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Building a Canadian Data Platform under the Strategy for Patient-Oriented Research

McGrail, K¹*

¹Population Data BC

Background with rationale

The diversity of Canada's health systems and policies offers fertile ground for natural experiments, comparative analysis, and sharing of best practices. Investments over the last 25 years, measured in hundreds of millions of dollars, have created provincial centres with rich health and social data, national health surveys and more recently, clinical and other data. While much progress has been made within individual provinces and territories, challenges with comparability and timely access to data between jurisdictions remain.

Main aim

Our aim is to develop a distributed network that facilitates and accelerates multi-jurisdictional research.

Methods/Approach

Our team includes data stewards, clinicians, decision-makers, patients, and researchers who are recognized as international leaders in data systems, access governance and engagement. The objectives for the Canadian Data Platform are to: create a data access support system that helps navigate multi-jurisdiction requests; to harmonize and validate definitions for important chronic diseases and other key variables to facilitate multi-jurisdictional research; to continue to expand the sources and types of data and linkages available; to develop the technology infrastructure required to improve the data access request process, data documentation, and re-use of algorithms; to create supports for advanced analytics and infrastructure for data collection and analysis; to establish strong partnerships with patients and the public and with Indigenous communities; and to build strong governance and enable national coordination.

Results

Our Data Access Support Hub will open in the fall of 2019, at which time we will have an inventory of data available across

our network, and the beginnings of a catalog of algorithms and harmonized data.

Conclusion

Building cross-national resources to support multi-jurisdictional research can be challenging in places where there are multiple levels of governance of health and social services. Our network is one example of an approach to addressing these challenges.

*Corresponding Author:

Email Address: kim.mcgrail@ubc.ca (K McGrail)