

Pan-Canadian Real-world Health Data Network (PRHDN): An update and dynamic consultation
28Mar16

The objectives of this panel are (a) to provide an update on the PRHDN status (b) to share information and gain attendee feedback about potential collaborative activities with key partners and (c) to spend a minimum of 20 minutes on real-time voting to obtain attendee input on short-term PRHDN priorities (e.g., priority algorithms to be validated).

Provincial centres across Canada hold rich sources of health and social data that are linked at the person-level. The Strategy for Patient Oriented Research at CIHR has provided further investments to strengthen provincial data resources and research capacity. In addition to this, a subset of standardized and enriched administrative health care data is managed nationally by the Canadian Institute for Health Information (CIHI), an extensive array of complementary survey- and census-based social and geography-based information is collected and maintained by Statistics Canada, and several pan-Canadian investments are creating large, national survey data sets.

While Canada has an immense depth and breadth of information, health data are often not comparable from one province to another, or cannot be shared across provincial boundaries due to legislation or other barriers, thereby limiting use to single-province studies. There is now growing interest in enabling multi-province studies—even when data are not directly comparable—and in sharing experiences to make effective use of linked or linkable administrative data.

The Pan-Canadian Real-world Health Data Network (PRHDN) would establish deliberate overlap so that leading provincial and pan-Canadian organizations from across Canada work together on investments which evolve existing Canadian data and expertise into world-class multi-province data infrastructure. The PRHDN will be a distributed data network that allows researchers and policy/decision makers to make effective use of “real-world” administrative data holdings without requiring that data leave provincial boundaries. Under the PRHDN, organizations from across Canada will independently hold prepared data that are comparable, and researchers, policy makers and decision makers will be provided with services, tools and resources to enable coordinated use of the data.

Most of the elements required for a world-class data platform exist in Canada already, as can be seen from member organizations of the PRHDN and participants on this panel. Working from and building upon the expertise and current infrastructure at existing provincial and national organizations, the PRHDN will bring together and make available existing and new core research data infrastructure in the form of algorithms, harmonized common data and common analytic protocols in priority areas. Key partnerships will ensure that the PRHDN has a transformative impact.

The PRHDN is committed to engaging with and being responsive to researcher needs. After providing an update on relevant activities from each participating organization, we will pose a series of questions to attendees, seeking their input on PRHDN objectives for the coming year. Specifically, we are interested in hearing what key data need to be developed (e.g. geography-based information to add to detailed individual-level health data) and what priority algorithms (e.g. chronic disease, costs, continuity) will help seed cross-provincial research. The panel will use live voting technology to solicit audience input.

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