HDRN Canada

Scientific Director and CEO’s Report

May 16 2023

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**Overview:** The first section of this report highlights major initiatives and accomplishments since the last Board meeting in February 2023, 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 1: High Level Progress Update

### Key progress since the last board meeting:

* Work to launch the Pragmatic Trials Training Program is progressing. The aim is to have the call out for applicants starting at the end of May (intake rolling over a few months to secure full complement of trainees) with trials project planning starting in Fall 2023. Current efforts include establishing the advisory committee to guide the work and securing an online portal that can house the training materials. The hope is that an existing portal can be leveraged to reduce costs and build upon curriculum resources offered by complementary trials training grants.
* HDRN Canada will be hosting its first public-facing knowledge sharing event, the *Health Data For All Of Us Forum,* on 25th April 2023. This event is conceived and led by the Public Advisory Committee with planning and logistics support from the Patient Engagement Working Group and the central team. This event is hybrid in-person and online and has reached maximum attendance with 60 people registered to join in-person and over 300 online.
* A number of presentations were accepted for the May 2023 Canadian Association for Health Services and Policy Research (CAHSPR) conference. This is a great networking and promotion opportunity for HDRN Canada.

### Major milestones for coming quarter

* HDRN Canada will be holding its annual in-person Leads Team meeting on April 26-27. This is a key opportunity for network members to meet in-person to develop strategy and plan for the coming year.
* The initial work done to establish methods and instruments for managing multiple common data models within HDRN Canada is complete. Next steps and resourcing for the project will be discussed at the in-person Leads meeting in April.
* HDRN Canada is planning a series of events to learn about the state of the science of federated analysis. An ad hoc steering group will be created to oversee and plan this work with the objective of launching a project plan in Fall 2023.

### Anticipated and ongoing challenges

* Projects to Advance the Algorithm Inventory have been delayed for a variety of reasons, including approval of data sharing agreements in some provinces. It will be several months before projects are completed, publications are finalized, and additions to the Algorithm Inventory are made available to researchers. This lengthy process may impact user perceptions of the Inventory as a resource for state-of-the art information about algorithms to measure population health, health service use, and the determinants of health.

### High Level Key Performance Indicators

|  |  |  |
| --- | --- | --- |
| **Strategic Goal** | **Indicator** | **Update for This Report** |
| Develop and Improve Services and Supports for Data Access | # of visits to the DASH website | Total unique visitors from February 1, 2003 – April 11, 2023: 419 |
| # of visits to the Dataset Inventory website | Total unique visitors from February 1, 2003 – April 11, 2023: 330 |
| # of algorithms in inventory | 185 algorithms listed in the inventory (same as at the last Board meeting) |
| # of datasets in inventory | 564 datasets listed in the inventory (increase of 13 since the last Board meeting) |
| Supportive and Engaged Legislative and Policy Ecosystem and Community of Data Users | # of webinars | Five public and internal webinars or town halls were held since the last Board meeting:   * Two IDEA town halls to discuss concepts and gather input from the internal network * DASH French public-facing webinar * Internal discussion session on the status of setting up a data centre in Saskatchewan * Internal discussion session on ongoing work of the network |
| New partnerships in development | 1. Immigration, Refugees, and Citizenship Canada: data linkage partnership 2. Canadian Primary Care Research Network – Primary Care Information System Committee: invitation to HDRN Canada to join Committee |
| Diversify & Harmonize Data + Support Innovative & Privacy-Sensitive Data Use for Researchers | Enhancements/updates to resources supporting access to multi-regional data | * Updates to the Data Assets Inventory Training Guide are now in progress. The last update to this guide was in January 2022. * Development of DASH Portal overview video for internal users * Enhancements to DASH Portal interface and forms (Data Access Request Form) |

# Section 2: 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 1: Develop and Improve Services and Supports for Data Access

### Key developments since last meeting

* Several enhancements have been implemented to the Data Access Support Hub (DASH) Portal (e.g., Data Access Request forms) to respond to evolving stakeholder needs and further streamline the data access process for researchers.
* The Modelling and Informatics Group (MIG) is working with the DASH to improve guidance for data centres in relation to how their local activities fit within the shared workflow model for data access applications. This recent work focused specifically on data delivery and analysis activities that can take place in parallel at some data centres. This tool allows HDRN Canada to track data access-related processes and monitor timelines.
* In addition, the DASH and MIG will move to the latest version of the application workflow model which is better aligned for automation. Initial attempts to automate (later this year) will be restricted to the activities of DASH (rather than data centres) as a first step.
* The DASH and MIG are working to consolidate the large list of variables requested by researchers as part of their data access requests. This work is one step in the formation of an ‘information item dictionary’ that will be a new resource for researchers and data centres when requesting data and preparing datasets.

### Successes

* The DASH and the Manager of Partnerships held individual meetings with each HDRN Canada member organization to check in, promote engagement, and identify needs and areas of improvement.
* The DASH is currently supporting 30 active projects and supported 7 projects for the Spring Canadian Institutes of Health Research (CIHR) grant competition. A total of 22 active projects have reached the formal data request stage of the data access process. It is anticipated that 6 of these projects will be completed by May 2023. DASH staff across data centres continue to meet regularly to ensure projects are progressing well.

### Challenges

* Ensuring that project turnaround times are well managed continues to be a top priority for the DASH. Timelines are significantly influenced by the complexity of projects, as well as internal and external factors impacting processes across data centres. The DASH is working with data centres to understand local challenges and identify efficiencies to minimize impacts to turnaround times.

### Risks

* None identified at this time.

## Goal 2: Diversify and Harmonize Data, and Support Innovative and Privacy-Sensitive Data Use

### Key developments since last meeting

* The initial work done to establish methods and instruments for managing multiple common data models within HDRN Canada was completed by a cross-working group team.
* In conjunction with a cross-workgroup team, the MIG established effective methods for generating information items from the popular common data models CNODES and OMOP. This work also identified assets holding data (at participating data centres) corresponding to these information items, and also free-form specifications of how that data might be extracted. An initial set of three pairs of related tables from CNODES and OMOP was chosen for this purpose.
* The Inclusivity, Diversity, Equity, and Accessibility (IDEA) Team and the Algorithms and Harmonized Data (AHD) Working Group developed a process to proceed with the Data Assets Inventory Labeling Project. From a researcher’s perspective, the labels are useful to understand the contents of health and social data across Canada. The annotations created were useful in improving the efficiency of the Common Data Model (CDM) Information Item project. The classification formed by these annotations can be used by other projects.
* Related to the above, there is the opportunity for the AHD Working Group and IDEA Team to educate researchers on best practice definitions of sensitive concepts and to accurately represent data assets available at member organizations. In brief, the dataset labels will be pilot tested in Manitoba and Nova Scotia, and a living guidance document with FAQs will be developed. Work is expected to begin in May 2023.
* Labels that are considered sensitive will be applied to all datasets in the Inventory; the labels are considered sensitive because they refer to concepts and terms that are evolving over time and that require accurate and culturally appropriate definitions: assessment, disability, ethnicity, race, housing, justice, migration, sex, gender. Troubleshooting support and guidance documents will be created for data centres to annotate data assets accurately.
* The AHD Working Group started a new project to support transparent reporting of algorithms that have been used in multi-jurisdictional studies, but not validated. The project will support the publication of algorithms to measure population health, health service use, and the determinants of health, by providing a template and guidelines for reporting about comparative studies of algorithms in multiple jurisdictions.

### Successes

* The establishment of methods and instruments that permit HDRN Canada to support multiple common data models and therefore the communities of researchers that use them.
* The MIG successfully guided a team of 7 data centre representatives in establishing Information Items related to the common data models CNODES and OMOP. This work was completed ahead of schedule and the methods established appear robust. Further work will complete an assessment of whether data centres have the required coverage of data for the kinds of studies intended to be supported by these models.
* The position of Data and Documentation Coordinator has been filled. This position will support the AHD Working Group. Initial projects for the position include:
* Updating the Data Assets Inventory (DAI) Training Guide (last update was January 2022), and
* Preparing a guidance document to support data centres in the dataset labeling project.

### Challenges

* Previous work on establishing more formal provenance information about data assets listed in the Data Assets Inventory is currently on hold.
* Projects to Advance the Algorithm Inventory are delayed for a variety of reasons, including approval of data sharing agreements in some provinces. It will be several months before projects are completed, publications are finalized, and additions to the Algorithm Inventory are made available to researchers. This lengthy process may impact user perceptions of the Inventory as a resource for state-of-the art information about algorithms to measure population health, health service use, and the determinants of health.
* It was recommended that the AHD Working Group explore methods to connect the Data Assets Inventory and Algorithm Inventory to increase the visibility of the Algorithm Inventory. For example, datasets listed in the Algorithm Inventory could be cross-referenced to the Data Assets Inventory. This project is not likely to begin until summer 2023 because the position of Data and Documentation Coordinator was only recently filled.

### Risks

* None identified at this time

## Goal 3: Ensure Purposeful and Ongoing Public and Community Involvement

### Key developments since last meeting

* Planning for the knowledge sharing event, the *Health Data For All Of Us Forum*, on 25th April 2023, is progressing well. We have a sold-out audience of 60 people registered to join in person and over 300 online.
* The Public Advisory Council (PAC) are meeting in-person the day before the Forum, which will be its second in-person meeting. A number of PAC members have been actively involved in planning the Forum. PAC members are also presenting and leading discussions at the Forum.
* The PAC’s two Interest Groups (on IDEA and Communications, respectively) continue to meet.
  + IDEA group: An infographic on IDEA principles and how they are reflected in PAC operations has been drafted and will be included in the PAC Onboarding Guide. The group is also discussing how the PAC can recruit new members (with a focus on young adult members) applying IDEA principles, and will present their suggestions at the upcoming in-person PAC meeting.
* A manuscript describing the process used to develop the Social Licence for Uses of Health Data report is being drafted for submission to BMJ Open, and includes members of the public, including PAC members, as co-authors.

### Successes

* The abstract on the Social Licence for Uses of Health Data project submitted to the CAHSPR conference, May 2023, was accepted for an oral presentation.
* An additional Research Assistant was appointed to support the work of the PAC and Public Engagement Working Group.
* A review of the Public Engagement work plan demonstrated significant progress by the Public Engagement team, for example: a PAC Onboarding Guide is now complete; Members of the Public Engagement Working Group continue to attend and present at PAC and external meetings/webinars (including the SPOR National Community of Practice); plain language materials have been created on HDRN Canada’s public engagement and key projects (including a glossary of key terms related to public engagement and data-intensive health research as part of the “health data research 101” deliverable”).

### Challenges

* Personnel changes at HDRN Canada member organizations resulted in a loss of two members of the Public Engagement Working Group with knowledge and experience. We are using this as an opportunity to revisit the membership of the Public Engagement Working Group and seek wider representation.
* The resignation of one of the younger members of the PAC highlighted the need to consider how to recruit and especially how to retain younger members. This will be discussed at the April PAC meeting.

### Risks

* The *Health Data For All Of Us* Forum is the first event of its kind planned by the PAC and Public Engagement Working Group. Risks are inherent with any public event, especially one that is hybrid online and in-person, employs simultaneous interpretation, and will have participants with very different levels of knowledge of health data and of data-intensive health research. The planning committee has worked to mitigate the risks of such an event, including identifying a back-up for one presenter who may have to leave at short notice.

## Goal 4: Establish and Strengthen Partnerships and Provide Leadership for Evolving Data Practices

### Key developments since last meeting

* A meeting on March 17 between representatives of HDRN Canada and Immigration, Refugees, Citizenship and Canada (IRCC) enabled sharing information on the provincial data linkage program and policy relevant research priorities. A follow-up meeting on April 12th confirmed our commitment to partner with IRCC with the goals of expanding the HDRN Canada data centres participating in the provincial data linkage program and to developing 1-3 multi-regional projects that build on existing jurisdictional work, respond to IRCC priorities, and showcase the impact of multi-regional research.
* Data centres in Quebec and Saskatchewan expressed interest in joining the existing Canadian Longitudinal Study on Aging (CLSA) partnership. The Saskatchewan data centre will proceed once their third-party data linkage process is finalized and operational, which is expected to occur in early 2024. The Quebec data centre agreed to a meeting with CLSA representatives, currently scheduled for May 3rd.
* A briefing deck reflecting early thinking on new access pathways for health and social system data users and private sector data users was discussed at the In-Person Leads meeting in April 2023.
* A guest speaker presented at a HDRN Discussion series on April 13 at the invitation of the Privacy Team. The presentation by Dr. Teresa Scassa was on Canada's proposed Artificial Intelligence law and a comparison of that law to what is proposed or in place in the EU and the UK.

### Successes

* A new Engagement and Partnership Development Framework was endorsed by the Executive Committee and discussed at the In-Person Leads meeting in April 2023. The Framework is accompanied by a dashboard and tracker which is used as a tool for setting priorities, tracking and reporting progress.
* There was a successful meeting of the SPOR CDP Advisory Committee on February 14th. Subsequently, an agenda plan for the next four meetings was developed in collaboration with Committee members.
* Four data centres have fully executed CLSA data sharing agreements (British Columbia, Manitoba, Nova Scotia and Newfoundland and Labrador), and two have data sharing agreements currently out for signature (New Brunswick and Ontario)
* One AtlanticPath data sharing agreement is complete (New Brunswick), and the other three Atlantic data centres are progressing with their reviews (Nova Scotia, Prince Edward Island, and Newfoundland and Labrador).
* Both AtlanticPATH and CLSA are moving into the data transfer/linkage phase of discussions, and are working to establish a target date for data to be available in data centres for researchers to request.

### Challenges

* The Privacy Team is working on resources related to establishing interpretation of/acceptance of participant consent between centres for data being shared. Work is also being done on navigating the request from some partners to share line-level data back to requestors. This is challenging as some data centres are unable to do this.
* From the MIG’s perspective the existing Glossary resource is an important communication tool. It is, however, prone to changes/additions/currency as work continues elsewhere within HDRN Canada. As a consequence, it has proved difficult to maintain this resource.

### Risks

* None identified at this time

## Goal 5: Strengthen Data Use to Improve Equity, and Support Indigenous-led Data Sovereignty

### Key developments since last meeting

* The Indigenous Data Team (IDT) initiated engagement for a potential First Nations-led research project with several communities in different regions across Canada.
* The IDT is exploring HDRN Canada relationships with several Indigenous organizations that have a mandate to advance Indigenous data initiatives. We are looking to understand if there are areas where HDRN can be responsive and supportive to Indigenous-led data priorities and strategies. In particular, the IDT has had new exploratory discussions with Métis researchers and organizations as we look for ways to support the work.
* The IDT continues to develop an Indigenous-led team and community research capacity, which includes supporting Indigenous researchers and students.
* The IDEA Team has three active sub-groups working on the following tasks:
  + Environmental Scan: a draft report of the environmental scan will be shared with the IDEA Team and with the HDRN Canada Leads ahead of the in-person meeting in April
  + Data Labels and Descriptions: a sub-group was established to review and provide guidance for labels and their descriptions on the Data Asset Inventory. Work was recently restarted with collaboration between the AHD working group and the IDEA sub-group
  + KPIs and Measures – the newest IDEA sub-group will begin meeting in Spring 2023 to identify meaningful ways of measuring and evaluating IDEA, both within the IDEA Team and within HDRN Canada as a network. Outputs may relate to the findings of HDRN Canada’s interim evaluation.
* The IDEA Lead will present at the upcoming in-person Leads Team meeting. The presentation will provide a roadmap of how HDRN Canada can come to an IDEA strategy and include a facilitated discussion around feasibility of time commitments and resources. We will specifically discuss engagement strategies outside of the IDEA Team, education opportunities, and shared commitment and accountability.
* The IDEA Lead and Fellow submitted two abstracts to the American Public Health Association conference to be held in Atlanta this fall.
* 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.

### Successes

* The IDEA definitions and principles document is in its final stages of development with internal and external launches planned in April/May
* The IDEA Team Lead worked with the CIHR Pragmatic Trials Training Program manager to outline key IDEA deliverables within the scope of the grant. The IDEA Lead will be a member of the Advisory Group for the duration of this grant and provide support for the implementation of IDEA throughout.
* The IDEA Fellow and Lead will present at the upcoming CAHSPR conference in Montreal in May 2023.

### Challenges

* The IDT Manager went on leave for one-year beginning March 2023. IDT work will now be shared among other team members.
* The IDT continues to balance competing priorities of Indigenous research education for HDRN Canada internally and building partnerships with Indigenous communities.
* Building Indigenous-led data teams and prioritizing supporting Indigenous-led work also continues to be a challenge.

### Risks

* None identified at this time

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

### Key developments since last meeting

* HDRN Canada’s interim external evaluation was completed by the external contractor and submitted to CIHR along with HDRN Canada’s response to the recommendations in the report. The evaluation results were overwhelmingly positive on work achieved by HDRN Canada to date and suggested areas for improvement or increased focus rather than course corrections for the network. A public-facing overview of the evaluation report and HDRN Canada’s response will be made available in the near future.

### Successes

* HDRN Canada successfully hired two new additions to our communications team, a coordinator and a knowledge translation officer. The team is now working on an overarching communications strategy for the network and is already working to establish new or revamped methods of communications across the network (newsletter, webinars, reporting resources, etc.).
* The MIG continues to work closely with the main working groups of HDRN and, more recently, cross-working groups in which the MIG has provided leadership.

### Challenges and 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

* A meeting with Australia’s Population Health Research Network is scheduled for May 1st to discuss partnership opportunities.
* The HDRN Canada Partnerships Manager was invited to join the Canadian Primary Care Research Network’s Primary Care Information System Committee.
* The Canadian Agency for Drugs and Technologies in Health (CADTH) Memorandum of Understanding has advanced through negotiations and is with CADTH for final review. We completed a brief survey of their data needs to inform planning. Two requests from the Post Market Drug Evaluation Program of CADTH are currently being handled by the Canadian Institute for Health Information (CIHI).
* Representatives of HDRN Canada will participate in a panel session on data access at the upcoming CADTH Symposium on May 17th.

### Successes

* The Institute for Health Services and Policy Research at CIHR agreed to collaborate with HDRN Canada to promote HDRN Canada data access through newsletter, social media, and specific funding opportunities. There are also shared interests in IDEA and improving data literacy that may be pursued in partnership.

### Challenges and Risks

* CADTH’s data needs are time sensitive because they directly inform decision making. As part of the planning work, HDRN Canada will need to consider how it can provide data services that are responsive to the client’s timeframes.