HDRN Canada 

Scientific Director and CEO’s Report

September 13 2023



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

### Key progress since the last board meeting:

* HDRN Canada successfully hosted its first Public Forum, Health Data For All Of Us, on April 25, 2023. Over 40 people attended in-person and ~200 people joined online from across Canada. Feedback from attendees was generally very positive. A number of communications products have been developed, including a detailed summary of the event. A related academic paper detailing HDRN Canada’s work on social license is drafted and will be submitted to BMJ Open in September with 13 public/patient representatives included as authors.
* Phase 1 of the Common Data Model (CDM) Information Items project is completed by four participating sites (BC, AB, MB, ON). We are offering support to other sites that have the time and interest to join this work. Phase 1 was focused on developing methods and instruments to enable data centres to support multiple CDMs and/or create a generalizable process to satisfy the needs of research communities efficiently. All sites are enthusiastic about this work, so the focus for phase 2 will be determining how to implement sustainably with recognition of the variety of the local technology and business practices.

### Major milestones for coming quarter:

* HDRN Canada is re-developing new and refined key performance indicators (KPIs) within each of its Working Groups, Teams, and Council to inform an updated Performance Measurement Framework based on the Strategic Plan 2021-2026. The re-development of KPIs will be finalized in Fall 2023.
* HDRN Canada will be hosting in-person meetings with several Working Groups and Teams on October 4-5. This is a key opportunity for network members to meet in-person, develop strategy, and plan for the coming year within and across different teams.
* The HDRN Canada Pragmatic Trials Training Program is progressing. The call of applications will open in September 2023 with results announced by December 2023 and training starting early 2024.
* HDRN Canada is finalizing a funding agreement with the Canadian Agency for Drugs and Technologies in Health (CADTH) / the Canadian Drug Agency Transition Office (CDATO). This will support the initial scoping of HDRN Canada’s Real World Evidence Service to serve pan-Canadian health sector organizations. The work will start in September and be completed by March 2024. Related to this, several HDRN Canada representatives were invited to join the Data Advisory Group and associated working groups coordinated by CDATO.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.

### Anticipated and ongoing challenges:

* Enhancing the ability of researchers to search the Data Assets Inventory (DAI) has presented challenges such as confusion with similar labels with different meanings and missing content within data assets. To address these challenges, standardized templates for data asset descriptions and a review processes for the labels are being developed to improve the accuracy and functionality of the DAI.