Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

Scientific Director and CEO's Report

The first section of this report highlights major initiatives and accomplishments since the last Board meeting in November 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 first annual Public Advisory Council (PAC) report was developed, refined with input from PAC members and posted to the HDRN Canada website
- HDRN Canada has entered into an agreement with the Public Health Agency of Canada (PHAC), in partnership with the Quebec SPOR SUPPORT Unit, to lead a process to create a Health Data Social Licence White Paper that will provide critical information that supports the implementation of the Pan-Canadian Health Data Strategy. The process will take ~ five months to complete and white paper content will be determined by at least 30 experienced public and patient advisors (at least 10 of which will be Francophone). The PHAC contract, valued at $40,000 including taxes, is the first external funding provided to and managed by HDRN Canada.
- The Inclusion, Diversity, Equity, and Accessibility (IDEA) Team has been formed, with representatives from across HDRN Canada data centres and working groups/teams, and the first meeting was held in January 2022.
- The full proposal to the Canadian Foundation for Innovation Major Science Initiative was submitted. The request was for $43million. We will hear in June whether the proposal is successful.
- The letter of intent for the Strategic Science Fund was submitted. We will be notified in April if HDRN Canada is invited to submit a full proposal.
- Our Strategic Plan is formally launched.

Major milestones for coming quarter

- Two ad hoc meetings have been planned to help move forward work plans in the areas of supports for multi-regional analysis and expanding resources available in the algorithms inventory, specifically around measures that cannot be validated with an external "gold standard" data set.
- 2022-2023 annual work plans will be requested from sites so that funding can be distributed in advance of the next fiscal year. These plans include the funding each site requests for the year and key deliverables.

Anticipated and ongoing challenges

- The approach to harmonizing data definitions, required to fully implement the Data Assembly Plan, is still under discussion within HDRN Canada. This is a complex area in part because it sits at the boundary, and sometimes crosses, from the business of HDRN Canada to the business of our data centre organizations. Use of formal ontologies will help move this work forward. Discussion across working groups are underway to address this challenge.

HIGH LEVEL KEY PERFORMANCE INDICATORS

Strategic Goal	Indicator	Number
Develop and Improve Services and Supports for Data Access	# of visits to the DASH website	Total unique visitors from Nov 1, 2021 - Jan 31, 2022: 484 Monthly average: 161
	# of visits to the Dataset Inventory website	Total unique visitors from Nov 1, 2021-Jan 31, 2022: 492 Monthly average: 164
	# of intake forms received to date and since the last Board meeting (Nov. 24)	73 intake forms received to date, 4 of which were received since Nov 24
	# of data access request forms received to date and since the last Board meeting (Nov. 24)	13 data access request forms received to date, 2 of which were received since Nov 24
	# projects that DASH supported in grant application	20 projects to date
	# of algorithms in inventory	172 algorithms listed in the inventory (0 increase since last Board meeting)
	# of datasets in inventory	543 datasets listed in the inventory (5 increase since last Board meeting)
Diversify and Harmonize Data, and Support Innovative and Privacy-Sensitive Data Use	Enhancements / updates to resources that support access to multi-regional data	Drafted DASH Request Standard Operating Procedures document (internal facing resource) Implemented enhancements to the DASH Application Tracker

<u>ADDITIONAL INFORMATION ABOUT HDRN CANADA PROGRESS AND CORE WORK</u>

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

Goal: Develop and Improve Services and Supports for Data Access

Key developments since last meeting

- The Data Assembly Plan, an integral part of the data access process, has now reached a sufficiently mature state to seek the opinions of other working groups. Its completion will require several basic questions related to harmonization, automation, and participant responsibilities to be answered.
- Technical development of the DASH Portal is ongoing.
- Development of program monitoring reports to increase the ability to report on requests as they move through the various request stages has begun, with refinements to the DASH Application Tracker being a key component of this work.
- Expectations regarding response and turnaround times for DASH staff are being reviewed and refined.
- A DASH Operations Manual and Standard Operating Procedures document have been developed. These are key internal resources to support DASH operations across data centres.
- Several modelled resources exist covering the data access process and the operations of DASH. Versions of these are in a form which makes them difficult to consume and use for operational purposes. Lucid chart has been chosen as a tool for a more interactive and integrated presentation of these resources. The data access workflow has been converted and other important resources – the use case, glossary, and standard operating procedures – will be integrated going forward. This will provide a one-stop resource for modelers, DASH staff, and external appreciation of the approach taken by HDRN Canada for its data platform.

Successes

- Since the last Board meeting, DASH supported four new requests through the intake process and continued to support over thirty active requests. A total of thirteen projects have reached the formal data request stage of the process and of these, three projects are at the agreement drafting/signing stage and one is at the data analysis stage. DASH staff across data centres continue to meet regularly to ensure that projects are progressing well.

Challenges

- Supporting complex projects where researchers are looking for central pooling of data for analysis remains a challenge. Effort is required to assess alternate options for analysis where HDRN Canada processes and policies are not yet established. Cross-working group discussions are being planned to determine what options are available in the short/long term.
- The completion of the DASH Data Assembly Plan requires certain fundamental questions to be answered, mostly by working groups, but importantly, some at the level of HDRN Canada.

Risks

- Researchers are not satisfied with the lack of options for pooling line-level data for analysis
    - Mitigation: Additional language will be developed for the DASH website to expand on the options/limitations given current provincial/territorial data policies. DASH will continue to be transparent about these options upfront with researchers, and emphasize the distributed nature of our network.
- The ad hoc group to talk about supports for multi-regional research will provide a clear set of tools and development plan that DASH will be able to communicate to the research community
- DASH will work with the Modelling and Informatics Group (MIG) to identify an appropriate pilot project to explore options for analyzing data in a distributed way.

Goal: Diversify and Harmonize Data, and Support Innovative and Privacy-Sensitive Data Use

Key developments since last meeting

- A new process was developed to integrate COVID-19 data updates into routinely-conducted Data Asset Inventory updates. This process will reduce time required by data centres to prepare updates and was piloted in January 2022. This process also included new input options to capture provenance of each data asset.
- The metadata specialist who joined the Manitoba team in January 2021 has been working with the MIG on a semantic labelling project. The goal of the project is to produce standardized, descriptive labels for all data assets in the Data Assets Inventory. The project will facilitate metadata standardization and will improve database search capabilities for researchers. All labels are in the process of being finalized and sites with data holdings in the Data Assets Inventory have begun the process of annotating their data using 15 labels generated by sites with the MIG.

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Successes

- A plan to annotate data assets with Indigenous content or custodians has been developed jointly by the Indigenous Data Team, the Inclusion, Diversity, Equity and Accessibility Fellow, DASH working group, Algorithms and Harmonized Data (AHD) Working Group, and the MIG. The intent is to identify data assets that may have specific access requirements or considerations for use because of Indigenous content. The first round of collection of this information was piloted in January 2022. More information will be provided as this work develops.
- A resource page was launched in December 2021 that lists algorithms and indicators developed by pan-Canadian partners, including Statistics Canada, the Canadian Institute for Health Information, and the Public Health Agency of Canada. This [resource page](#) will benefit researchers who conduct multi-jurisdictional studies by providing a single access point to the many algorithms and indicators that have been used by these organizations to define measures of population health, health service use, and the determinants of health in pan-Canadian data.

Challenges

- 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 delay sites from providing timely updates to the Data Assets Inventory.
- Heterogeneity in the descriptions of the contents of the Data Assets Inventory may hamper researchers in their searches of the Inventory to identify relevant data for their cross-jurisdictional studies. Semantic labels are one approach to improve search capabilities, by standardizing the database information available at each site. However, given that they provide a very basic level of information, other metadata sharing initiatives will need to be considered.

Risks

- No risks are anticipated at this time.

Goal: Ensure Purposeful and Ongoing Public and Community Involvement

Key developments since last meeting

- The seventh and eighth meetings of HDRN Canada's Public Advisory Council (PAC) were held in November 2021 and January 2022 and focused on:
  - November 18, 2021:
    - Discussion of a draft modified "data grid" intended to incorporate previous PAC member suggestions about how to use a table to provide a high-level summary of the kinds of data available at various HDRN Canada organizations.

- PAC member advice on the HDRN Canada Strategic Plan (mostly focused on improving the clarity of the document for non-research stakeholders).
- PAC-initiated changes to the PAC Terms of Reference, in particular to emphasize the PAC's role in advising HDRN Canada about communications with the public.
  - January 20, 2022: guest presentation by HDRN Canada's IDEA Team Lead, to share information about IDEA at HDRN Canada with PAC members and create the time and space for PAC member discussion about what the PAC should be striving for regarding IDEA in its own work.
- A new member from PEI has joined the Public Engagement Working Group.

Successes

- A new HDRN Canada Public Engagement Fellow, based on Newfoundland and Labrador, has accepted an offer of employment and will start work beginning March 1st. The Fellow will be co-supervised by the Public Engagement Working Group Chair and a Public Engagement Working Group member who works at the same site, Memorial University of Newfoundland.

Challenges

- The PHAC-funded Health Data Social Licence White Paper project has been paused due the impacts of COVID-19 including illness of project core team members and delays in hearing back from the references of people who applied to be part of the project. The initial project plan was to have synchronous participant team web meetings in early February, but it was determined that would not be possible. All applicants have been informed that the project will be resumed when we can check references and schedule meetings with more certainty. PHAC has agreed that timelines will be revised as soon as we can resume planning with confidence (likely in February or March 2022).

Risks

- Inclusive methods and processes to bring in diverse perspectives take more time than standard approaches, require flexibility in response to individual and group needs, and don't completely eliminate the risk that the views held by the majority will dominate discussions and findings.
- There is no single "public" or universally shared view on how to learn about and act on the health data-related advice, values, and preferences of members of the public.

Goal: Establish and Strengthen Partnerships and Provide Leadership for Evolving Data Practices

Key developments since last meeting

- The first project with Health Data Research (HDR) Alliance member CanPath is approaching completion, with analysis underway in two provinces and beginning in the remaining province. Learnings from this pilot project will support how we approach future projects with HDR Alliance members and, more broadly, other researchers.
- Data sharing agreements with the second member of the HDR Alliance, the Canadian Longitudinal Study on Aging (CLSA), are underway in all seven provinces with data centres undergoing legal review.

Successes

- The Privacy Team continues to grow with additional members joining from Nova Scotia and Yukon. The growth of this team speaks to the value of what such a team can contribute to finding the balance between privacy safeguards and data access.
- The Privacy Team-led study, with support from DASH and the HDR Alliance, is examining the barriers to administrative data sharing across provincial and territorial borders (e.g., policy, legislation). The project is in the data collection phase and is on target for data completion at the end of the quarter.
- A joint report and presentation from HDRN Canada and the Canadian Agency for Drugs, Technologies and Health (CADTH) was given to the Executive of the Drug Safety and Effectiveness Network Transition Team and Health Canada about gaps in data availability to support drug decision making; future work will involve a joint implementation plan for addressing these gaps as part of the CADTH-HDRN Canada partnership.

Challenges

- Staffing changes meant a delay in the distribution of the internal survey on HDRN Canada data center's secure research environments (SREs). The survey has now been distributed however and results will be available for summary in the next quarter. The survey will provide the network with information on best practices for SREs and guidance for new centres setting up these systems.
- There is more potential than capacity in the Partnerships area at present.

Risks

- Perceptions by existing partners that the network is pursuing new opportunities before completing existing commitments.
- Mitigation: Core partnerships (e.g., HDR Alliance members) are prioritized, with a staged, cautious approach to expanding opportunities for new partnerships using

clear criteria (Partnerships Framework). Ongoing, internal communication across working groups and teams that support operationalizing partnerships remains integral to understanding capacity and workload, and to ensure coordinated responses externally.

Goal: Strengthen Data Use to Improve Equity, and Support Indigenous-led Data Sovereignty

Key developments since last meeting

- The Indigenous Data Team (IDT) continues to work on advancing four identified priorities: Connection, Communication, Research, and Transformation, both internally and externally to HDRN Canada.
- Over the last several months, the IDT Lead has been connecting with HDRN Canada Member Organizations across Canada to build relationships, better understand the roles of various stakeholders, and identify Indigenous-related data priorities. These discussions have helped to highlight some of the high-level priority areas around Indigenous data governance that need further work.
- The IDT is curating and organizing an Indigenous data sovereignty online resource library. This is being developed through a website that will be vetted by the IDT Lead.
- The hiring process for an IDT research assistant is underway. The IDT is also seeking the support of an Indigenous student to help facilitate the development of an Indigenous-led data governance conference.
- The IDT is organizing an internal advisory made up of people from HDRN Canada member organizations to help expand understandings of what partners are priorities across the network and to contribute to discussions that highlight HDRN Canada priorities.
- The IDEA Team continues to contribute to activities at HDRN Canada and helping to identify opportunities to embed IDEA in operations and in the data research process.
- Work continues on the Accessible Information Strategy, with key conversations about website accessibility underway. Communications staff have also received training on accessible word and pdf documents with additional training planned for the next quarter.
- The IDEA Team has prepared a panel submission for the upcoming CAHSPR conference with a focus on the IDEA and IDT work underway at HDRN along with work in progress at HDRN Canada Member Organizations.
- The IDEA Team is preparing two publications, with the goal of submitting to peer reviewed journals by April 2022

Successes

- A Data for Equity and Indigenous Data Sovereignty newsletter is in the process of being translated to introduce our joint initiatives on a broader scale. An additional space will be added to the HDRN Canada website where our joint work will be

contained, where relevant conferences and events will be announced, and where we are compiling a joint resource library.

- The IDT continues to contribute to the ways that the Indigenous data governance landscape are unfolding at HDRN. This includes deepening the network's understanding of the importance of Indigenous-led data initiatives and governance priorities, which is evidenced by the substantial IDT contributions to the development of the Strategic Plan.
- The IDT has been making connections between HDRN Canada and First Nations' governed organizations in Canada. In progress is a formalized relationship between one of these organizations through the creation of an MOU. This relationship continues to grow and the final MOU is ready for circulation and approval by all parties, the announcement of the formal relationship is forthcoming.
- The IDT is developing publications that are being shared and discussed across the network.
- The IDEA Team has been formed, with representatives from across HDRN Canada data centres and working groups/teams, and the first meeting was held in January 2022. With the introductory meeting complete, upcoming meetings will focus on reviewing and confirming the draft Terms of Reference and setting priorities for the coming year. We will also be actively discussing assumptions about IDEA and the role of pubic and stakeholder engagement within the activities prioritized.
- In January the IDEA Lead facilitated a session with the PAC to better understand their assumptions and goals for creating an inclusive, diverse, equitable, and accessible public advisory committee.

Challenges

- There is significant work to be done in order to embed de-colonial data principles throughout the network. At this time the IDT is not in a position to take on additional work, but the potential to do so is there. Project potential, grant opportunities, and other ways to contribute to the capacity of Nations is increasing regularly. Greater capacity and more experts in this field are needed in order to do more. As mentioned above, a hiring process is underway for two roles to support IDT work (one ongoing research assistant for general IDT work and one short-term student for a specific project).
- The IDEA Team includes 20+ members with a broad range of knowledge and expertise, with some coming from an operations background and other from a data or research background. Facilitating and channeling a group of this size will be a challenge. Once the group has identified priorities, we will work to find the right mix of sub-groups and meeting practices that provide all members the opportunities to share their skills, develop new skills, and grow connections across the network.
- Defining IDEA-related priorities remains challenging given the distinct needs of HDRN Canada as an organization, the diverse needs of HDRN Canada data centres, and the breadth of data that flow throughout the network.

- There remains a significant number of identified projects to be acted on to embed IDEA throughout HDRN Canada. Beyond the IDEA Lead, dedicated time and attention remain at a premium and are needed in order to pursue new deliverables/grant funding/educational opportunities.

Risks

- One of the initiatives currently on the table is an Indigenous data annotation project with the MIG and the AHD teams. Discussions are still underway but a meaningful understanding that this sort of work is historically embedded in colonial-thinking is necessary in order to limit the risks of further perpetuating harms. That is not to say that this work cannot or should not be done, it is to be certain that we are doing this work in a way that is considerate of the time needed to do it well. It is important for everyone involved to understand better the work, the potential for harm, and offer some Indigenous-led suggestions from Nations around the world that have effectively mitigated some potential challenges. In order to help with this understanding, the IDT is leading a literature scan and writing that will be shared with the teams involved and eventually with the network.

Success Factor: Cohesive Network with Effective and Sustainable Operations

Key developments since last meeting

- The MIG ontology workshop in October was well-received by members of DASH; a similar workshop for the AHD working group is pending (the initial date being affected by COVID). Ontologies are highly formal semantic resources which permit rigorous definition of entities and their relationships in any domain where collaboration is vital. They can be applied to the data application process, data descriptions, algorithms, and methods of analysis.
- The glossary continues to be transformed to an explicitly ontological structure.
- Suitable tools have been identified (e.g. Lucid chart) to ensure a uniform, integrated presentation of MIG/WG models and information resources available to DASH, site staff and their operations.
- Each HDRN Canada data centre has been asked to identify a single site contact for HDRN Canada-related queries. This group of site contacts will help move work forward at sites if escalation is required (e.g., to remove a roadblock to HDRN Canada work) and will be the contact to help route work within a data centre.

Successes

- MIG continues to work closely with the main working groups of HDRN Canada.
- Two priority setting-focused meetings of the Leads Team have taken place in the last quarter. Out of these discussions, that built upon the discussion at the in-person Executive meeting in November 2021, two ad hoc groups are being established to

move work forward on distributed analysis and adding additional resources to the Algorithms Inventory.

Challenges

- We are at a point in the development of the data platform that requires substantial cross-working of workgroups to consider and act on a set of important questions which will strongly mold future development of the data environment and data access application process.

Risks

- None of note at this time.

Success Factor: Supportive and Engaged Legislative and Policy Ecosystem and Community of Data Users

Key developments since last meeting

- The IDT Lead has been connecting to the broader Indigenous community regularly through invitations to conferences, community presentations and panels. These external 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.
- Gathered from all of the discussions and connections have been some specific priorities related to Indigenous data, sovereignty, and health. The IDT hopes to share some of these priorities at the next CAHSPR conference.

Successes

- A workshop was delivered to the Annual Members Meeting of the Canadian Critical Care Trials Group (CCCTG) on incorporating administrative data linkage into studies and trials; over 90 members were in attendance. As a result of this workshop, work has started with the CCCTG to develop an intranet page for their network with resources on administrative data linkage for clinical trials.
- Ongoing engagement with and some influence on the development of recommendations that will come from the Expert Advisory Group on the Pan-Canadian Health Data Strategy.

Challenges and Risks

- Data access policy and legislation-related resources developed by HDRN Canada frequently need updating to reflect changes occurring across the network. This is resource intensive but necessary to ensure resources are accurate and of use to researchers.
- There are more opportunities than capacity, and many local and pan-Canadian challenges faced by our network members.