Réseau de recherche sur les données de santé du Canada

Health Data Research Network Canada

Scientific Director and CEO Report

The first section of this report highlights major initiatives and accomplishments since the last Board meeting in September 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:

- An accessibility audit of the HDRN Canada website was recently undertaken by an external company. As a result, an accessibility plugin will be added to the HDRN website that will allow users to select modifications to the website (e.g., remove pictures, change contrast). Other changes suggested in the audit will be implemented over the next six months.
- HDRN Canada submitted a Notice of Intent to the Canadian Foundation for Innovation Major Sciences Initiative Fund in September. The request was for $42 million over a 5-year period (2023/24-2028/29) for operating and maintenance costs of HDRN Canada data centres. We were notified on November 4 that we are one of 18 NOIs (of 37 submitted) invited to proceed to the competition. The full proposal is due in early February, 2022.

Major milestones for coming quarter

- HDRN Canada will be submitting a Letter of Intent for the Federal Strategic Science Fund in January 2022. The request will be for tens of millions over five years for work on Real World Evidence (including but not limited to Electronic Medical Record data, the Canada Health Data Research Alliance, and other new data acquisitions and data partnerships). If successful, the funding period would be from April 1, 2024 to March 31, 2029.
- The Strategic Plan is being professionally formatted and will be launched publicly in the near future. It was launched internally at a meeting open to all staff on October 6, 2021.
- An IDEA Team will be formed with experts from across HDRN Canada. Terms of Reference for this group is near finalized and members will be sought over November and December.

HIGH LEVEL KEY PERFORMANCE INDICATORS

Strategic Goal	Indicator	Number
Develop and Improve Services and Supports for Data Access	# of visits to the DASH website	190 unique visitors during the month of October
Develop and Improve Services and Supports for Data Access	# of visits to the Dataset Inventory website	404 unique visitors during the month of October
Develop and Improve Services and Supports for Data Access	# of intake forms received to date and since the last Board meeting (Sept. 1st)	56 intake forms received to date, 6 of which were received since Sept. 1st
Develop and Improve Services and Supports for Data Access	# of data access request forms received to date and since the last Board meeting (Sept. 1st)	11 data access request forms received to date, 1 of which has been received since Sept. 1st
Develop and Improve Services and Supports for Data Access	# of algorithms in inventory	There are currently 172 algorithms list in the Algorithm Inventory
Develop and Improve Services and Supports for Data Access	# of data assets in inventory	There are 537 data assets currently listed in the Data Asset Inventory
Diversify and Harmonize Data, and Support Innovative and Privacy-Sensitive Data Use	Enhancements / updates to resources that support access to multi-regional data	Updates to DASH intake form Updates to data access inventory Updates to DASH processes Additions to COVID data page High level DASH cost estimates prepared and page created on website

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ADDITIONAL INFORMATION ABOUT HDRN CANADA PROGRESS AND CORE WORK

The following provides an update on our work, organized to align with our strategic goals and success factors articulated in our strategic plan

Goal: Develop and Improve Services and Supports for Data Access

Key developments since last meeting:
- Consideration is being given to how the modelled data access application process can be specified in a formal language that will permit automation of the application process. This includes, for example, accommodating the sequencing of Data Access Support Hub (DASH) and data centre operations, such as DASH guidance, feasibility and governance.
- A Data Assembly Plan template was developed to facilitate collaboration and ensure harmonization of data extraction across sites for data access requests. The template is being piloted now.
- The introduction of a more formal Data Assembly Plan offers a uniform experience for research groups when specifying their data and cohort requirements. In addition, the Data Access application model has been altered to highlight the conceptual distinction between data custodians and their data holdings, and the trusted research environment in which analysis will take place.
- Continued development of the central DASH data access request form to streamline the data request process for researchers
- Enhanced DASH Intake Form to add new elements to streamline the intake process

Successes
- Since the last Board meeting, DASH supported six new requests through the intake process, and continued to provide support to over 50 active requests.
- Created new DASH Resource page on the HDRN website to accommodate growing content and consolidate resources for researchers such as guidance on requirements for consent forms where data linkage is intended.
- Developed a DASH Operations Manual, an internal resource to support DASH central operations.
- Developed high-level cost estimates for data-related services provide by HDRN Canada and created a website for this information.

Challenges
- The precise method of harmonizing data definitions, required to implement the data assembly plan, has still to be agreed upon. Use of formal ontologies will help move this work forward.

- Supporting 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 and increased process development needs.
  - Mitigation: close monitoring of staff capacity and continuous improvement efforts to streamline processes. An additional coordinator was hired to support DASH central operations and another staff person will join the team in December to support program development.

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

Key developments since last meeting
- A new process is being 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.
- Data cataloguing tools developed by Maelstrom are being tested using two of the validation studies to advance the Algorithms Inventory. We have chosen Maelstrom for this pilot because it is an internationally-recognized tool for capturing information about observational cohort studies and because it is already used by researchers in Canada and internationally. Our pilot study will provide valuable insights into the role of Maelstrom in harmonizing variable names, health conditions, and cohort information for HRDN Canada.
- A 1.5-hour workshop about ontologies will be offered by the Modelling and Informatics Group (MIG) to the Algorithms and Harmonized Data (AHD) Working Group. The workshop will demonstrate how ontologies can be used to harmonize the contents of the Dataset Inventory.
- Dr. Lisa Lix, Chair of the AHD Working Group, is leading the development of a synthesis paper about the Algorithms Inventory. This paper will assist the Working Group to identify gaps in the Inventory and aid in planning new projects to expand the Inventory. This paper builds on a recent scoping review about the quality of administrative health databases in Canada.

Successes
- A media release that highlights the four multi-jurisdictional validation studies was publicized widely by HDRN Canada. The study teams are in the midst of applying for data access through the DASH. The results of the validation studies will be incorporated into the Algorithms Inventory.

- The metadata specialist who joined the Manitoba team in January 2021 has been working with the Modelling and Informatics Group 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 sites with data holdings in the Data Assets Inventory have begun the process of annotating their data using more than 30 labels generated by sites.
- A process to annotate data assets with Indigenous content or custodians is being developed jointly by the Indigenous Data Team, Inclusion Diversity Equity and Accessibility Fellow, Data Access Support Hub, Algorithms and Harmonized Data Working Group, and Modelling and Informatics Group. The intent is to identify the data assets that may have specific access requirements or considerations for use because of Indigenous content. More information will be provided as this work develops.
- A resource page is being created that will list 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 aid 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.
- Quarterly updates to the [Data Assets Inventory](#) were collected from sites in October and are now being uploaded to the public website. By Winter 2021, this process will become more automated; sites will be able to enter their updates on a centralized portal maintained by HDRN Canada.

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 contents of the Data Assets Inventory need to be addressed in order to improve search capabilities for researchers. We anticipate that the semantic labels currently being applied to the Data Assets Inventory will substantially improve search capabilities.
- In regard to most kinds of analysis within a trusted environment for analysis, significant agreement will likely be needed between data custodians and trusted environments for analysis.

Risks
- No risks are anticipated at this time.

Goal: Ensure Purposeful and Ongoing Public and Community Involvement

Key developments since last meeting:
- The sixth HDRN Public Advisory Council (PAC) meeting was held on September 29, 2021. The main discussion items were:
  - PAC member feedback on the HDRN Strategic Plan, and
  - Updating the Terms of Reference for the PAC.
- The first annual PAC report is under development and will be issued by the end of 2021
- The Public Engagement Working Group continues to meet monthly, recent work includes:
  - Supporting the PAC, e.g., preparing agendas, presentation materials, summary documents,
  - Developing a document that articulates the proposed scope and deliverables for HDRN's Public Engagement Plan (i.e., activities and deliverables that build upon current work with the PAC and specific projects), and
  - Consulting with SPOR-funded initiatives and entities, and members of the PAC, to ensure that the scope of HDRN's Public Engagement Plan would be valued and complement vs. duplicate the work of other initiatives funded by the Canadian Institutes of Health Research (CIHR) Strategy for Patient-Oriented Research (SPOR).

Successes
- HDRN has hired a new part-time bilingual coordinator to support the PAC in French and English.
- PAC members have responded to a survey about what went well and not so well in the last year; the survey results are being used to inform PAC meeting agendas.
- In partnership with the Unité de soutien SSA Québec (also known as the Quebec SPOR SUPPORT Unit), the Public Engagement Working Group revised its $40,000 proposal to develop a Social Licence White Paper requested by the Public Health Agency of Canada (PHAC), contracting is expected to be completed in November.
- Finalizing a series of illustrations involving people and their data that will be used in multiple HDRN materials.

Challenges
- The main challenges have been related to difficulties with meaningful engagement of PAC members, exacerbated by the fact that PAC members have not met in person.

- HDRN Canada's Public Engagement Fellow resigned to attend medical school beginning July 2021; this has slowed down the progress on several projects and we are still seeking a new person for the role.

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
- A new internal survey on HDRN Canada data center's secure research environments (SREs) will be undertaken by the Privacy Team in Fall 2021. The survey will provide the network with information on best practices for SREs and guidance for new centres setting up these systems.
- Work on the HDR Alliance continues. A 'Playbook' outlining the principles and requirements for membership has been drafted and shared with current Alliance members CLSA and CanPath for review.

Successes
- HDRN Canada is working to support the development of new data centres in Canada. Support has been provided to PEI and Saskatchewan as they set up their site models and work through legal and privacy requirements. Support will also be provided to Yukon and Northwest Territories; those data centres will begin to receive funding for their development from HDRN Canada in the near future.
- The Privacy Team is leading a study to determine the root of ongoing barriers to administrative data sharing across provincial and territorial borders (e.g., policy, legislation). Ethics board approval of this project has recently been obtained.

Challenges
- The distributed staffing and funding of the network can at times make it challenging to ensure cross-network identification, prioritization of and support for new data-related partnerships.

Risks
- Without prioritization of funding staff times to support implementation of key partnerships at the site-level (data integration, data access, etc.), there is a risk that researchers will work with sites independent of HDRN Canada.

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

Key developments since last meeting

- Work has begun on an Accessible Information Strategy which will be implemented in the next six months. This strategy includes technical updates to the HDRN website suggested by an external audit and the creation of internal document templates and associated training for staff.
- An interim Anti-Bullying, Harassment, and Discrimination Policy has been developed to address a gap in policy for incidents that occur across staff at different HDRN member organizations. A final version of the policy is to be adopted by January 2022.
- The Indigenous Data Team (IDT) continues to work on advancing four identified priorities: Connection, Communication, Research, and Transformation, both internally and externally to HDRN.
- Over the last several months, the IDT Lead has been connecting with HDRN 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 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. As part of the commitment to research, these priority areas are being explored through available literature, rapid reviews, and research projects that are under development.
- The IDT is continuing the work of 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.

Successes

- HDRN Executive approved the creation of an IDEA Team in October rather than a community of practice as had previously been planned. The creation of this Team provides a longer-term investment and commitment to embedding IDEA operationally within HDRN and developing an IDEA strategy for multi-region data research.
- The IDEA Lead and the IDT Lead have worked to identify overlap between their respective work areas and prepared a plan called Data for Equity and Indigenous Data Sovereignty that includes the joint creation of resources and a research project. This initiative was approved by the Executive in October.

- 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 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 once an MOU is finalized and approved by all parties, a formal announcement will be made.

Challenges
- Defining priorities remains challenging given the distinct needs of HDRN as an organization, the diverse needs of HDRN data centres, and the breadth of data that flow throughout the network.
- 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. While the IDEA Team identifies expertise broadly defined in roles across the network (governance, privacy, analytics, pubic engagement, etc.), it remains to be seen if this model will require additional expertise outside of the network
- There is significant work to be done to embed IDEA throughout HDRN. While there is support from Leads and Exec, lack of capacity often leads to a slower pace. It is hoped that the IDEA Team will fill in some needs in this area.
- There is often a tension between needing time to raise awareness about issues related to IDEA and taking action to change habits, policies, etc. Without action, some issues can seem intangible, but without proper awareness personal investment by network members can be low. Finding a balance remains a challenge.
- 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. However, at this time, support is needed in order to complete some of the above-mentioned tasks and assist in taking on more.

Risks
- Because of current lack of IDT support staff, there are some requests that are coming through that are not garnering the attention they deserve. This may mean that things do not get completed, slip through the cracks, or do not get completed as well as they could. This is less than ideal and could lead to a disservice to the Nations that the IDT serves. This is being addressed.

Success Factor: Cohesive Network with Effective and Sustainable Operations

Key developments since last meeting

- The MIG has introduced a series of workshops on the use of ontologies within HDRN. The latter 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.

Successes

- MIG continues to work very effectively in support of DASH, Privacy and partnerships working groups and their informatics needs, i.e. as a cross-team support and connector.
- An HDRN glossary has been constructed in an ontological manner to allow for common understanding of key terms across the network.
- The bank account for HDRN Canada has been set up and we are ready to receive the funding for the Social Licence Project when that is transferred from the Public Health Agency of Canada.
- A series of bi-weekly discussion sessions ("town halls") have been established for staff that provide another venue to talk about key new papers or reports, new ideas, emerging opportunities, and / or issues that would benefit from broad input. These have been well-attended and topics include:
- The tri-council policy statement and US National Institutes of Health current calls for comments on proposed changes. This session provided input to a submission the Panel on Research Ethics in Canada to share our views on proposed changes related to ethics for multi-regional projects and the issue of broad consent.
- Data for Equity and Indigenous Data Sovereignty - Proposal for Joint Objectives
- HDRN Canada website accessibility plugin demonstration and IDEA next steps
- HDRN Canada strategic plan

Challenges

- Responding to opportunities is important for HDRN Canada, however recent grant funding opportunities have required substantial across the network and may cause delays in the completion of other ongoing work.

Risks

- None of note at this time.

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

Key developments since last meeting

- The fourth meeting of the SPOR CDP Advisory Committee took place on October 15th; there are now 13 SPOR-funded entities represented on the Committee. Minutes can be found here.
- HDRN Canada is working with the SPOR SUPPORT Unit Council on Phase 2 funding and associated launch of communities of practice, including one on data platforms and services.

Successes

- The Scientific Director and CEO had a conversation with Dr. Tammy Clifford from CIHR on September 14. There was no particular agenda for this, but Dr. McGrail requested the time given Dr. Clifford's role as the VP in relation to the CDP and because of the Board's encouragement to maintain connection to our major funder.
- Dr. Clifford is taking on a new VP role in Learning Health Systems, recognizing CIHR's strategic orientation to this area (e.g. mandate of SUPPORT Units in phase 2). The change came about because of CIHR's strategic plan and input from governing council (with five of six major things landing in Dr. Clifford's previous portfolio). This change in effect is a separation of operational and strategic elements.
- This means that the strategy area of CIHR (e.g. Sarah Viehbeck) will stay with Dr. Clifford as well as part of the science policy team. Her portfolio will include preparedness and health emergencies, patient oriented research (implying that while SPOR may morph, the aim of POR will remain), data-related initiatives, clinical trials, and knowledge mobilization. The portfolio Dr. Clifford will be leaving will focus on programs / operational areas.
- HDRN Canada was an invited guest at CIHR and Canadian Agency for Drugs Technology and Health (CADTH)'s jointly led Best Brains Exchange on drugs for rare diseases; the network also was asked to be a member on Health Canada and CADTH's Real-World Evidence Steering Committee and the Drug Safety and Effectiveness Network's Data Working Group
- HDRN Canada is co-chairing a Data Strategy Working Group with CIHR Network of Clinical Trial Networks to support improved data collection and analytics for clinical trials in a real-world context.
- HDRN Canada will be launching a News Feed website in the near future. Through this News Feed, HDRN Canada will be able to more broadly communicate its activities to a wider cross-section of stakeholders, in a more flexible, dynamic and responsive way. Articles will showcase works in progress and the day-to-day efforts of the Network as opposed to the complete and highly polished content of the main HDRN Canada website.

Challenges and Risks

- Ensuring that we reach appropriate audiences for our work across Canada can be challenging. We are building communications partnerships and leveraging existing avenues (SPOR communications groups and mailing lists) to reach our wide array of stakeholders.