - Data from health registries
  - Other healthcare systems
  - Other real-world data sources



# Resources for Partner Engagement









Rowena Dolor, MD, MHS

Professor Emeritus  
Duke Clinical Research Institute  
Duke University School of Medicine

# Study Design

## Engagement

- Patient engagement is central to all PCORnet® Studies
- The Front Door team can recommend best practices
- Engagement strategies may vary depending on the stage of the project, as well as the project design

| Type of Front Door Request   |  A. Early "knock" looking to understand PCORnet and associated policies   |  B. Prep to Research or "Rapid Query"   |  C. Small data projects that only involve simple queries that provide results to Coordinating Center (CC) as amalgamated patient counts |  D. Data projects that plan to use de-identified or limited Private Health Information patient-level data from multiple sites. No plan to review charts or look at identifiable information |  E. Data projects that plan to use identifiable patient level data from multiple sites. May also plan to review charts |  F. Observational or Interventional Studies that involve patients (including studies that have waiver of consent) |
|------------------------------|--|--|--|--|---|--|
| ALL REQUESTS                 | <ul style="list-style-type: none"> <li>• CC provides basic resources about PCORnet, PCORnet principals and capacity (including information related to Engagement)</li> <li>• CC offers initial meeting with Front Door Staff to answer questions. Engagement Core staff attend initial call for calls involving patient-level data or patient recruitment</li> <li>• CC sends the PCORnet overview slide deck as well as the engagement recommendation and offer consultative support/another meeting as needed</li> </ul> |  |  |  |   |  |
| Additional CC Cores involved |  | <ul style="list-style-type: none"> <li>• CC connects with Query Fulfillment (QF) team (if project meets criteria for a rapid query by Front Door)</li> <li>• CC posts all query activity and results on iMeet</li> <li>• Once a quarter, the CC explicitly sends the report to all committees (similar to what is currently done for the Study Designation reports)</li> <li>• Quarterly list of Front Door Queries is provided to the Engagement Committee and CC Engagement Core for Review</li> </ul> |  | <ul style="list-style-type: none"> <li>• CC connects with Common Data Model (CDM) and QF teams as needed</li> <li>• The CC Engagement Core will review any study team plans, provide feedback, and suggest an appropriate plan for engagement</li> </ul>                       |   |  |

# Recommended Engagement Activities for Study Teams

For **Observational or Intervention studies involving patients**

- Recommend a ***Comprehensive Engagement Plan***
- Dissemination to patient, other stakeholders, AND
- Individual input on design, implementation, interpretation, dissemination, OR
- Group input (e.g., Community Engagement Studios, Chat Session, surveys, interviews, online polling, etc.)
- Stakeholders involved in one or more: governance, leadership, design, implementation, dissemination
- Stakeholders as co-authors/co-presenters
- **Stakeholders involved in all phases of the project (e.g., Co-I, consultant, study team, Advisory Council, etc.)**

# Tools, Education & Training



## Resources

Explore our resources for improving research through better practices

### Research

Explore innovative tools and models that can be used throughout every stage of your research project - from generation of a hypothesis to disseminating results.

SEARCH RESEARCH

### Data

Improve the quantity and quality of data used in your study with innovative resources and tools. Data networks should follow the principles of efficiency, interoperability, transparency, reproducibility, security, and inclusivity of stakeholders.

SEARCH DATA

### Engagement

Search best practices for engaging a variety of stakeholders throughout the research process. Engagement means active involvement of all stakeholders.

SEARCH ENGAGEMENT

- Explore the [Resources section](#) for useful documents related to Research, Data and Engagement



# Engagement Domain Resources



NETWORK RESEARCH DATA ENGAGEMENT FRONT DOOR

Search... [x] [Reset]

| Resource Type                    | Network Partners                       | Audience                          |
|----------------------------------|--|-----------------------------------|
| All (48)                         | All (48)                               | All (48)                          |
| Checklist (2)                    | ADVANCE (5)                            | Clinicians (20)                   |
| Communications and Outreach (14) | Greater Plains Collaborative (GPC) (5) | Hospitals and Health Systems (35) |
| Education (38)                   | INSIGHT - NYC (3)                      | Industry (30)                     |
| Evaluation (4)                   | OneFlorida+ (2)                        | Patients (33)                     |
| Guide (20)                       | PaTH (11)                              | Payers (7)                        |
| Manual (2)                       | PCORnet Coordinating Center (17)       | Policy Makers (25)                |
| Policy (2)                       | PEDSnet (1)                            | Purchasers (1)                    |
| Presentation/Webinar (17)        | REACHnet (7)                           | Researchers (45)                  |

Resource Type: Template, Guide  
Audience: Researchers

KEYWORDS | [Engagement](#)

Resource Type: Guide, Policy  
Audience: Researchers, Training Institutions

KEYWORDS | [ADVANCE](#) [Education](#) [Engagement](#) [Guide](#) [Policy](#) [Researchers](#) [Resources](#) [Training Institutions](#)

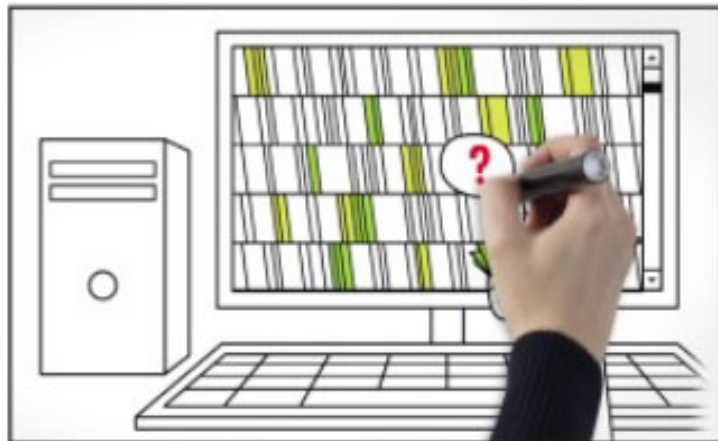
- Search best practices for engaging a variety of stakeholders throughout the research process
- Dropdown options to narrow your search by resource type, network partner, and/or audience.





# Example Engagement Resource

**Decoding the PaTH of EHR data:  
How it's collected, how it's protected**  
*via a chocolate making analogy*



Where is our health data stored and how can it be used to answer important research questions?

<https://www.pcori.org/sites/default/files/4016-PaTH-EHR-Data-Visual-Guide.pdf>

<https://www.youtube.com/watch?v=xX5FHU573VM>

A screenshot of a YouTube video player. The video title is "De-coding the PaTH of EHR data: How it's collected, how it's protected". The channel name is "PaTH Network" with 31 subscribers. The video player includes a search bar, a play button, and a subscribe button. The video player interface also shows a progress bar and various control icons.



# Understanding EHR Data...With Chocolate



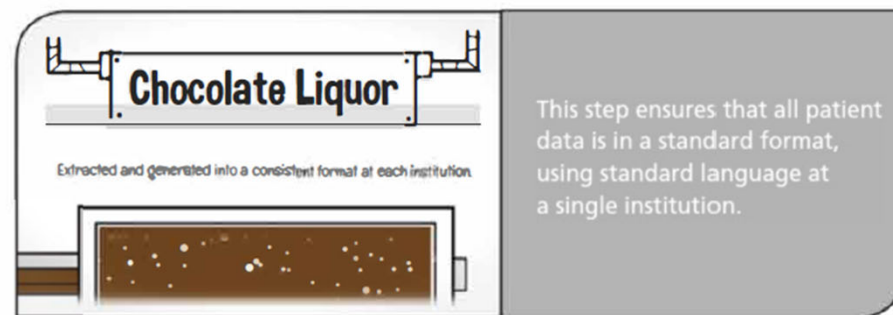
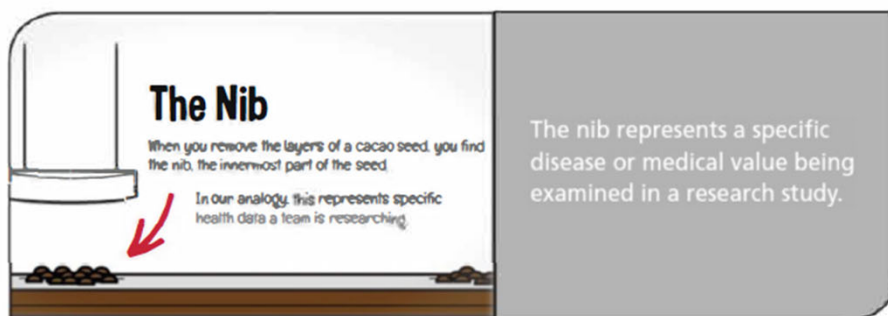
Each institution has a system for collecting health information, storing it electronically, and protecting it.



Each pod on the cacao tree represents individual electronic health records where patient health information is stored.




Several seeds are contained in a cacao pod. Similarly, several health data are contained in a patient's electronic folder. The seeds represent a patient's medical history.





### Chocolate Crumb

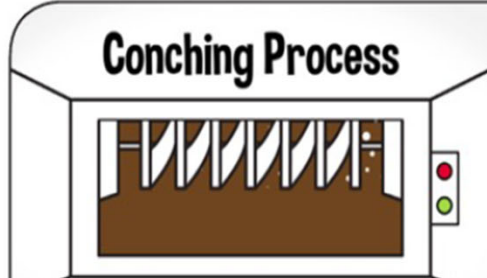


This step, de-identifying data, is crucial in research using EHR data because it ensures patient confidentiality.

Once the crumb is formed by adding milk and sugar, there's no way to separate the individual nibs, or in our analogy, patients' EHRs. This makes it impossible to connect health information with a patient's identity before the data is stored and protected behind each network institution's firewall.



### Conching Process



Common Data Model = CDM

The CDM organizes data from multiple institutions into a standard structure so that each healthcare system is speaking the same language.



### Chocolate Molds



Chocolate Bar = Each Site's Dataset

Now you're ready to dive into the treat, or for researchers, when they can dive into data, make connections, help answer important questions, and improve health outcomes.

# PCORI Engagement Resources

## FOUNDATIONAL EXPECTATIONS FOR PARTNERSHIPS IN RESEARCH



<https://www.pcori.org/engagement-research/engagement-resources/foundational-expectations>

# Questions and Discussion



Adrian Hernandez, MD, MHS

Vice Dean and Executive Director  
Duke Clinical Research Institute  
Duke University School of Medicine

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# Q&A





**46<sup>th</sup>**  
**ANNUAL**  
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# Thank You!