

CEO / Scientific Director Report

Health Data Research Network (HDRN) Canada
November 23, 2022

Overview: 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.

SECTION 01: High Level Progress Update

Key progress since the last board meeting:

HDRN Canada was successful in its application to the CIHR Pragmatic Trials Training Grant Application. This is the application that was led by Dr. Amit Garg and funding will flow to Western University. The grant period is September 1, 2022-August 30, 2025 and \$3.48 million over 3 years. *This news is currently under embargo, until CIHR makes a formal announcement.*

HDRN Canada also supported a CIHR Clinical Trials Platform Grant that was successful (and also under embargo). It is to be determined what HDRN Canada's role in this grant will be.

The Health Data Social Licence White Paper now referred to as "Social Licence For Uses Of Health Data. A Report On Public Perspectives" was finalized and was very well received by the Public Health Agency of Canada. A communications plan for the report is now being developed.

HDRN Canada submitted a large grant application to the Strategic Science Fund on September 19th to create a platform to gather real world data for real world evidence. Applicants will be notified in spring 2023 if they were successful.

Major milestones for the coming quarter:

HDRN Canada's interim evaluation is underway and the report will be finalized in December 2022/January 2023.

Privacy Team deliverables "Guidelines: How Privacy Compliance and Research Ethics Board Approval Work Together for Research Using Administrative Data -Top 10 Misunderstandings" and the "HDRN Canada Data Sharing Agreement Checklist" are being translated and will be added to the HDRN Canada website as resources for researchers in the near future.

Anticipated and ongoing challenges:

Staffing remains a challenge. HDRN Canada is working to fill vacancies as quickly as possible to ensure momentum is not lost. HDRN Canada's Central Team is helping to advance work where possible until staffing vacancies can be filled.



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 September 15, 2022 – October 15, 2022: 211
	# of visits to the Dataset Inventory website	Total unique visitors from September 15, 2022 – October 15, 2022: 152
	# of intake forms received to date and since the last Board meeting	91 intake forms received to date, 6 of which were received since September 15, 2022
	# of data access request forms received to date and since the last Board meeting	17 data access request forms received to date, 2 of which were received since September 15, 2022
	# projects that DASH supported in grant application	38 grant supported projects to date, 4 of which were received since September 15, 2022
	# of algorithms in inventory	185 algorithms listed in the inventory (increase of 5 since last Board meeting)
	# of datasets in inventory	551 datasets listed in the inventory (same as last Board meeting)
Diversify & Harmonize Data + Support Innovative & Privacy-Sensitive Data Use for Researchers	Enhancements/updates to resources supporting access to multi-regional data	Enhancements to DASH Portal interface and forms (Intake Form, DAP Form) Update to DASH standard operating procedures documentation

SECTION 02:

Additional Information About HDRN Canada Progress & Core Work

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

Goal 01: Develop and Improve Services and Supports for Data Access

--

Key developments since last meeting:

- Several enhancements have been implemented to the DASH Portal (Intake and Data Assembly Plan forms, integration of Feasibility Assessment template) to respond to evolving stakeholder needs and further streamline the access process for researchers.
- Developed additional operational reports, including an interactive reporting tool, for HDRN Canada internal audiences to track and report on DASH activities and progress.
- A first version of a machine-readable version of the Data Access Support Hub (DASH) Data Access Workflow Model (AWM) has now been created as a series of diagrams that have associated syntactic representations that can be consumed by software. When executed, the software will generate the same sequential workflow that DASH currently uses to govern its mediation of applications to individual data centres. The existing sequential workflow has not required modification as a result of this work. The method by which a software engine would guide DASH decisions using the machine-readable version of the workflow has been described to DASH and feedback received. It is anticipated that the initial introduction of the engine/workflow will not increase DASH workload significantly, and will be completely transparent to data centres. Introduction is anticipated in nine to 12 months

Key developments since last meeting, continued:



- The Lucid Chart version of the existing sequential application workflow is nearing completion, and will open up new avenues of interaction between the Modelling and Informatics Group (MIG) and DASH in support of the DASH application process.
- Meetings with Algorithms and Harmonized Data (AHD) Working Group and data centres to review collection of provenance information for data assets within the Data Asset Inventory (DAI). Initial collection focused on identification of data custodians and controllers.

Successes

- The DASH continues to support over 20 active projects and has convened over 40 calls with researchers and DASH data centre representatives to support these projects. A total of 17 active projects have reached the formal data request stage of the access process; four of these projects are at the agreement stage, and eight are at varying data assembly stages. It is anticipated that five of these projects will be fully completed within the next three months. DASH staff across data centres continue to meet regularly to ensure projects are progressing well.
- The DASH collaborated with Australia’s Population Health Research Network (PHRN) in hosting a joint workshop and oral presentation at the September 2022 International Population Data Linkage (IPDLN) conference which were well received. A knowledge exchange session between the two networks is planned for November 2022.
- Challenges
- Issues regarding the Data Assembly Plan (which describes how data are generated and released) and the analysis part of the application workflow (relating to local analysis, distributed analysis or pooled analysis) are still works in progress.
- Ensuring that project turnaround times are well managed continues to be a top priority for the DASH. Project timelines are significantly influenced by the complexity of projects, and the myriad of internal and external factors impacting processes across multiple sites. The DASH is working with data centres to understand the local challenges and identify efficiencies that could be gained to improve timelines for future projects. To manage researcher expectations, the DASH continues to communicate expected timelines to researchers throughout the process (Intake call, Project Kick-Off call, ad-hoc emails/calls).

Risks

- None identified at this time.

Goal 02: Diversify and Harmonize Data, and Support Innovative and Privacy-Sensitive Data Use

--

Key developments since last meeting:

- Site annotation of data assets for a further set of semantic labels is in progress with the AHD Working Group. The Inclusivity, Diversity, Equity and Accessibility (IDEA) Team is also reviewing the labels.
- Members of the AHD Working Group met with representatives from the SAIL Databank (UK) about work they have done using the OMOP (Observational Medical Outcomes Partnership) common data model developed by OHDSI (Observational Health Data Sciences and Informatics). The information from this meeting is being used to guide the development of a project plan to research, test and recommend a common data model format for HDRN Canada.

Successes



- There is renewed consensus on the use of Information Items as a means of representing data requirements within the Data Assembly Plan. A method has been discussed at a recent HDRN Canada Leads Team meeting which enables the co-use of common data models alongside the proposed information item dictionary that satisfies the needs of multiple research communities, and data centres concerns regarding the resource requirements of introducing common data models into their data selection and assembly processes.
- A conference presentation about a synthesis review of the Algorithms Inventory was presented at the IPDLN conference in September 2022. Another conference presentation about federated learning methods for data de-identification was also presented at the conference

Challenges

- We are working to identify a suitable project to assess the use of distributed analysis by researchers. Candidates have been submitted and will need to be assessed by the MIG and DASH.
- A new Data Documentation and Analysis position was posted by the University of Manitoba to support the Algorithms and Harmonized Data Working Group. This position has not as yet been filled. HDRN Central project management staff and senior graduate students at the University of Manitoba will support the work.

Risks

- None identified at this time.

Goal 03: Ensure Purposeful and Ongoing Public and Community Involvement

Key developments since last meeting:

- Six new members were recruited to the Public Advisory Council (PAC). The new members attended their first meeting in September. This meeting focused on:
 - The content of the 2021 Annual Report;
 - The Health Data Social Licence White paper, the name of which was changed on the advice of the PAC to remove reference to White Paper, due to the way "white paper," at least from some Indigenous perspectives, recalls documents from the past now seen as harmful to Indigenous people; and
 - The Data Grid that shows which organizations in HDRN Canada hold what kinds of data. The PAC previously advised on the format of the grid and which labels to include.
- The September PAC meeting was followed by the PAC's first in person meeting on October 17. The in-person meeting was very successful and allowed the PAC members to get to know each other better. The in-person meeting focused on:
 - Getting to know each other;
 - An overview of HDRN Canada;
 - Discussion of the Public Engagement Plan and the PAC's role in it;
 - A presentation on Inclusion, Diversity, Equity and Accessibility and Indigenous Data Sovereignty and how these are key lenses through which HDRN Canada conducts its work; and
 - Communication tools available to be used across HDRN Canada and with the broader public.
- The Public Engagement Plan has been drafted and was shared with the PAC for comments. PAC members have requested to see the accompanying budget



Successes

- The Health Data Social Licence White Paper now referred to as Social Licence For Uses Of Health Data. A Report On Public Perspectives, was finalized and was very well received by the Public Health Agency of Canada. A communications plan for the report is now being developed.

Challenges

- It has not been possible to recruit a Francophone living outside of Quebec to join the PAC despite recruitment efforts. An approach was made to an individual who was a member of the interim PAC to see if she was interested in joining or able to recommend someone to join the PAC, and she confirmed she will join the PAC.

Risks

- Once the Public Engagement Plan has been approved by the PAC and HDRN Canada, the focus will be on implementation of the plan. There are risks inherent with the implementation of any new plan/service. To mitigate against risk, implementation of the plan will be the focus of the Public Engagement Fellow's work for the next six months. Additionally, the budget for Public Engagement has been reviewed to ensure there are sufficient funds to implement the plan. Regular updates will be provided to the PE Working Group to allow for course correction as necessary.

Goal 04: Establish and Strengthen Partnerships and Provide Leadership for Evolving Data Practices

–

Key developments since last meeting:

- The regional CanPath cohort-HDRN Canada data centre workflow document with the partner was finalized.

Successes

- Continued strong collaboration with Canadian Agency for Drugs and Technologies in Health (CADTH) as we work towards joint memorandum of understanding and workplan.
- Alliance member partnership with the Canadian Longitudinal Study on Aging (CLSA) is progressing.
- The data sharing agreements between CLSA and six of a potential eight data centres are in the final review stages. They have been returned to the data centres for final comments and/or signature. A harmonized data user process is being drafted by the data centres to ensure compliance with the terms of the data sharing agreement.
- The first DASH request to use CLSA data has been received and is undergoing review.

Challenges

- The Strategic Partnerships portfolio is undergoing a staffing transition, so there has not been capacity to undertake any new work in this area.
- The first of four Data Sharing Agreements with CanPath's Atlantic cohort has been with University of New Brunswick (UNB) legal counsel for review since September. UNB counsel has met with Dalhousie University to clarify outstanding concerns. It is the intention of Dalhousie University to use this first agreement as a template for agreements with PEI's Secure Island Data Repository (SIDR) and Newfoundland and Labrador's Centre for Health Information (NLCHI). The agreement for sharing with Health Data Nova Scotia (HDNS) will be an internal agreement as CanPath's Atlantic cohort and HDNS have the same legal authority.



Risks

- Ongoing attention is required to ensure original commitments to partners such as CanPath and CLSA are maintained as new areas of work for HDRN Canada are pursued.
-

Goal 04: Strengthen Data Use to Improve Equity, and Support Indigenous-led Data Sovereignty

Key developments since last meeting

- The IDEA Team has three active sub-groups working on the following tasks:
 - IDEA Team Definitions and Principles: a process to decide on the definitions of Inclusion, Diversity, Equity, and Accessibility was undertaken. This sub-group also worked to identify the IDEA Team's Principles for Working Together. These key documents will be added to the IDEA Team Terms of Reference. Additionally, we are working with the Strategic Communications manager to share this work across the network and develop a process to adapt the definitions and principles to HDRN Canada as an organization.
 - 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 fall 2022; report to follow.
 - Data Labels and Descriptions: a sub-group has been established to review and provide guidance for labels and their descriptions on the Data Asset Inventory. A presentation was made to the IDEA Team in September with work underway through fall 2022.
- The IDEA Lead gave a presentation at the Fall SPOR CDP Advisory Committee Meeting. Topics of discussion included disaggregated data and opportunities for collaboration in the IDEA space amongst SPOR entities.
- The IDEA Team is preparing a publication, with the goal of submitting to peer reviewed journals by Dec. 2022.
- The IDEA Team is preparing an introductory resource guide and webinars for all HDRN Canada staff and Leads and Executive Committee members which will be released in early 2023.
- The IDEA Lead continues to contribute to activities across HDRN Canada and help to identify opportunities to embed IDEA in operations and in the data research process. Most recently, this has included contributions to the interim evaluation of HDRN Canada and contributions to the Strategic Science Fund grant that was submitted in September, 2022.

Successes

- The Indigenous Data Team (IDT) team has continued important exploratory conversations in the development of national Indigenous collaborations, including with the First Nations Information Governance Centre.
- The IDT Team contributed to the development of an HDRN Canada-led application to the SSF through the inclusion of an Indigenous-led pathfinder project.
- The IDT Team submitted a workplan to move IDT priorities forward in response to the outgoing IDT lead's Seven Seasons final report.
- The IDEA Lead presented at the IPDLN conference in Scotland. The talk provided an overview of IDEA at HDRN Canada, work to date, and future opportunities.



- An IDEA Fellow has been hired. 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.
- The IDEA Lead presented a new resource, IDEA in Everyday Decision Making, at the October Leads meeting. This resource will be operationalized in HDRN Canada onboarding practices, agenda templates, and explored more in an upcoming discussion session.

Challenges

- The IDT Lead resigned in August, leaving a significant gap in the IDT resources and more broadly within the HDRN Canada's capacity to support Indigenous-led research initiatives and Indigenous data sovereignty work. The IDT is responding to the outgoing lead's report, which recommends a refocusing to respond to the well-known capacity challenges among Indigenous researchers, among other key recommendations.
- IDT and the HDRN Canada are challenged both by its capacity to support Indigenous-led data initiatives and understanding its role within the broader Indigenous data governance landscape. IDT is in the process of consultative restructuring and reprioritizing to address both challenges.
- With the departure of the IDT Lead, the shared work between the IDT Lead and the IDEA Lead, notably the Data for Equity? Newsletter, has paused. This work will continue following the restructuring and prioritization of the IDT.
- 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 and educational opportunities. Additional resources may be needed.

Risks

- None identified at this time.

Success Factor: Cohesive Network with Effective and Sustainable Operations

--

Key developments since last meeting:

- HDRN Canada is moving from use of Confluence to Google Workspace. The transition is already underway and it is anticipated that use of Confluence will cease in Spring 2023.
- 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. A job posting to recruit for a Communications Officer has been posted.
- A Finance Coordinator was hired and started work with HDRN Canada on November 2.
- A Strategic Communications and Funder Relations Manager was hired and started work with HDRN Canada on September 19.

Successes

- The MIG continues to work closely with the main working groups of HDRN Canada.



Challenges

- The MIG responds to decisions and outputs coming from all working groups. From a modeling perspective, a coherent, understandable set of models is essential and necessitates cross-group 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 modeling and outputs.
- In regard to the above, the MIG-developed HDRN Canada Glossary needs to be updated and made more accessible to encourage its wider use by working groups. Currently the DASH uses the glossary the most within HDRN Canada.

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 sixth meeting of the Strategy for Patient Oriented Research (SPOR) Canadian Data Platform (CDP) Advisory Committee was held on October 26, which focused on a presentation by the IDEA Team Lead
- A number of HDRN Canada data centres engaged with their provincial/territorial government partners during the development of the SSF grant application to ensure awareness of HDRN Canada's application and to gather feedback on how the proposed Real World Data Platform can be of most benefit to policy makers.
- Many HDRN Canada leaders presented at the 2022 International Population Data Linkage Network, a major opportunity for networking and learning among data centres worldwide.

Challenges and Risks

- None identified at this time.

