



PopMedNet: Collecting and Using Metadata in Distributed Research Networks



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HPHCI: Harvard Pilgrim Health Care Institute; LPP: Lincoln Peak Partners

Background

- Distributed research networks are increasingly being utilized to facilitate comparative safety and effectiveness research and support public health surveillance activities.^{1,2}
- PopMedNet™ (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 Name: Harvard Pilgrim Health Care, Acronym: HPHCI, Parent Organization: None

Contact First Name: Jeffrey, Contact Last Name: Brown, Contact Phone: 617-509-9986, Contact Email: jeffL_brown@email.o

Organization Description: Harvard Pilgrim is a full-service health benefits company serving over 1.2 million members throughout Massachusetts, New Hampshire, Maine and beyond. Our mission is to improve the quality and value of health care for the people and communities we serve. Harvard Pilgrim's provider network includes physicians who practice in a variety of settings, including individual practices, small medical groups and large multi-specialty groups. Harvard Pilgrim's network has over 135 hospitals and 28,000 doctors and clinicians.

Collaboration Requirements and Additional Information for this Organization: HPHCI is open to collaboration on observational and prospective research. All research must include an HPHCI Institute (HPHCI) Department of Population Medicine (DPM) research collaborator. HPHCI does not sell data. HPHCI has a research data warehouse that can be augmented with state registry data and linked to EHR data.

Research Capabilities: Research is conducted by the HPHCI Institute (HPHCI) Department of Population Medicine (DPM). DPM is a Harvard Medical School department affiliated with the HPHCI. We have expertise across a range of clinical areas and topics, including medical product safety surveillance, public health surveillance, drug policy, child health studies, and obesity prevention. We manage several distributed health data networks, including FDA Mini-Sentinel, NIH Health Care Systems Research Collaboratory DRN, MDPHnet, and the HCDnet. We also are a member of the HMO Research Network. More info here: www.populationmedicine.org

Willing to Participate In: Observational Research, Clinical Trials, Pragmatic Clinical Trials

Organization Data: Registry & Research, DataMarts, Users

Type of Data Collected by the Organization: None, Outpatient, Enrollment, Laboratory Results, Biorepositories, Patient Reported Behaviors, Other, Inpatient, Pharmacy Dispensings, Demographics, Vital Signs, Patient Reported Outcomes/Health Status, Prescription Orders

Data Models: MSCDM, I2B2, HMORN VDW, OMOP, ESP, Other

Electronic Health Records Systems: Type, EHR System, Start Year, End Year

Organization Metadata

Response: Documents

Name	Type
SPAN ADHD	Research DataSet

Description: A subset of the HMORN VDW for comparative effectiveness research

RoPR URL: -

Classification	Conditions Of Interest	Purposes
Disease/Disorder/Condition	Behaviors and Mental Disorders	Effectiveness

Organizations with this registry: 3

DataMarts with this registry: 0

[+] Global Rare Diseases Registry	Registry
[+] Rare Tumor	Registry
[+] Cancer Registry	Registry

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.

Data Domains: Specify the data domains used, including any standard code sets or other available data elements.

Inpatient Encounters, Encounter ID, Dates of Service, Provider/Facility Identifier, ICD-9 Procedures, ICD-10 Procedures, ICD-9 Diagnosis, ICD-10 Diagnosis, SNOMED, HCPCS (including CPT), Disposition, Discharge Status, Other, Outpatient Encounters, Encounter ID, Dates of Service, Provider/Facility Identifier, ICD-9 Procedures, ICD-10 Procedures, ICD-9 Diagnosis, ICD-10 Diagnosis, SNOMED, HCPCS (including CPT), Other, Prescription Orders, Prescription Order Dates, RxNorm, NDC (National Drug Codes), Other

Longitudinal Capture, Patient ID, Capture Start, Capture Stop, Other, Laboratory Test Results, Order Dates, Result Dates, Text Name, Text Descriptions, LONC, SNOMED, Results Interpretation, Other, Outpatient Pharmacy Dispensing, Pharmacy Dispensing Dates, NDC (National Drug Codes), RxNorm, Days Supply, Amount Dispensed, Other, Biorepositories

Demographics, Sex, Date of Birth, Date of Death, Zip Code, Race, Ethnicity, Other, Patient Reported Information, Health Behavior, Health Related Quality Of Life (HRQL), Patient Reported Outcome (PRO), Other, Vital Signs, Temperature, Height, Weight, Length, BMI, Blood Pressure, Other

DataMart Metadata

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 greater 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.

Project	Request Type	Name	Submit Date	Requestor	Organization	ID
[+] Demo	Query Composer	Patients with diabetes	2/21/2014 6:31:46 AM	Melanie Davies	Operations Center	304

Priority	Due Date	Purpose Of Use	Level of PHI Disclosure	Requestor Email
Medium	2-24-2014	HRESCH	Aggregated	melanie_davies@hphci.org

Description: All patients with 250 or condition = type 1 diabetes or condition = type 2 diabetes between 2008-2012, >=4 visits, and over 40 years old. S

Task Order	Activity	Activity Project	Requester Center	Workplan Type
n/a	n/a	Not Selected	Not Selected	Not Selected

[+] Demo	Query Composer	Diabetes + HTN	2/21/2014 6:38:57 AM	Melanie Davies	Operations Center	309
[+] Demo	Query Composer	Diabetes + HTN, no stroke	2/21/2014 6:57:21 AM	Melanie Davies	Operations Center	311

Request Metadata Search Results

References

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- Behrman RE, et al., Developing the Sentinel System – a national resource for evidence development. New England Journal of Medicine 2011; 364(6): 498-99.
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- Fleurence RL, et al., Launching PCORnet, a national patient-centered clinical research network. J Am Med Inform Assoc. doi:10.1136/amiainjnl-2014-002747 [Epub ahead of print]
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- PopMedNet: <https://www.popmednet.org>