PCORnet Front Door

Total Visitors January 1, 2020 to August 11, 2023 = 673

- 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 January 1, 2020 to August 11, 2023. 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.

Includes data based on requestor self-report and Front Door assessment from January 1, 2020 to August 11, 2023. Requests are attributed to the year they are received. N=673
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.

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What Funders do Front Door Visitors Target?

- Front Door visitors seeking to use PCORnet for research funded by a 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 January 1, 2020 to August 11, 2023. Network Collaborator Requests and Study Designation Requests were discontinued prior to November 1, 2018 with the initiation of PCORnet 2.0. N=673.
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.

### Requests Breakdown

<table>
<thead>
<tr>
<th>Year</th>
<th>Active</th>
<th>Info-seeking only</th>
<th>Not a good fit/not applicable</th>
<th>Submitted, funded</th>
<th>Submitted, pending</th>
<th>Submitted, not funded</th>
</tr>
</thead>
<tbody>
<tr>
<td>2020</td>
<td>103</td>
<td>70</td>
<td>9</td>
<td>45</td>
<td>12</td>
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<td>2021</td>
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<td>7</td>
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<td>99</td>
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<td>92</td>
<td>63</td>
<td>42</td>
<td>2</td>
<td>15</td>
<td>11</td>
</tr>
</tbody>
</table>

Includes data based on requestor self-report and Front Door assessment from January 1, 2020 to August 11, 2023. 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=673.
What is the Number of Front Door Study Designation Requests Approved?

Total requests approved January 1, 2020 – August 11, 2023 = 33

- 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 January 1, 2020 to August 11, 2023. 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.
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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

Eligible DataMarts: PCORnet 3.0 DataMarts that include EHR data and were approved prior to August 1, 2023. 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.

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

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


Includes data from PCORI, PCORnet, and PCRF as of August 1, 2023.
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=254
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.

<table>
<thead>
<tr>
<th>Year</th>
<th>Amount</th>
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<tbody>
<tr>
<td>2023</td>
<td>$26,014,671</td>
</tr>
<tr>
<td>2022</td>
<td>$26,096,251</td>
</tr>
<tr>
<td>2021</td>
<td>$276,069,874</td>
</tr>
<tr>
<td>2020</td>
<td>$95,279,421</td>
</tr>
<tr>
<td>2019</td>
<td>$126,743,610</td>
</tr>
<tr>
<td>2018</td>
<td>$136,435,976</td>
</tr>
<tr>
<td>2017</td>
<td>$60,674,375</td>
</tr>
<tr>
<td>2016</td>
<td>$21,863,833</td>
</tr>
<tr>
<td>2015</td>
<td>$58,549,418</td>
</tr>
</tbody>
</table>

Includes* funded projects through August 1, 2023. N=254. Funded amount=$827,727,429
*Includes Legacy PCORnet Network Partners*
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*Funded amount=$827,727,429
*Includes Legacy PCORnet Network Partners*
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.
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 3.0 DataMarts that include EHR data and populate the LAB_RESULT_CM table and were approved prior to August 1, 2023. 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. The observed drop in 2022 in the total number of labs mapped to LOINC is due to a decrease in the number of DataMarts who underwent data curation in January 2022.
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 3.0 DataMarts that include EHR data and populate the LAB_RESULT_CM table and were approved prior to August 1, 2023. 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 3.0 DataMarts that include EHR data, inpatient, ambulatory, and/or emergency department encounters, do not use date obfuscation, and were approved prior to August 1, 2023.

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.

*This is an artifact of the pandemic since we are comparing July 2020 to average volume.*
Utilization of 2+CRNs
Total Projects=74

<table>
<thead>
<tr>
<th>Year</th>
<th>% Utilization 2+ CRNs</th>
<th>n</th>
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</thead>
<tbody>
<tr>
<td>2015</td>
<td>44% (n=4)</td>
<td></td>
</tr>
<tr>
<td>2016</td>
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<tr>
<td>2017</td>
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<td>2018</td>
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</tr>
<tr>
<td>2019</td>
<td>33% (n=12)</td>
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<tr>
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<tr>
<td>2021</td>
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<td></td>
</tr>
<tr>
<td>2022</td>
<td>33% (n=10)</td>
<td></td>
</tr>
<tr>
<td>2023</td>
<td>19% (n=3)</td>
<td></td>
</tr>
</tbody>
</table>
Thank you.

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Visit us at www.pcornet.org to get the relationship started.