HDRN Canada

Scientific Director and CEO’s Report

December 3 2020

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**Overview:** The first section of this report highlights major initiatives and accomplishments since the last meeting in September 2020, major new 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:

Eight multi-jurisdictional requests (including letter of support requests and project intake) have been received since the last Board meeting, with a total of 34 since the launch of the Data Access Support Hub (DASH). Ten of these requests relate to COVID-19.

### Responding to research priorities:

* We continue to provide ~ monthly updates on new resources. Additional information on COVID-19 vaccination data availability is being gathered and will be added to the website in the near future.

### Partnerships and collaborations (additional detail provided in Strategic Partnerships section below):

* HDRN Canada continues to receive interest in collaboration from across the country.
* We continue to see interest in and utility of establishing and providing leadership for the Canada HDR-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.
* The first meeting of the SPOR CDP Advisory Committee took place on September 29, 2020. The meeting’s focus was on the development of a strategic data acquisition roadmap for the network.

### Finance and administration:

* Nothing new to report.

### Progress on major work streams for the coming year

* Four teams were selected through a call for proposals to co-develop new algorithms. The selected researchers will provide content knowledge and input, while HDRN Canada will provide methodological and analytic supports for algorithm development and validation. This is a significant new undertaking for HDRN Canada and appears to be well-received by the research community.
* Our new Public Advisory Council met for the first time in November 2020 (more detail on this below).

### Anticipated challenges

Continued desire for researchers to be able to access data from multiple jurisdictions that are combined in a single location for analysis*.*

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

The following provides an update on the Strategic Goals and Success Factors in the Strategic Plan

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

The DASH continues to be a highly valued and productive group. Work continues on metadata, mapping similarities and differences in provincial and territorial processes, and collaborating with other working groups and the privacy team. The DASH working group is continuously monitoring and improving services, seeking and responding to input from users, and developing internal-facing tools for improved monitoring and reporting of DASH requests.

### Algorithms and Harmonized Data Working Group

* Determinants of Health (DOH) Measures: A Systematic Review to Enhance the Algorithm Inventory
* A systematic review was conducted to identify published Canadian studies that have developed and / or validated DOH measures for population-based data. Data extraction for these studies is underway. The extracted data will be added to the Algorithm Inventory.
* A rapid review approach was undertaken to identify published Canadian studies that have developed and / or validated measures of race / ethnicity for population-based data. Key informants were contacted to identify relevant studies. Data extraction from these studies is currently underway. The extracted data will be added to the Algorithm Inventory.
* Evaluation of Resources
* The Working Group support team has identified several options for gathering researcher feedback about these inventories. Data will soon be collected using: (a) pop-up surveys for website users, and (b) records of the number of hits and keywords searched for by website users.
* Collaboration with the Modelling and Informatics Group on improvements to the Dataset Inventory
* Semantic labelling of site-specific data assets is underway. This involves the use of a set of standardized labels that will be determined and used to annotate datasets. This will improve the discoverability of datasets within the Dataset Inventory.

### Public Advisory Council and Public Engagement Working Group

In September and October 2020, the PAC Selection Subcommittee of HDRN Canada’s Public Engagement Working Group (PE WG) completed interviews with 21 of the 41 people who applied to be members of the PAC. Interviews were conducted by pairs of interviewers in the applicant’s first language of English or French, or their language of preference in cases where the applicant’s first language was neither French nor English. Based on the interviews, 11 individuals were offered positions on the PAC, all of whom accepted. The PAC members are diverse in terms of their geographic location within Canada, language and gender.

These initial PAC members will have two- or three-year terms, and future PAC members will have three-year terms. This will result in the PAC gaining new members every three years, ensuring that new perspectives come into the PAC regularly.

The PAC Terms of Reference specifies the PAC will have 12-15 members. The PAC Selection Subcommittee is continuing to seek three additional PAC members, including at least one new member who is Indigenous.

In October 2020, the Chair of the PAC organized one-on-one discussions with each of the 11 new members and used live simultaneous French-English interpretation for Francophone members.

On November 5, 2020, an orientation meeting was held for the PAC members. The meeting agenda included roundtable introductions during which every member shared one “hope” to complement written biographies that were submitted in advance. The PAC Chair gave a brief presentation on “Ways of Working” followed by a presentation by the Scientific Director / CEO about HDRN Canada which included slides describing in-scope and out-of-scope activities for HDRN Canada and the PAC. The meeting was conducted using live simultaneous English-French interpretation leveraging the built-in Zoom interpretation function which appeared to work well (to be confirmed in post-meeting surveys).

Near-term work for the PAC and PE WG will focus on preparing materials for the next PAC meeting on December 7, 2020, and final versions of the English and French webinars which will be recorded and posted on the HDRN Canada website by January 2021.

The HDRN Canada Executive approved funds for a new Public Engagement Fellow. The fellowship will be 12 months, renewable once to a maximum of 24 months. The Fellow will work under the supervision of PE WG Lead and Scientific Director / CEO on projects related to public engagement and the PAC. Interviews have been completed and an employment offer will be made by mid-November 2020.

### Indigenous Data Team

The Indigenous Research Team has hired a new Lead who is currently being oriented to the position. The new Team Lead is an Anishinabekwe from Teme Augama Anishnabai and a PhD candidate in rural and northern health, with a focus on Indigenous data sovereignty. The Team Lead will be continuing the advancement of HDRN Canada’s Indigenous research plans, contributing an Indigenous data sovereignty perspective to documents and reports as needed, and will be advancing discussions and capacity around Indigenous data sovereignty within research and data environments nationally.

The Indigenous Research Team is developing a work plan and strategy for Indigenous engagement for HDRN Canada. The finalized workplan will be presented by the Indigenous Research Team in December 2020. The plan outlines three priority areas for the Indigenous research team moving forward: Indigenous data sovereignty, capacity building, and research.

HDRN Canada is funding an epidemiologist to assist 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.

### 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’s Scientific Director and CEO continues to participate in 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. This is likely to lead to opportunities to participate in development and/or demonstration projects related to AI.
* The first meeting of the SPOR CDP Advisory Committee took place on September 29, 2020 (draft meeting minutes available on confluence [here](https://wiki.hdrn.ca/x/VojR)). The meeting’s focus was on the development of a strategic data acquisition roadmap for the network. Of the data types presented for the roadmap discussion (EMR, social and race and ethnicity data), the most discussion was had on race and ethnicity data (equity data more broadly) and agreement that this was a priority. This topic will come back to the next committee meeting which will have a focus on patient and public engagement.
* 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 was "Promoting equality of opportunity in a changing society: identifying policies that work". We were not invited to proceed to the next stage of the competition (there were 400+ applicants and 30 were moved forward). We will be seeking other opportunities to move this partnership forward, perhaps through application to other funding opportunities for a similar themed grant.
* As part of the national Digital Research Infrastructure (DRI) strategy, Innovation, Science and Economic Development Canada (ISED) has invested $375M of its five-year funding to establish a new national not-for-profit organization, the New Digital Research Infrastructure Organization (NDRIO). NDRIO is seeking to advance the establishment of a sustainable Digital Research Infrastructure (DRI) ecosystem for Canadian researchers. Two members of HDRN Canada’s Executive have signed on as Associate Members representing the network. HDRN Canada is currently preparing a White Paper in response to a call from NDRIO seeking input from the Canadian digital research community. Through this White Paper, HDRN Canada will be positioned as an established network with strong history of collaboration that NDRIO can leverage to help “close the gap” in the national DRI ecosystem. HDRN Canada sees an opportunity for NDRIO to fund people needed to review projects / programs of research and to support integration with other data infrastructure to help Canada realize its potential with respect to health and social data
* Under the leadership of one of our Executive members who is also a primary care physician, work continues with the Canadian Primary Care Sentinel Surveillance Network (CPCSSN) to explore potential funders of EMR data development

Upcoming work for Strategic Partnerships includes:

* *Finalizing the Framework for Linkage with Pan-Canadian Networks and Cohorts*: Being developed with the DASH and Privacy Teams to support future onboarding of new data holdings in our data centres
* *Policy on Private Sector Research and Partnerships*: Another cross-team initiative, an inventory is being developed of policies and practices within data centres for working with the private sector so that we can develop guidance for the private sector that both respects local policies and identifies areas for alignment in process
* *Canada HDR-Alliance*: Continuing to work with CanPath as our first HDR-Alliance member to shape the partnership model while we explore opportunities to work with other aligned groups seeking to advance data availability for researchers across Canada

### Privacy Team

The Privacy Team continues to provide general advisory support to HDRN working groups and leads. In particular, this last quarter the Privacy Team provided ongoing guidance and information related to privacy concerns raised from incoming DASH requests and partnership development inquiries.

Other projects include facilitating the development of a brief Policy for Collecting and Internal Sharing HDRN Canada Member Expertise & Experiences, and leading the development of a set of guidelines on consent form wording to permit administrative data linkage. This set of guidelines will serve as a tool for researchers to ensure ethics compliance in relation to administrative data work when developing consent forms. After consultation from stakeholders, the guidelines will be made available on the DASH website.

Work on both the cross jurisdiction data sharing doctrinal analysis and the HDRN Data Centre Governance and Operations Survey (an internal survey sent to each HDRN Canada data centre to gather information on different operating models) is ongoing and summary reports are targeted for completion by the end of Q4 2020-2021. Other projects initiated since last reporting include: assisting with the data sharing agreements for data sharing between CanPath / AtlanticPath and Atlantic data research centres, preparation of general data ethics guidelines, initiating an HDRN privacy glossary to build harmonized privacy and governance language across the network, and preparation for a Maternal Infant Child and Youth Research Network (MICRYN) conference panel presentation in January 2021.

### 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 activities since the September Board meeting:

* Collaboration with the DASH WG on:
* *Site data access processes*: the access workflow model has been created and is now stable. It was recently reviewed with respect to studies which access or affect Indigenous communities and their data. In conjunction with DASH all provinces were consulted as to how they engage with Indigenous communities along with a careful review of the model. Following these discussions, additions to the model were recognised, but did not result in overall distortion of the existing model.
* *Workflow sub-processes and information exchanges*: the sub-processes of the access workflow are under review to determine their precise information inputs and outputs. This work accompanies DASH’s development of standard intake and site submission forms.
* *DASH project monitoring and reporting model*: Automation through the access workflow model will permit project status and operational activity to be obtained directly. However, prior to substantial automation this information must still be available and a temporary monitoring and reporting model has been developed to enable information collection and reporting for this purpose. This work was completed in November 2020 and small-scale software development has begun to enable this capability (at Population Data BC).
* *Data Linkage*: Work on a standardised data-linkage framework was completed allowing representation of all the site data linkages encountered, with the flow of data and identifiers carefully modelled. Further analysis found that the linkages encountered could be categorised by just three groups if certain minor variations were ignored. The important factors were: where study identifiers are created, where linkage is performed, and where data is filtered by crosswalk files (sets of identifier tuples). This work was completed in October 2020 and covered seven provinces, CIHI and StatCan. Future work will look at alternative linkages in which final linked datasets may be placed with third-party secure analysis facilities (SAFs).
* Collaboration with the AHD WG on improvements to the dataset inventory, including:
* *Metadata model and semantic labelling*: the first two phases of this work are now complete. Sites provided sets of labels covering their data holdings which were subsequently harmonised by MIG and working definitions provided. These were fed back to sites for confirmation of, or suggested changes to, labels and definitions. A final table of harmonised labels by site-use was also constructed. The outputs from this work were sent to a team at Universite de Sherbrooke to place these label entities within an ontological framework. Their work will be applied to small groups of related labels at a time with feedback to sites and corresponding application to the Data Assets Inventory to improve data search capabilities.
* Secure Analysis Facilities
* *(Pooled analysis, meta-analysis, and) Distributed analysis*: the MIG is taking a closer look at the nature of secure analysis facilities and, in particular, the modes of analysis possible for various configurations of single or multiple SAFs. A team at Universite de Sherbrooke has looked closely at methods of distributed analysis where data are held at multiple SAFs. (This is direct analysis, not meta-analysis.) A report has been produced summarising this work and its conclusions.
* Technology investigations and external engagements
* *IBM:* MIG has prepared a short document, including diagrams, to provide IBM with a concise summary of the structure of HDRN Canada, its processes, and foundational models. It is hoped that this will allow IBM to recognise products it has which can be leveraged as HDRN Canada projects move forward.