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Title

Considerations for creating a Restricted Data Environment with complete primary care electronic medical record data

Priority 1 (Research Category)

Big Data

Presenters

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Abstract

Background: Historically, primary care databases have been limited to subsets of the full electronic medical record (EMR) data to maintain privacy. With the progression of artificial intelligence (AI) techniques (i.e., machine learning, natural language processing, and deep learning), practice-based research networks (PBRNs) have an opportunity to utilize previously difficult to access data to conduct essential primary care research and quality improvement. However, to ensure patient privacy and data security, novel infrastructure and processes are required. We describe the considerations related to accessing complete EMR data on a large-scale within a Canadian PBRN.

Setting: Queen’s Family Medicine Restricted Data EnvironMent (QFAMR), Department of Family Medicine (DFM), Queen’s University, Canada

Methods: QFAMR is a central holding repository hosted at the Centre for Advanced Computing at Queen’s University. Complete, de-identified EMR records (e.g., full chart notes, PDFs, and free text) from approximately 18,000 patients from Queen’s DFM can be accessed. An iterative process over 2021-2022 was used to develop QFAMR infrastructure in collaboration with Queen’s DFM members and stakeholders.

Results: In May 2021, the QFAMR standing research committee was established for review and approval of all potential projects. DFM members consulted with Queen’s University computing, privacy, legal, and ethics experts to develop data access processes, policies and governance, agreements, and associated documents. Initial QFAMR projects involved applying and improving de-identification processes for DFM-specific full-chart notes. Five major elements were recurrent throughout the QFAMR development

process: data and technology, privacy, legal documentation, decision-making frameworks, and ethics and consent.

Conclusion: Overall, the development of the QFAMR has provided a secure platform to successfully access data-rich primary care EMR records without data ever leaving Queen's University. Although accessing complete primary care EMR records has certain technological, privacy, legal, and ethical considerations and challenges, QFAMR is a significant opportunity to conduct novel and innovative primary care research.