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The Nascent Pan-Canadian Real-world Health Data Network (PRHDN)

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Objectives

Canada's large single payer health systems have created provincial centres with rich, population-wide health and social data holdings that are linkable at the person level. Complementary federal data include a subset of standardized and enriched administrative healthcare data at the Canadian Institute for Health Information, Statistics Canada's extensive array of survey- and census-based social and geography-based information, and large national datasets that are being created through pan-Canadian initiatives. Unfortunately, these data assets are rarely combined in multi-province or pan-Canadian studies, often because data are not directly comparable from one province to another, or cannot be shared due to legislative or other barriers. There is now growing interest in enabling multi-province studies - even when data are not directly comparable - and in sharing experiences to make more effective use of linked or linkable administrative data across Canada.

Approach

Nine provincial and national organizations have created a detailed Implementation Plan for the new PRHDN distributed data network. Without requiring that record-level data leave provincial boundaries, the PRHDN will create shared core research data infrastructure: (i) validated algorithms that implement case definitions applicable across provinces, (ii) harmonized common data and (iii) common analytic protocols. The PRHDN will also establish complementary infrastructure including dedicated personnel to assist researchers and decision makers, joined-up training and capacity building sessions, opportunities to share learning and experience related to linking new datasets such as electronic medical records and omic datasets, and forums for knowledge translation and exchange with decision makers.

Results

The PRHDN is already bringing together expertise from across Canada as researchers, decision makers and data custodians begin to identify opportunities for enhanced use of health data in Canadian research, policy making and practice. A simple PRHDN website has been created (<https://www.prhdn.ca/>) and more than 200 researchers and policy/decision makers have become members of the PRHDN consortium. Surveys of consortium members are identifying priorities for the first algorithm validation work (to-date the top four priorities are mental health, cardiovascular disease, diabetes and respiratory disease) and the PRHDN Leads Team is functioning as a decision-making body, e.g., in discussions with Statistics Canada.

Conclusion

Working together, provincial and national organizations across Canada have identified concrete steps that can be taken to enable multi-province and pan-Canadian studies based on administrative data within one year of the start of funding. The PRHDN Leads Team is currently discussing the PRHDN vision and Implementation Plan with potential funders.

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