HDRN Canada

Scientific Director and CEO’s Report

May 22, 2024

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# High Level Progress Update

## Key progress since the last Board meeting:

* HDRN Canada successfully hosted its second annual Public Forum, Health Data For All Of Us: Earning Trust through Transparency, on April 23, 2023. Over ~80 people attended in-person and ~200 people joined online from across Canada. Learnings and plans for disseminating themes and audience input are underway.
* Significant progress has been made in implementing the Observational Medical Outcomes Partnership (OMOP) common data model (CDM). An interim report was submitted to the Canadian Drug Agency Transition Office (CDATO), highlighting key achievements, lessons learned, and the next steps.
* The Real World Evidence Service (RWES) initiative delivered the final report and output tables for the two use cases to Canada’s Drug Agency (CDA) and CDATO.
* The DASH organizational review and the draft HDRN Canda IDEA Strategy are complete. Both reports have been circulated throughout the network for feedback.
* We submitted a full draft of a Canada Foundation for Innovation grant (~$14M) for review at UBC. Invitation to move forward will be announced in June. This is a complex, multi-institutional grant that is focused on support for open science with sensitive data, harmonized data and common data models, and infrastructure for federated analysis.

## Major milestones for the coming quarter:

* The OMOP CDM pilot project, including the replication study, is anticipated to conclude by Fall 2024. A formal evaluation will be conducted shortly after.
* Consultations with the DASH Working Group members and Site Leads are underway to develop a work plan to address the recommendations in the DASH review.
* In the coming quarter, the draft IDEA Strategy will be presented to the Exec for approval and Board for endorsement and the action planning and phasing will follow shortly.
* At the annual Leads in-person meeting, we solidified the start-up of a new internal Working Group on Indigenous data. This will be an opportunity to share challenges and successes across the network. We are continuing to develop relationships with Indigenous communities and organizations, and are supporting the development of an Indigenous-led research project.

## Anticipated and ongoing challenge:

* We are entering our last three years of funding from CIHR, and so we anticipate that sustainability will now be a more pointed and ongoing part of our work.
* We are hearing more about challenges to DASH requests, in particular, for the inclusion of smaller provinces. This is an area for focused attention in the coming months.