PopMedNet: Collecting and Using Metadata in Distributed Research Networks

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Background

- Distributed research networks are increasingly being utilized to facilitate comparative safety and effectiveness research and support public health surveillance activities.[1,2]

- PopMedNet[TM] (PMN) is a scalable and extensible informatics platform designed to facilitate the implementation and operation of distributed health data networks. PopMedNet now supports a range of distributed networks, including the FDA Mini-Sentinel, NIH Health Care Systems Research Collaboratory Distributed Research Network (DRN), MDPHnet, HMORNnet, CRNnet, and PCORnet.[3-7]

- As these networks grew in size, complexity, and level of querying activity, it has become increasingly important to improve the capture and use of institutional, data source, and request metadata to enhance network operations and collaboration.

- Capturing information about network use will allow networks to more easily learn from the use of the network and address the problem of siloed learning.

- In 2014, the PopMedNet team at Harvard Pilgrim Health Care Institute (HPHCI), in collaboration with the PopMedNet technology partners, Lincoln Peak Partners, and the network coordinating centers for Mini-Sentinel, PCORnet, and the NIH Health Care Systems Research Collaboratory DRN, developed new methods for capturing and reporting on specific metadata related to the collaboration and query activity for each network.

Numbers of requests, organizations, and DataMarts in PopMedNet networks:

Network	Requests	Organizations	DataMarts
Mini-Sentinel	1044	21	20
MDPHnet	729	5	3
PCORnet	293	116	81
Health Data Collaboration	176	16	18
NIH Collaboratory DRN	126	16	14
* As of 2/26/2015			

Objectives

Goals of the projects were to develop and implement (1) new metadata capture approaches and tools, and (2) querying and reporting functionality to leverage the newly collected metadata to improve within and across network collaboration and efficiency.

For more information visit https://popmednet.atlassian.net/wiki/display/DOC/Manage+your+Organization%2C+Datamart%2C+and+Registry+Metadata or scan the QR code on the left.

Methods

- In 2014, the PMN team at HPHCI held requirements gathering sessions with stakeholders from Mini-Sentinel, PCORnet, and NIH Health Care Systems Research Collaboratory DRN networks, including coordinating center staff and network administrators, to define necessary searching and reporting functionality and metadata elements to capture.

- Stakeholders identified organization, data source, and query metadata as key areas for new functionality. The development teams assessed the requirements to ensure that the changes would meet the specific needs of each network while being general and extensible enough to be seamlessly implemented for all other distributed research networks using PMN
  - Organization metadata: includes information such as the organizational descriptions (e.g., health plan, hospital), available data resources (e.g., claims, registries), local expertise, data models supported, and willingness to participate in different types of research activities (e.g., clinical trials, observational).
  - Data source metadata: focuses on a specific resource and includes information such as data model, data elements, and periods of data capture.
  - Request metadata: includes information such as request descriptions, requester, and dates.

- PopMedNet profile input screens for organizations, DataMarts (queryable data sources), and registries were expanded to capture standardized information about each of these entities. When available, existing metadata standards were adopted. Additionally, the request input screen was expanded to capture additional request metadata.

- An additional discovery functionality was developed to allow users to search for and report on organizations, data resources, registries, or requests that meet specific criteria.

- Access control layers were developed to manage existing metadata and how much information specific users can view. This provides for networks to customize the permissions based on network governance.

Organization Metadata

Registry and Research Data Set Search Results

Results

- These new software features were incorporated into the PMN software and released to each network in 2014. Networks are using the new metadata capture and reporting functionality for a range of purposes.

- PCORnet has focused effort on improved collaboration, which is evident with the data partners updating their organization and registry data to make it easier for others to find them for partnerships.

- Mini-Sentinel is using the request metadata to allow the network coordinating center to more easily search for and report on requests with specific parameters such as requests that have certain drugs or outcomes.

DataMart Metadata

Request Metadata Search Results

Conclusions

- As adoption and use of distributed networks grow, there is an increasing need to capture network metadata to improve network operations, encourage collaboration, and **enable network learning.**

- The new metadata capture and search tools were successfully implemented across all PMN networks.

- The value of distributed networks will grow with the ability to capture and use network and request metadata. When development funding is coordinated across stakeholders that share common goals, more robust and cohesive functionality can be developed and utilized by several networks, achieving grater economies of scale.

Recommendations

Additional functionality should be considered that would expand and improve the following areas:
- Searching and reporting: implement advanced searching functionality that allows the users to customize their searches and the report output.
- Metadata capture: include additional metadata elements (e.g., include research domains/expertise).
- Access controls: refine the permission levels to more finely restrict viewing, editing, and searching metadata elements.
- Collaboration tools: implement tools for users to securely communicate and share information with other collaborators across the network within PMN.

References

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