



## Scientific Director and CEO's Report

The first section of this report highlights major initiatives and accomplishments since the last meeting in December 2020, major new milestones for the coming quarter, 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.

### **HIGHLIGHTS**

- **Supporting multi-jurisdictional research:** Six multi-jurisdictional requests (including letter of support requests and project intake forms) have been received since the last Board meeting, with a total of 40 since the launch of the Data Access Support Hub (DASH). Eleven of these requests relate to COVID-19.
- **Responding to research priorities:** We continue to provide ~ monthly updates on new resources. The briefing notes can be downloaded from the [French](#) and [English](#) HDRN Canada COVID-19 webpages. 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):**
  - The Canadian Longitudinal Study on Aging (CLSA) has confirmed their membership in the Canada HDR Alliance, along with the existing member the Canadian Partnership for Tomorrow's Health (CanPath). This partnership aims to streamline requests to linked data through the DASH and enable the development of data access processes and methodologies that are consistent across HDRN Canada sites.
- **Finance and administration:**
  - HDRN Canada's reporting for CIHR was submitted in December. In January 2021 CIHR asked a small number of questions for clarification all of which have been answered. We expect to receive a more formal response to the report later in 2021.
  - HDRN Canada sites are preparing work plans and related budget requests for the 2021-2022 fiscal year.
  - We are reviewing our budget forecast to accommodate the one-year extension of the SPOR CDP grant because of COVID-19.
- **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 teams are working on scientific protocols, with both methods and scientific support from the Algorithms and Harmonized Data Working Group. Each team will sign a memorandum of understanding outlining mutual expectations, ways of working, and expected outcomes of the projects.
  - The DASH Working Group is developing a common data access request form, a key tool to make multi-jurisdiction applications easier, as well as tracking systems



to better report project status. Both of these tools are targeted for completion in Q1 2021-2022.

- **Anticipated challenges:**

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

## **ADDITIONAL INFORMATION ABOUT HDRN CANADA PROGRESS AND CORE WORK**

The following provides an update on the HDRN Canada Working Groups and Teams who are continuing to advance our work:

### **1. The Data Access Support Hub (DASH) Working Group**

The DASH continues to be a highly valued and productive group. In addition to supporting multi-jurisdictional data access requests, work continues on mapping similarities and differences in provincial and territorial processes, developing a common data access request form, and collaborating with other working groups and the privacy team. Working with the Modeling and Informatics Group, DASH continues to refine a data access workflow model, and is developing internal-facing tools for improved monitoring and reporting of DASH requests. DASH is also working with the Strategic Partnerships Team to develop a framework for data linkage with pan-Canadian networks / cohorts, a policy on private sector research / partnerships, and supporting Canada HDR Alliance activities. The DASH Working Group is continuously monitoring and improving services, seeking and responding to input from users. This group is a key interaction point between HDRN Canada and our network data organizations.

### **2. Algorithms and Harmonized Data Working Group**

Highlights of the ongoing Algorithms and Harmonized Data Working Group include:

- Projects to advance the Algorithms Inventory
  - With support from scientific and methods liaisons who have volunteered from amongst the membership of the Working Group, the four research teams are working to develop a comprehensive scientific protocol that will be submitted through the DASH intake form for site-specific review, costing, and queries.
  - A Memorandum of Understanding (MOU) between each research team and HDRN Canada is under review by the research team members and their universities. It is expected that these will be completed and signed soon.
  - Statistics Canada Geospatial Project Collaboration
  - Statistics Canada is developing socio-economic indicators at low levels of geography to support health research. This aligns with the interests of the HDRN Canada and we are working on ways to support and promote this work.



- Data Assets Inventory
  - The Data Access Inventory was launched in early 2020 with a first round of data collection from partner sites to identify which data assets in their possession are available to researchers. A first round of updates is currently being collected and further updates will now be collected on a quarterly basis.
  - The Working Group will be working with jurisdictions that are not currently represented in the Data Assets Inventory later this year as new data centres take shape in those jurisdictions. A next step is to improve the search capabilities of the Inventory, by creating standardized metadata (i.e., labels) for the databases included in the Inventory.

### **3. Public Advisory Council and Public Engagement Working Group**

Webinars aimed at members of the public were presented in French and English on January 13, 2021. The presenters for each webinar included one member of the Executive Committee and one member of the Public Advisory Council (PAC). Both webinars were recorded and are available under the Resources heading of the website: <https://www.hdrn.ca/en/about/resources> and <https://www.hdrn.ca/fr/propos/ressources>.

The PAC has met twice since the last update to the HDRN Canada Board, and PAC members provided advice via email on a resource document for research participant consent for data linkage that is being developed by the Privacy Team.

The December 7, 2020 PAC meeting focused on:

- Facilitated breakout groups in which PAC members provided advice about draft plain language text intended to help members of the public understand what is happening with their data.
- A presentation from Dr. Jennifer Walker followed by dialogue about HDRN Canada's planned work related to Indigenous data.

The February 11, 2021 PAC meeting focused on:

- A brief update on how the PAC member advice on plain language text provided at the December PAC meeting is being used.
- A brief presentation by the lead of HDRN Canada's Privacy Team about how PAC member input is being incorporated into a resource document focused on informed consent for data linkage.
- Approximately 45 minutes spent in breakout groups and large group discussion for PAC members to identify priorities for the PAC, and HDRN Canada more broadly.

Canada's Public Engagement Fellow, Tara Upshaw, started work in January 2021 under the supervision of the PE WG Lead and Scientific Director / CEO. The fellowship is for 12 months, renewable once to a maximum of 24 months. To start, the Fellow's work is focused on the planning and conduct of a series of deliberations with members of the public aimed at developing and refining simple plain language text about data use. The



deliberations will build upon work published in the article [Plain language about health data is essential for transparency and trust](#) as well as PAC member advice. Thus far, more than 30 Canadian and international researchers and members of the public have confirmed their interest in participating in the deliberations. By Spring 2021, the Fellow will initiate work with the Public Engagement Working Group on the second major output expected from the fellowship, the development of a HDRN Canada Public Engagement Plan.

#### **4. Indigenous Data Team**

The Indigenous Data Team has created a preliminary plan for advancing Indigenous data sovereignty both internally and externally to HDRN Canada. This includes three overarching areas where engagement and relationship-building will be needed to inform and continue to develop a plan for action: Indigenous data sovereignty, capacity building, and research. The preliminary plan was presented to and approved by the Executive Committee and shared with the Public Advisory Council and the Leads team.

The Indigenous Data Team is continuing to develop their work plan and strategy for Indigenous engagement for HDRN Canada. The Team has been reaching out internally and across network organizations in order to build relationships and connections and to find ways to provide support. The Indigenous Data Team Lead will continue to provide an Indigenous data sovereignty perspective to documents, research, conferences, and reports as needed, and will be advancing discussions and capacity around Indigenous data sovereignty within research and data environments nationally. We are also discussing ways to build internal capacity within the Indigenous Data Team.

Current collaborations between the Indigenous Data Team and members of the First Nations Information Governance Committee (FNIGC) have led to the development and submission of an abstract for a panel discussion during the 2021 CAHSPR Conference. This collaboration will contribute to discussions on the applicability of national and international Indigenous data governance frameworks (i.e., The First Nations' Principles of OCAP® and the CARE Principles for Indigenous Data Governance) that may improve the implementation of Indigenous data sovereignty mechanisms into current mainstream data ecosystems.

#### **5. Strategic Partnerships**

Highlights of partnerships work since December include:

- The Canadian Longitudinal Study on Aging (CLSA) confirmed their membership in the Canada HDR Alliance, as a second member joining the Canadian Partnership for Tomorrow's Health (CanPath). This partnership aims to streamline requests for linked data through the DASH and enable the development of data access processes and methodologies that are consistent across different jurisdictions.
- HDRN Canada receives many requests from external groups interested in working together. An internal Relationship Framework was developed to provide a coordinated



approach for HDRN Canada to define, prioritize and manage relationships so we can achieve our mission more efficiently and effectively.

- A Pan-Canadian Health Data Strategy (pCHDS) is under development to fill gaps between data used in the provinces / territories and pan-Canadian insight for shared learning, spreading of innovation, and collective action. The scope of this strategy will touch data used for healthcare delivery, health systems policy, population health, and public health. The pCHDS is being led through PHAC in collaboration with provinces and territories, with Vivek Goel as its champion. HDRN Canada's Scientific Director and CEO is a member of the Expert Advisory Group for the pCHDS.
- HDRN Canada prepared a White Paper in response to a call from New Digital Research Infrastructure Organization (NDRIO) seeking input from the Canadian digital research community. This paper was supported by multiple external collaborators, including the Canadian Primary Care Sentinel Surveillance Network (CPCSSN), who cross-referenced HDRN Canada in their papers.
- Work continues together with pan-Canadian and provincial primary care EMR entities to explore partnership and funding opportunities for EMR data development; the importance of funding this work was further called out in other NDRIO White Paper submissions.
- A portion of the funding provided to the NDRIO to coordinate funding and strategic directions for national DRI activities related to advanced research computing, data management, research software and cybersecurity within the DRI ecosystem is being set aside for "pathfinder projects". When more details about the opportunity are available, a group will be formed by the HDRN Canada Executive to discuss strategy for how to respond to the call and possible areas of focus. Initial ideas for focus were COVID-19 variants, COVID-19 vaccination, and control of chronic disease during the pandemic.
- Currently, HDRN Canada is focused on using SPOR CDP grant funding to provide services and supports to public sector researchers seeking to perform multi-jurisdictional research. However, there have been several requests and inquiries from private sector organizations. There is an interest in having DASH respond to private sector requests in the future, but DASH is very busy with public sector requests, and considerable consultation and operational policy work would be required for HDRN Canada to establish overarching policies and processes for work with private sector requestors. An interim process has been developed and approved to divert private sector requests from the DASH so that requests are managed by individual HDRN Canada Organizations.

Upcoming work for Strategic Partnerships includes:

- Framework for Linkage with Pan-Canadian Networks and Cohorts: This framework is being developed with the DASH and Privacy Team to support future onboarding of new data holdings in our data centres. It will allow us to scale up the Canada HDR Alliance model.
- *Policy on Private Sector Research*: Consultation and policy work to develop a strategy for responding to research requests from the private sector.



- *Leveraging in-kind commitments made by IBM:* Multiple exploratory meetings took place between HDRN Canada and IBM in 2020 to identify areas to make use of the \$1M / year in kind supports committed in our 2018 grant application. Together with the Modeling and Informatics Group, HDRN Canada will continue to work with IBM to identify innovative infrastructure areas for collaboration that are in line with the network's long-term technology vision.

## **6. Privacy Team**

The Privacy Team continues to ensure the delivery of general advisory support for HDRN Canada Working Groups and Leads. It is also answering inquiries for incoming DASH requests and partnership development.

Ongoing projects include:

- The completion of a first draft of the HDRN Canada Data Governance and Operational Survey Results. This survey gathered information on policies and procedures from HDRN Canada sites to enable the production of best practices and other documentation. Planning is now underway for the next stages of the Survey to fill gaps in information.
- Work on the Cross Border Jurisdictional Data Sharing Doctrinal Analysis continues. This includes the completion of the initial search and compilation of provincial and territorial personal health legislation by a sub-group of the Privacy Team. A document is now with the larger Privacy Team for feedback.
- The document Guidelines: Informed Consent Wording for Administrative Data Linking is in draft form and distributed for review and comment to research stakeholders, including the HDRN Canada Public Advisory Council, researchers, and various REBs.
- Initial meetings between CanPath / AtlanticPath and Atlantic HDRN Canada data centres to enable data linkage identified preliminary work, and that work is now underway.

New projects initiated since December include exploratory meetings for data sharing opportunities with Immigration, Refugee and Citizenship Canada (IRCC), the Canadian Longitudinal Study on Aging (CLSA), and the Canadian Red Cross (CRC). Other topics in review by the Privacy Team include privacy and the development and use of synthetic data, establishing definitions for key privacy terms for inclusion in an HDRN Canada glossary, and examining the potential impact or opportunities stemming from pending federal privacy legislation amendments.



## 7. Modeling and Informatics Group

Key activities since the December Board meeting:

- Collaboration with the DASH Working Group on:
  - Data Access Workflow sub-processes and data exchanges: the sub-processes of the Data Access Workflow Model continue to be reviewed to determine the precise data exchanges that take place. Five sub-processes related to eligibility of a project and the feasibility of providing data for that project have been analysed in detail and will shortly be presented to the DASH WG for their consideration. This work accompanies DASH's development of standard intake and site data access request forms.
  - DASH project monitoring and reporting model: A prototype monitoring and reporting data model has been developed and is being tested by members of DASH. It is hoped this application, which will assist with the management of project applications by DASH, will go live within the next month or so.
  - Data Linkage Workflow Model: This work, which focuses on the linkage of external data or research data to site holdings of administrative data, is largely complete. Additional work will be done, including looking at alternative linkage topologies in which final linked datasets may be placed with third-party trusted environments for analysis.
- Collaboration with the AHD WG on improvements to the data asset and algorithms inventories, including:
  - The Data Assets Inventory: a small set of semantic labels associated with laboratory data has been selected to be applied by sites to the data assets within the Inventory. This will offer increased efficiency when searching for appropriate data assets and is a step along the path to increasing automation.
  - The Algorithms inventory: A Function Specification Model has been developed to provide a framework for managing data processing algorithms.
- Other contributions:
  - Trusted Environment for Analysis (aka secure analysis environment or facility): Discussions around the character of secure environments continue.
  - Methods of distributed analysis: an interim report is drafted, with a final version available within the next 6-8 weeks. This looks at methods of analysis that can be applied to data held at individual sites without the need to pool data at a single site.