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Implementation of An Integrated Network for Health Research in Quebec

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Abstract

Health data warehouses represent a valuable resource for health research. We have developed an infrastructure capable of providing health researchers in the province of Quebec with a toolkit to access the clinical data warehouses contained in the major academic health centres and the provincial health administrative systems. This demonstration will highlight the components that allowed the successful implementation of an integrated network to accomplish this task. Acceleration of the pace and increases in the volume and quality of health research within the province, in other jurisdictions and possibly world-wide is now an attainable goal.

Keywords:

health databases, information management, patient data privacy, database management systems, computing methodologies, health services research

Introduction

Health research done in the conventional, paper-record environment is tedious, expensive and reliant on data with varying quality. Large repositories of health data are invaluable resources to researchers and planners in health care. In the province of Québec, Canada, these repositories are housed in clinical data warehouses within the large teaching hospitals and the administrative data warehouse at the Régie de l'assurance maladie du Québec (RAMQ) – the provincial health services payer. The Infostructure de Recherche Intégrée en Santé (IRIS) - Québec project is a Canada Foundation for Innovation funded initiative to construct an integrated network for health research in the province. Its goal was to create secure access to these data warehouses, enable the linkage of patient records through the use of a provincial Master Person Identifier (MPI) and ensure that resultant datasets returned to researchers conform to privacy standards.

Methods

The IRIS-Québec architecture is a distributed, federated data warehouse model. The RAMQ already manages the MPI. The research warehouses of clinical data were constructed to ensure the highest standards of data quality. People: Researchers wishing to access these data warehouses no longer have to queue for specialized data analysts and programmers. The researchers' toolkit is a web-based, user-friendly interface that drives a powerful system with the following functions: selection of variables from the extensive data dictionary across the warehouses, building of complex queries using logical operators, a temporal relation tool to define time-dependencies of variables, a crosstabs manager, and a data extraction manager. Previously onerous and lengthy authorization steps have been streamlined into an electronic approval process which is reliable, timely and track able. Privacy: A novel "inference controller" was developed to ensure individual data privacy. This software computes the probability of the presence of an unique, potentially re-identifying profile when multiple databases are linked. The researcher's toolkit allows the dynamic modification of data query parameters in order to achieve the desired data precision without violating privacy rules Processes: Data sharing agreements were established with each partner institution. Software agents were installed at each data source to manage queries, connectivity, linkages, and data flows. Each agent contains a copy of the inference controller engine. Performance: is maintained by de-coupling the phases of a research project from the raw data extractions. The creation of the complete cohort data cube is triggered only on submission of the finalized project profile. We will demonstrate the operation of the Toolkit through sample queries.

Conclusion

The architecture of our system can potentially be extended to other biomedical information sources such as genomics, proteomics and geneology databases and create new capacity for health and bio-medical research. This architecture can also be potentially replicated in other jurisdictions. Scaling such a system to the international level can result in enabling health and bio-medical research in the global community.

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