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.
- PopMedNet (PMN) is a scalable and extensible informatics platform designed to facilitate the implementation and operation of distributed health data networks.

Objectives

- Goals of the project were to implement and develop (1) new metadata capture approaches and tools that (2) support leveraging to an extent that the newly collected metadata improve within and across network collaboration and efficiency.

Methods

- In 2014, the PMN team at HPHCI held requirements gatherings sessions with stakeholders from Mini-Sentinel, HPCP/MDRN, and NH Health Care Systems Research Collaboratory (DRN), networks, including coordinating centers, site and network administrators, to define necessary searching and reporting functionality and metadata elements to capture.

Results

- PopMedNet 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.

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.

Recommendations

- Additional functionality should be considered that would expand and improve the following areas:
  - 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.
  - Additional discovery functionality was developed to allow users to search for and report on organizations, data resources, registries, or request metadata that 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.
  - Access controls: refine the permission levels to more finely restrict viewing, editing, and searching metadata elements to capture.
  - Additional functionality will be developed to allow users to search for and report on organizations, data resources, registries, or request metadata.

References