S18: Using PopMedNet™ to Support a Large Scale Multi-Site Research Network: Lessons from PCORnet

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PCORnet Distributed Research Network Operations Center
(DRN OC)

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Disclosure

- No disclosure or relationships with commercial interests

Learning Objective

After participating in this activity, the learner should be better able to:

* Evaluate the scalability of the PopMedNet platform across different distributed research networks
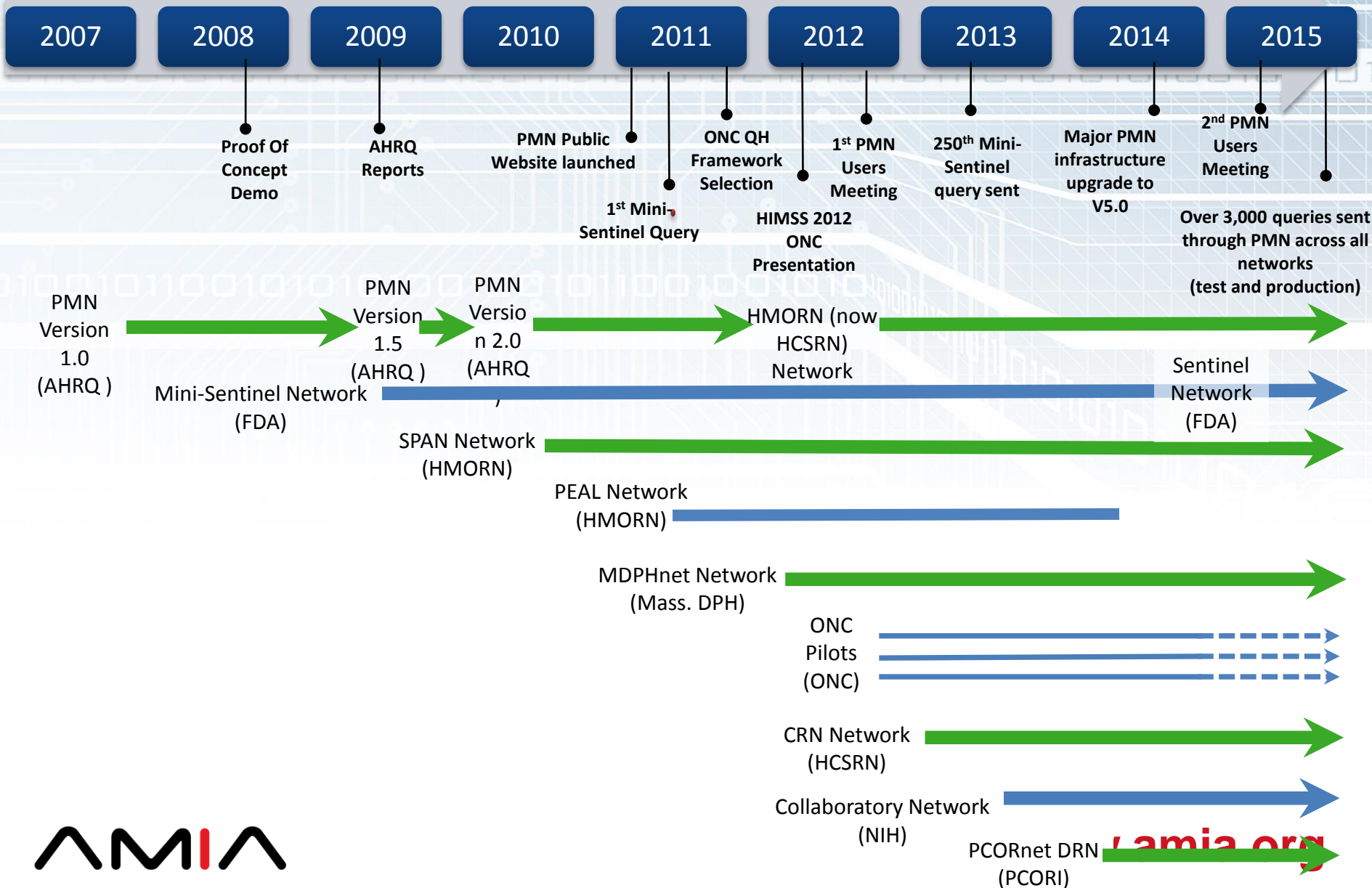
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Agenda

- PopMedNet (PMN) overview

- Describe PMN implementation for the PCORnet Distributed Research Network (PCORnet DRN)

- Explain approaches to address challenges

- Summarize lessons learned

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PopMedNet (PMN) Platform: Powering Distributed Data & Distributed Analysis

- Mature architecture using an approach shown to be **accepted by health plans, clinical sites and other data holders**

- Data partners **maintain control** over their own data

- **Distribute code** to partners for local execution

- **Provide results**, not data, to the requestor

- Standardize the data using a **common data model**

- All activities **audited** and **secure**
  - Meets the **privacy, proprietary, security, and research integrity** demands of health plans and other data holders institutions' IT departments

- Especially well suited for **multi-site, multi-use networks**

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PopMedNet Timeline

2007	2008	2009	2010	2011	2012	2013	2014	2015

Proof Of Concept Demo

AHRQ Reports

PMN Public Website launched

1st Mini-Sentinel Query

ONC QH Framework Selection

HIMSS 2012 ONC Presentation

1st PMN Users Meeting

250th Mini-Sentinel query sent

Major PMN infrastructure upgrade to V5.0

2nd PMN Users Meeting

Over 3,000 queries sent through PMN across all networks (test and production)

PMN Version 1.0 (AHRQ)

PMN Version 1.5 (AHRQ)

PMN Version 2.0 (AHRQ)

HMORN (now HCSRN) Network

Sentinel Network (FDA)

Mini-Sentinel Network (FDA)

SPAN Network (HMORN)

PEAL Network (HMORN)

MDPHnet Network (Mass. DPH)

ONC Pilots (ONC)

CRN Network (HCSRN)

Collaboratory Network (NIH)

PCORnet DRN (PCORI)

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PMN Usage Statistics*

Network	Requests**	Organizations	DataMarts	Users
Mini-Sentinel	1457	22	23	126
MDPHnet	857	5	4	62
PCORnet	458	119	70	210
Health Data Collaboration	275	20	29	72
NIH Collaboratory DRN	205	16	13	43
Total Across all PMN networks	3,252	182	139	513

* As of 11/11/2015
** Inclusive of test requests

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Network Coordinating / Operations Center

| Reporting | Project Management & Consultation | Policies and Procedures | Query Fulfillment | Etc.... |

PopMedNet Query Tool Web Portal

| Reporting / Searching | Security & Access Controls | Workflow Management | Query Distribution & Response |
| Metadata Capture | Activity Monitoring & Notifications | Data Characterization Tools | Etc.... |

PopMedNet DataMart Client Software installed locally at each Data Partner

Data Partner Site 1

Data Partner Site 2

Data Partner

Site 3
- Node 1
- Node 2

Data Partner

Site 4
- Node 1

Site 5
- Node 1

Data Partner Site 6

Other Data Resource/ Node

...

Data Partner Site 49

Data Partner Site 50

Multiple Networks Sharing Infrastructure

- Each organization can participate in multiple networks

- Each network benefits from architecture and security improvements while maintaining their unique governance and policies

- Networks share analytic tools, lessons learned, and system improvements

- Each network controls its governance and coordination

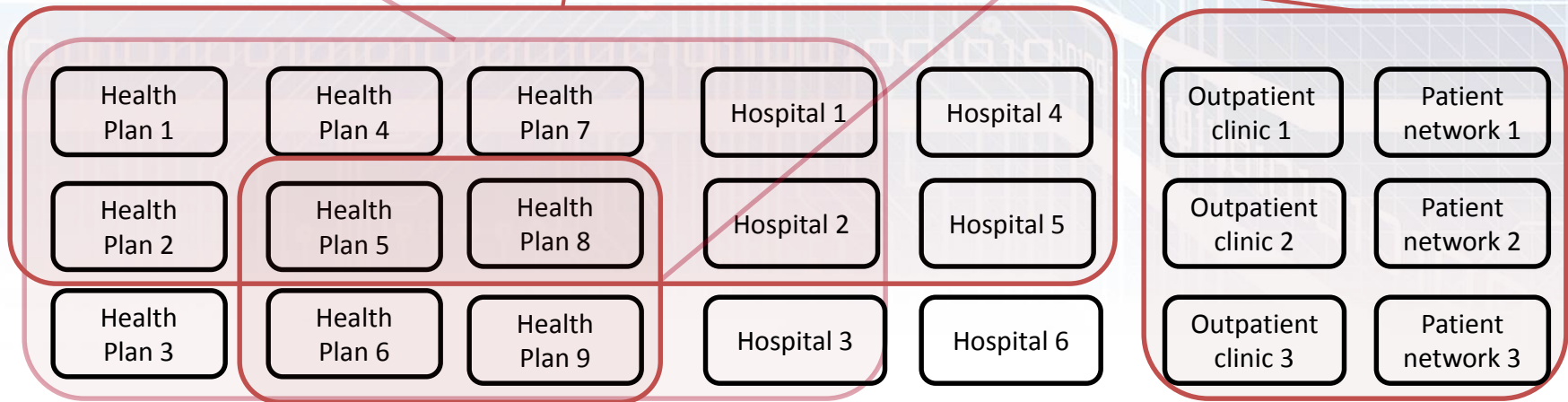- Funding from each network can be leveraged across initiatives to contribute to the PMN platform

Multiple Networks Sharing Infrastructure
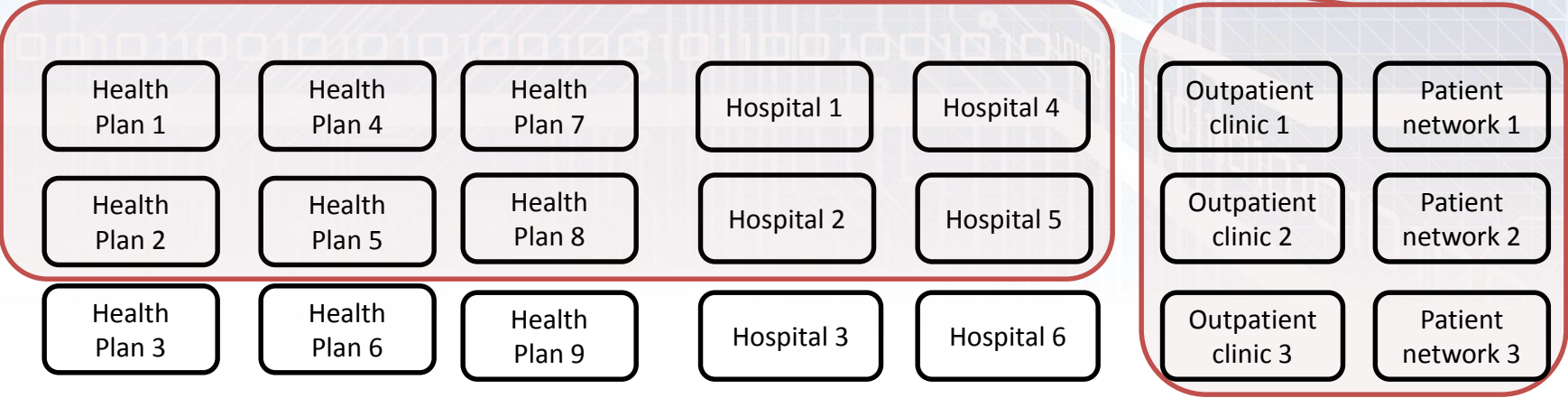
Multiple Networks Sharing Infrastructure
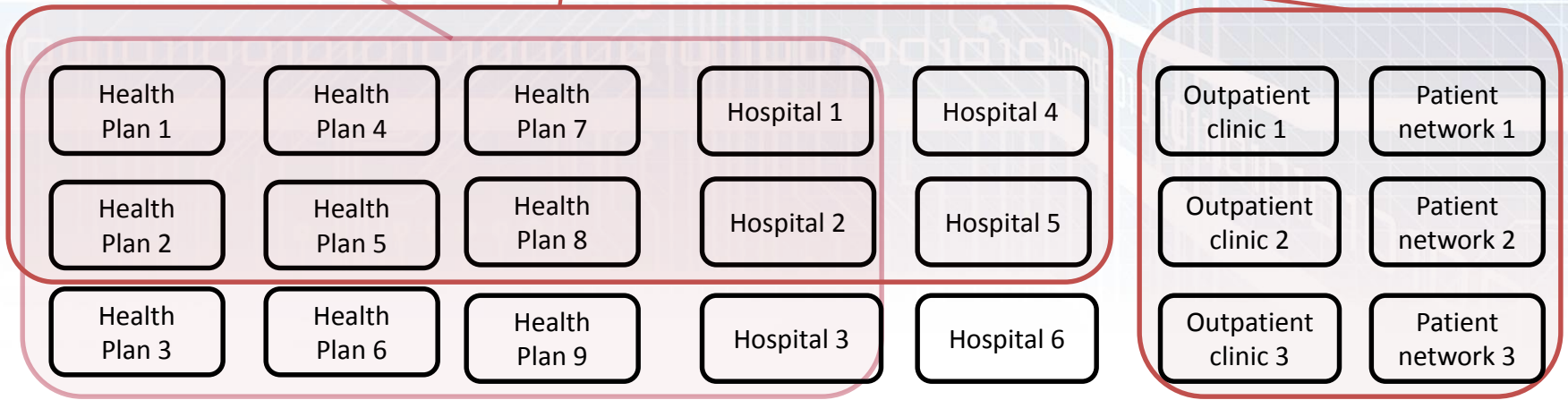
Multiple Networks Sharing Infrastructure

PCORnet Distributed Research Network (PCORnet DRN)

- Largest PMN network to date
  - A true "network of networks" including Clinical Data Research Networks (CDRNs) and Patient-Powered Research Networks (PPRNs)
  - Over 100 diverse sites with over 70 unique PMN installations and over 200 users

- Most complex PMN network
  - Multiple network configurations, governance, and workflow processes to address

- Phase 1: Ambitious 18 month period to implement PMN for PCORnet among many other activities and milestones

Challenges

1. **Largest PopMedNet (PMN) network to date**

2. **Overall network architecture evolving** as individual networks were being established

3. Sites need to **install the PMN DataMart Client locally**

4. **Need to increase the sociotechnical component of PMN** to address the goals of PCORnet

5. Need to meet PCORnet goals while **leveraging resources and tools from other networks**

Challenge 1: Largest PMN Network

Is the PMN infrastructure able to support the size and complexity of the PCORnet DRN?

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Largest PMN Network: Our Approach

- Completed major infrastructure upgrade (PMN v5.0)
  - Architecture upgraded to address performance issues
  - Security overhaul
  - Implemented a full REST based API
  - PMN operational database optimized
  - This work was supported by the Sentinel Network
- Dedicated staff for onboarding activities, configuring complex access controls, PMN configurations and software testing
  - Manual process to set-up and update the access controls for 100+ organizations, 70+ DataMarts, and 200+ users

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Largest PMN Network: Our Approach

- Most of the PCORnet participants are new to PMN, needed to rapidly establish trust and implement the infrastructure at the same time
  - Dedicated help desk and staff for PCORnet DRN PMN support
  - Provided demos, overviews, test data and sample queries to participants, 1:1 meetings

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Challenge 2: Network architecture evolving

Overall **network architecture evolving** as individual clinical and patient-powered networks established themselves

Can PMN accommodate the various configurations and workflows?

Can PMN respond to dynamic changes in the organization of the network?

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Network architecture evolving: Our Approach

- Leverage existing PMN functionality to represent the PCORnet sub-networks (CDRNs and PPRNs)
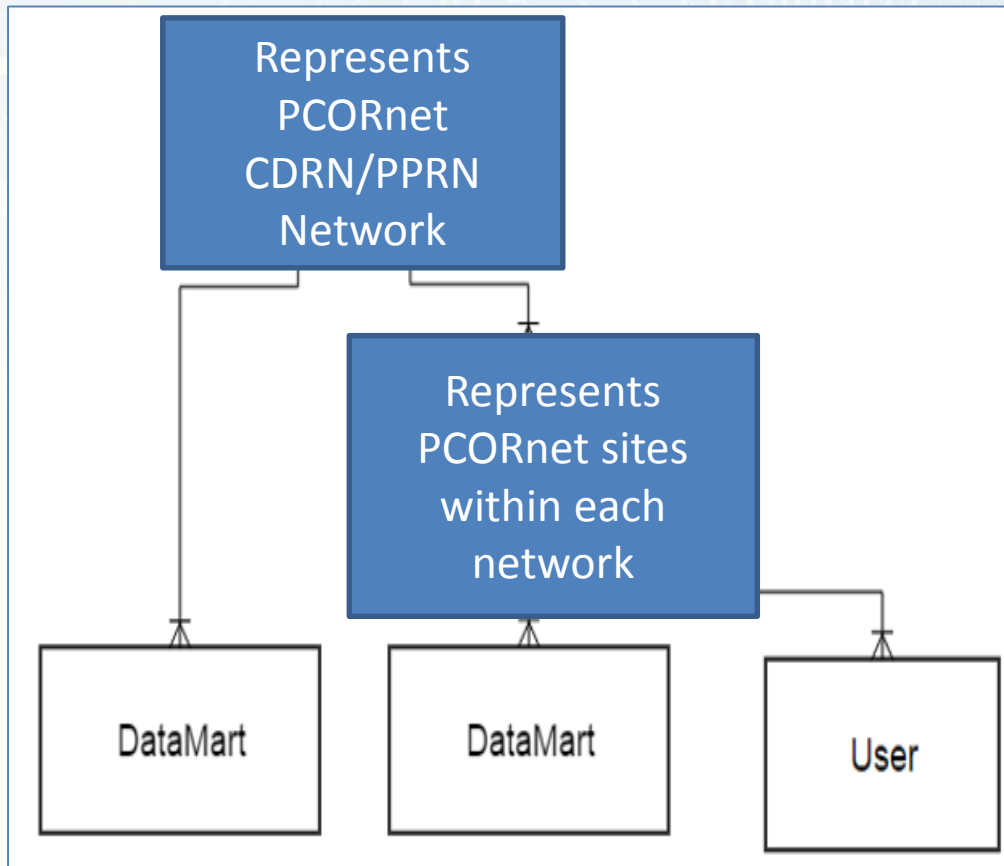
Entity	Description
Organization	A collection of Users and DataMarts that represents a real-world organization/site. May be standalone or linked with another Organization as a Parent or Child. Parents and Children may have multiple DataMarts or no DataMarts at all.
DataMart	Collection of queryable data that adhere to the CDM Used to process requests.
User	A person participating in a network. A user may only be a member of one Organization. A user can respond to queries on behalf of other organizations as governance permits.

Network architecture evolving: Our Approach

Network architecture evolving: Our Approach

Query Distribution and Response Workflows

- PMN offers networks and sites flexibility in how they receive and respond to queries from the PCORnet DRN Operations Center (DRNOC)
  - 3 existing PMN workflows were configured for PCORnet DRN
  - Customization available for users to receive email notifications throughout request cycle
  - Flexible options for participation: users can have a range of permissions, including the ability to respond to queries on behalf of multiple organizations to meet unique governance policies

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PCORnet Request Cycle Option 1

PCORnet DRN Operations Center (DRNOC)

1

6

PCORnet DRN Query Tool Portal

CDRN /PPRN 1 CC

PMN DataMart Client at CDRN CC

2

5

3 PMN DataMart **4**

3 PMN DataMart **4**

Data Source: RDBMS with PCORnet CDM Data from Site 1

Data Source: RDBMS with PCORnet CDM Data from Site 2

Site 1 Data Source
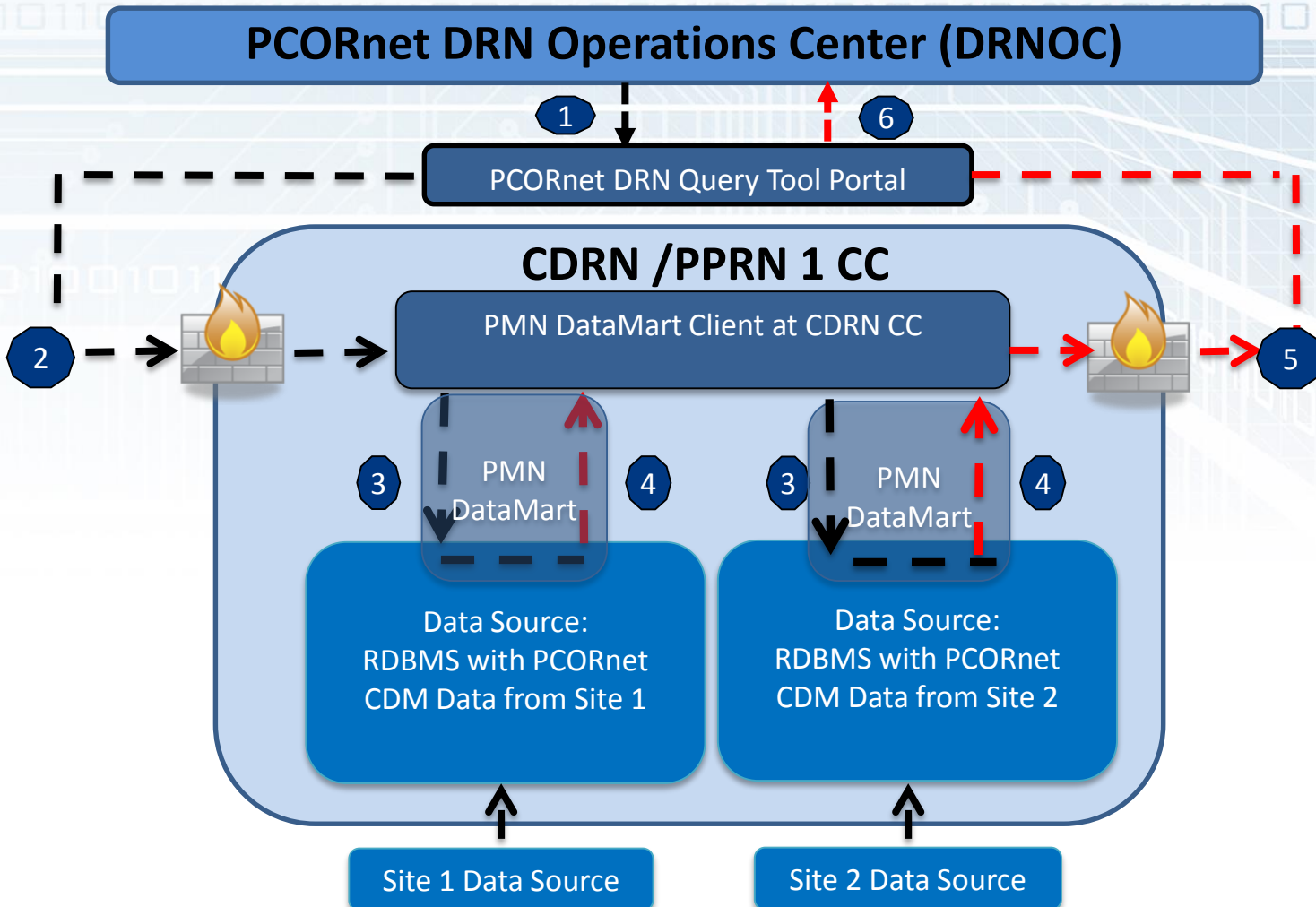
Site 2 Data Source

1. PCORnet DRNOC creates and submits query to selected sites

2. CDRN retrieves query

3. CDRN reviews and runs query for each site against the PCORnet CDM via the PMN DataMart Client and DataMarts - Data Sources for each site.

4. CDRN reviews results

5. CDRN returns results via secure network

6. PCORnet DRNOC views results aggregated or by site in PMN Portal

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PCORnet Request Cycle Option 2
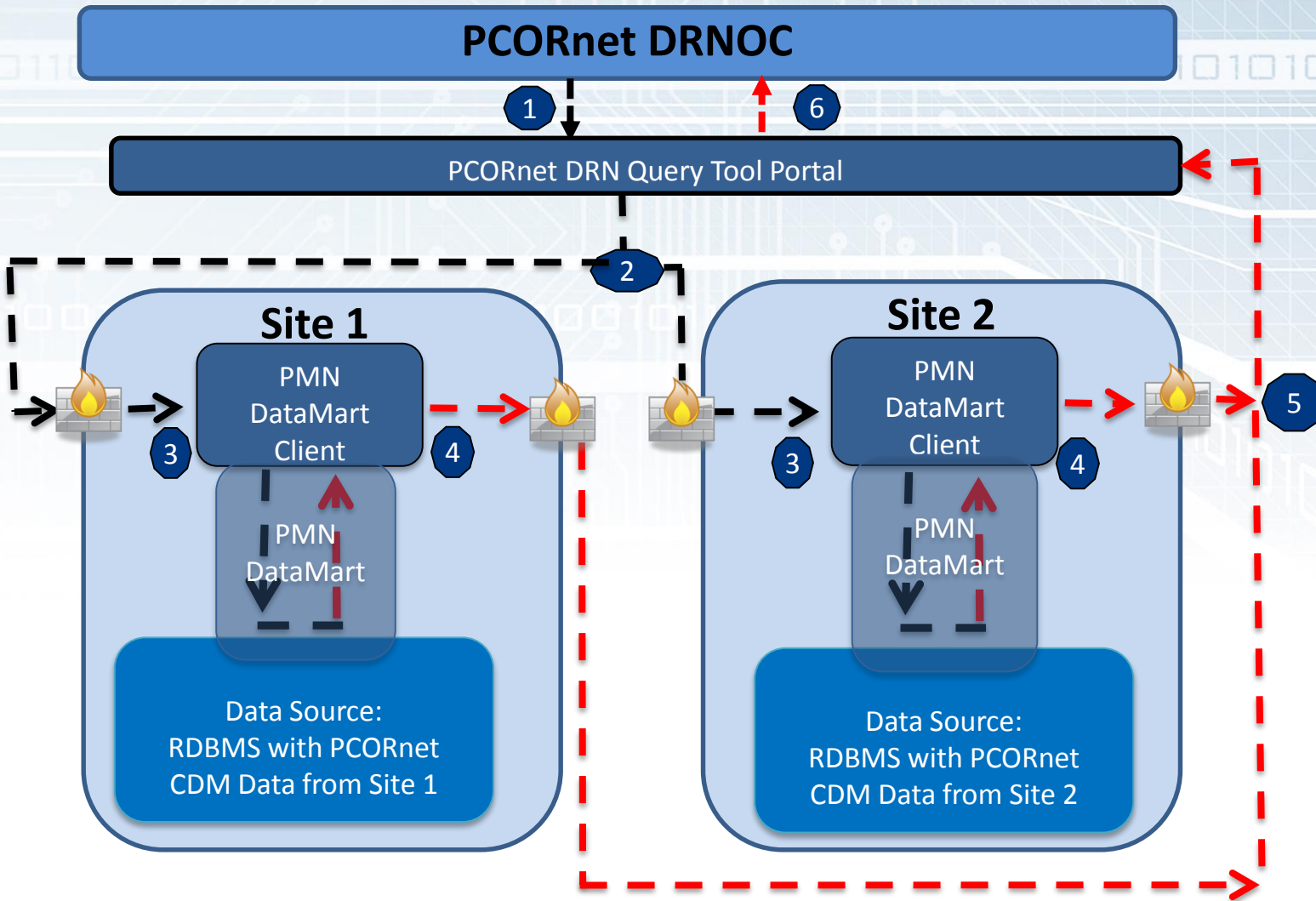
PCORnet DRNOC

1

6

PCORnet DRN Query Tool Portal

2

Site 1

PMN DataMart Client

3

4

PMN DataMart

Data Source: RDBMS with PCORnet CDM Data from Site 1

Site 2

PMN DataMart Client

3

4

PMN DataMart

Data Source: RDBMS with PCORnet CDM Data from Site 2

5

1. PCORnet DRNOC creates and submits query to selected sites

2. Individual sites retrieve query

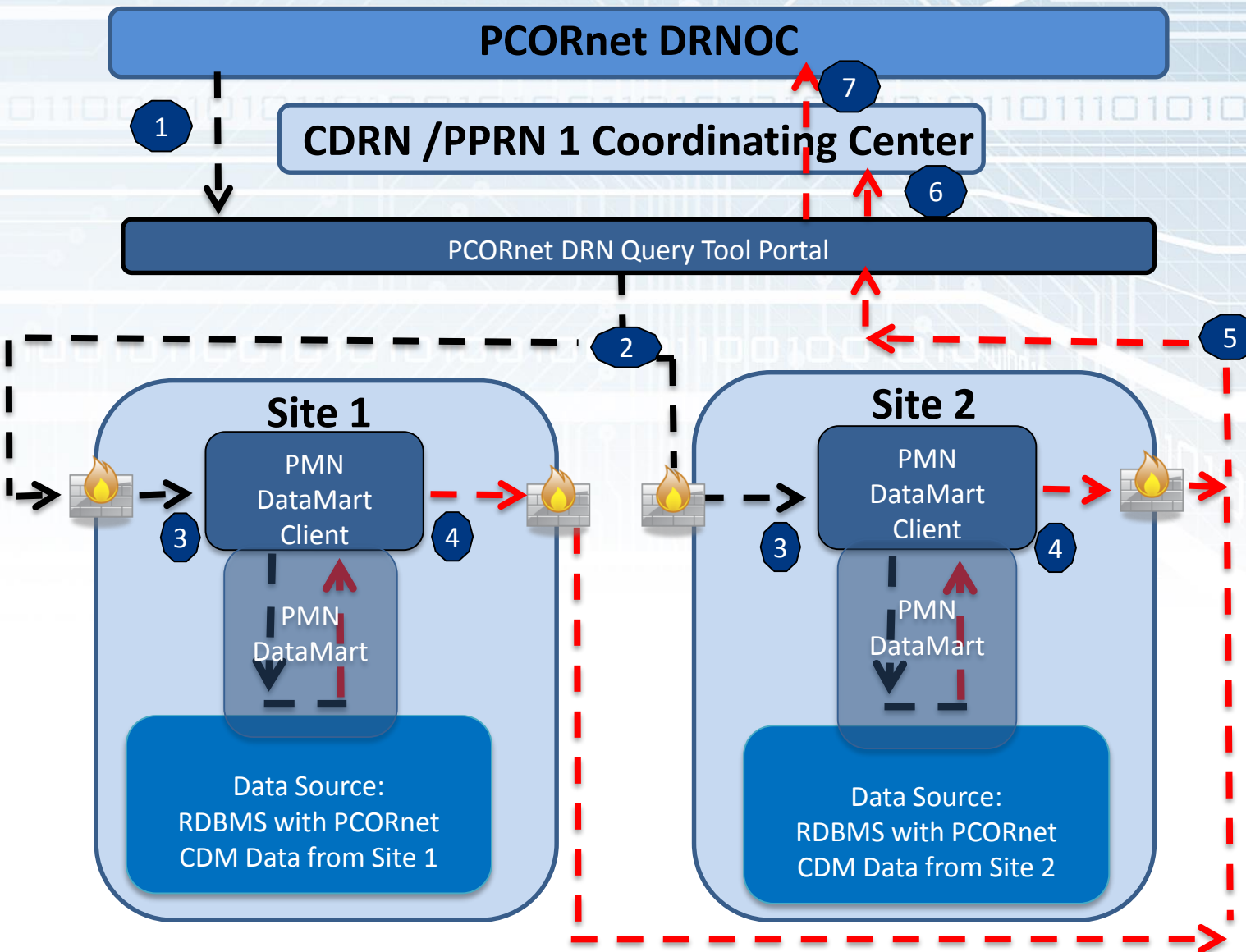3. Sites review and run query against the PCORnet CDM via the PMN DataMart Client

4. Sites review results

5. Individual site returns results via secure network

6. PCORnet DRNOC views results in PMN Portal

-CDRN has options to receive query notifications throughout cycle

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PCORnet Request Cycle Option 3

PCORnet DRNOC

1

CDRN /PPRN 1 Coordinating Center

7

PCORnet DRN Query Tool Portal

6

2

5

Site 1

PMN DataMart Client

3

4

PMN DataMart

Data Source: RDBMS with PCORnet CDM Data from Site 1

Site 2

PMN DataMart Client

3

4

PMN DataMart

Data Source: RDBMS with PCORnet CDM Data from Site 2

1. PCORnet DRNOC creates and submits query to selected sites

2. Individual sites retrieve query

3. Sites review and run query against the PCORnet CDM via the PMN DataMart Client

4. Sites review results

5. Individual sites return results via secure network

6. CDRN/PPRN CC reviews and approves results in PMN Portal

7. PCORnet DRNOC retrieves results in PMN Portal

-CDRN has options to receive query notifications throughout cycle

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Challenge 3: Sites need to install the PMN DataMart Client locally

How much technical support will be needed to support the diverse group of participants?

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Sites need to install the PMN DataMart Client locally: Our Approach

- Updated online documentation
  - Wikis, FAQs, YouTube videos, etc.
  - 1:1 support
- Troubleshooting in a variety of local environments
  - Oracle, SQL Server, Postgres, MySQL
  - Windows, Linux, iOS
  - Some sites with central IT departments others with limited technical support
- Collaborate with sites and technology partners to conduct security assessments
- Provide testing environments during onboarding

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Challenge 4: Increase sociotechnical component of PMN

PCORnet engages patients, care providers, and health systems in clinical research – how do we increase the sociotechnical component of PMN?

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Increase sociotechnical component of PMN: Our Approach

- Extend the collaborative PMN tools by leveraging the support of the NIH Health Care Systems Research Collaboratory and FDA Sentinel networks
  - Improved the capture and use of metadata for:
    - Participating institutions
    - Registries & research data sets
    - DataMarts (data sources)
    - Requests
  - Improved discovery tools including:
    - Metadata searching tools
    - Connecting organizations that use similar registries & research data sets

Challenge 5: Leveraging work from other PMN networks

The PCORnet common data model is different from the other PMN networks - can we leverage any existing PMN reporting, analytic, and workflow tools for PCORnet?

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Leveraging from other work: Our Approach

- Rapid Data Characterization Tool
  - Extend the existing PMN tool that characterizes the distribution and missingness of select variables
  - Utilizes a data model based on data QA & characterization output that can be implemented for any network
- Reports
  - Network activity and audit reports available to PCORnet
  - Request searching and exporting available
- Workflow
  - Multiple workflow options for request review and approval available
  - Coming soon: New workflow engine and task manager developed for the FDA Sentinel network can be leveraged for PCORnet

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Lessons Learned

- We have been continuously improving our processes since the 1st PMN implementation
- Be realistic
  - We learned to be realistic about how much work was needed to implement just the baseline PMN functionality
  - Don't underestimate the level of support that is needed
- Get creative
  - With limited resources and an ambitious timeline, we had to leverage existing functionality and processes in ways that still achieve PCORnet goals
- Be flexible
  - We used multiple tracking tools to capture the implementation status and changes in network architecture while the network evolved
  - Adapt business process to the system
  - Design the system to be modular and anticipate future needs
- Recognize the small successes
  - Recognizing when sites responded to test queries (from an unrelated network and data model) was important & illustrated that the system works and helped build trust and collaboration
  - The small step in capturing institutional metadata facilitates discoverability and the sociotechnical component of PMN

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Questions?

Thank you!

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