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Pan-Canadian Real-World Health Data Network: Building a National Data Platform

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Introduction

Researchers and decision makers from across Canada use linked provincial administrative data for analysis and to address research and policy questions. Currently there are several impediments to working harmoniously across provincial boundaries. A group of academic and policy researchers are working to address these multi-jurisdictional obstacles.

Objectives and Approach

Researchers and data organizations from across Canada are working together as the Pan-Canadian Real-World Health Data Network PRHDN). PRHDN aims to: (1) create harmonized data, algorithms and analytic protocols, and (2) link administrative databases to other types of data, including electronic medical records, clinical trials records, "omics data" and records from pan-Canadian cohort studies. PRHDN's vision is to construct a unified, documented infrastructure to advance pan-Canadian population-based research and analysis. This presentation incorporates material that is part of PRHDN's response to a funding call to create national, collaborative infrastructure.

Results

Scientists and staff at PRHDN organizations will create three main categories of infrastructure: 1) Algorithms: Reusable processes, ideally in the form of documented code, which implement a common approach or definition, e.g. to define cases or to create derived variables; 2) Harmonized Common Data: Based on the Sentinel model, we will establish a standardized subset of harmonized common data that are analysis-ready; 3) Common Analytic Protocols: Complementing work of the Canadian Network for Observational Drug Effect Studies (CNODES), we will establish processes for distributed analysis with common analytic protocols and meta-analysis of results to provide pan-Canadian estimates. Source data would remain within jurisdictional boundaries and only aggregate results would be pooled across jurisdictions. Details of these approaches will be presented.

Conclusion/Implications

This initiative will improve coordinated access to distributed data from across Canada that is built once then used by many stakeholders for a variety of purposes including: research, benchmarking, performance monitoring to identify gaps and opportunities for improvement, multi-jurisdictional evaluations of novel interventions and inter-jurisdictional comparisons.