



Scientific Director and CEO's Report

The first section of this report highlights major initiatives and accomplishments since the last Board meeting in May 2021, major new milestones for the coming quarter, and anticipated challenges. Following this overview, the remainder of the document offers additional details on areas of significant investment and / or importance to HDRN Canada's mission.

HIGHLIGHTS

Key progress since the last board meeting:

- The Institut de la Statistique du Québec (ISQ) is officially becoming an HDRN Canada data centre. We have been working towards this from our inception. This means that we are working toward full integration with DASH, and at that point we can facilitate researcher requests that involve data from Quebec for the first time (beyond Quebec data held at the Canadian Institute for Health Information and Statistics Canada).
- The Northwest Territories (NWT) have submitted and had approved their first work plan to HDRN Canada. Funding will be transferred to NWT to enable the creation of a single access point for research data access requests. This will enable NWT to participate in HDRN Canada work as a data centre (estimated timeframe for completion of the set-up of the data centre is ~18 months). The discussion leading to this great outcome highlights the importance of partnering with members in the north with an understanding that is relevant to their quite different context.
- We are continuing discussions with the First Nations Information Governance Council on the potential for them to become a network member, and another "jurisdiction" in terms of funding. These discussions have been useful if still somewhat formative.
- ICES submitted an Expression of Interest for Canada Foundation for Innovation (CFI) funding for Major Science Initiatives (MSI) on behalf of HDRN Canada. The proposal – which is intended to cover operational costs of pan-Canadian infrastructure - will be built around funding to offset data extraction costs so that fees charged to researchers can be reduced.
- In response to a request from the Public Health Agency of Canada (PHAC) and the Pan-Canadian Health Data Strategy, the Public Engagement Working Group developed a proposal for a new project Essential Requirements for Social Licence Related to Health Data. With \$40,000 funding from PHAC, HDRN Canada will convene groups comprising members of the public and patient advisors, and lead a process to have them develop a short Health Data Social Licence White Paper from the public/patient perspective. Once procurements have been completed (target September), this will be the first funding directly to HDRN Canada as opposed to via UBC (or another network organization). The Quebec SPOR Support Unit will be a



partner, contributing staff time and other in-kind support to ensure deep involvement of non-bilingual Francophones in the project.

Major milestones for coming quarter

- The Modelling and Informatics Group and Metadata Specialist are undertaking pilots of semantic labelling for the data assets in the Data Asset Inventory. Semantic labelling will permit more reliable, precise, and efficient searches for specific kinds of data by researchers. The goal to have all sites begin annotating their data by Fall 2021.
- Two literature reviews will be undertaken to add new measures to the Algorithms Inventory.
- The four algorithm projects are progressing through the data access process. A media release that highlights these projects will be publicized widely through all channels available to HDRN Canada in the coming months.

Anticipated and ongoing challenges

- As increasing numbers of opportunities for partnership and collaboration are brought forward to HDRN a clear process for prioritization of resources is needed.

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:

Data Access Support Hub (DASH) Working Group

Successes

- Since the last CEO Report, DASH supported 6 new requests through the intake process, and continued to provide support to over 40 active requests.
- In June 2021, DASH implemented its Application Tracker, a role-based tool to track DASH project status, enhance DASH team coordination, and facilitate more meaningful activity reporting. Post-implementation enhancements are ongoing.
- A joint workshop was held between HDRN Canada and Australia's Population Health Research Network (PHRN) in June 2021 to share knowledge and highlight shared experiences coordinating multi-jurisdictional research. Ongoing engagement and information exchanges are in progress to build the relationship with PHRN.

Challenges

- An increased volume of research requests is anticipated ahead of CIHR's fall grant deadline (early September 2021), which may require shorter turnaround times than usual to support researchers' requests for cost estimates and/or letters of support.



- DASH often receives complex projects where researchers are looking for central pooling of data for analysis. Effort is required to assess alternative options where HDRN Canada processes and policies are not yet established.

Risks

- DASH resource/capacity to support rapidly growing number of requests.
 - Mitigation: close monitoring of staff capacity and continuous improvement effort to streamline processes. Hiring of two additional personnel to support DASH central operations is in progress.
- Requestors do not see value-add for DASH services.
 - Mitigation: proactive management of requestor expectations; develop communication and outreach strategy with HDRN Communications team.

Algorithms and Harmonized Data Working Group

Successes

- COVID-19 Data Listing:
 - A comprehensive list of all COVID-19 data held across partner sites was added to the HDRN website. It encompasses lab testing, vaccination and surveillance data by province/territory. A comparison feature was built into the website display so that any interested party can quickly identify the data available in each jurisdiction. The website also contains a summary of the fields available within each jurisdiction based on a standardized list of data collection areas/topics suggested by the Public Health Agency of Canada.
- Projects to Advance the Algorithms Inventory
 - Memorandums of understanding have been signed for two projects with the other two awaiting signatures. The teams are in the midst of applying for data access.
 - Scientific and methods liaisons are guiding the development of these four validation studies through reviewing statistical analysis plans and supporting data access and ethics applications.
 - The research teams are providing important feedback to HDRN Canada about the DASH intake process and are aiding in the development of standardized templates for scientific protocols and statistical analysis plans. These standardized templates will be made available to any research team conducting a multi-jurisdictional study, to streamline the research progress.
- Metadata
 - A process to annotate data assets for Indigenous custodians and controllers as well as for Indigenous data or data sets that may contain a significant proportion of Indigenous peoples is being developed with the Indigenous Data Team, Inclusion Diversity Equity and Accessibility Fellow, Data Access Support Hub, Algorithms and Harmonized Data Working Group, and the Modelling and Informatics Group. This annotation process will clearly indicate



which assets may have specific access requirements or considerations for use because of Indigenous content. This annotation project is one component of HDRN's substantiation of support for Indigenous data sovereignty.

- Data Assets Inventory
 - Updates occur on a quarterly basis and by October the process will become more automated with sites able to enter their updates through a centralized portal on the website.
- Algorithms Inventory
 - To update the Algorithms Inventory, the literature search of multi-regional population health measures was re-run in May; 21 new algorithms were added to the inventory as a result.
 - The literature search of multi-regional measures of the determinants of health was re-run in July. The search identified 263 articles for review. A review of titles and abstracts is currently underway.
 - A feedback survey was added to the Algorithms Inventory, to gather feedback from users on its content and presentation. This information will be used to alter the format and guide directions for expansion.

Challenges and Risks

- One project to advance the Algorithms Inventory remains significantly delayed because of COVID-19; the clinical data needed to validate chronic pain measures in administrative data will not be collected for several months.
- COVID-19 continues to contribute to some delays with some sites being not as able to provide timely updates to the Data Assets Inventory.
- Heterogeneity of the contents of the Data Assets Inventory need to be addressed in order to improve the search capabilities for researchers using the Inventory. It is anticipated that the semantic labelling work address some of these issues and improve search capabilities.

Public Advisory Council and Public Engagement Working Group

Successes

- The Public Advisory Council continues to meet and members are also providing advice outside of regular meetings.
 - The fifth PAC meeting was held on June 17th 2021.
 - The main agenda item was a representative of Maelstrom Research presenting on the complexity of collecting and harmonizing data related to race and ethnicity. There were many questions and suggestions.
 - Members also voted on and discussed terms they like and don't like for data-holding organizations. "Data repositories" and "data centres" scored high; "data platform" and "data trust" were among those that did not.



- PAC members are now reviewing the draft strategic plan, especially the section about public engagement
- The Public Engagement Working Group continues to meet monthly. Recent work includes:
 - Supporting the PAC, e.g., preparing agendas, presentations, and summary documents.
 - Conducting a survey of public and patient engagement practices of HDRN Member Organizations and collaborators.
 - Based on the survey results, the Public Engagement Working Group articulated the scope for a preliminary draft HDRN Public Engagement Plan and is now refining the scope through conversations and presentations with the leads from other SPOR entities.
 - Working Group membership has expanded to include Statistics Canada.

Challenges and Risks

- The main challenges have been related to difficulties with meaningful engagement of PAC members, e.g., bringing materials to the PAC that seed good discussions, knowing how to respond to PAC advice in cases where it doesn't align with what HDRN actually does or can influence. Overall, the engagement of PAC members is getting better as their knowledge increases and HDRN develops better agendas and discussion topics, but there is still room for improvement.
- PAC members have responded to a survey about what went well and not so well in the last year; survey results will be used to inform future meeting agendas.
- HDRN Canada's Public Engagement Fellow resigned to attend medical school beginning July 2021. This has slowed down the progress on several projects with public engagement work streams that HDRN is leading. Interviews for the next Public Engagement Fellow are in progress.

Indigenous Data Team

Successes

- The Indigenous Data Team (IDT) has identified a need to better understand the Indigenous health data governance landscape across HDRN member organizations. The IDT lead is designing a multi-phased environmental scan project. Work is currently being done to develop a project proposal that will be presented and vetted by the HDRN Leads and Executive Committees in the coming months. Currently the IDT is engaging, building relationships, and seeking project development guidance from HDRN member organizations.
- The IDT Lead is connecting to various members of the Indigenous community to listen, learn, and grow. These connections are contributing to the sharing and expansion of Indigenous data sovereignty and governance knowledge and helping to build relationships and network with Indigenous Peoples, nations, and organizations, while connecting HDRN to the broader Indigenous community.



- The IDT is continuing to build-on existing connections and relationships with a First Nations' governed organization in Canada, the First Nations Information Governance Centre (FNIGC), to ensure that HDRN work being conducted with First Nations priorities in mind. This includes presenting together at the Canadian Association for Health Services and Policy Research Conference on "*Honouring Indigenous Data Sovereignty within Mainstream Data Environments by Weaving Together Current Indigenous Data Governance Strategies*". This was an opportunity to share and discuss the relationship between the globally developed CARE Principles and the First Nations' Principles of OCAP®; a paper will be developed based on this workshop.
- The IDT Lead was the first author of a manuscript published in June in the International Journal of Population Data Science. The paper is entitled 'The SEEDS of Indigenous Population Health Data Linkage' and can be found: <https://doi.org/10.23889/ijpds.v6i1.1417>
- This paper will be presented on at a webinar on September 22, 2021. Event details here: https://www.popdata.bc.ca/events/etu/webinar/SEEDS_Sep22_2021
- The IDT is collaborating with the HDRN inclusivity, diversity, equity, and accessibility (IDEA) Fellow to create a platform to improving data environments for all. This joint Data for Equity and Indigenous Data Sovereignty initiative is currently being finalized and will be presented for vetting purposes to the HDRN Leads and Executive teams.

Challenges and Risks

- There is a lot of work to be done and at present capacity is limited for the IDT. While there is a lot of support and a willingness to advance Indigenous data priorities, a lack of capacity does mean that things do not get completed very quickly. Eventually, the IDT will have some support and initiatives such as training development, resource curation, and policy writing will be able to move up from the bottom of the priority list.

Strategic Partnerships

Successes

- The partnership with CanPath was recently profiled in the partner's [Annual Report](#).
- Cross-network collaboration is ongoing to initiate a Steering Committee with the Canadian Longitudinal Study on Aging (CLSA) to facilitate new data sharing agreements and other collaboration objectives for this Alliance partner.
- Partnership with the Canadian Agency for Drugs Technology and Health (CADTH) is developing to position the HDRN Canada as having the data, the staff, and the infrastructure to support real-world evidence studies on questions of interest to policy and decision-makers.
- Discussions with the CIHR Network of Clinical Trial Networks for COVID-19 to do public deliberations on consented data are underway that will strengthen and complement policy and legislative work on data sharing.



Challenges

- The CanPATH collaboration found some of the holes and limitations in our current DASH processes. As a result, HDRN Canada immediately worked to resolve those issues, and is providing funding to support an additional analysis of data that will help inform our approach to distributed analysis.

Risks

- If above feedback continues from partners, the network risks researchers using alternate data sources/approaches to complete their studies, independent of HDRN Canada.
 - Mitigation: Strong alignment with organizations with similar mandates (in both research and technology) will continue to be prioritized.

Privacy Team

Successes

- The document *Guidelines: Informed Consent Wording for Administrative Data Linking* is complete. It provides information for researchers on recommended consent form content to inform participants of their study data linking to administrative data. The final document is now available on the DASH website in both English and French.
- A draft set of questions for the second network wide Data Governance and Operational Survey are being circulated for review. The questionnaire is focused on secure research environments. Interviews will be conducted in September 2021. The purpose of this work is to inform network partners of our shared best practices and to serve as a guiding document for new data centres joining the network.
- One of the network's partnerships has provided the Privacy Team with a unique opportunity to examine perceived policy roadblocks to administrative data sharing across regions for research. The CIHR Network of Clinical Trials Network for COVID-19 has indicated a willingness for the Privacy Team to conduct a formal policy analysis through a clinical trial requiring access and linkage to administrative data in all provinces. A real time study will allow for our understanding of roadblocks and challenges surrounding administrative data sharing across regions to go from anecdotal events to concrete examples which can be shared to inform policy. This study will complement both the legislative analysis referred to below and planned public deliberations with this group mentioned in the Partnerships section of this report.
- Through monthly meetings and "email rapid response requests," the Privacy Team continues to provide support to other HDRN Canada working groups and leads. Requests have included questions on privacy interpretation, confidentiality practices, informed consent practices, and regional REB considerations.



Challenges and Risks

- Infographics of the first HDRN Canada Data Governance and Operational Survey summary did not come to fruition as anticipated. Further consultation with communication staff has provided valuable feedback on disseminating findings from annual bench marking exercises. A clear topic with focused and informed understanding of the benchmarking exercise intent will improve future knowledge translation.
- The data for the Cross Border Jurisdictional Data Sharing Doctrinal Analysis, a summary table of Canadian jurisdictional legislative authority in relation to administrative data research, has been shared both within and outside of HDRN Canada. Completion of both an academic paper and translation of the findings into a practical information tool was paused because of loss of staff and institutional reorganization. Recent changes to the staffing situation, however, will now allow this work to resume.

Modeling and Informatics Group

Successes

- The AppTracker application, which allows DASH to manage applications for access to data, is now live and is consistent with the Application Workflow Model as it currently stands. Experience with AppTracker by DASH will assist in the completion of the Application Workflow Model, which will support harmonisation and subsequent automation of the full research application process.
- The first phase of development of an archetypal use-case to assist the development of automation within the Canadian Data Platform has been completed by the Modelling and Informatics Group (MIG). This covers researchers' first contact with the DASH portal – the user interface for applications for data - and the subsequent process of DASH guidance provided to researchers to assist with cohort and data requirements prior to any contact with individual sites. Importantly, it establishes the role of DASH local staff at this stage of a multi-jurisdictional application for data.

Challenges

- The approach to harmonisation of data and processes, and ultimately automation as proposed by MIG, has at its core common information structures, and shared processes to leverage them. These need to be agreed by all stakeholders. For example, the content of the various concept dictionaries and the algorithms produced by various groups need to be accessible through common information processes and structures.
- MIG has had several discussions with sites and the Indigenous Data Team regarding how Indigenous data might be managed and its relationship to the management of non-Indigenous data. From an informatics perspective, concepts such as controllership, metadata and cohort and data metrics were identified, but it is to be



determined whether these informational approaches to the co-management of Indigenous and non-Indigenous data are an acceptable way forward.

Risks

- The Canadian Data Platform is conceived as a set of interoperating services and described by a set of mutually consistent models developed by MIG and others. Importantly, the ability to separate the models allows for a stepwise approach to data and workflow harmonisation and automation. This gives sites choice in what way, and how fast, and how far they go down the automation route. The MIG feel that a better understanding is required of this aspect of MIG's work by managers and technical personnel at the sites and there is a need to make clearer what models and choices have currently been embraced (mostly with DASH so far), and what choices remain going forward. In a sense, there is a need to understand sites' perceptions regarding automation and its limits if we are to achieve an effective and efficient data platform. We must clarify the desired level of automation aimed at by the network. This is a pressing issue, and further delay in decision-making increases the risk of not being able to deliver automation within the currently funded timeframe.
- Work related to data harmonization is spread across multiple working groups and teams. Clearer collaboration pathways and scope for each group or team will need to be developed in the near future.

Inclusivity, Diversity, Equity and Accessibility (IDEA) Community of Practice

Successes

- In April and May, feedback from key contacts within HDRN was obtained on existing and needed IDEA initiatives
- A draft IDEA strategy was presented to the HDRN Executive and Leads Committees in June. This plan emphasizes four pillars: structure; principles and policies; education; and tool creation
- An HDRN IDEA Community of Practice is in development. This community will help to establish a network of IDEA champions and support the work outlined in the IDEA strategy. A primary goal of this group in 2021/22 is to develop IDEA guiding principles for HDRN Canada.
- The IDEA fellow and the Indigenous Data Team Lead are working on a joint initiative focusing on Data for Equity and Indigenous Data Sovereignty that will include resources and a speaker series

Challenges and Risks

- There is a lot of potential for IDEA work to be done within HDRN; deciding on priorities can be a challenge given the diverse needs and priorities of data centres across Canada
- There are few IDEA experts in Canada and those working on related IDEA projects across the network are often doing so outside of their current responsibilities.



Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

Building capacity and resources to inform and support the IDEA strategy is important and will take time.

- There is a risk that IDEA work becomes siloed within HDRN and the responsibility of one or two individuals. Our long-term goal is to build capacity and awareness so that everyone at HDRN can identify issues related to inclusion, diversity, equity, and accessibility.