Front Door Requests
Total=635

2021 Q1 32 Q2 27 Q3 31 Q4 38
2022 Q1 35 Q2 42 Q3 40 Q4 35
2023 Q1 74 Q2 74 Q3 57 Q4 69
2024 Q1 81

Includes data from January 1, 2021 to February 29, 2024. Requests are attributed to the month they are received. Visitors request: Data Network Requests, Network Collaborator Requests, Proposal Developments, Consultations, and General Information. N=635

Front Door Network Request Funding Outcomes
Total=635

Number of Requests

2021: Active 6, Info-seeking only 59, Not a good fit/not applicable 40, Submitted funded 11, Submitted pending 7, Submitted not funded 5

2022: Active 4, Info-seeking only 59, Not a good fit/not applicable 65, Submitted funded 8, Submitted pending 5, Submitted not funded 11

2023: Active 70, Info-seeking only 85, Not a good fit/not applicable 54, Submitted funded 6, Submitted pending 33, Submitted not funded 26

2024: Active 60, Info-seeking only 8, Not a good fit/not applicable 13, Submitted funded 0, Submitted pending 0, Submitted not funded 0

Includes data based on requestor self-report and Front Door assessment from January 1, 2021 to February 29, 2024. Requests include: Data Network Requests, as well as Active and Closed Requests. N=635

Visitors to Front Door by Requestor Type
Total=635

2021: Academic Partner 86, Federal Partner 4, Industry Partner 10, Other 28
2022: Academic Partner 88, Federal Partner 5, Industry Partner 6, Other 53
2023: Academic Partner 160, Federal Partner 10, Industry Partner 12, Other 92
2024: Academic Partner 58, Federal Partner 3, Industry Partner 1, Other 19

Includes data based on requestor self-report and Front Door assessment from January 1, 2021 to February 29, 2024. Requests are attributed to the year they are received. "Other" requestors that visit the Front Door are requestors such as CRAs, consulting companies, tech companies, vendors, patient groups, health departments, etc. N=635

Visitors to Front Door by Targeted Funding Source
Total=635

Legend: Not Applicable, PCORI, Industry, Foundation, Federal

2021: Not Applicable 44; Targeted: 29 (PCORI), 4, 1, 21 (Federal), 3; Funded: 11, 8, 5
2022: Not Applicable 64, 1; Targeted: 24, 4, 18, 6; Funded: 17, 9, 9, 1
2023: Not Applicable 86, 1; Targeted: 81, 8, 39, 1; Funded: 30, 7, 9, 1
2024: Not Applicable 25; Targeted: 39, 6, 1; Funded: 8, 2

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, 2021 to February 29, 2024. N=635

Visitors to Front Door by Request Type
Total=635

Legend: Network Collaborator Request, Data Network Request, Proposal Development, Consultation

2021 Q1: 24,7,1; Q2: 24,2; Q3: 28,1,1; Q4: 30,5,1
2022 Q1: 32,2; Q2: 39,1; Q3: 36,3,1; Q4: 29,3,3
2023 Q1: 66,4,4; Q2: 64,7,3; Q3: 47,7,3; Q4: 60,6,3
2024 Q1: 75,3,3

Includes data based on requestor self-report and Front Door assessment from January 1, 2021 to February 29, 2024. N=635

Data Quality Check Evolution: Foundational Data Quality Checks

Legend: Data Persistence Checks, Data Completeness Checks, Data Plausibility Checks, Data Model Conformance Checks, Cumulative Measures

Jan 2016 (v1) CDM v3.0: 7,4,2
Nov 2016 (v2): 11,6,4
Jul 2017 (v3) CDM v3.1: 11,5,10
Jan 2018 (v4): 11,5,11
Jul 2018 (v5) CDM v4.1: 12,7,12
Jan 2019 (v6): 13,7,12
Oct 2019 (v7) CDM v5.1: 13,8,12,3
Mar 2020 (v8): 14,8,13,3
Jan 2021 (v9): 16,8,13,3
Jul 2021 (v10): 17,8,15,3
Jan 2022 (v11) CDM v6.0: 19,8,15,3
July 2022 (v12): 19,8,15,3
Jan 2023 (v13): 19,9,15,3
July 2023 (v14) CDM v6.1: 19,9,15,3
Jan 2024 (v15): 19,9,15,3

Data Quality Date (Version) and CDM Version

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. Data as of January 30, 2024

Key Foundational Data Quality Checks

Goal (100)
% of Network
Legend: Lab Mapping, Medications
Years: 2016 2017 2018 2019 2020 2021 2022 2023 2024

Eligible DataMarts: DataMarts that include EHR data and were approved prior to January 30, 2024. Within PCORnet, a DataMart refers to a specific data source consisting of data collected, captured or otherwise obtained by the local health care system. This data source houses data in a standard manner. 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.

Publication Altmetrics Scores
Total=719

Legend: Publications with Altmetric Score >20, Number of Publications

2015: Total 40, 9
2016: Total 43, 10
2017: Total 80, 17
2018: Total 93, 27
2019: Total 67, 11
2020: Total 79, 12
2021: Total 115, 19
2022: Total 79, 20
2023: Total 123, 27

Includes data from PCORI, PCORnet, and PCRF as of February 16, 2024.

Utilization of PCORnet Resources
Total Projects=260

Legend: CC, Single IRB, 2+ CRNs, CDM

2015 (n=10): 0%, 50%, 50%, 100%
2016 (n=10): 0%, 50%, 50%, 60%
2017 (n=23): 4%, 65%, 17%, 87%
2018 (n=27): 7%, 59%, 30%, 63%
2019 (n=37): 5%, 68%, 32%, 65%
2020 (n=64): 2%, 67%, 22%, 64%
2021 (n=36): 3%, 58%, 44%, 75%
2022 (n=26): 4%, 58%, 31%, 85%
2023 (n=24): 25%, 63%, 33%, 79%
2024 (n=3): 0%, 100%, 0%, 33%

Includes funded projects only.

Funded Studies by Funder Type
Total Projects=260

Legend: Private Donor, PCORI, Industry, Foundation, Federal, Academic Partner

2015: 1, 4, 5
2016: 6, 2, 1
2017: 5, 3, 11, 1
2018: 7, 1, 11, 6
2019: 3, 26, 4, 1, 3
2020: 8, 13, 27, 15, 1
2021: 3, 11, 15, 1
2022: 2, 20, 3, 1
2023: 5, 3, 15, 1
2024: 1, 2

*Funded amount=$898,765,852; "Other" funders are private donors; *Includes Legacy PCORnet Network Partners. Data as of February 29, 2024.*
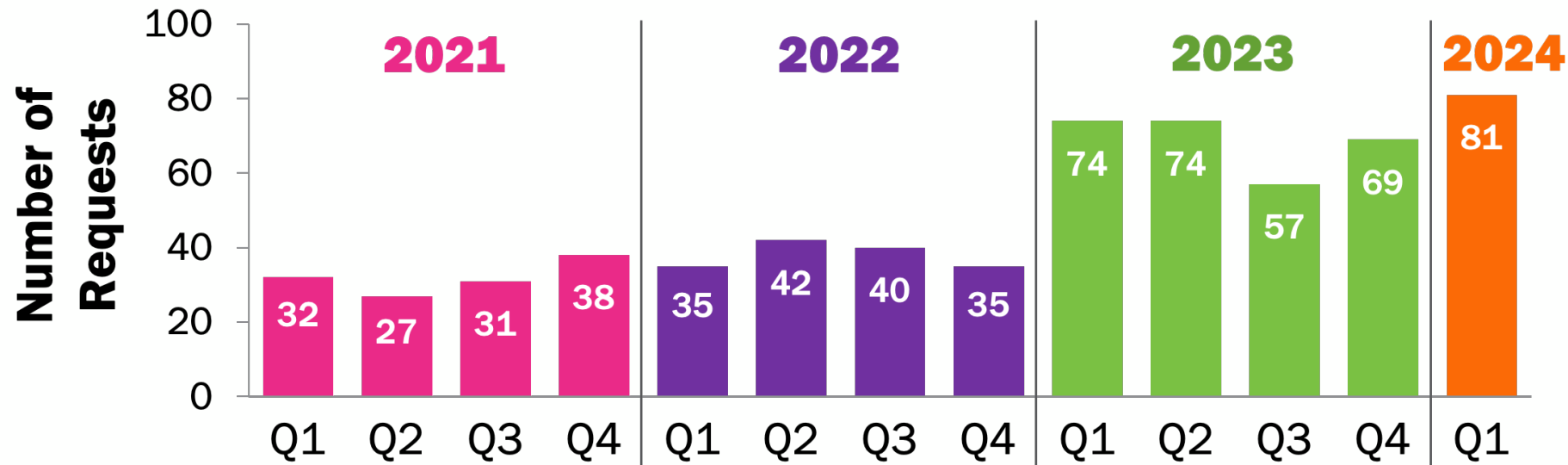
PCORnet® Front Door
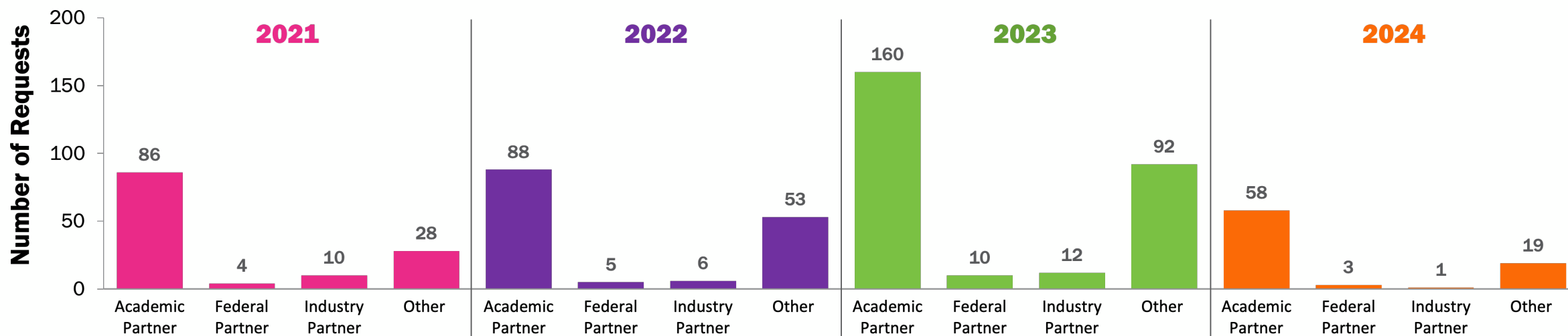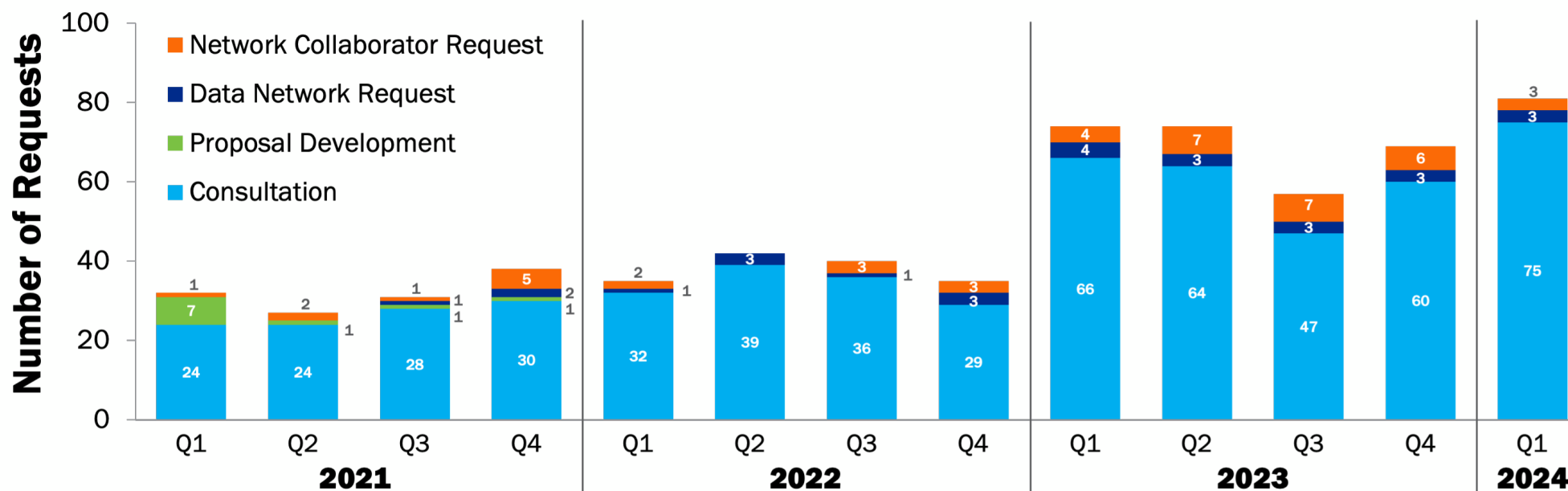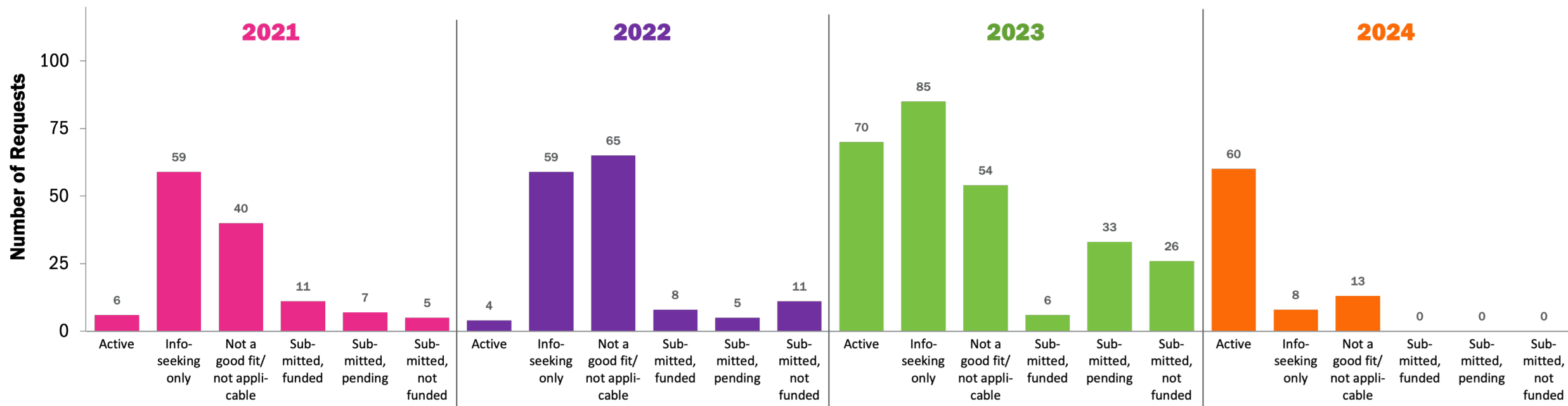## Total Visitors January 1, 2021 to February 29, 2024 N=635

○ 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, 2021 to February 29, 2024. N=635.
Requests are attributed to the month they are received. Visitors request: Data Network Requests, Network Collaborator Requests, Proposal Developments, Consultations, and General Information.
Data as of February 29, 2024.

Who Visits the Front Door?

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

Number of Requests

2021
- Academic Partner: 86
- Federal Partner: 4
- Industry Partner: 10
- Other: 28

2022
- Academic Partner: 88
- Federal Partner: 5
- Industry Partner: 6
- Other: 53

2023
- Academic Partner: 160
- Federal Partner: 10
- Industry Partner: 12
- Other: 92

2024
- Academic Partner: 58
- Federal Partner: 3
- Industry Partner: 1
- Other: 19

Includes data based on requestor self-report and Front Door assessment from January 1, 2021 to February 29, 2024. N= 635. Requests are attributed to the year they are received.

"Other" requestors that visit the Front Door are requestors such as CRAs, consulting companies, tech companies, vendors, patient groups, etc.

Data as of February 29, 2024.

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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 January 1, 2021 to February 29, 2024. N=635.
Data as of February 29, 2024.

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
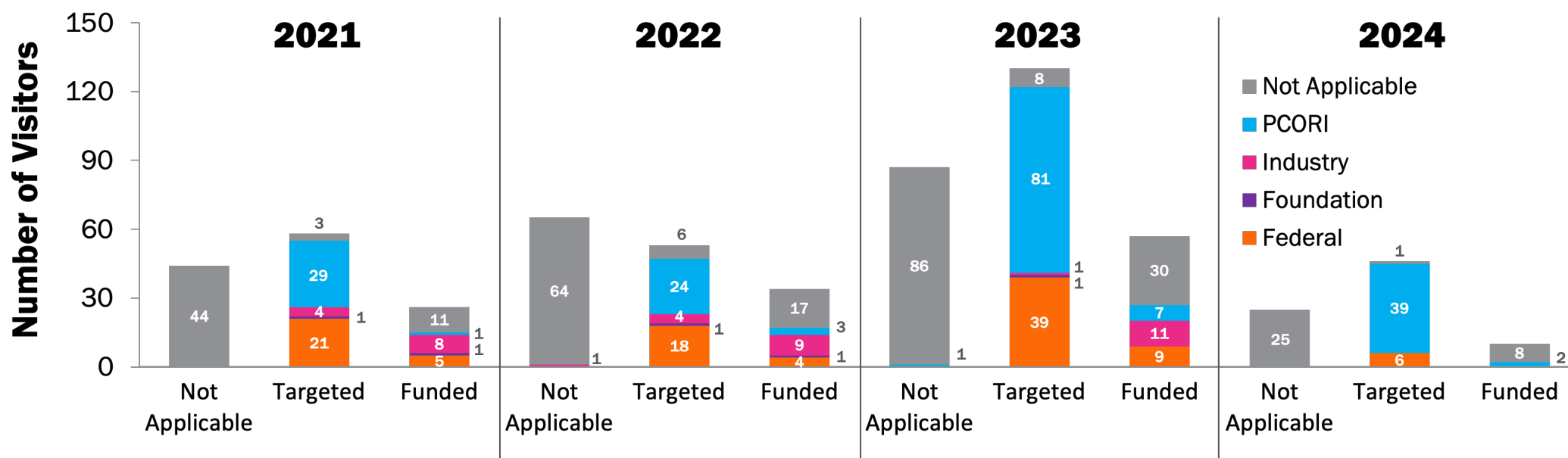
Includes data based on requestor self-report and Front Door assessment from January 1, 2021 to February 29, 2024. N=635.
Notes: Targeted-intention or plan to submit to an identified funding source; Not applicable: information seeking only and/or not a good fit for PCORnet resources. Data as of February 29, 2024.

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 January 1, 2021 to February 29, 2024.
Requests include: Data Network Requests, as well as Active and Closed Requests. N=635.
Data as of February 29, 2024.

What is the Number of PCORnet® Studies?
Total PCORnet® Studies as of March 6, 2024 = 41

- PCORnet® Studies are designed to ensure that the PCORnet® brand and mission are exemplified in current research projects that leverage the PCORnet infrastructure.

- PCORnet® Studies are committed to sharing study progress, metrics, lessons learned, best practices, and research findings with the Network.
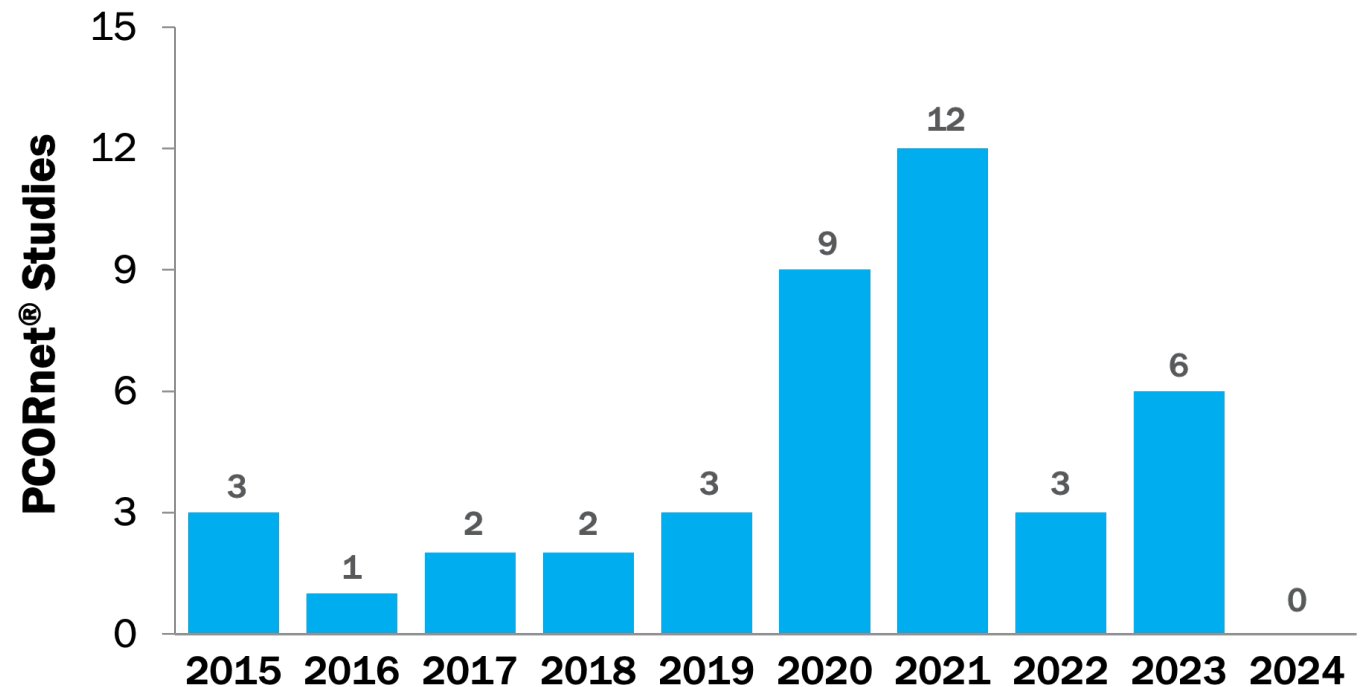
PCORnet® Studies are attributed to the year they are funded. N=41.
Data as of March 6, 2024.

What is the Number of PCORnet® Studies by Funding Source?
Total PCORnet® Studies as of March 6, 2024 = 41

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
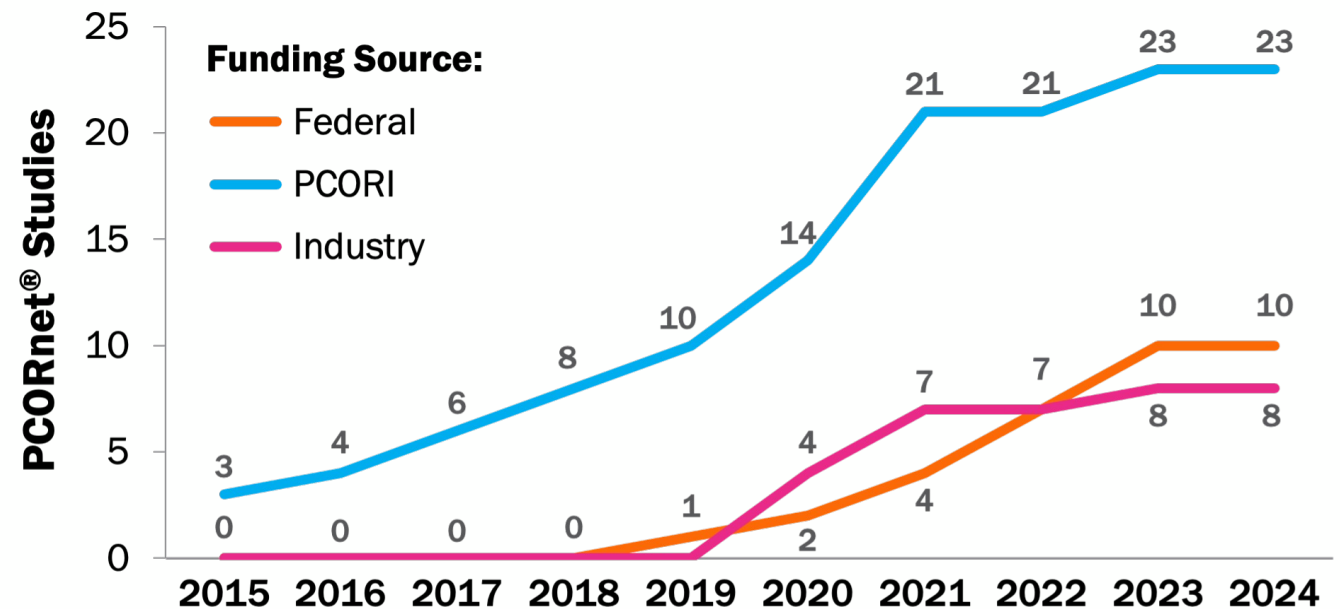
PCORnet® Studies are attributed to the year they are funded. N=41.
Data as of March 6, 2024.

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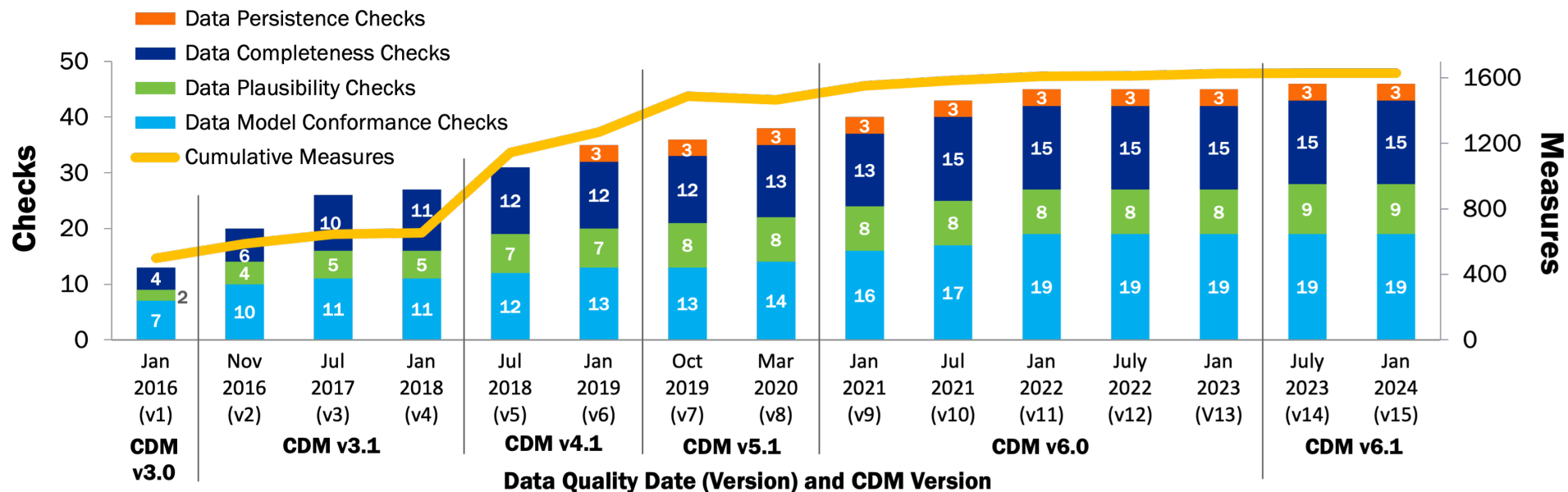
Growth in foundational data quality checks over time. Checks: Rules such as "Values must conform to CDM specifications." Measures: The number of CDM tables and/or fields affected by the checks. Data as of January 30, 2024.

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
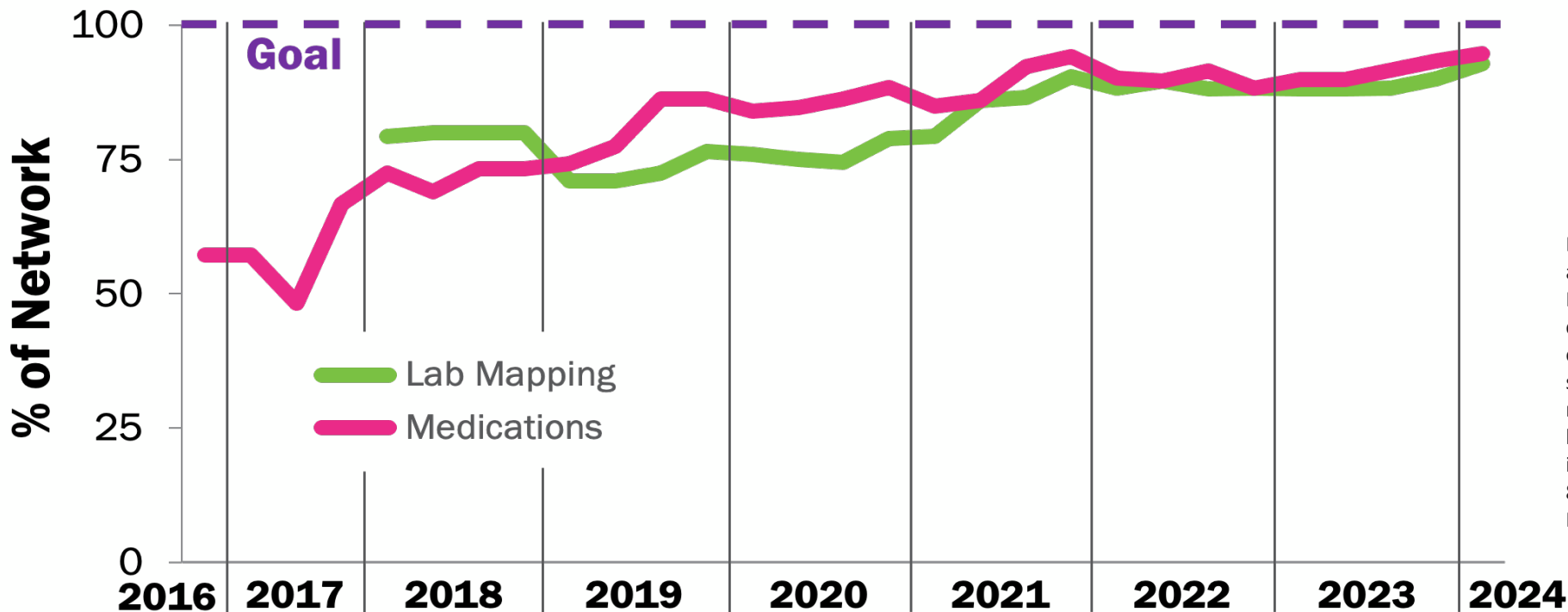
Eligible DataMarts: DataMarts that include EHR data and were approved prior to January 30, 2024. Within PCORnet, a DataMart refers to a specific data source consisting of data collected, captured or otherwise obtained by the local health care system. This data source houses data in a standard manner. 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. Data as of January 30, 2024.

719 Publications about PCORnet® Studies

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

Block JP, Boehmer ZK, Forrest CB, et al. **Cardiac Complications After SARS-CoV-2 Infection and mRNA COVID-19 Vaccination - PCORnet, United States, January 2021-January 2022.** MMWR Morb Mortal Wkly Rep. 2022 April 8; 71(14):517-523. doi: 10.15585/mmwr.mm7114e1.

4978
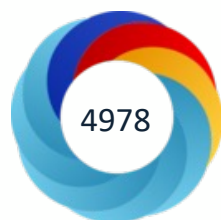
Naggie S, Boulware DR, Lindsell CJ, et al. **Effect of Higher-Dose Ivermectin for 6 Days vs Placebo on Time to Sustained Recovery in Outpatients With COVID-19: A Randomized Clinical Trial.** JAMA. 2023;329(11):888–897. doi:10.1001/jama.2023.1650

5351

Highest scored publication as of February 16, 2024

- Publications with Altmetric Score >20
- Number of Publications

Year	Altmetric >20	Total
2015	9	40
2016	10	43
2017	17	80
2018	27	93
2019	11	67
2020	12	79
2021	19	115
2022	20	79
2023	27	123
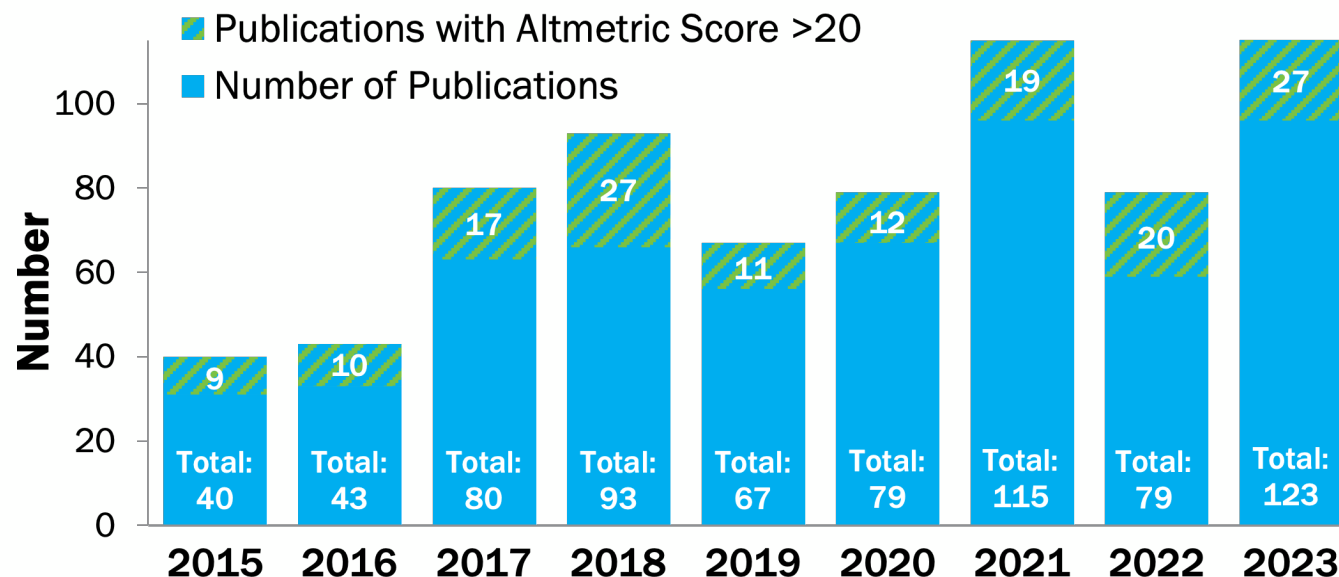
Includes CRN reported publications as of February 16, 2024.

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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)
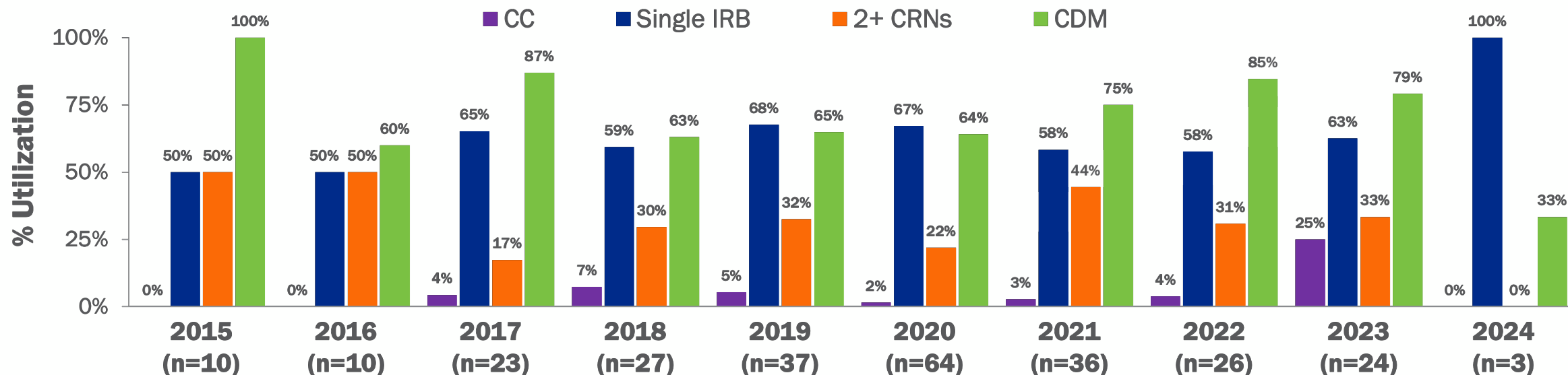
Includes funded projects only. N=260
Data as of March 6, 2024.

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.

2024 ($45,125) — $35,125 Academic Partner, $10,000 Federal

2023 ($77,164,896) — $38,781,237; $400,000; $8,252,056; $29,731,603

2022 ($20,206,858) — $60,000; $19,303,594; $691,954; $151,310

2021 ($269,819,983) — $5,000; $202,127,836; $7,094,576; $60,592,571

2020 ($124,130,866) — $2,346,988; $21,246,879; $10,000; $38,583,110; $61,943,889

2019 ($131,167,805) — $667,000; $119,171,575; $550,317; $1,066,690; $9,712,223

2018 ($129,734,197) — $9,626,500; $75,756,332; $82,000; $330,987; $43,938,378

2017 ($65,366,819) — $10,725; $38,446,586; $1,613,330; $2,839,876; $22,456,302

2016 ($17,344,691) — $40,000; $3,368,433; $173,632; $13,762,626

2015 ($63,784,612) — $12,580,545; $51,024,067; $180,000 Private Donor

Legend:
- Academic Partner
- Federal
- Foundation
- Industry
- PCORI
- Private Donor

*Funded amount=$898,765,852. N=260.
*Includes Legacy PCORnet Network Partners.*
Data as of March 6, 2024.

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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.

Funded Studies vs. year (2015–2024)

Legend:
- Private Donor (gray)
- PCORI (blue)
- Industry (magenta)
- Foundation (purple)
- Federal (orange)
- Academic Partner (green)

2015: Private Donor 1, PCORI 5, Federal 4
2016: PCORI 6, Federal 2, Academic Partner 1, Private Donor 1
2017: PCORI 5, Industry 3, Foundation 3, Federal 11, Academic Partner 1
2018: Private Donor 1, PCORI 7, Industry 2, Federal 11, Academic Partner 6
2019: Private Donor 3, PCORI (top), Industry 4, Federal 26, Academic Partner 3, (1)
2020: PCORI 8, Industry 13, Foundation 1, Federal 27, Academic Partner 15
2021: PCORI 9, Industry 11, Federal 15, Academic Partner 1
2022: Private Donor 2, Foundation 1, Federal 20, Academic Partner 3
2023: PCORI 5, Foundation 3, Federal 15, (1)
2024: Academic Partner 1, Federal 2

*Funded amount=$898,765,852. N=260.
Includes Legacy PCORnet Network Partners.
Data as of March 6, 2024.
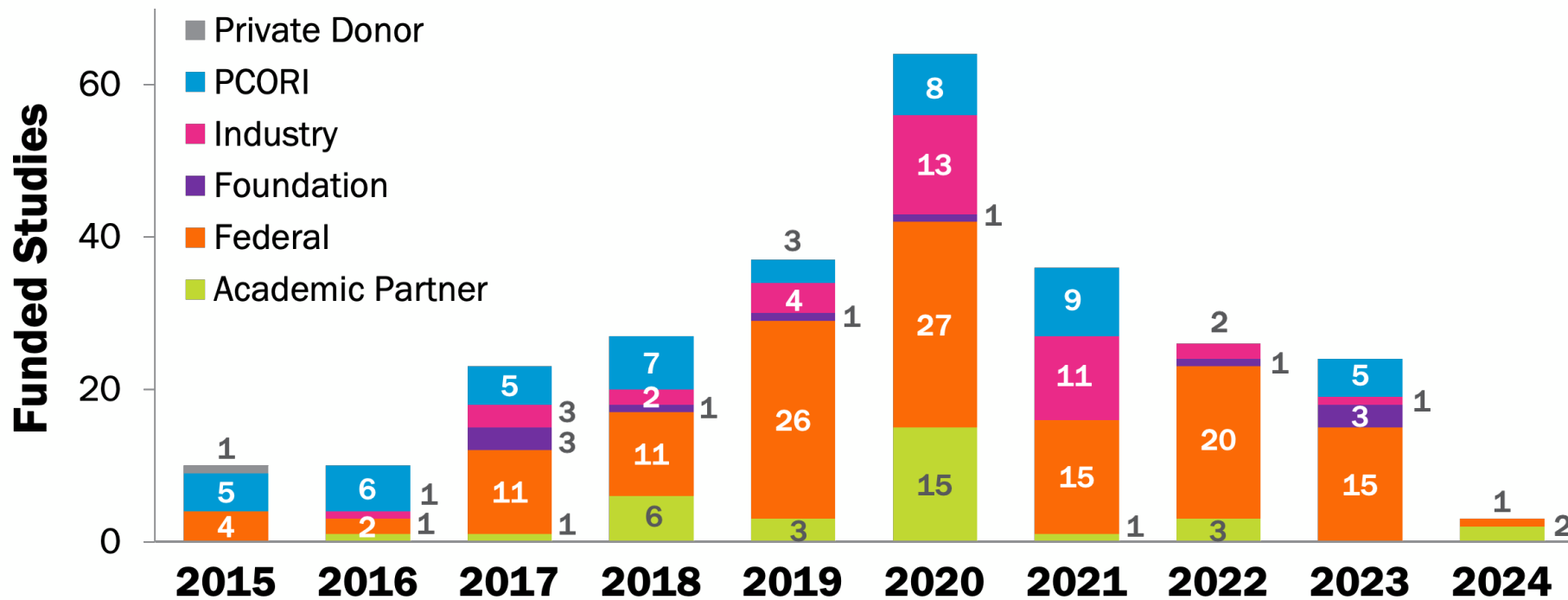
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Dimensions of Data Quality in PCORnet®

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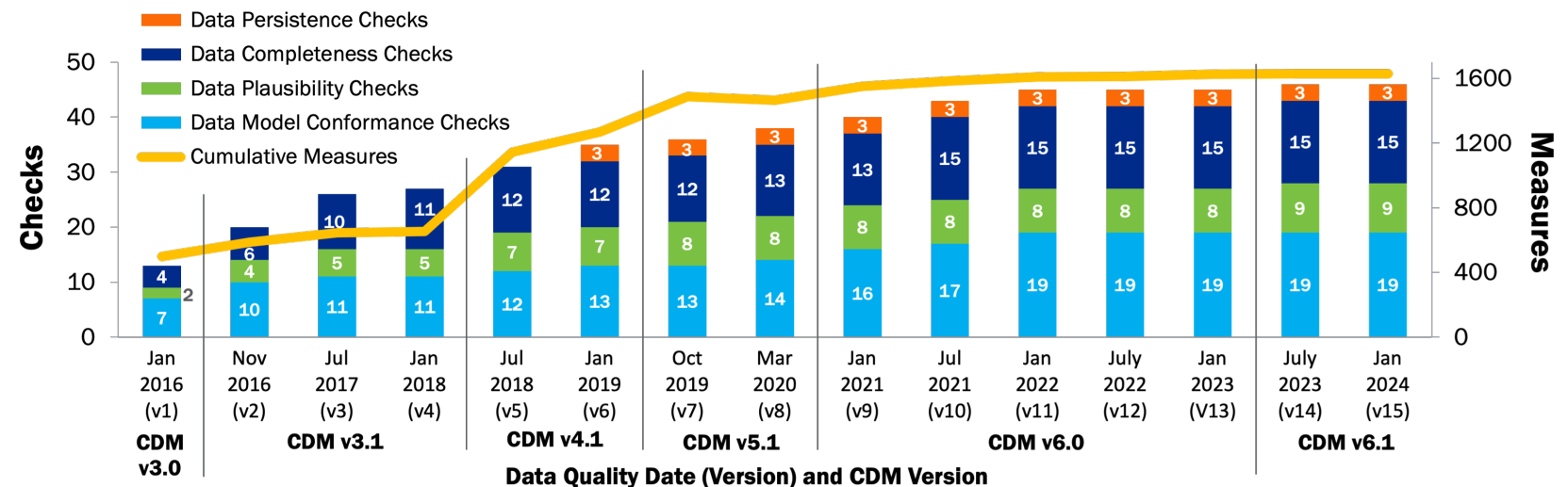
Growth in foundational data quality checks over time. Checks: Rules such as "Values must conform to CDM specifications."
Measures: The number of CDM tables and/or fields affected by the checks. Data as of January 30, 2024.

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
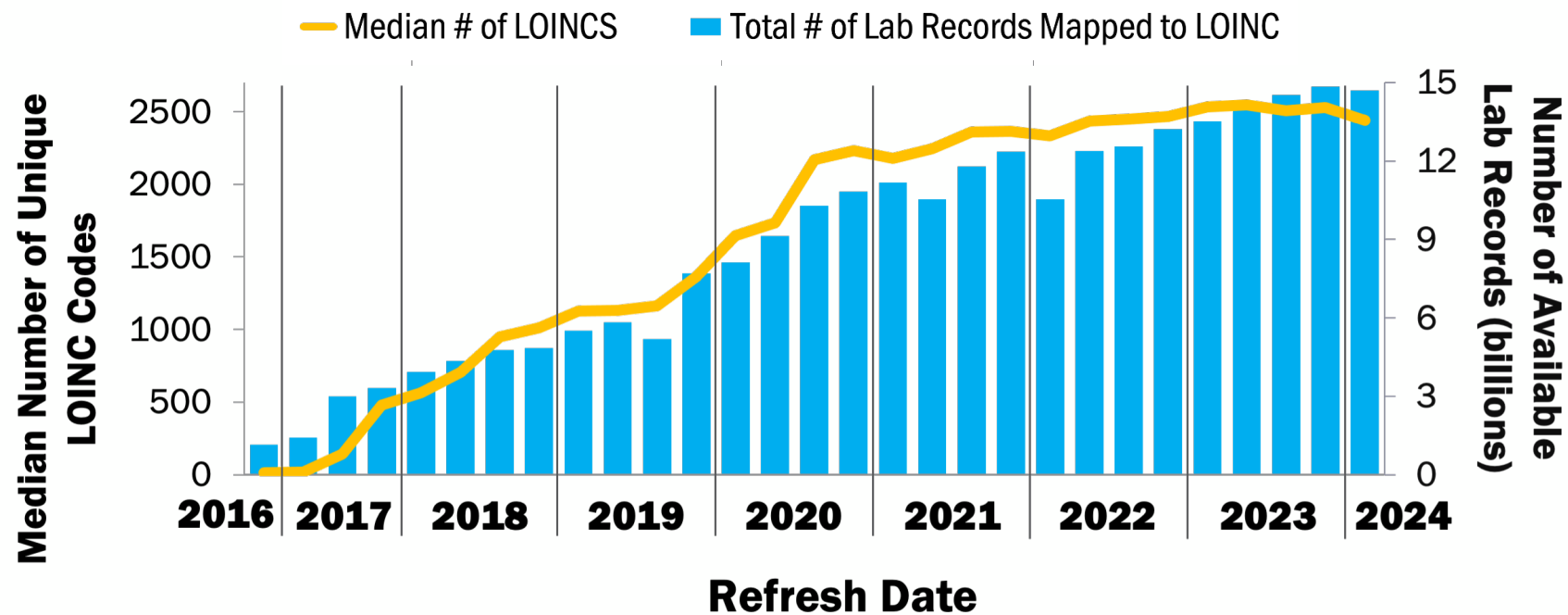
Eligible DataMarts: DataMarts that include EHR data and populate the LAB_RESULT_CM table and were approved prior to January 30, 2024. Other Notes: Each column indicates the number of available laboratory results across the network, in billions. The line shows the median number of unique LOINC codes within 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.

Data as of January 30, 2024.

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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
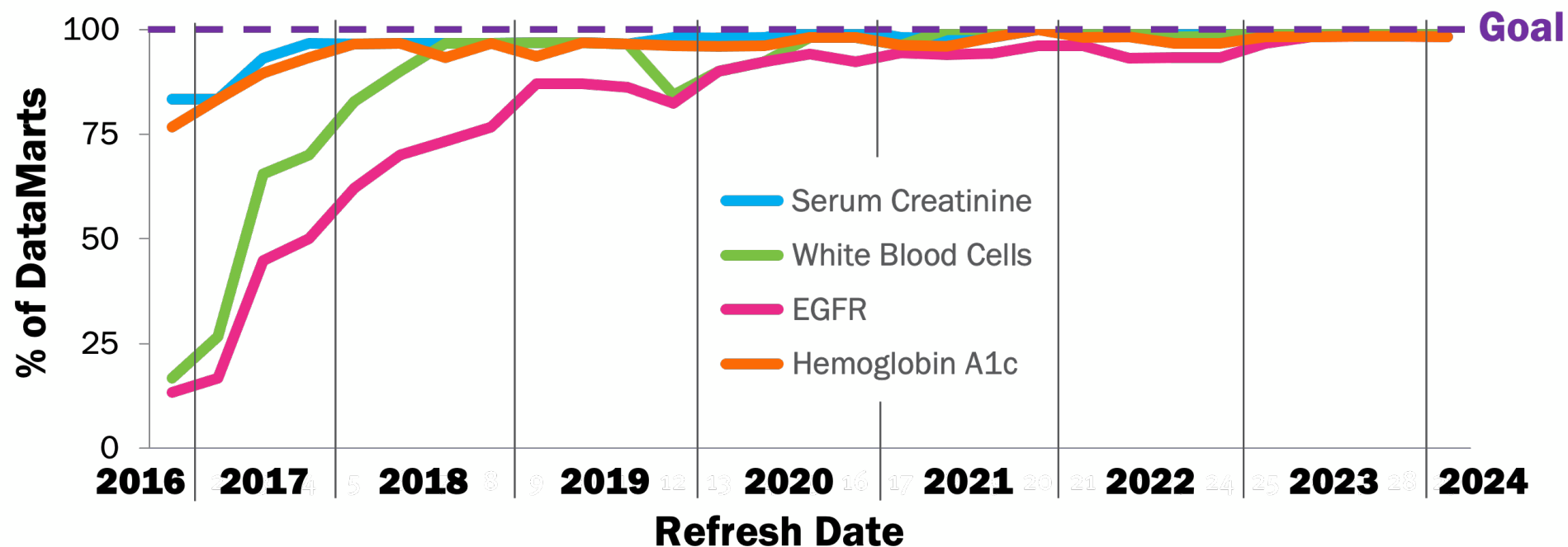
Eligible DataMarts: DataMarts that include EHR data and populate the LAB_RESULT_CM table and were approved prior to January 30, 2024. Note, we selected 4 labs to monitor over time. These labs were chosen based on the needs of early PCORnet studies. Data as of January 30, 2024.

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

% of DataMarts (y-axis: 0% to 100%)

Goal — 100% (dashed line)

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

X-axis: 2016, 2017, 2018, 2019, 2020, 2021, 2022, 2023, 2024

Refresh Date
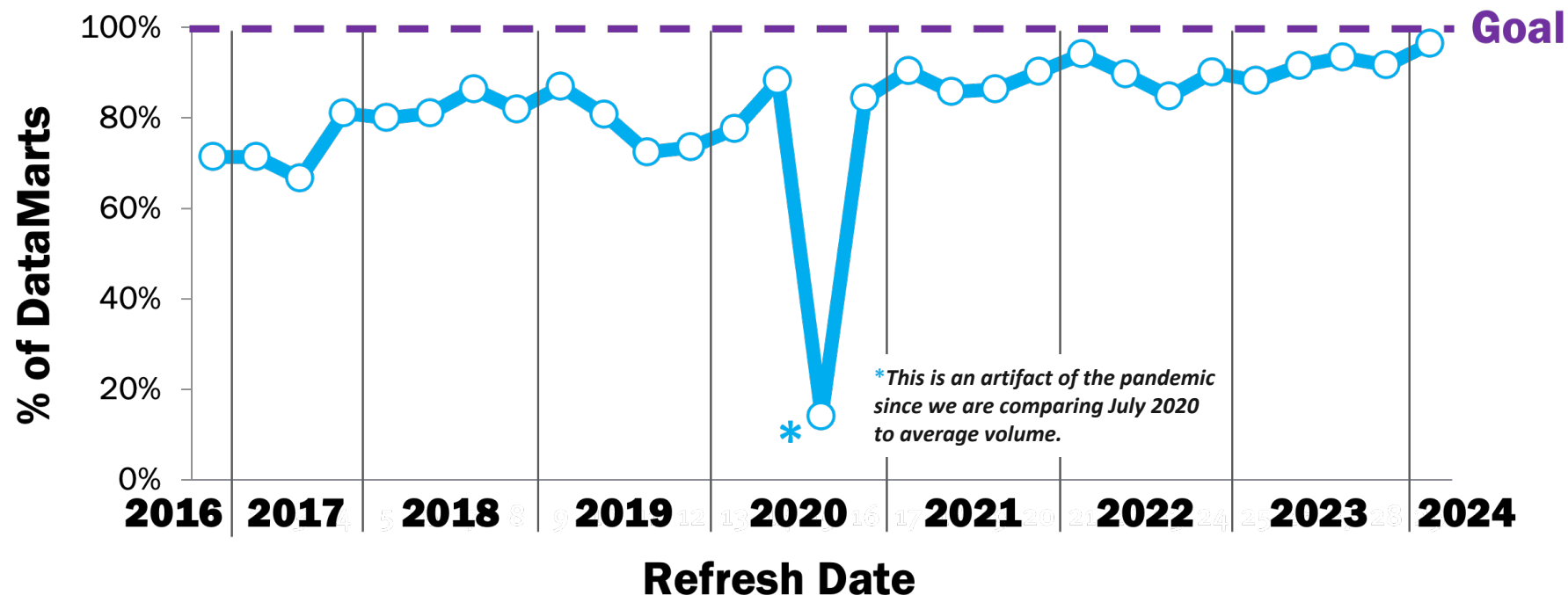
Eligible DataMarts: DataMarts that include EHR data, inpatient, ambulatory, and/or emergency department encounters, do not use date obfuscation, and were approved prior to January 30, 2024.

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.
Data as of January 30, 2024.

EHR DataMarts with an encounter latency of ≤ 3 months

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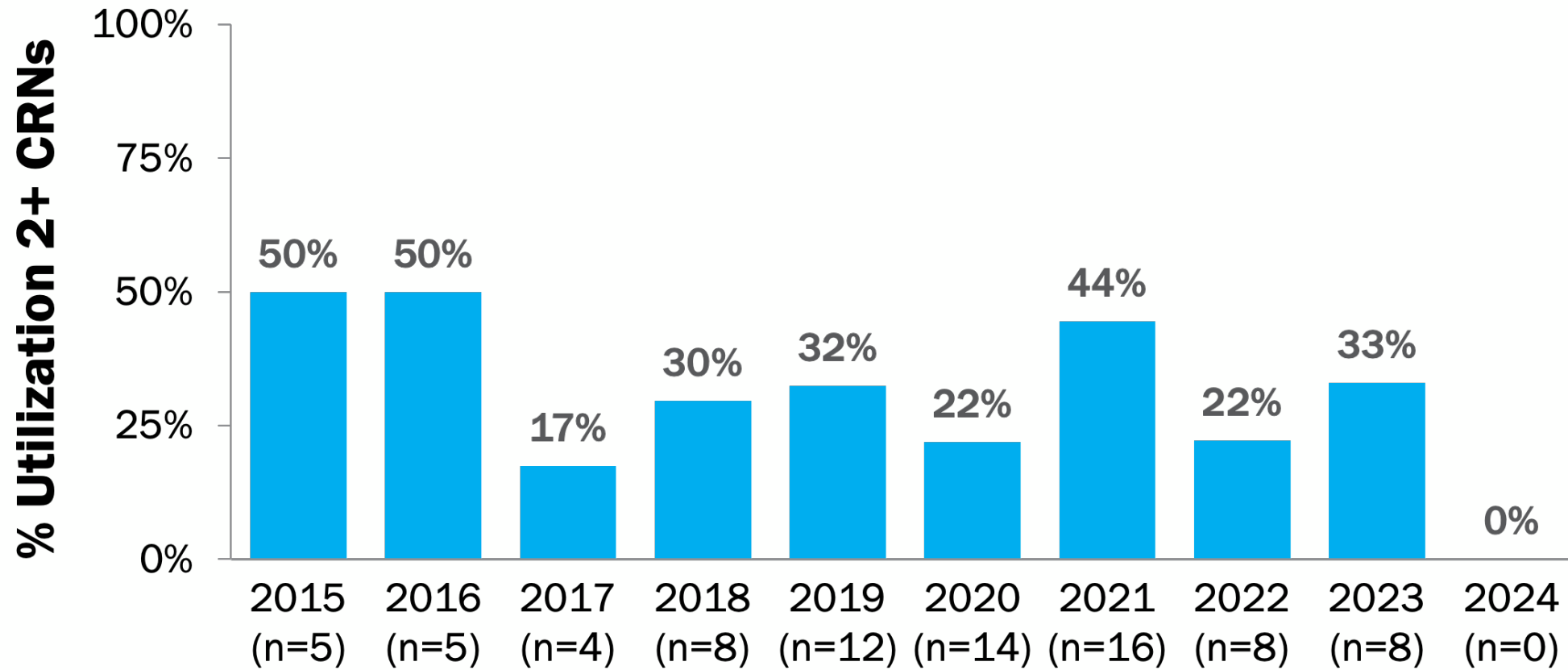
Thank you.

Work with PCORnet.

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