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PCORnet Distributed Research Network Operations Center (DRN OC)
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
Agenda

• PopMedNet (PMN) overview
• Describe PMN implementation for the PCORnet Distributed Research Network (PCORnet DRN)
• Explain approaches to address challenges
• Summarize lessons learned
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
PopMedNet Timeline

2007
- Proof Of Concept Demo

2008
- AHRQ Reports

2009
- PMN Public Website launched

2010
- 1st Mini-Sentinel Query

2011
- OCN QH Framework Selection

2012
- 1st PMN Users Meeting

2013
- 250th Mini-Sentinel query sent

2014
- Major PMN infrastructure upgrade to V5.0

2015
- 2nd PMN Users Meeting

PMN Version 1.0 (AHRQ)
- Mini-Sentinel Network (FDA)

PMN Version 1.5 (AHRQ)
- SPAN Network (HMORN)

PMN Version 2.0 (AHRQ)
- PEAL Network (HMORN)

HMORN (now HCSRN) Network

Sentinel Network (FDA)

MDPHnet Network (Mass. DPH)

ONC Pilots (ONC)

CRN Network (HCSRN)

Collaboratory Network (NIH)

PCORnet DRN (PCORI)
# PMN Usage Statistics*

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

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

Health Plan 1  Health Plan 4  Health Plan 7  Hospital 1  Hospital 4
Health Plan 2  Health Plan 5  Health Plan 8  Hospital 2  Hospital 5
Health Plan 3  Health Plan 6  Health Plan 9  Hospital 3  Hospital 6

Outpatient clinic 1  Patient network 1
Outpatient clinic 2  Patient network 2
Outpatient clinic 3  Patient network 3
Multiple Networks Sharing Infrastructure

Health Plan 1
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Outpatient clinic 1
Outpatient clinic 2
Outpatient clinic 3
Patient network 1
Patient network 2
Patient network 3
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?
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
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
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?
Network architecture evolving: Our Approach

- Leverage existing PMN functionality to represent the PCORnet sub-networks (CDRNs and PPRNs)

<table>
<thead>
<tr>
<th>Entity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Organization</td>
<td>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.</td>
</tr>
<tr>
<td>DataMart</td>
<td>Collection of queryable data that adhere to the CDM Used to process requests.</td>
</tr>
<tr>
<td>User</td>
<td>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.</td>
</tr>
</tbody>
</table>
Network architecture evolving: Our Approach

Clinical Sites A – E are the Children or individual sites of the Demo CDRN

<table>
<thead>
<tr>
<th>Name</th>
<th>Acronym</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Site A</td>
<td>CSA</td>
<td>Demo Clinical Data Research Network</td>
</tr>
<tr>
<td>Clinical Site B</td>
<td>CSB</td>
<td>Demo Clinical Data Research Network</td>
</tr>
<tr>
<td>Clinical Site C</td>
<td>CSC</td>
<td>Demo Clinical Data Research Network</td>
</tr>
<tr>
<td>Clinical Site D</td>
<td></td>
<td>Demo Clinical Data Research Network</td>
</tr>
<tr>
<td>Clinical Site E</td>
<td></td>
<td>Demo Clinical Data Research Network</td>
</tr>
<tr>
<td>Demo CDRN</td>
<td>DCDRN</td>
<td></td>
</tr>
</tbody>
</table>
Network architecture evolving: Our Approach

This organization has a DataMart available for querying.

This organization is participating in the network but does not have a queryable DataMart.
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
PCORnet Request Cycle Option 1

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
PCORnet Request Cycle Option 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 site returns results via secure network
6. PCORnet DRNOC views results in PMN Portal
- CDRN has options to receive query notifications throughout cycle
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
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?
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
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?
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?
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
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
Questions?

Thank you!

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Acknowledgements

• Harvard Pilgrim Health Care Institute
  – Jeffrey Brown
  – Melanie Davies
  – Kyle Erickson
  – Chayim Herzig-Marx
  – Casie Horgan
  – Lindsey Petro
  – Gabrielle Purcell
  – Jessica Sturtevant
  – Zachary Wyner

• Lincoln Peak Partners
  – Bruce Swan
  – James Hancock

• Duke Clinical Research Institute
  – Lesley Curtis
  – Jenny Ibarra
  – Laura Qualls
  – Shelley Rusincovitch
  – James Topping