PCORnet Front Door
Total Visitors November 1, 2018 – October 31, 2021 = 440

- The PCORnet Front Door team interacts with a variety of requestors that are interested in leveraging PCORnet resources.

- An intake team educates requestors, advises on research designs, and connects opportunities with investigators across the Network.

Includes data from November 1, 2018 to October 31, 2021. Requests are attributed to the month they are received. Requests include: Data Network Requests as well as the status of Active and Closed Requests based on requestor self-report and Front Door assessment. Network Collaborator Requests and Study Designation Requests were discontinued prior to November 1, 2018 with the initiation of PCORnet 2.0.
Who Visits the Front Door?

- Requestors are frequently academic investigators, but also include funders representing federal, foundation, and industry partners.

In 2018, 2019, 2020, and 2021, the number of requests from various partners is as follows:

- **2018**: 6 Academic Partners, 1 Federal Partner, 1 Industry Partner, 2 Other
- **2019**: 65 Academic Partners, 6 Federal Partner, 15 Industry Partner, 24 Other
- **2020**: 151 Academic Partners, 11 Federal Partner, 15 Industry Partner, 40 Other
- **2021**: 64 Academic Partners, 4 Federal Partner, 11 Industry Partner, 24 Other

Includes data based on requestor self-report and Front Door assessment from November 1, 2018 to October 31, 2021. Requests are attributed to the year they are received. N=440
Why do they Visit the Front Door?

- Requestors often require consultation and support to understand how to leverage PCORnet resources to enhance their research.

- In some instances, the Front Door team supports proposal development, including how to properly budget for a project utilizing PCORnet partners and resources.

Includes data based on requestor self-report and Front Door assessment from November 1, 2018 to October 31, 2021. Network Collaborator Requests and Study Designation Requests were discontinued prior to November 1, 2018 with the initiation of PCORnet 2.0. N=440.
What Funders do Front Door Visitors Target?

- Front Door visitors seeking to use PCORnet for research funded by variety of sources
- Targeted funders include the federal agencies, foundations, industry, and PCORI

Targeted-intention or plan to submit to an identified funding source; Not applicable: information seeking only and/or not a good fit for PCORnet resources. Includes data based on requestor self-report and Front Door assessment from November 1, 2018 to October 31, 2021. Network Collaborator Requests and Study Designation Requests were discontinued prior to November 1, 2018 with the initiation of PCORnet 2.0. N=440
What is the Outcome for Front Door Requestors?

- The Front Door continues to follow up with Requestors to track funding outcomes.
- The research request cycle means learning about leveraging PCORnet, submitting a proposal, and learning of a funding decision from the potential funder.

Includes data based on requestor self-report and Front Door assessment from November 1, 2018 to October 31, 2021. Requests include: Data Network Requests, as well as Active and Closed Requests. Network Collaborator Requests and Study Designation Requests were discontinued prior to November 1st 2018 with the initiation of PCORnet 2.0. N=440
What is the Number of Front Door Study Designation Requests?

Total requests November 1, 2018 – October 31, 2021 = 19

- The Front Door receives requests for PCORnet Study Designation

- PCORnet Study Designation is designed to ensure that the PCORnet brand and mission are exemplified in current research projects that leverage the PCORnet infrastructure. Studies granted PCORnet designation commit to sharing study progress, metrics, lessons learned, best practices, and research findings with the Network.

Includes data from November 1, 2018 to October 31, 2021. Requests are attributed to the month they are approved. Study Designation requests were discontinued prior to November 1, 2018 with the initiation of PCORnet 2.0.
What is the Number of Front Door Study Designation Requests?

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CDC COVID-19: Electronic Health Data Project

- CDC-Funded Study
- Query Response of participating DataMarts

Percent DataMart query fulfillment response on time and data in final report.

n=Participating DataMarts
CDC COVID-19 Query

- PCORI-Funded Study
- Project supports a subset of sites with the goal of enhancing their existing data infrastructure in order to better support research projects in COVID-19-associated coagulopathy.
- Query Response of participating DataMarts

COVID-19 ENHANCEMENT PROJECT (Coagulopathy)
Percent DataMart query fulfillment response on time and data in final report.
n=Participating DataMarts
How does PCORnet move from raw data to fit-for-purpose?

- PCORnet leverages a number of real-world data sources
- Must assure that the underlying data are suitable for research
- PCORnet utilizes a two-stage curation process
  - Foundational: Transform raw data into **research-ready** data
  - Study-specific: Ensure data are **fit-for-purpose** for a given study or analysis

Growth in foundational data quality checks over time. **Checks**: Rules such as “Values must conform to CDM specifications.” **Measures**: The number of CDM tables and/or fields affected by the checks.
Improving data quality over time

- Foundational data curation is a **continuous learning cycle**
  - Continuous assessment of performance
  - Close gap between foundational and study-specific curation — add new data checks based on study findings

*This is an artifact of the pandemic since we are comparing April 2020 to average volume.

 Eligible DataMarts: PCORnet 2.0 DataMarts that include EHR data and were approved prior to November 1, 2021. Data latency is also limited to DataMarts that do not use date obfuscation and include inpatient, ambulatory, and/or emergency department encounters. Other notes: Data latency is measured as the difference in months between the month when the data curation query was executed and the most recent month in which encounter data were ≥75% complete. Lab mapping is the percentage of DataMarts that map at least 80% of their lab records to LOINC. Medications is the percentage of DataMarts that map at least 80% of their Prescribing records to the preferred RXNORM codes.
400 Publications about PCORnet

- Publications and presentations about PCORnet infrastructure and research have increased over time


Includes data from PCORI, PCORnet, and PCRF as of Q4 2021 November 2, 2021.
Utilization of PCORnet resources

- Projects that leverage PCORnet resources do so in a number of ways.
- Most rely on the PCORnet Common Data Model (CDM), and an increasing number of projects engage in more than one Clinical Research Network (CRN).

Includes funded projects only.
N=168
Who is funding research in PCORnet?

- PCORI funds many research projects that utilize PCORnet infrastructure.
- Increasingly, other sponsors recognize the value of funding research that leverages PCORnet.

Includes funded projects only through November 2, 2021. N=168. Funded amount=$803,071,242.40
Dimensions of data quality in PCORnet

- **Conformance** — Data adhere to the format of the CDM
  - Fields do not contain values outside of the CDM 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 CDM table between refreshes

Growth in foundational data quality checks over time.

**Checks:** Rules such as “Values must conform to CDM specifications.”

**Measures:** The number of CDM tables and/or fields affected by the checks. Includes data from PCORnet Data Curation team.
Assessing data availability through data curation

- Standardization allows PCORnet to query all partners quickly and efficiently because the raw data have been converted to a common terminology.

Eligible DataMarts: PCORnet 2.0 DataMarts that include EHR data and populate the LAB_RESULT_CM table and were approved prior to November 1, 2021. Other Notes: Each column indicates the number of available laboratory results across the network, in billions. The line shows the median number of unique LOINC codes within a DataMart.
Improvements in data completeness

- PCORnet data curation process is used to monitor whether partners are populating key concepts of interest
- The completeness of certain lab tests has seen marked improvement over time

Eligible DataMarts: PCORnet 2.0 DataMarts that include EHR data and populate the LAB_RESULT_CM table and were approved prior to November 1, 2021. Other notes: We selected 4 labs to monitor over time. These labs were chosen based on the needs of early PCORnet studies as well as input from the Collaborative Research Groups.
Understanding the availability of recent data

- Up-to-date data are critical if data from PCORnet are to serve as outcomes and endpoints in pragmatic clinical trials.
- A latency calculation was developed for ADAPTABLE and later incorporated into foundational data curation.

Eligible DataMarts:
PCORnet 2.0 DataMarts that include EHR data, inpatient, ambulatory, and/or emergency department encounters, do not use date obfuscation, and were approved prior to November 1, 2021.

Other Notes: Data latency is measured as the difference in months between the month when the data curation query was executed and the most recent month in which encounter data were ≥75% complete.
## Utilization of 2+CRNs

**Total Projects=60**

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<th>Year</th>
<th>Utilization (%)</th>
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<td>100%</td>
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</table>
Thank you.

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