HDRN Canada

Scientific Director and CEO’s Report

February 21 2023

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**Overview:** The first section of this report highlights major initiatives and accomplishments since the last Board meeting in November 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 1: Highlights

### Key progress since the last board meeting:

* In December, 2022, a Data Access Support Hub (DASH) Webinar was held with the public to provide information on the DASH and services provided in advance of the March 2023 CIHR project grant deadline. There were 116 attendees at the webinar and the recording of the webinar has been posted on [HDRN Canada’s YouTube Channel](https://www.youtube.com/watch?v=tNuDD7hJ7sY) and viewed >100 times, showing there is high interest in the services the DASH provides.
* HDRN Canada was successful in its Canadian Institutes for Health Research (CIHR) grant application to lead a Pragmatic Trials Training Grant. A project manager has now been hired to lead this work. The [CIHR announcement](https://www.canada.ca/en/institutes-health-research/news/2023/01/reinforcing-canadas-clinical-trials-infrastructure-training-and-research.html) about this grant, led by Dr. Amit Garg, and other recently-funded clinical trials grants is now publicly available.
* A number of abstracts were submitted by HDRN Canada’s working groups and teams to the CAHSPR Conference. We hope to have a strong showing at the May, 2023, conference from HDRN Canada.

### Major milestones for coming quarter

* HDRN Canada’s Public Engagement Working Group and Public Advisory Council are planning the first annual Knowledge Summit event. This event is tentatively titled: *Health Data for All of Us: Sharing Ideas and Priorities*. The event is geared towards members of the public and aims to gather input on priorities related to health data.
* HDRN Canada’s annual in-person Leads Team meeting is being planned for April, 2023. This event is an opportunity for the Team to discuss strategy and plan for the coming year.
* A pilot project is underway to assess the feasibility of using Information Items to enable data centres to onboard any common data models and/or create a generalizable process to satisfy the needs of multiple research communities. An interim report on the project will be presented at the in-person HDRN Canada Leads Team meeting in April, 2023.

### Anticipated and ongoing challenges

* Staffing remains a challenge across the network. HDRN Canada is working to fill vacancies as quickly as possible to ensure momentum is not lost.

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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 November 1, 2022 – January 20, 2023: 466 |
| # of visits to the Dataset Inventory website | Total unique visitors from November 1, 2022 – January 20, 2023: 977 |
| # of intake forms received to date and since the last Board meeting  | 94 of intake forms received to date, 2 of which were received since November 1, 2022 |
| # of data access request forms received to date and since the last Board meeting  | 21 data access request forms received to date, 3 of which were received since November 1, 2022 |
| # projects that DASH supported in grant application | 40 of grant supported projects to date, 2 of which were received since November 1, 2022 |
| # of algorithms in inventory  | 185 algorithms listed in the inventory (same as last Board meeting) |
| # of datasets in inventory  | 547 datasets listed in the inventory (decrease of 4 since the 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 | Enhancements to DASH Portal interface and forms (Intake Form, Data Access Request Form) |

# High Level Key Performance Indicators

# 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 DASH online portal (e.g., Intake and Data Access Request forms) to respond to evolving stakeholder needs and streamline the access process for researcher users.
* The DASH Working Group is working closely with the Institut de la Statistique du Québec, a new HDRN Canada member organization, to onboard them to the DASH.
* A user survey has been developed to gather feedback from researchers who have completed a project via the DASH.
* Working with the DASH Working Group, the Modelling and Informatics Group (MIG) is:
* establishing effective methods for generating Information Items from researcher requirements that have been submitted to the DASH as part of the Data Assembly Plan, which is part of the Data Application Request form. Information items are a means of talking about data without reference to their explicit and varied representation in individual databases at each data centre,
* adapting the Data Assembly Plan to incorporate the growing list of Information Items, and
* establishing a pilot project for distributed analysis using synthetic data and SAS (a statistical analysis software) code. Initially, a study submitted to the DASH was to be selected by mutual agreement by the DASH, MIG and the research team, to demonstrate the proposed methods of distributed analysis. This proved challenging and it is now proposed a purely synthetic study be developed and executed.

### Successes

* The DASH continues to support over 20 active projects and has convened over 30 calls with researchers and site representatives to support these projects since November, 2022. A total of 17 active projects have reached the formal data request stage of the access process, and of these, one project is at the agreement stage and eight are at varying data assembly/analysis stages. It is anticipated that five of these projects will be completed by March 31, 2023.
* DASH staff across data centres continue to meet regularly to ensure that projects are progressing well.

### Challenges

* 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 data centres. The DASH is working with data centres to understand 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 (e.g., during the intake call, the project kick-off call, and via ad-hoc emails/calls).

### 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

* Site annotation of data assets for a set of 22 data category labels is complete with the AHD Working Group. The Inclusivity, Diversity, Equity and Accessibility (IDEA) Team is reviewing additional labels for annotation.
* In conjunction with a cross-workgroup team, the MIG is establishing effective methods for generating Information Items from popular common data models (CDMs) such as the Canadian Network for Observational Drug Effect Studies (CNODES) and the Observational Medical Outcomes Partnership (OMOP) models. This will also establish the data assets corresponding to these Information Items and how such data might be extracted. An initial set of three pairs of related tables from CNODES and OMOP have been chosen for this purpose.
* The MIG is monitoring the completion of data category labeling by sites for the 21 agreed labels. Many sites have now done this, but a few remain, and some others will not annotate at this time. These data categories form a classification scheme for the data held in individual data assets by sites.
* One of the developers of the Health Data Research (HDR) UK Phenotype Library gave a presentation to the Algorithms and Harmonized Data (AHD) Working Group members in December, 2022, to explore potential collaborations. The AHD Working Group is investigating the potential to use the Library as a prototype for creating a National Concept Dictionary. The Library was created by a multi-institutional development team; it now contains over 1000 different phenotypes and content (i.e., meta data) from various sources. Key features for application to a Canadian context include:
	+ The Library uses a general data model to accommodate data from a variety of sources to support international research,
	+ The Library provides a secure environment for users from multiple sites/centres, and
	+ An advantage of this data model is the ability to have distinct branding for the data and individual data centres, while maintaining information in a single location.

### Successes

* Regular meetings are being held to discuss how to incorporate CDMs into the data assets that are available at each site. This work is being supported by the Central Team, with input from multiple working groups and data centre representatives. This work involves scoping CDMs to identify uses, barriers, and challenges for different models. The goal of the scoping activities is to identify what needs to be done around implementation of a CDM and project parameters.
* Ten sites now have data assets listed in the Data Assets Inventory (DAI). Half of these sites completed the last quarterly update in December 2022. This update involved using a new online interface developed by HDRN Canada. Previously, sites submitted their update using an Excel spreadsheet. This update significantly changed the information requested from sites. These changes were made after consultation with members of the AHD Working Group, MIG, and DASH Working Group, as well as technical experts from individual data centres. A pilot project to evaluate this online interface was conducted with two sites and their feedback was used to modify and refine the final online interface.
* A [blog post for the Algorithm Inventory](https://blog.hdrn.ca/2022/12/hdrn-canada-seeks-multi-region-studies-for-algorithm-inventory/) calling for researchers to submit their studies was posted in December 2022.
* Almost all of the sites that house COVID-19 datasets have provided updated information about these datasets in the Data Assets Inventory.

### Challenges

* The term of the HDRN Canada metadata specialist has now concluded. There is the potential for a loss of continuity of activities, but this has largely been mitigated by assigning tasks to HDRN Canada Central Team staff and members of the AHD Working Group and MIG.
* The MIG has assisted the AHD Working Group with a review of first efforts at provenance for data assets, which focused initially on which organizational entities provision data to sites, and which entities authorize that provision. Sites have not been clear on the definitions of these entities and have sought further guidance. For now this effort is on hold.

### Risks

* None identified at this time

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

### Key developments since last meeting

* The Public Engagement (PE) Plan, and the PE budget for financial year 2023 – 2024 have been approved by the Public Advisory Council (PAC) and HDRN Canada’s Budget and Resource Allocation Committee. The plan is being translated into French; implementation of the plan has started.
* The PAC Orientation package has been developed, work is now focusing on alignment with HDRN Canada’s Staff onboarding documentation
* The PAC’s two Interest Groups (on IDEA and Communications, respectively) continue to meet.
* The IDEA group’s goal is to provide public perspectives on topics and practices related to IDEA, especially within the Network
* The Communication group’s goal is to provide ideas and suggestions to HDRN Canada about how to better communicate with different audiences/publics
* The date for the first Knowledge Sharing event has been set, April 25th 2023, the day following the April 2023 in-person PAC meeting. A subset of PAC members, PE Working Group members, and others from HDRN Canada are planning the event.

### Successes

* An additional Francophone member (from outside of Quebec) has been recruited to join the PAC.
* An article on PE has been published in the Conversation titled: [*How can health data be used for public benefit? 3 uses that people agree on*](https://theconversation.com/how-can-health-data-be-used-for-public-benefit-3-uses-that-people-agree-on-196847). It describes the work developing the document, Social Licence for Uses Of Health Data: A Report on Public Perspectives.
* An abstract about the same document has been submitted to the CAHSPR conference, May 2023
* An evaluation of the Social Licence for Uses of Health Data project has been completed using an online survey that was sent to members of the public who participated in the project. The results of this evaluation will be included in a second manuscript focused on the process that was used to generate the findings of the report.

### Challenges

* Personnel changes within HDRN Canada partner agencies have caused some loss of Public Engagement knowledge and experience. A review of the terms of reference and purpose of the PE Working Group has been undertaken to ensure that there is clear understanding of the goal of the PE Working Group and that the most appropriate individuals are representing HDRN Canada partner organizations on the group.

### Risks

* The Knowledge Sharing summit is the first event of its kind planned by the PAC and PEWG. 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. A planning committee has been established to work through these topics to ensure a successful event.

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

### Key developments since last meeting

* The MIG is updating the Glossary with improved ontological structure. The Glossary is seen as an important communication tool for the conception of the Canadian Data Platform by participants, both internal and external, to HDRN Canada. Particular versions may be created for specific audiences to aid interpretation as needed.
* Efforts are being planned to build a number of privacy-related resources, including:
* resources for public/patient data privacy awareness. A list of topics will be developed for short presentations (e.g., “Who owns my health data”) that will be recorded and made available on the HDRN Canada YouTube channel,
* a multi-region privacy training package that can be used by all HDRN Canada partners, and
* a data access agreement checklist that outlines data sharing requirements in each jurisdiction.
* The Privacy Team is nearly finished a manuscript on reconsent which looks at their work with Canadian Longitudinal Study on Aging (CLSA) as a case study.
* A new Manager of Partnerships for HDRN Canada was hired and started on December 12, 2022. The Manager is in the process of reviewing and refreshing the partnership framework and priorities for going forward.
* Partnership with Canadian Agency for Drugs and Technologies in Health (CADTH) is progressing well.
	+ A Memorandum of Understanding is in progress and expected to be finalized in the next quarter.
	+ The DASH has received three project requests from the Post-Market Drug Evaluation Program at CADTH for consideration.
	+ A member of HDRN Canada’s Executive will represent HDRN Canada on a joint panel at the upcoming CADTH symposium on May 16-18, 2023.

### Successes

* The Privacy Team is leading projects related to the Alliance, particularly the data sharing agreements with CLSA and Atlantic Path.
* HDRN Canada was a co-author of the recently published report on how to improve the availability of, and timely access to, health system data for drug safety and effectiveness evaluations by the Drug Safety and Effectiveness Data Access Sub-Working Group. CADTH and CIHR were co-chairs of this Sub-Working Group. A link to the Report is [embedded in this document](https://www.cadth.ca/sites/default/files/hta-he/HC0029-data_access_sub_working_group-en.pdf).

### Challenges

* Data sharing agreements with Alliance members (CLSA and CanPath) are taking a long time to execute due to time for legal review by both HDRN Canada member organizations and those of the partners. The CLSA agreements were started in October 2022 are currently with CLSA for review. The CanPath agreements for the Atlantic provinces are still in process.

### 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) has submitted and received approval for two work plans that outline the next steps of the IDT in 2022-2024. Ongoing conversations are being held to develop concrete plans to align HDRN Canada’s approach to Indigenous data sovereignty efforts.
* The IDT Manager was recruited and onboarded to provide the IDT with administrative coordination and project management services.
* Initiated planning for an Indigenous-led research project through HDRN Canada.
* 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 along with identifying key principles for working together. These definitions and principles have now been added to the IDEA Team Terms of Reference and will be presented to all other HDRN Canada working groups and Teams at the end of January, 2023. Opportunities will be provided for all HDRN Canada staff to be involved as we work to gain shared understanding and accountability across the network.
	+ Environmental Scan: a survey has been developed to gauge the current state of IDEA activities across HDRN Canada organizations and SPOR SUPPORT Units. The survey was circulated in Fall 2022 with responses requested by January, 2023. The sub-group will analyze results and present findings back to the IDEA Team and to the larger network by March, 2023.
	+ 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 winter 2023
	+ KPIs and Measures – the newest IDEA sub-group will begin meeting in February 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 Team is preparing a publication, with the goal of submitting to peer reviewed journals by Spring 2023.
* 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 Team Lead was part of the successful CIHR Training grant application and will serve as the equity, diversity and inclusion advisor for this grant and will receive support for implementation ideas from the IDEA Team.
* Two IDEA related abstracts were submitted to the upcoming CAHSPR conference to be held in Montreal in May 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.
* The MIG is working with the IDEA team to ensure compliance of definitional work related to data and Information Items.

### Successes

* Initiated planning of a national, Indigenous-led research project through HDRN. This project has the potential to be a critical opportunity for HDRN Canada to support First Nations data sovereignty efforts in several provinces across Canada.
* Developed and received approval for IDT’s work plans for the next year.

### Challenges

* The IDT Manager will begin 1-year of leave in mid-March. Concrete plans will be in place before March to ensure that the coordination of the IDT and IDT-affiliated projects will keep momentum.
* Bridging conversations between technical and IDEA-related concerns remains challenging. Dedicated time is needed to develop common understands of what is required to make interdisciplinary work effective and successful.
* 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.

### Risks

* None identified at this time

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

### Key developments since last meeting

* A French version of the DASH Webinar that was held in December has been scheduled for February 2, 2023. Additional DASH webinars will be scheduled throughout 2023 to provide information to researchers on the DASH process to aid them in their grant applications.
* The redesign of the HDRN Canada website is underway to improve accessibility and user experience/engagement. The process should be complete by early May, 2023.
* A Communications Officer has been hired and will be starting in February 2023. This role will support the Strategic Communications lead.

### Successes

* The HDRN Canada newsletter has been refreshed and renamed “HDRN Canada Data Points / RRDS Points de données. The newsletter has a new branded look and feel. The latest issue is available [here](https://app.cyberimpact.com/newsletter-view-online?ct=Xa59sw6mpQwoH02rJD7wxF_OoYu7sGNMWF_H1SvawdV0YBjtvmEJRD-VfHh9kc-hpkiXuGuFQyAhqwis4Aka9Q~~).
* An End of Year message was sent out from the Scientific Director and CEO to HDRN Canada’s almost 1,000 subscribers. The messages are available at these links [English version](https://app.cyberimpact.com/newsletter-view-online?ct=iQlrOMsrsm1DNepvFwiDAIZf_pMR96TyYu_yAXR_e9ObzyyOtknQbT2TkJ02ylfp7qwEpVZ3w_AtTtmtDl4ewA~~) | [French version](https://app.cyberimpact.com/newsletter-view-online?ct=yhoHxd6DrVU6s7QJLzqxknzN4J16Nt0GrtNKwY3JTEVn4_JWRCl_wIAtRR3yfM2vSqqeG5U0f2EZB3-_cb-CnQ~~).
* The MIG continues to work closely with the main working groups of HDRN.
* An interim report from HDRN Canada’s external evaluation has been provided to the coordinating team. The final evaluation report is expected in February 2023, and we anticipate will provide valuable information on areas where HDRN Canada can improve and on key accomplishments to date.

### Challenges

* The MIG responds to decisions and outputs coming from all work groups. From a modeling perspective, a coherent, understandable, set of models is essential and necessitates cross-workgroup efforts at resolution of various issues. For example, the IDEA Team introduced additional considerations when communicating to external users, and these are being worked through with the MIG.
* In regard to the above, the HDRN Canada Glossary developed by the MIG needs to be brought up-to-date and made more accessible to encourage its wider use by working groups. Currently, the DASH uses the glossary most.

### 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 Data Platforms and Services Community of Practice (CoP) met on 28th November, discussions focused on the purpose of the CoP, engagement of the public on the CoP, and opportunities for joint work with other SPOR entities
* The SPOR CDP Advisory Committee met on October 26, 2022 and received a presentation on Advancing Approaches to Equity-Related Data: IDEA at HDRN Canada. Next meeting will be held on February 14, 2023 with presentations on the Pragmatic Trials Training Platform and CDM initiatives.

### Challenges and Risks

* None identified at this time