

Scientific Director and CEO 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:

* + DASH has implemented the DASH Data Access Request (DAR) Form in the DASH website portal. This will further streamline the access request process for researchers by removing the burden of having to complete multiple local DAR forms.

# HDRN Canada’s 18-month report was submitted to CIHR in July. The final version of the report is attached to the Board package for your information.

* + Submission of application to CIHR’s Clinical Trials Fund for the HDRN Canada Pragmatic Trials Training Platform on July 12, 2022 (development of budget, facilitating 40+ letters of support and grant writing).
  + HDRN Canada singed a MOU with the Population Health Research Network in Australia, focused on mutual learning and collaboration related to data access for multi-regional research. The announcement of this partnership has been made public on the HDRN Canada website: <https://www.hdrn.ca/en/news/hdrn-canada-announces-partnership-population-health-research-network-phrn-australia>

# Major milestones for coming quarter

# A company, The Evidence Network, has been hired to conduct HDRN Canada’s interim evaluation. Work on the evaluation began in early August and will continue to the end of November when the report will be completed. Engagement activities with the Board will be held in September/October to gather input.

# HDRN Canada’s Public Advisory Council will be meeting in-person for the first time on October 17.

# Our Leads Team is meeting in-person on October 18-19 to discuss strategy and implementation of the Strategic Plan. This is the Team’s first in-person meeting since 2019 due to the COVID-19 pandemic.

# The Privacy Team is developing two new resources for the DASH website:

# Guidelines for researchers with respect to addressing the differences between REB approval and privacy compliance.

# A set of requirements for developing a data sharing agreement with each HDRN Canada data centre.

# We created a new position for “Strategic Communications and External Funder Relations” and have hired a very experienced person into this role. She will be starting on September 19.

# We are a preparing a large grant for the Strategic Science Fund which will be submitted September 19.

# Anticipated and ongoing challenges

* + A number of staff have moved on to new opportunities in recent months, including the Indigenous Data Team Lead, Administration and Finance Coordinator, Communications Coordinator, Metadata Specialist, and Manager of Partnerships. These changes reflect widespread trends seen in Canada and the U.S. with employees seeking new opportunities once pandemic restrictions eased. HDRN Canada is working to fill vacancies as quickly as possible to ensure momentum is not lost.

# HIGH LEVEL KEY PERFORMANCE INDICATORS

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| Strategic Goal | Indicator | Number |
| Develop and Improve Services and Supports for Data Access | # of visits to the DASH website | Total unique visitors from May 27, 2022 – August 24, 2022: 466Monthly average: 155 |
| # of visits to the Dataset Inventory website | Total unique visitors from Feb 1, 2022– March 31, 2022: 356Monthly average visitors: 119 |
| # of intake forms received to date and since the last Board meeting (May 17) | 85 intake forms received to date, 5 of which were received since May 27, 2022 |
| # of data access request forms received to date and since the last Board meeting (May 17) | 15 data access request forms received to date, none of which were received since May 27, 2022 |
| # projects that DASH supported in grant application | 34 grant supported projects to date, 3 of which were received since May 27, 2022 |
| # of algorithms in inventory | 180 algorithms listed in the inventory (increase of 8 since last Board meeting) |
| # of datasets in inventory | 551 datasets listed in the inventory (decrease of 3 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 | Implemented DASH Data Access Request (DAR) FormEnhancements to DASH Portal interface and forms (Intake Form, Data Assembly Plan [DAP] Form) |

## 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

* Developed and implemented new processes and supporting documentation (Portal Guidebook for Researchers, Standard Operating Procedures) as part of the implementation of the DASH Data Access Request (DAR) Form.
* Implemented several enhancements to the DASH Portal (Intake and Data Assembly Plan [DAP] forms) and to the DASH Application Tracker to respond to evolving stakeholder needs.
* Developed operational and program management reports for HDRN Canada Executive Committee and Leads Team audiences.
* Supported 5 projects during the summer and fall CIHR grant competitions by providing feasibility reviews and cost estimates to researchers.
* The Data Access Workflow Model (AWM), which models the data application processes at multiple sites, has now been rendered in Lucid Chart permitting further shared development by the Modelling and Informatics Group (MIG) and DASH. The basic workflow model is supplemented by a set of layers which cover: (1) flow arising from exceptional conditions; (2) DASH and site standard operating procedures (SOPs) which apply to specific sub-processes; (3) detailed listing of the inputs and outputs associated with a sub-process and their location within the major application documents: Intake, DAR and DAP; and (4) glossary entries for the terms used in the other layers. Layer (1) is populated and layers (2), (3) and (4) will be populated in due course.
* To support the release of the AWM, further work is being done on a machine-readable version which can be consumed by a workflow/execution engine. The language for this has been selected (DadaGem) and the AWM is being cast in this form presently. This formal language (and its associated diagrams) may result in minor, but important, modifications to the AWM to ensure consistency between the two representations. Once this work is done, the basic-layer AWM can be released for external consumption and further work by MIG and DASH. The possible audience(s) for the Lucid AWM model (e.g., DASH staff, data centres, researchers, informatics community, etc.) is to be determined.

# Successes

* **Implementation of the new DASH DAR Form** in the DASH portal to further streamline the access request process for researchers. The single DASH DAR form removes the burden on researchers having to complete multiple local data request forms. **This is a key milestone for DASH, as researchers have often cited multiple forms as a substantial pain point**.
* Since the last Board meeting, DASH has continued to support over 20 active projects and has convened over 50 calls with researchers and DASH site representatives to support these projects. A total of 14 active projects have reached the formal data request stage of the access process. Of these, 3 projects are at the agreement stage and 6 are at varying data assembly stages. It is anticipated that 5 of these projects will be completed within the next 4 months. DASH staff across data centres continue to meet regularly to ensure that projects are progressing well.
* On behalf of HDRN Canada, DASH drafted a Memorandum of Understanding (MOU) with Australia’s Population Health Research Network (PHRN). Recent collaborations between the two networks include the planning for a joint workshop and oral presentation at the September 2022 International Population Data Linkage (IPDLN) conference.
* Incorporation of original AWM into Lucid Chart (basic layer).

# Challenges

* Ensuring that project turnaround times are well managed continues to be a top priority for DASH. Project timelines are significantly influenced by the complexity of projects, and the myriad of internal and external factors impacting processes across multiple sites. DASH is working with sites to better understand and summarize estimated turnaround times for projects. With more information captured in the DASH App Tracker, DASH is looking at how these estimates compare to actual project turnaround times to determine if further efficiencies can be gained. To manage researcher expectations, DASH continues to communicate expected timelines to researchers throughout the process (Intake call, Project Kick-Off call, ad-hoc emails/calls)
* The model where some sites employ an iterative approach in which data placement and analysis go in cycles may have implications for the AWM and is being explored.
* Regarding the Data Assembly Plan (DAP), described in the previous (May 2022) Board Report, several basic questions relating to harmonization, automation, and participant responsibilities remain to be answered. Discussions with the Executive Team and others will determine strategy on moving these conversations forward.

# Risks

* None identified at this time.

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

# Key developments since last meeting

* Recent work in support of the Algorithms and Harmonised Data working group (AHD), regarding the use of data category labels in the Data Asset Inventory (DAI), has been completed and awaits approval before final deployment in the DAI application. This provides for a simple, first effort, at organising the information items in the dictionary generated by researchers/sites, before we proceed to alternative, and improved, methods of organisation, such as common data models and ontologies (all these methods of organisation can co-exist). These methods of organisation provide alternative data search capabilities within the DAI, which should appeal to varied researcher communities.
* Three staff members (accounting for 2.0 FTE) affiliated with Manitoba Centre for Health Policy and the George & Fay Yee Centre for Healthcare Innovation have either left their positions or their terms have completed. This has resulted in gaps in the completion of existing projects and the inability to start new projects associated with the Algorithms Inventory and the Data Assets Inventory. One new position, which will be situated within the George & Fay Yee Centre for Healthcare Innovation will be posted shortly; a short-term (i.e., 6-month) Metadata Specialist position has now been posted.

# Successes

* Availability of Data Category labels for use within the Data Access Inventory (subject to approval).
* The Projects to Advance the Algorithms Inventory continue to proceed at a good pace. Data analyses or data access approvals are being conducted for all projects. While there have been some challenges associated with the signing of agreements between individual universities and data access sites, the issues have been documented and are useful for informing DASH for future projects.
* Eight participating sites completed the first phase of the semantic label project; the goal of this project is to assign generic labels to databases in the Data Assets Inventory, to improve searchability of the Inventory.
* A conference presentation about a synthesis review of the Algorithms Inventory was accepted for the International Population Data Linkage Network meeting in September 2022.
* A blog post about this synthesis review has been posted here: <https://blog.hdrn.ca/2022/07/building-supports-for-multi-regional-research-the-algorithm-inventory/>.

# Challenges

* The development of the Information Item Dictionary referenced above and described in the previous (May 2022) Board Report, encourages an asset-neutral approach to data availability. Actual data assets are chosen later in the data access application to the DASH. This re-orientation for researchers, from data assets (with data models) to information items (which populate the DAP), will need to be formally accepted by the working groups.
* The programme of work investigating the theoretical implications of the use of privacy-preserving distributed analysis techniques is progressing well. However, investigation of the practical implications of these techniques has not progressed significantly. The theoretical approach has been described in several MIG presentations earlier this year. A practical investigation has been agreed in principle and design but awaits organisation.
  + Distributed analysis will be one of three ways in which data can be analysed within a trusted environment for analysis; the others being local analysis followed by meta-analysis, and, possibly rarely, analysis of a small subset of pulled data at a central trusted site, where governance allows this.

# Risks

* The inability to find suitable individuals for available positions at Manitoba Centre for Health Policy and the George & Fay Yee Centre for Healthcare Innovation may slow future work on the Data Assets Inventory and planned projects associated with the common data model.

### Goal: Ensure Purposeful and Ongoing Public and Community Involvement

# Key developments since last meeting

* The tenth meeting of the Public Advisory Council (PAC) was held in May 2022 and focused on:
  + A presentation by representatives from the Public Health Agency of Canada (PHAC) and the Patient Advisors Network on the Culture of Data Sharing and the Pan-Canadian Health Data Strategy. This presentation was followed by a lively question and answer session.
  + An update on the PAC recruitment process to replace those members who have terms that ended in June 2022
  + An update on the work of the PAC Interest groups: Communication and IDEA.
* The first in-person PAC meeting is being planned for October 2022
* The Plain Language About Data project has restarted. The project was put on hold when the previous Public Engagement Fellow left.
* Building on the scoping work completed by the previous Chair of the Public Engagement Working Group, work has begun on the development of a full HDRN Canada Public Engagement Plan that includes strategic goals (aligned with the HDRN Canada Strategic Plan), timelines, resources, and communications.
* There have been a number of changes to the Public Engagement Team:
  + The Chair of the Public Engagement Working Group and Executive lead stepped down and has been replaced by a member of the Public Engagement Working Group.
  + A new Public Engagement Fellow has been appointed.
  + Membership of the Public Engagement Working Group has altered slightly with a new representative from Quebec and Ontario.

# Successes

* The draft conclusions of the Health Data Social Licence White Paper, developed for PHAC, have been presented to Ministers and PHAC. The final document will be submitted in early Fall.
* The recruitment for new members of the PAC is proceeding well; the quality of the applications was very good. The successful applicants will have been informed by Labor Day.

# Challenges

* No applications were received for the PAC from Francophones living outside of Quebec.
  + Targeted recruitment efforts to attract applicant from outside Quebec will be developed.
* Attendance at the last two PAC meetings declined somewhat (to about 50%). Feedback indicates that this is partly because all meetings have been virtual.
  + An in-person meeting is planned for October 2022.
* Concerns regarding the continuity between PAC meetings have been raised, noting that it is difficult to maintain momentum.
  + PAC Interest groups have formed to address continuity of key issues such as Communications and IDEA.
  + Standing agenda items will be included.
  + An additional meeting will be added to the annual meeting schedule.
* The PAC has raised concerns regarding how to explain the work of HDRN Canada to the general public.
  + The PAC has set up a Communications Interest Group, which is focused on addressing this issue.

# Risks

* The September meeting of the PAC will include new members. As with changes to any governance structure there is a risk that the new PAC may not gel / function as effectively. To mitigate this risk an orientation meeting with the PAC Chair will be offered to all new members. Additionally, the October in-person meeting will provide an excellent opportunity for all the members to get to know each other.

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

# Key developments since last meeting

* Presentation at the 2022 Canadian Association for Health Services and Policy Research (CAHSPR) conference on the HDR Alliance.
* A memorandum of understanding (MOU) has been drafted with the Canadian Agency for Drugs and Technologies in Health (CADTH) and HDRN Canada, which is currently undergoing review.
* HDRN Canada’s Manager of Partnerships has accepted a new position at ICES, with the hiring process for a replacement underway.

# Successes

* An application to CIHR’s Clinical Trials Fund for the HDRN Canada Pragmatic Trials Training Platform was submitted on July 12, 2022. HDRN Canada staff led the development of budget, facilitated 40+ letters of support, and grant writing.
* Integration of HDRN Canada into CADTH’s workflow for new Post Market Drug Evaluation (PMDE) program as data facilitator (referenced in MOU described above).
* The Privacy Team worked on guidelines for researchers with respect to addressing the differences between REB approval and privacy compliance, highlighting 10 misunderstandings about the REB and privacy compliance. When revisions are complete, this tool will be shared with the network in September and made available, after approval and translation, on the DASH website.
* A second research tool for data sharing was developed as a result of an ongoing alliance with a national study to share regional data findings with multiple provinces. A set of requirements for developing a data sharing agreement with each HDRN Canada partner has been drafted. This tool will be shared with the network in September and made available, after approval and translation, on the DASH website.
* A Privacy Team poster summarizing its project examining the barriers to administrative data sharing across borders was shared as an electronic poster presentation at CAHSPR 2022.
* Although a few members of the Privacy Team left due to retirement and changes in employment other members have joined which has kept the membership numbers consistent.
* Privacy Team members led 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.
* Data collection wrapped up in late April for this already delayed internal survey seeking to establish a benchmark for HDRN Canada data center’s secure research environments (SREs). The write up of findings has been prolonged due to annual leave and other demands on time.
* The HDRN Canada Privacy Team has yet to recruit a member from Alberta. With more initiatives to evolve data sharing and privacy practices it will be important to have representation from all Canadian provinces and territories on the team.

# Risks

* Ongoing attention is required to ensure original commitments to partners are maintained as new areas of work for HDRN Canada are pursued

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

# Key developments since last meeting

* The IDEA Team continues to contribute to activities at HDRN Canada and help to identify opportunities to embed IDEA in operations and in the data research process.
* The IDEA Team has three active sub-groups working on the following tasks:
  + Accessible Communication within HDRN Canada: new pdf and docx templates are now in use within the network; the website is being redesigned and upgraded, and a presentation given to all staff in June 2022 about accessible communication and design. A statement will be added to the new website about HDRN Canada’s commitment to accessible communication.
  + IDEA Team Definitions and Principles: a process to decide on the definitions of Inclusion, Diversity, Equity, and Accessibility was undertaken and now in its first round of review. This sub-group also worked to come up with the IDEA Team’s “Principles for Working Together,” which is also under review.
  + Environmental Scan: a survey has been developed to gauge the current state of IDEA activities across HDRN Canada organizations and SPOR SUPPORT Units. This survey will be delivered in the fall with a report to follow.
* The IDEA Lead will give a presentation at the upcoming IPDLN conference in Scotland. The talk will provide an overview of IDEA at HDRN Canada, work to date, and future opportunities.
* The IDEA Team is preparing a publication, with the goal of submitting to peer reviewed journals by December 2022.
* The IDEA Team is preparing an introductory resource guide and webinars for all HDRN staff, Leads, and Exec which will be released in fall 2022.
* An IDEA Fellow has been hired and will start work late August. Their area of expertise is disaggregated data and gender diversity. Along with forwarding work and preparing deliverables in those areas, the IDEA Fellow will participate in paper writing and advising on IDEA Team initiatives.
* HDRN Canada’s Indigenous Data Team lead has left the organization as of August 12, 2022. Plans are underway to hire a new Team Lead.

# Successes

* The IDEA Team is contributing to ongoing conversations and work towards the advancement of diverse population data governance, distributed analysis, and metadata – in September the IDEA Team will review the semantic labels prepared by the AHD and MIG working groups.
* The IDEA Lead contributed to the CIHR Clinical Trails Training Grant application and will serve as the EDI Lead for the grant if successful.

# Challenges

* 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.
* 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.
* With the departure of the IDT Lead, the shared work between the IDT Lead and the IDEA Lead – “Data for Equity?” – has paused. The continuation of this work will depend on hiring an IDT Lead and their priorities in this space.

# Risks

* None identified at this time.

### Success Factor: Cohesive Network with Effective and Sustainable Operations

# Key developments since last meeting

* HDRN Canada was notified that its application to the Canadian Foundation for Innovation (CFI)’s Major Science Initiative opportunity was not successful. Feedback provided by CFI will be incorporated into all of HDRN Canada’s future applications to strengthen then. Also, work developed for this application has been useful to HDRN Canada for other applications, such as the Strategic Science Fund and Pragmatic Trials Training Platform CIHR grant applications.
* A number of staffing changes have happened on the Central staff team.
  + The Communications Coordinator and Administration/Finance Coordinator have moved on to new opportunities. Job postings to recruit for these positions as well a Project Coordinator position are underway.
  + A Strategic Communications and External Funder Relations specialist has been hired and will start work with HDRN Canada on September 19th.
* HDRN Canada’s Leads Team is meeting in-person on October 18-19 to discuss strategy and implementation of the Strategic Plan. This is the Team’s first in-person meeting in over two years due to the COVID-19 pandemic.
* Our full application to the Strategic Science Fund is due on September 19th. Work is ongoing with partners to ensure the application leverages their work and addresses key priorities that HDRN Canada is best placed to deliver on.

# Successes

* The Modelling and Informatics Group (MIG) continues to work closely with the main working groups of HDRN Canada to ensure coordination across groups.
* The Request for Proposals process to identify a company to conduct HDRN Canada’s interim evaluation is completed with The Evidence Network selected as the top candidate. Contracts were finalized and work on the evaluation began in August and will continue to the end of November.

# Challenges

* MIG responds to decisions and outputs coming from all work groups. From a modelling perspective, a coherent, understandable, set of models is essential and necessitates cross-workgroup efforts at resolution of various issues. In this regard, there is increasing interest in the IDEA group, specifically in relation to inclusion and accessibility of modelling and outputs.

# 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

* Held a second SPOR Data Platforms and Services Community of Practice meeting, with guest presentations from the Canadian Clinical Research Network and the lead on an application to the SPOR National Collaboration competition.
* Held a fifth SPOR CDP Advisory Committee meeting, with a focus on receiving input into the Trials Training Platform grant.

# Challenges and Risks

* None identified at this time.