HDRN Canada

Scientific Director and CEO’s Report

May 28 2020

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**Overview:** The first section of this report highlights major initiatives and accomplishments over the last year, major milestones for the coming year, and anticipated challenges. Following this overview, the rest of the document offers additional details on areas of significant investment and / or importance to HDRN Canada’s mission. Your feedback on striking the right balance of detail for these updates will be appreciated

# Section 1: 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.

### 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. (More details on this are provided in the material below.)
* 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 data

### 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. Further details can be found in the CPD Finance Snapshot and Full Grant Budget.
* 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
* 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.

# Section 2: Additional Information About HDRN Canada Progress and Core Work

Just over one year ago, on April 23, 2019, Canada’s Minister of Health announced funding for a new initiative which would make it easier for researchers to access and analyze health data across multiple provinces and territories. Over the past year, HDRN Canada was incorporated as a federal nonprofit entity with an independent governing Board of Directors, and has made significant strides towards developing infrastructure to meet its goals and objectives. The following provides an update on the HDRN Canada working groups or teams who are advancing this work:

### The Data Access Support Hub (DASH) Working Group

In February 2020, HDRN Canada launched DASH, a single-stop online portal through which researchers can access information and services to help plan and execute multi-jurisdictional research. DASH services include a single data request for multi-jurisdictional data, and the ability to track the progress of their application.

Currently, researchers can access an inventory of datasets that are available for request, a database of algorithms for measures of population health, health service use, and the determinants of health, and an inventory of data access requirements and procedures at HDRN Canada member organizations via the DASH website. Additional resources will be added on an ongoing basis to aid researchers’ use of HDRN Canada data.

Since launching, staff at the DASH have responded to inquiries from researchers across Canada on a wide range of topics, including studies on wait times for a primary care provider, children with neurodevelopmental disabilities, diabetes, other chronic illnesses, and more. Fifteen project requests have been received to May 7, 2020. Every HDRN Canada Organization that has data available (province, territory, CIHI and StatCan) has had their data requested in at least three of these studies.

Upcoming work for the DASH Team includes:

* Development of a central data request form to replace multiple center-specific forms
* Documentation of existing Indigenous data access policies and procedures to make available through DASH
* Advancing data sharing and linkage (in conjunction with Privacy Team). DASH will compile information on the various legal frameworks around data sharing across our network and identify legislative barriers

### Algorithms and Harmonized Data Working Group

The Algorithms and Harmonized Data (AHD) working group has launched two key resources for researchers, which are available on the DASH website:

* Inventory of Existing Algorithms
* Contains information from a systematic review undertaken by HDRN Canada to identify existing published algorithms. All algorithms included in this inventory have been validated or tested for feasibility of implementation in two or more Canadian provinces and territories. Currently 140+ multi-jurisdiction algorithms from 34 existing validation or feasibility studies are included in this inventory.
* HDRN Canada Data Assets Inventory
* Provides overview information on the 380+ datasets that can be requested for research projects. Additional data assets acquired at HDRN partner sites will be added over time.

Upcoming work for the Algorithms and Harmonized Data Working Group includes:

* Issuing a call for proposals for new algorithm studies that could be undertaken using data available from HDRN Canada Organizations. Successful proposals will be invited to submit a DASH application to obtain data for their research and will be supported by HDRN Canada staff in the data analysis.
* Conducting a systematic review on determinants of health, looking at published research as well as national resources such as StatCan and CIHI
* Developing a training guide to update the dataset and algorithm inventory using standardized processes
* Collecting metadata and applying harmonized semantic labels from across the network, piloting the process at the Manitoba Centre for Health Policy

### Interim Public Advisory Committee and Public Engagement Working Group

HDRN Canada is committed to including a diversity of voices and perspectives through its Public Advisory Council (PAC) and Public Engagement (PE) Working Group.

Over the last year, HDRN Canada has been guided by feedback and recommendations from its interim PAC (iPAC). As of April 2020, the iPAC has accomplished it primary purpose which was to help HDRN Canada identify the mandate, terms of reference and recruitment process for the permanent PAC. HDRN Canada is in the process of having recruitment materials translated into French and will begin recruiting French and English members of the permanent PAC in May/June with the first meeting of the PAC planned for 2020.

The PE Working Group has worked closely with the iPAC on public engagement including developing and holding an initial “beta version” English webinar about HDRN Canada and its activities for ~45 invited members of public. The English beta has been refined based on participant feedback and is being translated into French so that a second “beta version” webinar in French can be held in June 2020.

HDRN Canada will then finalize the webinar content and provide it (and record it) in English and French in fall 2020.

### Indigenous Data Team

The Indigenous Research Team is developing a plan for Indigenous engagement for HDRN Canada. A work plan and engagement strategy have been developed for 2020/21 and additional content will be developed in the coming year.

An Ontarian researcher has received a grant for rapid implementation of COVID-19 testing for First Nations and Metis peoples, and HDRN Canada is working with the Indigenous Research Team to identify ways to support this project.

### Strakeholder Partnerships

Effective engagement of external stakeholders and partners will be essential to the long-term success of HDRN Canada. Highlights of partnerships work over the past year and in progress includes:

* Ongoing international collaboration with Health Data Research UK, including drafting a Memorandum of Understanding that is currently with the partner for review
* 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
* 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 [Link]
* Developed guidance for local Canadian SPOR SUPPORT Units on content that could be included related to HDRN Canada in their next round of grant applications to CIHR
* Finalized SPOR CDP Advisory Committee terms of reference and recruited 10 people from 10 different SPOR-funded entities across Canada for the first meeting in late summer/early fall 2020
* Provided eight letters of support for funding applications to research teams interested in conducting multi-jurisdictional research
* Developed a co-branded briefing note with the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) focused on EMR data which would enhance Canada’s ability to understand and manage COVID-19 beyond and before cases become acute. The briefing note will be refined further with CPCSSN then used in discussions with potential funders of EMR data.
* HDRN Canada and Canadian Research Data Centre Network (CRDCN) are partnering on the New Frontiers Research Fund - Transformation Stream Letter of Intent entitled, "Promoting equality of opportunity in a changing society: identifying policies that work". The grant would be worth up to $4m per year for six years. We are currently seeking support from the Chief Statistician from Statistics Canada.
	+ There were 460 Notices of Intent and apparently only about 30 Letters of Intent will be chosen for the final application stage where only 6 will win.
	+ The research goals stem from Canada having a relatively high degree of equality of opportunity by international standards, with some evidence of ongoing decline. The pandemic almost surely will worsen this problem, as it is likely that low SES individuals, particularly children, will suffer more short-term and long-term harm. At the same time, all levels of government, but perhaps particularly provincial governments who face health and education costs, are facing even more straitened circumstances and will want to understand the return on every dollar that they spend.
* Hence our research goals include:
1. determining how equality of opportunity in all its manifestations, including health and education, differs across the country and across groups and is changing over time
2. determining which policies are most effective per dollar in enhancing equality of opportunity
* But because data on matters such as health and education are largely provincial while data on income, immigration and Census demographics are federal, addressing the first two goals involves a third challenge:

(c) developing a flexible data ecosystem provide analytical links between provincial/territorial administrative microdata to Statistics Canada and other federal survey and administrative microdata

### Privacy Team

HDRN Canada has established a team of privacy staff from across HDRN Canada Organizations who provide advice and expertise. The team also serves as a key resource to ensure appropriate compliance with privacy legislation and regulations, and application of international privacy principles and best practices. Key areas of work for this group have been:

* Reviewing DASH website content for privacy considerations, including development of the privacy statement/policy for this website
* Discussions on a joint privacy review across HDRN Canada Organizations

Upcoming work for the Privacy Team includes:

* Working with the DASH Working Group to advance data sharing and linkage
* Legislative analysis and framework development in response to several provinces implementing legislative changes and setting new precedents around data sharing
* Review of Privacy Ethics from a network perspective looking at the policies of internal HDRN Canada Organizations and external partners