



Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

Scientific Director and CEO's Report – Sept 16, 2020

HIGHLIGHTS

- **Supporting multi-jurisdictional research:** Twenty-six multi-jurisdictional project requests have been received since the Data Access Support Hub (DASH) had its soft-launch in December 2019 and the more formal launch in February 2020. Every HDRN Canada Organization that has data available (province, territory, CIHI and StatCan) has had their data requested through these studies. Several of these requests relate to COVID-19.
- **Responding to research priorities:** In response to the COVID-19 pandemic, the organizations that make up HDRN Canada are demonstrating pan-Canadian leadership to ensure relevant sources of data are available, that access processes are expedited where possible, and that this information is shared with researchers. HDRN Canada is issuing ~ monthly COVID-19 briefing notes that summarize COVID-19 data, studies and tools across HDRN Canada. The briefing notes can be downloaded from the [French](#) and [English](#) HDRN Canada COVID-19 webpages. In addition, metadata information on HDRN Canada organizations that have linkable COVID-19 tests results data (five provinces) has been provided on the website to assist researchers in planning their studies.
- **Partnerships and collaborations:**
 - HDRN Canada has signed a letter of intent to partner with the International COVID-19 Data Research Alliance.
 - HDRN Canada's Scientific Director and CEO has been asked by the federal government to join the Global Partnership on Artificial Intelligence (GPAI) as a Canadian representative on their Data Governance Working Group.
 - The Canadian Partnership for Tomorrow's Health (CanPath) has become the first member of the Canada HDR-Alliance (modelled on the HDR UK Data Alliance). This Alliance is designed to enable HDRN Canada to work with external data partners to expand sources and types of data available to researchers via the DASH in a coordinated way.
- **Exploring pursuit of charitable status:**
 - The Executive will be discussing funding method options in September. The methods include voluntary contributions from partner organizations or a scaled "membership" fee for HDRN Canada. The lawyers have been notified that this work will likely be coming to them before the end of the year and have no outstanding concerns at this time.
- **Finance and administration:**
 - Site work plans for 2020 / 21 are in place and those funds are now being distributed to network organizations. CIHR funds are planned to cover the remuneration of a total of 40.9 FTEs across the network and 3.5 FTEs for network management and coordination.
 - Taking into account current and anticipated ongoing travel restrictions, recent adjustments to this year's budget include a redistribution of funds earmarked for meetings, network travel, and conference participation. Funds intended for investment in technical infrastructure and equipment have likewise been distributed among the latter half of this fiscal and future years.
 - HDRN Canada has signed the Directors and Officers Insurance policy with Trisura. As each data centre is subject to their own organizations privacy and security policies, and HDRN

- Canada does not hold any data itself, we are not pursuing additional cybersecurity insurance.
- CIHR has now provided formal notification that, because of COVID-19, all grant holders (including our grant) are being given an additional year to spend the grant funding. There is no change to the overall grant amount. The end date for the CDP grant period is now March 31, 2028.
 - **Major work streams for the coming year**
 - Development of a single central, coordinated data request form to replace multiple center-specific forms.
 - Further development of metadata, which will create common terminologies (or harmonized semantic labels) across jurisdictions as a building block for future automation.
 - Co-development of new algorithms with researchers who will provide content knowledge and input, while HDRN Canada will provide methodological and analytic supports for algorithm development and validation.
 - Establish an ongoing Public Advisory Council, SPOR CDP Advisory Committee and Strategic Advisory Council.
 - Implement Indigenous engagement strategy that will include addressing internal network and partner training and education needs and external relationship development.
 - Assessment of science and technology related to distributed analysis of data, and plans for (and ideally start on deployment of) supports for that. This will include both technical and policy / process work.
 - **Anticipated challenges**
 - Desire from researchers to create and have access to pan-Canadian, merged data sets that are accessible in a single location. While this is a natural desire, we are limited by legislative and procedural barriers in our capacity to deliver on this, at least in the short term. *There is work led by HDRN's privacy team to help identify ways to address this challenge.*
 - Positioning HDRN Canada in a complex data environment. This need has become more pointed because of COVID-19 and an even greater focus on pan-Canadian research. *The Canada HDR Alliance is one important initial response to this.*
 - Related to the above, HDRN Canada must prioritize the many opportunities that come our way, and then properly resource the things we choose to follow up on.