



Scientific Director and CEO's Report

The first section of this report highlights major initiatives and accomplishments since the last Board meeting in February 2022, 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 HDRN Canada Blog, “Inside HDRN Canada: Notes from Across the Network” was launched. It is available on the website [here](#). The Blog is a key resource for HDRN Canada to let stakeholder and the public know about ongoing work of the network in a less formal way than the “News” section of the HDRN Canada website.
- The IDT and IDEA Team's joint “Data for Equity?” newsletter has been edited and translated and has been released. An additional space has been added to the HDRN Canada website where resources and registration for the newsletter are available. The first newsletter issue is available [here](#).
- The DASH has completed a data request, meaning the research team has received all requested data.

Major milestones for coming quarter

- HDRN Canada is required by CIHR to conduct two external evaluations over the course of the Canadian Data Platform grant period. The first, a formative evaluation, is to be completed by March 31, 2023. The second, a summative evaluation, will be due by March 31, 2026. A request for proposals has been developed for the formative evaluation and the search for external individuals or companies to conduct the evaluation will be launched by the time of the Board meeting.
- HDRN Canada's 18-month report to CIHR is due on July 18th. The report covers the period from October 1, 2020, to March 31, 2022. An overview of the draft report will be shared with the Board at the May 17 Board meeting, with a decision then about when the draft will be shared.

Anticipated and ongoing challenges

- Overall, and across many teams, there are tensions between long-term ambitions and short-term aspirations to ensure we are responding to current needs of our stakeholders. These tensions do not represent difference of opinion about our mission or objectives, but acknowledge that responding to current needs may mean that it will take longer to get to the ultimate goal. This requires good communication (including internally) not just about what we are doing, but also why and how.



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 Feb 1, 2022 – March 31, 2022: 500 Monthly average: 250
	# of visits to the Dataset Inventory website	Total unique visitors from Feb 1, 2022– March 31, 2022: 404 Monthly average visitors: 202
	# of intake forms received to date and since the last Board meeting (Nov. 24)	77 intake forms received to date, 2 of which were received since Feb 22, 2022
	# of data access request forms received to date and since the last Board meeting (Nov. 24)	13 data access request forms received to date, 0 of which were received since Feb 22, 2022
	# projects that DASH supported in grant application	20 projects to date, 0 of which were received since Feb 1, 2022
	# of algorithms in inventory	172 algorithms listed in the inventory (same as last Board meeting)
	# of datasets in inventory	554 datasets listed in the inventory (increase of 11 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	Finalized DASH Request Standard Operating Procedures document (internal resource to support DASH personnel) Enhanced the DASH Portal Guide (internal resource to support DASH personnel)



ADDITIONAL INFORMATION ABOUT HDRN CANADA PROGRESS AND CORE WORK

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

Goal: Develop and Improve Services and Supports for Data Access

Key developments since last meeting

- Technical implementation of the Data Assembly Plan template in the DASH web portal is ongoing to support a second phase of pilot testing. This online tool aids sites in tracking the requirements and tasks associated with the data assembly phase of HDRN Canada data access requests.
- Technical implementation of the common DASH Data Access Request Form in the DASH web portal and associated interfaces is ongoing.
- Refinement of the DASH Application Tracker is ongoing to improve user-friendliness and support development of program monitoring reports. This will increase capability to report on requests as they move through the various request stages.
- The DASH Request Standard Operating Procedure document has been finalized. This is an internal resource to support DASH operations across data centres.
- The DASH has dedicated considerable time to the development of operational and program management reports for the Exec and Leads audiences. Examples of reports are included in the Board's May 17th meeting package (e.g., number of requests by site) and will be part of the discussion with DASH staff at the meeting.

Successes

- Since the last Board meeting, the DASH has completed one data request, where the research team has received all requested data. In addition, DASH supported two new requests through the intake process, and continued to support over 30 active requests. A total of 13 projects have reached the formal data request stage of the process and of these, 3 projects are at the agreement stage, one is at the data assembly stage and one at the analysis stage. DASH staff across data centres continue to meet regularly to ensure that projects are progressing well.

Challenges

- Ensuring that researchers' data requirements can be documented at the time of project intake in an efficient manner to minimize researcher burden. Discussions within HDRN Canada are ongoing and will provide direction on the future state and the tools and processes required. The DASH Data Assembly Plan may then be fully integrated into the project intake stage to further streamline the process and researcher experience.



Risks

- None identified at this time.

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

Key developments since last meeting

- The first prototype of a new web-based interface has been developed to collect updates for the Data Assets Inventory. It is anticipated that by October this system will be fully in use across participating data centres and that the process will be more user-friendly for sites to submit updates. Feedback is being sought from data centres on features they would like to see and training materials will be developed and rolled out over the coming months.
- Five of eight participating data centres have annotated their data holdings using the first 15 labels generated by the Modelling and Informatics Group. All participating data centres are expected to complete the annotations by the end of April. An analysis of the annotations to ensure reliability is currently underway.
- A prototype to enhance the Data Assets Inventory search process, to allow for searching by semantic label, is currently being tested.
- Information regarding provenance has been added to the dataset information pages.
- A program has been agreed to study the use of privacy-preserving distributed analysis techniques that allow data to remain in place at multiple sites while analysis is in progress. A demonstration project will use synthetic data at multiple sites to perform a linear regression analysis. This will allow the sites to become familiar with the techniques, establish any changes in governance required, and gain confidence that sites and researchers can rely on these techniques for a range of supported kinds of analysis. If successful, a live project will be selected that can make use of such techniques and agreement obtained to proceed in this manner. Distributed analysis will be one of three ways in which data can be analyzed within a trusted environment for analysis; the others being local analysis followed by meta-analysis, and analysis of a small subset of pulled data at a central trusted site, where governance allows this. The latter will likely be used only sparingly.

Successes

- An abstract about the synthesis of the Algorithms Inventory was submitted to the 2022 International Population Data Linkage Network conference. The synthesis identifies gaps and trends within the inventory as well as areas for future research.
- After experiencing significant delays due to COVID-19, the project to advance the algorithms inventory led by Morgan Slater is progressing with a scientific protocol being finalized and submitted to the DASH.



Challenges

- The full-text review from a new literature search on determinants of health measures has been completed with seven papers identified for inclusion into the Algorithms Inventory. Each search requires a large amount of resources in terms of staff time and there are diminishing returns in terms of how many articles and algorithms are identified for inclusion into the Algorithms Inventory in each search. More automated solutions are being explored to keep the inventory updated.
- 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 data centre. However, given that they provide a very basic level of information, other metadata sharing initiatives such as using a common data model or ontology will need to be considered.
- A significant proportion of the data assets (about 34%) in the inventory are held by Statistics Canada who are not currently participating in the semantic labelling project due to other internal projects taking precedence.
- Regarding a DASH dictionary, the challenge is to model and introduce a tool (and associated service) that can absorb various methods of organizing information items in a coherent way and allow researchers choice in how they identify and locate data in ways which are more suited to their interests. For example, researchers involved in drug safety studies may wish to identify and locate data based on information items and category labels associated with the Canadian Network for Observational Drug Effect Studies (CNODES) data model. Researchers with other interests may wish to use an ontological framework. Importantly, the tool, service and underlying model must provide a basis for harmonization and automation of data selection and extraction, including definition of cohort(s).
- Distributed analysis may require modifications to local site governance.

Risks

- None identified at this time.

Goal: Ensure Purposeful and Ongoing Public and Community Involvement

Key developments since last meeting

- The ninth meeting of the Public Advisory Council (PAC) was held in March 2022 and focused on:
 - Finalizing the updated PAC Terms of Reference for the PAC to focus on activities that PAC members see themselves having an impact on,
 - PAC member suggestions for expanded recruitment of new members given that several PAC members have terms that end in fall 2022,



- The creation of two PAC “Interest Groups” that will meet and work outside of PAC meetings: a Communications PAC Interest Group and an IDEA PAC Interest Group, and
- Discussing PAC member interest in an in-person meeting in fall 2022.
- Following a COVID-related pause, we have restarted the Health Data Social Licence White Paper project (funded by the Public Health Agency of Canada to inform the Pan-Canadian Health Data Strategy) and are on track to complete the project by summer 2022.
- A new member from Ontario has joined the Public Engagement Working Group which now includes people from BC, Ontario, Quebec, PEI, and Newfoundland and Labrador.

Successes

- The scope for the HDRN Public Engagement Plan has been finalized following discussions with the HDRN Public Advisory Council, the SPOR SUPPORT Unit Council, SPOR Network Directors, the Maritime SPOR SUPPORT Unit Scientific Leadership Team, and the Pan-Canadian Patient Council for the Primary and Integrated Health Care Innovations (PIHCI) Network. The scope will be used as the foundation for a full Public Engagement Plan that includes strategic goals (aligned with the HDRN Strategic Plan), timelines, resources, communications, etc.

Challenges

- The timeline for the Health Data Social Licence White Paper for the Public Health Agency of Canada is aggressive given the need to have all materials, and all inputs from tens of participants, translated into French and English.
- Mitigation: prioritize work on the Health Data Social Licence White Paper project, putting less time-sensitive work on other projects on pause whenever needed.

Risks

- PAC members are openly expressing the fact that they are finding it challenging to meet only via Zoom. It is possible that we will lose good members partly because of the burden of Zoom meeting.
 - Mitigation: Schedule an in-person PAC meeting in fall 2022.

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

Key developments since last meeting

- A panel presentation on the HDR Alliance has been accepted for this year’s CAHSPR conference.
- The HDR Alliance Playbook was completed and shared with Alliance members.



Successes

- HDRN Canada will be featured in the CIHR Network of Clinical Trial Networks for COVID-19 annual report (report is undergoing final review, will be shared when public).
- HDRN Canada is invited to speak at international RWE4Decisions event on April 27th and at the Scientific Meeting of the Canadian Critical Care Trials Group on May 31st.
- The Canadian Agency for Drugs, Technologies and Health (CADTH)-HDRN Canada partnership was profiled at CADTH's external launch of their new strategic plan; HDRN Canada has membership on their Steering Committee on [CADTH website](#).
- The Privacy Team is working with the Canadian Longitudinal Study on Aging (CLSA) on a joint publication about consent language in longitudinal cohort studies.
- The Privacy Team continues to grow, with additional members joining from other HDRN Canada working groups in addition to members from Manitoba and Northwest Territories. We continue to be encouraged by the interest and growth of this team.
- The Privacy Team hosted special guest Alexander Bernier (from the McGill Centre for Genomics and Policy) who spoke on challenges being faced by pan-Canadian data sharing across borders. Over 50 participants from across the HDRN Canada attended this Privacy Team event.
- Work priorities for the Privacy Team for 2022 have identified the development two guidelines for researchers: 1) addressing the differences between REB approval and privacy compliance and how the two work together, and 2) privacy requirements for researchers new to administrative data access requests. Other priorities include:
 - The development of a data access agreement requirements check list for each,
 - Start flushing out vetting and guidance on vetting for the sharing of aggregate data for distributed analysis, and
 - The need for a data set prioritization tool; how to identify what data sets are of most relevance to the network.
- Data collection continues for the Privacy Team's study examining the barriers to administrative data sharing across provincial/territorial borders and early findings have been accepted for an electronic poster presentation at CAHSPR 2022 (May 31-June 2).
- Immediate staffing challenges have been addressed with the appointment of part-time privacy team coordinator assigned to help ensure privacy team projects move forward.
- Privacy Team members have been invited to lead a CHEER webinar on May 3rd on "Importance of Data Sharing and Demystifying the Process"



Challenges

- There continues to be more potential than capacity in the Partnerships area at present.
- Participation has been slower than expected for the internal survey seeking to establish a benchmark for secure research environments (SREs). Survey responses are still pending from a couple of sites, however this is a resource issue as people balance the demands on their time. Final data collection meetings for this project are scheduled during April-May 2022.

Risks

- None identified at this time.

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.
- The IDT Lead continues to connect with HDRN Members from 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. A student from Laurentian University is assisting in the curation of resources.
- The hiring process for an IDT research assistant is underway.
- The IDT would like to host a conference, likely in the fall, dependent on when additional support is available (above mentioned research assistant).
- The IDT is organizing an internal advisory made up of people from HDRN member organizations to help expand understandings of what partners are priorities across the network and to contribute to discussions that highlight HDRN priorities. The team is almost assembled, though still waiting on replies from some of the Member Organizations.
- The IDT lead continues to present at events and build an external network of individuals interested in Indigenous data governance.
- The IDEA Team continues to contribute to activities at HDRN and helping to identify opportunities to embed IDEA in operations and in the data research process.



- Work continues on the Accessible Information Strategy, with accessible pdf and docx templates in production and an accessible logo in consultation stages with the original logo designers. Training on accessibility will continue into the next quarter.
- The IDEA Lead will host a panel on IDEA at the upcoming CAHSPR conference. The focus will be on the IDEA and IDT work underway along with work in progress at HDRN Canada Member Organizations.
- An abstract on IDEA @ HDRN has been submitted to the upcoming IPDLN conference (September 2022)
- The IDEA Team is preparing two publications, with the goal of submitting to peer reviewed journals by June 2022
- The IDEA Team is preparing an introductory resource guide for all HDRN staff, Leads, and Exec which will be released in fall 2022.

Successes

- The IDT continues to contribute to the ways that the Indigenous data governance landscape are unfolding at HDRN Canada and is organizing a plan for how to better deliver information to the network and beyond.
- 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. HDRN Canada is awaiting final vetting from the First Nations' partners on the MOU. A formal announcement of the relationship is forthcoming.
- The lead of the IDT is working on research projects that advance the conversation on Indigenous Data Governance and has been contributing to publications and resource development that are being shared and discussed across the network.
- The IDEA Team is contributing to ongoing conversations and work towards the advancement of diverse population data governance and distributed analysis
- The IDEA Team has worked to shape and confirm its Terms of Reference. This is a living document and will reviewed yearly.
- The IDEA Team is now working on creating a set of shared principles for working together.

Challenges

- There is significant work to be done in order to embed de-colonial data principles throughout the network. 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 to support IDT work. Further support will be needed.
- The IDEA Team includes 20+ members with a broad range of knowledge and expertise, with some coming from an operations background and others from a data or research background. Facilitating and channeling a group of this size remains a



challenge. Immediate needs include finding common ground regarding IDEA concepts and definitions and applying those as we create principles for working together.

- 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. Additional resources may be needed.
- While there is a sufficient understanding of IDEA in relation to operational functions across the network (i.e., hiring, policies, etc.) a broader understanding of how IDEA relates technical processes and assumptions about data research and researchers is needed. A plan to address this is in development, but dedicated time and commitment is needed to find HDRN Canada's place in these conversations.

Risks

- It is fundamentally important to be certain that we are doing Indigenous-related work in a way that is considerate of the time needed to do it well. Decisions for whether and how to move forward must come from Indigenous Peoples- this requires a deep involvement and knowledge from Indigenous Nations.

Success Factor: Cohesive Network with Effective and Sustainable Operations

Key developments since last meeting

- Following HDRN Canada's application to the Canadian Foundation for Innovation (CFI)'s Major Science Initiative opportunity in February, HDRN Canada and all other applicants have been asked to develop scenarios with cuts of 15% and 30% to the proposed project budget. This is in response to CFI receiving more applications than it is able to fund at the full amount. HDRN Canada has 3 meetings in late April with CFI to discuss our applications and how the budget cuts would impact the network. One of the meetings focuses on management, one on scientific excellence, and one is between the Board Chair and CFI.
- In collaboration with the Modelling and Informatics Group (MIG), The DASH has identified projects in which site behavior is variable in relation to data placement within a trusted environment and subsequent analysis. Presently, it is assumed that data placement is complete before analysis takes place. However, some sites employ an iterative approach in which data placement and analysis go in cycles. In addition, DASH and sites need to follow resource use when sites are involved in analysis on behalf of the researchers.
- A major tool for building Data Assembly Plans is the DASH Information Item Dictionary. This has yet to be formally realized, but the contents of this are expected to be provided by researchers' project data requirements, although initial priming of the resource could take place through the data centres. Information items consist of



things like: 'date of birth', 'diagnosis code', 'healthcare facility code', 'medication dose', but without any reference to how any of these items are encoded as data. A key issue is how information items are defined and organized. Researcher and site input will be essential, but appeals may be made to existing ontologies, semantics associated with recognized common data models, or more ad-hoc arrangements such as the category labels being developed through the AHD Semantic Labelling program for the Data Assets Inventory. Recent working group decisions indicate that these (multiple) methods of organization will need to be supported.

Successes

- A draft of the Charity Application has been completed and is being sent to HDRN Canada's lawyers for clarification of some language and review before final submission.

Challenges

- The above developments related to data placement within a trusted environment potentially place new requirements on the later parts of the data access workflow model. Further discussion is needed to solidify these requirements and from there establish whether any model changes are needed.
- MIG responds to decisions and outputs coming from all work groups. From a modelling perspective, a coherent set of models is essential and necessitates cross-workgroup efforts at resolution of various issues.

Risks

- None identified at this time.

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

Key developments and successes since last meeting

- The inaugural Data Platforms and Services Community of Practice (COP) meeting was held on April 4th that HDRN Canada is leading together with the SPOR SUPPORT Unit Council. The meeting included discussion of the COP's terms of reference, creating an HDRN Canada Cyber Security Team and Cyber Attack Case Studies.
- The fourth meeting of the SPOR CDP Advisory Committee took place on February 24th. Meeting minutes can be found [here](#).

Challenges and Risks

- None identified at this time.