# Scientific Director and CEO's Report

The first section of this report highlights major initiatives and accomplishments since the last Board meeting in March 2021, major new milestones for the coming quarter, and anticipated challenges. Following this overview, the remainder of the document offers additional details on areas of significant investment and / or importance to HDRN Canada's mission.

## HIGHLIGHTS

Key progress since the last board meeting:

- A fellow has been hired to develop and embed Inclusion, Diversity, Equity and Accessibility (IDEA) principles into our practices and to support researchers in investigating these topics.
- An HDRN Canada glossary has been finalized and is available on confluence here.
- A briefing note was prepared on the federal Bill C-11 proposing changes to the Personal Information Protection and Electronic Documents Act.

Major milestones for coming quarter

- HDRN Canada mission and vision development is ongoing with Optimus (the group with which the Board met). This work is targeted for completion in June-July 2021 and will be shared with the Board.
- A draft report on distributed statistical analysis has been prepared that lists methods, their feasibility in a distributed dataset context, and the statistical impact of the different methods. This report will be finalized in the near future and shared with researchers to help guide their project planning.
- A prototype for the Application Tracker is near complete. This is a role-based online tool to track Data Access Support Hub (DASH) project status, enhance coordination, and facilitate more meaningful activity reporting.

Anticipated and ongoing challenges

- The data access requests we are receiving are much more complex than simply processing. For example, many involve questions regarding data pooling, data sharing agreements, and linkage consent. Answering these questions requires substantial work upfront across HDRN Canada groups and teams but will provide learnings that can be applied to future data requests.
- The development of a common DASH service culture, a blend from the individual centres, is ongoing and is part of an evolving journey to bring true "value-add" to researchers.
- Public Advisory Council meetings and most materials are bilingual, but there have been glitches, e.g., simultaneous interpretation not being available in Zoom breakout rooms. The main risk is that some members become less engaged if they don't feel they or the PAC is having an impact.

- The inability to meet in-person has been an impediment to Network development, and perhaps particularly in the development of this group.

## ADDITIONAL INFORMATION ABOUT HDRN CANADA PROGRESS AND CORE WORK

The following provides an update on the HDRN Canada Working Groups and Teams who are continuing to advance our work:

### Data Access Support Hub (DASH) Working Group

Successes

- Nine different projects were supported in determining feasibility and developing cost estimates to meet the March 2021 CIHR grant application deadline. Positive feedback received from requestors, highlighted that this coordination service is "impressive and much needed".
- Since the last CEO Report in March, 14 new requests were supported through the intake process.
- A prototype for an Application Tracker, a role-based tool to track DASH project status, enhance DASH team coordination, and facilitate more meaningful activity reporting. Upcoming activities include: refine tool, develop tool artefacts, create documentation and processes for implementation.

Challenges

- The DASH distributed staff across HDRN Canada partner data centres continue to learn to work together as a cohesive team to deliver value-add coordination service.
- The increasing volume of requests with short turnaround time (for example, for grant applications) requires more efficient and streamlined way of preparing feasibility assessments and cost estimates.
- The complexity of projects received by DASH where researchers are looking for central pooling of data for analysis and effort required to assess alternative options where HDRN Canada processes and policies are not yet established.
- DASH data centres have recently begun an additional series of monthly meetings to discuss process optimization. This is in addition to the regular monthly discussions that cover the range of DASH activities.

Risks

- DASH resource/capacity to support rapidly growing number of requests.
    - Mitigation: close monitoring of staff capacity and continuous improvement effort to streamline processes.
- Requestors do not see value-add for DASH services.
    - Mitigation: proactive management of requestor expectations; develop communication and outreach strategy with HDRN Communications team.

## Algorithms and Harmonized Data Working Group

Successes

- Projects to Advance the Algorithms Inventory
    - Four research teams were selected in 2020 to work in partnership with HDRN Canada to conduct multi-jurisdictional validation studies of select measures of population health and/or health service use from administrative health data. The teams are in the midst of developing statistical analysis plans for these validation studies. The results of the validation studies will be incorporated into the Algorithms Inventory.
    - The scientific protocols developed by the teams were submitted through the DASH intake process for province-specific review, costing, and queries.
    - Scientific and methods liaisons have volunteered from amongst the membership of the Algorithms and Harmonized Data (AHD) Working Group to guide the development of these four validation studies.
    - A Memorandum of Understanding (MOU) between each team and HDRN Canada is under review by the research team members and their universities. When the MOUs has been finalized, they will be signed by the principal investigator of each research team.
    - The research teams are providing important feedback to HDRN Canada about the DASH intake process and are aiding in the development of standardized templates for scientific protocols and statistical analysis plans. These standardized templates will be made available to any research team conducting a multi-jurisdictional study, to streamline the research progress.
- MetaData Specialist
    - HDRN Canada hired a metadata specialist in January 2021 to support the development of metadata for various resources developed by the AHD Working Group and the Modeling and Informatics Working Group. These resources include the Data Assets Inventory, which includes a description of datasets held at data centres across Canada and at Statistics Canada, and COVID-19 datasets. The development of metadata for the Data Assets Inventory will improve the search capabilities of the Inventory.
- Data Assets Inventory
    - Updates to the Data Assets Inventory are now being collected and uploaded to the website. This is a web-based inventory that is used to capture descriptions of datasets held across Canada. Future updates will occur on a quarterly basis.

Challenges and Risks

- We anticipate that the validation studies will begin in summer 2020. However, one project has been significantly delayed because of COVID-19; the clinical data needed to validate chronic pain measures in administrative data will not be collected for several months.

- The MOU is essential to clarify the expectations for each research team and HDRN Canada. The MOU has taken substantial time to finalize because of the number of organizations involved and the need for review at each organization.
- COVID-19 has impacted some sites substantially, in terms of being able to provide timely updates to the Data Assets Inventory.
- Heterogeneity of the contents of the Data Assets Inventory need to be addressed in order to improve the search capabilities for researchers using the Inventory.

**Public Advisory Council and Public Engagement Working Group**

Successes

- The Public Advisory Council (PAC) has recently increased to 13 members from 12, and now fulfills its stated goal of having at least two Indigenous members. Brief biographies of PAC members are on the HDRN website here.
- The PAC meeting on April 15th 2021 PAC focused on:
    - Presentation of a simple table that provides high-level information about the data holdings of HDRN Organizations, followed by discussion to identify language that is unclear or confusing, and discuss possible alternative or additional ways to present information about data holdings.
    - There was also a brief overview of HDRN's nascent work on Inclusion, Diversity, Equity and Accessibility "IDEA@HDRN" which emphasized:
        - Most of HDRN's IDEA work will not be with the PAC as a whole but rather will involve direct, tailored engagement with the subpopulations/ groups that would be affected by or have a special interest in a topic
        - If there is something IDEA-related that a PAC member wants to discuss, they should feel free to raise it during PAC meetings, or privately with the Chair of the PAC or Chair of the Public Engagement Working Group. This would likely result in IDEA-related discussions and activities outside of PAC meetings.
- The Public Engagement Working Group continues to meet monthly. Recent activities include:
    - Supporting the PAC, e.g., preparing agendas, presentation materials, and summary documents.
    - Initiating work on the HDRN Public Engagement Plan, beginning with a voluntary survey of public engagement practices at HDRN Organizations and SPOR entities, so that the HDRN Public Engagement Plan will complement, and not duplicate, existing activities.
    - Work with HDRN Communications to procure illustrator services to develop images of people interacting with technology that can be used in public-facing materials developed by the Public Engagement Working Group and HDRN more broadly.

Challenges and Risks

- Outside of PAC meetings, individual PAC members have been providing advice on documents related to consent for the secondary use of data and participating in the international Plain Language about Data project led by HDRN. Members seem engaged and keen to make a difference.
- The main challenges have been related to difficulties some members have had getting a good handle on what HDRN does and does not do and on the relationship between HDRN and its member organizations.
- Meetings and most materials are bilingual, but there have been glitches, e.g., simultaneous interpretation not being available in Zoom breakout rooms. The main risk is that some members become less engaged if they don't feel they or the PAC is having an impact. The inability to meet in-person has been an impediment.

**Indigenous Data Team**

Successes

- The Indigenous Data Team (IDT) has been working on advancing the four identified priorities: Connection, Communication, Research, and Transformation, both internally and externally to HDRN.
- In each of these priority areas, recent successes have included the IDT Lead connecting with HDRN Canada partners in Alberta, Manitoba, Ontario, Quebec, and New Brunswick to build relationships, better understand the roles of various stakeholders, and to identify Indigenous-related priorities. The IDT Lead has also been connecting to the broader Indigenous community regularly through invitations to presentations, panels, and a podcast. These external connections are contributing to the sharing and expansion of Indigenous data sovereignty and governance knowledge, and helping to build relationships and network with Indigenous Peoples, nations, and organizations, while connecting HDRN to the broader Indigenous community.
- Additionally, the IDT is building on existing connections and relationships with some First Nations' governed organizations in Canada to ensure that the work being conducted through HDRN is done with First Nations priorities in mind. This includes the HDRN IDT meeting with First Nations' run and governed organizations and being accepted to the Canadian Association for Health Services and Policy Research Conference to share and discuss together the relationship between the globally developed CARE Principles and the First Nations' Principles of OCAP®
- Gathered from all of the discussions and connections have been some specific priorities related to Indigenous data, sovereignty, and health. As part of the commitment to research, these priority areas are being explored through available literature, rapid reviews, and research projects that are under development.
- Globally, the FAIR data principles (Findable, Accessible, Interoperable, and Reusable) have been advancing around mainstream data, metadata, and

infrastructure for many years. Models that are important to these areas for Indigenous data are also underway globally. The IDT is connected to these advancements through global relationships with Indigenous nations, people, interest groups, and organizations who are working towards asserting Indigenous data sovereignty and governance. Examples of these connections include active participation with the Global Indigenous Data Alliance (GIDA) and the International Indigenous Data Sovereignty Interest Group within the Research Data Alliance. These relationships are important to the national landscape due to the exceptional work and advancement being accomplished that address Indigenous data priorities, including co-creating and expanding on the CARE Principles for Indigenous Data Governance (Collective Benefit, Authority to Control, Responsibility, and Ethics).

Challenges and Risks

- There is so much work and potential for work to be done as part of the IDT within HDRN Canada. One of the challenges is a lack of capacity. Fortunately, there is a lot of support for the work that the IDT is advancing and processes are being put in place to address this and support will be arriving soon. This added support will have a positive impact on each of the pillars that the IDT is committed to advancing.

**Strategic Partnerships**

Successes

- The first joint meeting with CanPath and CLSA as part of the Canada HDR Alliance took place on April 15th; there will be a joint presentation at the Canadian Association of Health Services and Policy Research (CAHSPR) Conference on May 19th
- Ongoing engagement with IBM to maintain interest and commitment to collaboration.
- Close collaboration with the CIHR Network of Clinical Trial Networks for COVID-19 to support administrative data linkage and development of standardized documentation for clinical trials.

Challenges

- Concerns were raised by partners about opportunities for the network (and specifically DASH) to add more value than the sum of its parts. As a result, a comprehensive plan is being implemented across working groups/teams to improve efficiencies and communications to external research groups. The network is also working together to develop standard operating procedures to support researchers not familiar with meta-analysis.

Risks

- As noted in the Risk Summary Report agenda item, we continue to receive extensive interest from external organizations looking to collaborate (positive risk). HDRN's Relationship Framework outlines how we are prioritizing these requests, and will continue to be closely monitored.

## Privacy Team

Successes

- The Privacy Team has continued to provide general advisory support for HDRN Canada working groups and leads. The Privacy Team has responded to various general inquiries, but more specifically to questions in relation to consent and issues in relation to partnership development.
- A briefing note was prepared on the federal Bill C-11 proposing changes to the Personal Information Protection and Electronic Documents Act.
- We are near completion of the document Guidelines: Informed Consent Wording for Administrative Data Linking. This document has been created with the goal of providing guidance on what to include in consent forms informing participants of data linking to administrative data. The final document will be made available on the DASH website in English and French.
- The first HDRN Canada Data Governance and Operational Survey summary was reviewed, and it was decided that findings would be best presented through infographics. Drafts are currently being reviewed. It was also decided that a second version of the survey, to be undertaken this fiscal year, will focus on the current state of the secure research environments (SREs) of HDRN partner data centres. The intention is to develop or contribute towards an SRE best practice resource.
- Work continues to translate the Cross Border Jurisdictional Data Sharing Doctrinal Analysis into a serviceable resource for education and practical use. A summary table of Canadian jurisdictional legislative authority in relation to administrative data research was distributed this last quarter for review and the second draft is being prepared. A research paper on both the process of developing this resource and its findings is being drafted, as well as efforts to translate findings into practical information tools by way of infographic sheets.

Challenges

- The HDRN Canada Privacy Team, like our privacy colleagues elsewhere, continues to address the challenge of providing interpretation and guidance to researchers seeking access to administrative data in an environment of restrictive legislation and limited political will to address much needed policy change.

## Modeling and Informatics Group

Successes

- HDRN Glossary: a milestone has recently been achieved with the creation of a coherent vocabulary and made available for all HDRN partners through the HDRN confluence website. It answers one of the challenges identified early on: the need to share terms and their meanings.

Challenges and Risks

- External organizations: several external organizations are involved in similar areas of endeavour and there is a need to find complementarity with these external organizations, for example with the Digital Health and Discovery Platform (DHDP), IBM, Health Data Research UK, etc. To this end, members of the Modelling and Informatics Group (MIG) will continue to engage where necessary to ensure we have an adequate understanding of the wider landscape. We will, for example, apply to join relevant committees as part of DHDP, and have suggested that personnel from IBM attend some of our meetings.
- There are no risks identified currently in relation to any of the other work, for example data access and data harmonization.