HDRN Canada

Scientific Director and CEO’s Report

September 16 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.

# Section 1: 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. 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 (additional detail provided in Strategic Partnerships section below):

* 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. Further details can be found in the Full Grant Budget included in this package.
* 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.
* 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.

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

Over the past year, HDRN Canada incorporated as a federal nonprofit entity with an independent governing Board of Directors, and 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 continuing to advance 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. Since the launch, the DASH has received twenty-six project requests (as of August 19, 2020) covering a wide range of topics / studies, including the rapid development and implementation of a national COVID-19 ED Registry, impact of maternal cannabis use on pregnancy and early child development, optimizing medication regimens for individuals using multiple medications, and more. Every HDRN Canada site that has data available (province, territory, CIHI and StatCan) has had their data requested in at least three of these studies. Staff at the DASH supported researchers by providing feasibility assessments, cost estimates, letters of support, coordinated discussions / dialogue, as well as input into consent and / or agreement drafting that will facilitate specific research goals.

In addition to responding to researcher requests, DASH also focused on the following in the first five months of this fiscal year:

* Creation of a common data access work flow model across HDRN Canada data centres;
* Documentation and incorporation of data centres’ data linkage processes into a work flow model;
* Documentation of Indigenous data access policies and procedures across the data centres; and
* Continuous refinement of DASH intake form and processes and standard operating procedures.

Upcoming work for the DASH includes:

* Development of a central data request form to replace multiple center-specific forms, and
* 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 that are difficult to influence vs. procedural set up that may be open to change.

### 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 Canada sites will be added over time.

The Algorithms and Harmonized Data (AHD) working group is developing and leading multiple projects:

* COVID-19 Metadata
* Compiling information on the HDRN Canada jurisdictions that have COVID-19 laboratory testing data, including how often these data are updated, if the data can be linked to other administrative health data, and the characteristics of the testing datasets.
* Call for Proposals to Expand the Algorithms Inventory
* A call for proposals was issued and 17 proposals were received from national research teams by the due date of July 13, 2020. These proposals focus on describing new validation studies or feasibility studies using administrative data from multiple provinces / territories. All proposals are now being reviewed by a committee made up of members of the AHD Working Group and recommendations on which proposals should be approved will be brought to the Executive in September.
* Expand the Algorithms Inventory with Determinants of Health Measures
* A systematic review is underway to identify published Canadian studies that have developed and / or validated measures of the determinants of health for population-based data.
* Full-text screening of the articles identified for the systematic review is underway and data extraction will begin in September.

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

* Exploring the potential to develop a National Concept Dictionary in partnership with IBM Canada,
* Developing metadata to tag the content of the Datasets Inventory, and
* Working with successful teams in the *Call for Proposals to Expand the Algorithms Inventory* to develop and execute study protocols and develop new content for the Algorithms Inventory.

### Public Advisory Council and Public Engagement Working Group

* Working with the Interim Public Advisory Council, the Public Engagement Working Group (PE WG) used participant feedback to refine a beta version English HDRN Canada webinar and delivered the French beta webinar on June 21st to 21 people. The PE WG will use feedback from the participants of the beta French and English webinars to finalize the webinar slides and content. The final version of the webinar will be presented in French and English in fall 2020, and recordings of the webinars will be posted on the HDRN Canada website.
* Having accomplished its goal of establishing the plan and Draft Terms of Reference for HDRN Canada's Public Advisory Council (PAC), the Interim Public Advisory Council has disbanded with the exception of Frank Gavin, chair of the iPAC, who has agreed to chair the PAC and continue to be part of the PE WG. The draft Terms of Reference for the PAC (available on request) includes targets for diversity of PAC members, a minimum meeting frequency of five times per year, and the planned annual honoraria ($750 per member per year under normal circumstances).
* A PAC Selection committee has been established that is comprised of Frank Gavin and three other members of the PE WG. The opportunity for members of the public to join the PAC was distributed widely on June 15 through HDRN Canada email distribution lists, social media and via emails to groups that may be able to help with the recruitment of diverse members. Forty-one applications were received by the July 13 deadline with good diversity regarding geography, age and language (e.g., six Francophone applicants). Interviews of applicants will start the week of August 24th. Each interviewee has or will receive the draft Terms of Reference for the PAC in advance of their interview, and will be interviewed in their choice of French or English by two interviewers with whom they have no prior relationship using a standardized set of questions. The first PAC meeting will take place in fall 2020.
* The Terms of Reference and membership for the full PE WG has been finalized and includes one member from BC, four from Ontario, two from Quebec and one from Newfoundland and Labrador.

### 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.

HDRN Canada is funding an epidemiologist to assist Jennifer Walker with Indigenous COVID-19 analyses. This position is based at Laurentian University. More broadly, we are also working to see how HDRN Canada can support Indigenous communities and research teams looking at COVID-19.

The team is connecting with the Indigenous program staff at several of the HDRN partner sites to broaden our connections and perspectives and begin the process of understanding the existing data governance arrangements in each site.

### Strategic 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 quarter includes:
* HDRN Canada has signed a letter of intent to partner with the International COVID-19 Data Research Alliance, convened by Health Data Research UK and supported by the Gates Foundation, whose purpose is to set up a distributed data infrastructure for COVID-related therapeutics and treatments. HDRN Canada continues to work with Health Data Research UK, and a Memorandum of Understanding remains with the partner for signing while priorities have shifted to the COVID-19 Alliance described above.
* 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. GPAI is an international and multi-stakeholder initiative to guide the responsible development and use of artificial intelligence consistent with human rights, fundamental freedoms, and shared democratic values; its Secretariat is hosted at the OECD in Paris, France.
* 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](https://ukhealthdata.org/)), designed to enable HDRN Canada to work with external data partners to expand sources and types of data available to researchers in a coordinated way. Collaborative activities with the partner include supporting multi-jurisdictional research projects through the DASH and facilitating linkage with their regional cohorts and HDRN Canada data centres where not currently existing. This pilot partnership will inform the future state model for HDRN Canada’s data partnerships. To support future work with other pan-Canadian cohorts and networks, the Partnerships Team together with the DASH Team are working on a framework for linkage with our data centres.
* Conversations continue with HDRN Canada’s first private sector partner, IBM, about opportunities to further their $1M / year in-kind commitments made in the 2018 CIHR grant application to complement our existing network infrastructure with innovative expertise and technologies. As HDRN Canada’s first private sector partner, IBM will serve as a foundational pilot for our strategy for working with other private sector partners going forward. Over the coming months, the Partnerships Team will be working with the Privacy Team to develop a policy on private sector partnerships.
* A co-branded briefing note developed together with the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) that focuses on the potential for EMR data to enhance Canada’s ability to understand and manage COVID-19 beyond and before cases become acute is currently being shared with potential funders of EMR data development.
* HDRN Canada’s data centre leads from each participating jurisdiction have been collaborating on a strategic data acquisition roadmap that focuses on social data, race and ethnicity data, EMR data. Pan-Canadian data sharing and access were as identified as priorities by both our Leads Team and by individual members of the SPOR CDP Advisory Committee. The draft of the data acquisition roadmap is proposed to be a Year 1 deliverable for the Committee who will have their first meeting on Sept. 29, 2020.
* HDRN Canada and the Canadian Research Data Centre Network (CRDCN) partnered on a Letter of Intent submission to the New Frontiers Research Fund - Transformation Stream. The title and theme of this submission is "Promoting equality of opportunity in a changing society: identifying policies that work".

The grant would be worth up to $4million per year for six years and included a letter of support from the Chief Statistician at Statistics Canada.

* There were 460 Notices of Intent and apparently only about 30 Letters of Intent will be chosen for the final application stage and the expectation is six will be funded.
* 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.
* The ultimate objective is to create better, easier, more seamless potential for data linkage that crosses provincial and federal boundaries. We will be pursuing this broad objective regardless of the outcome of this specific grant – so the grant preparation serves a larger objective than this particular funding competition.

### Privacy Team

HDRN Canada’s Privacy Team, which has representation from multiple Canadian jurisdictions, continues to offer privacy support expertise to the other HDRN Canada Working Groups and Teams. The Team meets monthly to problem solve on shared privacy issues and discuss HDRN related projects. In addition, these meetings are an opportunity for knowledge sharing between members to harmonize privacy practices across HDRN Canada partners. For example, in July Michelle Marquis, Statistics Canada, shared a Confidentiality Classification Tool with the Team. This is an excellent resource with application potential for several of the HDRN Canada partners.

In June 2020, the Privacy Team, in cooperation with DASH Working Group and the Modelling and Informatics Group, developed a problem statement in relation to cross-jurisdictional data sharing and linkages. This concern, identified through the increasing DASH requests from researchers to access data from multiple jurisdictions in one location, has many legislative, political and logistical aspects to be considered. Under the direction of a privacy sub-team, a legislative analysis is being conducted examining both the legislative and policy environment across Canada to find potential solutions to this issue. The completion of this project is set for the end of Q3 this year.

A second initiative being led by the Privacy Team is the analysis and presentation of the findings collected from the HDRN Data Centre Governance and Operations Survey distributed at the end of May 2020. This survey was conducted internally with HDRN Canada sites to gain information on their different operating models, services provided and key policies. The survey results will capture the current research landscape related to access and secondary use of administrative data in Canada, particularly in relation to personal health information. A summary of these findings will help inform and assist the HDRN Executive, Working Groups and Teams with decision-making and the setting of strategic priorities. The deadline for this project is set for the end of Q3 this year with the development of bench marking and best practice documentation for HDRN partner use, guidance and, reporting set for Q4.

### Modeling and Informatics Group

The HDRN Canada Modeling and Informatics Group (MIG) has been established to:

* Provide standards and specifications to formalise, through models and terminologies, the activities of HDRN Canada Working Groups and special initiatives.
* Ensure coherence across HDRN Canada activities and enable automation.
* Propose HDRN Canada-wide orientation as it relates to modelling and implementation.

Key areas of work for the MIG over the coming year include:

* Collaboration with the DASH WG on:
* Site Access Processes: this work includes harmonizing site descriptions of their data access processes and documentation, developing a generalized workflow model that includes all process at HDRN Canada sites, and establishing a common data request form for DASH.
* Linkage Processes: detailed descriptions are being acquired for both routine and third-party linkages performed by HDRN Canada sites. This work will enable the development of a linkage model that DASH can use for research projects.
* Collaboration with the AHD WG on improvements to the dataset inventory, including:
* Semantic labelling of data assets: determine suitable semantic labels with which to annotate data sets, to improve the ability of researchers to find datasets that are relevant to their projects. The labels will be drawn from an ontology that will ultimately support end-to-end automation and be derived from the metadata work of the individual sites.
* Acquisition of site-specific labels as structural metadata: to identify consistent or equivalent category labels from multiple sites and agree standard category labels. Thereafter to introduce these labels (entities) into an ontological framework.
* MIG work
* Develop a glossary of terms for HDRN Canada to standardise the terminology we use to talk about all aspects of the project. MIG maintains a glossary of terms covering access processes, data descriptions, linkage and more.
* Investigation of third-party technologies that may be suitable for use within the CDP. The following technology companies / groups have been contacted and information provided: ConvergenceCT, DataBiology and Maelstrom. In addition, discussions have taken place with HDR-UK on their technological approach to data discovery and sharing.
* Developing a report on options for distributed analysis that will include feasibility information of using these methods.