



Scientific Director and CEO's Report – May 28, 2020

HIGHLIGHTS

- **Supporting multi-jurisdictional research:** Fifteen 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 (provincial, territorial, CIHI and StatCan) has had their data requested for at least three of 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 ~ biweekly 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.
- **Partnerships and collaborations:**
 - Ongoing conversations and developing collaboration with Health Data Research UK, including drafting a Memorandum of Understanding that is currently with the partner for review
 - Initiation of the development of an HDRN Canada Alliance model (modelled on the HDR UK Data Alliance) which would create a mechanism for HDRN Canada to work with data partners to expand sources and types of data available to researchers in a coordinated way
 - Ongoing conversations with IBM to identify potential areas for collaboration **to use the \$1 million/year in-kind commitments (\$7 million over seven years) included in IBM's letter of support in the 2018 CIHR grant proposal. At present, these conversations are focused on the potential of purchasing AI chatbot development services from IBM.**
 - Development of a New Frontiers in Research Funding application in partnership with the Canadian Research Data Centre Network (CRDCN). This has a low probability of success (the competition received 460 letters of intent) but we are pursuing this because it helps advance conversations with CRDCN and Statistics Canada about social data linkage.
 - A co-branded briefing note aimed at increasing Electronic Medical Record (EMR) data holdings has been developed with the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), and will be refined further with CPCSSN then used in discussions with potential funders of EMR
- **Exploring pursuit of charitable status:**
 - Members of the Executive Team have gathered information about the benefits and costs of pursuing charitable status. In brief, being a registered charity has the potential to make HDRN Canada a more attractive organization to potential funders/donors, and the overall work to establish HDRN Canada as a charity would be minimized if it is initiated soon.
 - An external consultant has provided information which addresses the risk that becoming a registered charity could result in HDRN Canada activities being interpreted as lobbying. The CRA has recently clarified that advocacy activities undertaken by charities are NOT considered to be lobbying, and defined the term Public Policy Dialogue and Development activities (PPDDA), which would specifically allow HDRN Canada to be a charity and work with policy makers without its activities being interpreted as lobbying.

- The process to become a charity in Canada requires electronic submission, could cost up to \$20,000 (one time direct charges for legal fees) and take ~ 6-7 months to complete. HDRN Canada is working to confirm a source of funding.
- **Finance and administration:**
 - As of March 31, 2020, HDRN Canada has invested 9.5% of the total funds it will receive from CIHR over seven years. CIHR funds are currently covering remuneration of a total of 15.3 FTEs across the network and 4.0 FTE for network management and coordination. Workplans for 2020/21 are in place and those funds are now being distributed to network organizations.
 - HDRN Canada staff have finalized a Performance Measurement Framework together with CIHR which will be the foundational guide for annual reporting
 - Feedback from CIHR on the 2018/19 Annual Performance Report was positive and included, "It is encouraging to see the SPOR CDP Data Access Support Hub (DASH) development is on track. The development of a governance structure and the creation of working groups along with the numerous consultations are positive steps towards meeting the goals of the first year of funding. According to the funding agreement, the SPOR CDP planned to spend \$6,995,375 in 2018-19 but only spent \$261,450 (4%) of the allocated funds. As the platform was only operational for five months at the time of reporting and an Operations Director only hired in April 2019, it is expected that spending will continue to ramp up particularly once the DASH portal is deployed in February 2020."
 - HDRN Canada is working with an insurer to establish Directors and Officers Insurance and also Cybersecurity Insurance for the Corporation even though we are not planning to hold any data at this time
- **Major work streams for the coming year**
 - Development of a central, coordinated (single) data request form to replace multiple center-specific forms
 - Further development of metadata, which will create common terminologies (or harmonized semantic labels) across jurisdiction as a building block for automation
 - Deployment of open call for co-development of algorithms. The intent is to invite researchers to identify priorities and 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, which will include addressing internal-facing 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 of 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 in our capacity to deliver on this, at least in the short term.
 - Positioning HDRN Canada in a complex data environment. This need has become more pointed because of COVID and an even greater focus on pan-Canadian research.
 - Related to the above, prioritizing the many opportunities that come our way, and then properly resourcing the things we choose to follow up on.