HDRN Canada

IDEA Team

Terms of Reference

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## Background

With feedback from HDRN Executive and Leads, it was agreed that an Inclusion, Diversity, Equity, and Accessibility (IDEA) Team be established. The Team will be one of many components driving the creation and execution of HDRN’s IDEA strategy.

## Purpose

The purpose of the HDRN’s IDEA Team is to:

1. Learn about and embed IDEA into every working group, team, or operational process central to HDRN;
* In order to achieve this, Team Members will commit to championing IDEA within HDRN working groups/Teams and/or their own organizations. This will look different for each Team Member; for example, assessing new or existing projects to identify areas to advance IDEA; applying IDEA concepts/practices to work throughout the network.
1. Challenge the status quo. Recognizing that we exist within institutions that have not been designed with Inclusion, Diversity, Equity, and Accessibility in mind, work undertaken with the IDEA Team will question the potentially damaging norms of our working/research environments. In so doing we will
2. Support the identification, development and implementation of IDEA strategies with consideration of the diverse needs for IDEA informed data research in Canada

The IDEA Team will be a space of learning and exchange, recognizing that each member will bring a specific set of knowledge, perspective, experience, or social position that will contribute to IDEA informed systemic change. Members can expect to both learn about IDEA (practices, policies, dissemination) and inform/identify areas for action. Based on interest and availability, members will also have the opportunity to work on identified projects.

## Scope and Objectives

The HDRN IDEA Team will develop a network of Team Members who are actively committed to IDEA informed change and provide guidance and advice for identifying, developing, and implementing inclusion, diversity, equity, and accessibility strategies at HDRN. Areas of concern range from issues relating to the collection, access, use, and dissemination of administrative Personal Information and Personal Health information in research and across the data lifespan to issues pertinent to the operation and co-creation of a distributed network.( HDRN is a distributed network in operational terms. It is a collective of interconnected but independent member organizations.) Ultimately, the work of this group should be beneficial to people who have been and continue to be systemically excluded from data research and further marginalized by the findings of data outputs.

Sub-groups may be formed to work on specific deliverables – including, but not limited to issues of data governance, partnerships, public engagement, and/or analysis relating to the use of data that identifies race and ethnicity, sex and gender, and/or disability. Where appropriate expertise does not exist on the Team, the Chair will work with Team Members and Leads to identify temporary Team members internal or external to HDRN member organizations with relevant skills to join the sub-group. Employees from HDRN member organizations will be welcome/encouraged to be involved in sub-groups, especially given time constraints of core Team members and/or expertise required to complete a deliverable.

Specific objectives and/or responsibilities:

* Share expertise and knowledge
* Develop knowledge and learn about IDEA concepts and strategies
* Adopt and leverage existing IDEA related resources, tools, and strategies in use at HDRN member organizations and beyond
* Compile/share information on various academic, legal, or policy frameworks around IDEA informed data collection, access, analysis, and dissemination.
* Inform priorities for education, training, data usage, and tool development at HDRN (these are identified in the HDRN plan, see Fig 1)

Team Members will be welcome to join sub-groups on issues not limited to the following:

* Develop common/standard HDRN IDEA principles and policies
* Develop or adapt tools and checklists that benefit from standardization or coordination to support HDRN member organizations as necessary in navigating IDEA informed data access, data usage, and research; these components will be made available to HDRN member organizations and to data researchers, widely defined.
* Review and/or provide relevant IDEA content for the HDRN website (i.e.: website IDEA statement, blog content, etc.)

Note; Given the cross-cutting nature of IDEA work, some projects or deliverables will be taken up by other HDRN working groups or piloted by HDRN member organizations. In these cases, we will aim to have an appropriate number of Team members contribute to the planning and execution of the deliverables

## Principles for Working Together

To be defined as a Team (sub-group formed May 2022 – work to be completed by Aug 2022)

## Membership

### Composition

Membership is open to representation from all HDRN Canada organizations. The HDRN IDEA Team will include those formally (i.e.: in EDI or IDEA specific roles) and informally (i.e.: in roles related to data governance, privacy, public engagement, analysis, research) invested in IDEA.

### Core Members

* All HDRN member organizations may have representation in the Team
* One member of each HDRN Working Group may be included in the Team
* One member from each SPOR SUPPORT Unit may be included in the Team

There is no cap on membership from one organization and no cap on membership as a whole.

An assessment of the composition of the HDRN IDEA Team will be conducted on an ad-hoc basis to determine if all necessary perspectives are adequately represented. Other members may be invited from time to time to present different perspectives.

As the Team is new to HDRN, ongoing conversations about the number of members and composition will be determined in consultation with the Team and with HDRN leadership. Navigating the line between being inclusive and having a Team be too big/unwieldly will be a distinct challenge to the Team.

### Affiliated Members

Affiliated Membership may be extended to IDEA professionals representing organizations or public bodies whose goals and objectives align with those of HDRN in relation to health equity, data access and use, and reporting. HDRN will not provide funding to Affiliated Members of the HDRN IDEA Team.

### Chair/Lead

Amy Freier, HDRN IDEA Lead/Manitoba Centre for Health Policy

### Exec Lead

Alan Katz, Manitoba Centre for Health Policy

### Coordinator/Administrative Support

TBD

## Dependencies

* Amy Freier and/or Alan Katz will report on the activities of the IDEA Team to the HDRN leadership – identified priorities and projects will be approved through the same channel
* As per the min specs requirements, funding is available for this work and can be requested by the site leads in the annual work plan to be approved by the Budget & Resource Committee.
* Any listed external members would not receive funding through HDRN Canada for this work
* Goals and deliverables for the HDRN IDEA Team will be responsive to the needs of the HDRN leadership and other working groups
* All developed forms, frameworks, policies, or processes are considered “live documents” in that they are subject to monitoring and changes as recommended either by the HDRN leadership, the HDRN IDEA Team, or through legislative or other changes

## Quorum/Decision Making

Quorum is required for decision-making. A quorum is the majority of the total current membership plus one (1). In the absence of quorum, it is at the Chair’s discretion if the meeting should continue, with items for discussion and review circulated to members who were unable to attend.

## Commitment

* The HDRN IDEA Team will meet monthly for a one-hour meeting. Meeting regularity and duration may occasionally change based on priorities and availability.
* It is recommended that members join for, at minimum, one year
* Members will participate in IDEA Team meetings and activities to advance the IDEA Team annual work plan.
* Be responsive to emails/requests where active participation outside of regularly scheduled meeting times is required.
* Adhere to the guiding principles for communication in all interactions with stakeholders and activities/deliverables on behalf of HDRN Canada.
* Inform IDEA Team of local activities that may impact the work/HDRN Canada network.
* Liaise with other related organizations in the region as required.
* Share regional knowledge and best practices with IDEA Team members to improve collective knowledge and build capacity.
* Connect with HDRN Canada Site Lead for regular updates on HDRN Canada activities and developments.
* If a member cannot attend a given meeting, a designate may be sent who is familiar with the aims of the Team and committed to cultivating an inclusive environment. Please notify the Team Lead or Coordinator
* Withdrawal from the group is sent in writing to the Chair, along with the name of a replacement member