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Understanding Inclusion, Diversity, Equity, and Accessibility in a Distributed Data Network: Environmental Scan Within Health Data Research Network Canada

Amy Freier^{1,2,*}, Laura Bowler^{1,2}, Hannah Owczar¹, Amédé Gogovor^{3,4}, Mamata Pandey⁵, John Riley⁶, Morgan Stirling^{1,2}, Jessica Duris⁷, Kimberlyn McGrail^{2,8}, and Nathan C. Nickel^{1,2}

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¹ Manitoba Centre for Health Policy, College of Community and Global Health, Rady Faculty of Health Sciences, University of Manitoba

² Health Data Research Network Canada

³ Department of Family Medicine and Emergency Medicine, Université Laval, Quebec, G1V 0A6, Canada

⁴ VITAM – Research Centre on Sustainable Health, Quebec, G1G 2G1

⁵ Saskatchewan Health Authority, Research, Room 414, St Andrews College, 1121 College Drive, Saskatoon, S7N 0W3

⁶ Ontario SPOR SUPPORT Unit (OSSU): Toronto, Ontario, CA

⁷ Department of Psychology, University of Manitoba, Manitoba, R3T 2N2, Canada

⁸ School of Medicine, Simon Fraser University, Surrey, BC, Canada

Abstract

Inclusion, Diversity, Equity, and Accessibility (IDEA) are critical in addressing systemic bias and advancing equitable data practices. Health Data Research Network Canada (HDRN Canada) initiated an environmental scan to understand IDEA activities within its member organisations and identify opportunities to embed IDEA principles into its operations and data research approaches. The scan aimed to understand: 1) how IDEA activities are organised and sustained across the network; 2) the availability of resources and policies to support IDEA initiatives; and 3) gaps and opportunities for HDRN Canada to standardise and enhance IDEA efforts. A survey was distributed to 19 member organisations between December 2022 and February 2023, covering six domains of inquiry. Data were analysed using descriptive statistics and narrative synthesis, with insights from HDRN Canada's IDEA Team ensuring validity. Eighteen organisations participated, revealing significant variability in IDEA implementation. The findings highlight systemic gaps, including fragmented policies, insufficient training, a reliance on volunteer efforts, and informal mechanisms to ensure equitable use of disaggregated data.

Keywords

IDEA; inclusion; equity; diversity; accessibility; environmental scan; administrative data; Health Data Research Network

*Corresponding Author:

Email Address: amy.freier@umanitoba.ca (Amy Freier)



Introduction

Critical conversations about Inclusion, Diversity, Equity, and Accessibility (IDEA) are occurring amongst population data scientists and data research centres, including in Canada [1–3]. Applied in the data research environment, concepts of IDEA align with organisational equity domains (hiring practices, policies, work culture, etc.) and with data equity domains (research practices such as data collection, data curation and cleaning, interpretation, and communication). Together, these domains encompass the environment that data research takes place in, the people who undertake data research, and the steps in the data research life cycle that all contribute to more robust, relevant, and equitable research outcomes.

Within Canada, both organisational and data equity domains of IDEA are being explored within Health Data Research Network Canada (HDRN Canada). HDRN Canada is a network of over 20 member organisations brought together to develop services and infrastructure aimed at increasing multi-regional data use; share knowledge; identify opportunities for collaboration; build advanced analytics; expand types and sources of data linkage; and establish partnerships with communities and stakeholders [4]. HDRN Canada member organisations provide access to various data including registries, surveys, and administrative data to conduct research on health and well-being, health care, health services use, and social policy within Canadian jurisdictions. HDRN Canada uses funding to hire staff who are embedded in member organisations, with the result that HDRN Canada has its own function and mission that is pursued collaboratively.

The governance structure that emerges within a network must operate in tandem, and often in tension, with established hierarchies and norms, supporting *unity* of purpose alongside *diversity* of member organisations' missions and priorities [5]. All member organisations are represented on the HDRN Canada Leads Team, which provides direction and advice on network activities. The Leads Team negotiates these tensions to prioritise high-impact projects.

Within HDRN Canada, an IDEA Team was established that comprised individuals from member organisations. This team leads and coordinates IDEA across the network's operational and data research initiatives. As founding members of the IDEA Team, the authors of this paper are united by experiences of systemic marginalisation (racial and ethnic marginalisation, gender discrimination, ableism, and ageism). Our expertise covers several academic domains, including population data science, disaggregated data practices, data equity, implementation science, and human rights; further, we have worked in various academic capacities, including research, human resources, and programme management. Combined, these factors related to lived experience, academic experience, and work experience contributed to our shared purpose of understanding and driving IDEA activities across the network.

Prior to developing an HDRN Canada IDEA Strategy and Action Plan, it was imperative to undertake an IDEA scan across the member organisations to identify strengths and opportunities for working together [6]. We wanted to know what work was already underway, what could be leveraged at a national level, and where significant gaps were in operations

and research capacities. Similar environmental scans have been published capturing the state of IDEA in academic organisational practices, but there were no similar findings that merged the domains of organisational practices and data equity, and even less guidance within distributed research networks.

The purpose of this paper is to share the process used to develop an environmental scan, thematic findings, and highlight recommendations as HDRN Canada promotes and establishes IDEA. Our work focused on both operational and data research practices, understanding that the environment in which data research takes place (including budgets, training, policies, etc.) is deeply connected to specific research practices that promote data equity. This report is meant to be informative for networks broadly, and other administrative data networks and data centres specifically.

Context

Both organisational domains of IDEA and data equity are themselves rich areas of inquiry.

There is a long history that accompanies IDEA in organisational practice [7–10]. IDEA in organisational practice can range from efforts to update an organisation's vision, mission, and strategy [11]; policies and institutional practices [12]; hiring targets and diversity measures [13–15]; along with learning and competencies [16–18]. Given the intricacies of HDRN Canada as a distributed network, where hiring is done indirectly by member organisations and staff are governed by local policies of member organisations, we limited ourselves to trying to understand practices of local IDEA Teams, employment and organisational policies (not including diversity metrics of staff in each member organisation), and educational activities.

Data equity encompasses many cognate and complimentary terms, including the quantitative critical race theory (QuantCrit) [19, 20], the racialisation of data [21–25], data justice [26–28], and algorithmic justice [29–32]. Data equity recognises that data are not neutral, and that personal and institutional biases, in addition to socio and political histories, may be present when analysing, interpreting, contextualising, and disseminating results [32–36]. Within the administrative data space, data equity acknowledges that historically marginalised communities are often over-represented in data sets yet have unequal and limited access to data, and that data misuse has the potential to further harm these communities [20, 32, 37] by reinforcing negative stereotypes, exacerbating issues like racial bias, or otherwise impeding social justice [38–40]. Moreover, a QuantCrit lens challenges the “unnaturalness” of categorising and grouping in data, which requires meaningful attention [41]. To mitigate the risks of bias and systemic racism in research, data centres must consider adopting strategies that adequately respond, embedding equity in processes within their control and moving towards data justice [28]. Data justice goes one step further than data equity, ensuring fairness in how people are made visible and represented because of their production of data and using the data to address systemic barriers.

Related, but separate from data equity, is Indigenous Data Sovereignty (IDSov) [42, 43]. IDSov is articulated by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) and reflected in Canadian laws [44]. Within Canada, the Ownership, Control, Access, and Possession (OCAP) are principles established over the last 30 years by the First Nations Information Governance Centre [45]. Other Indigenous Nations use distinct frameworks, such as OCAS among Métis Nations and IQ principles from Inuit people [46]. Within HDRN Canada, work towards asserting Indigenous data sovereignty is led by Indigenous researchers and communities. HDRN Canada is committed to respecting all principles of data sovereignty, taking direction from Indigenous communities and colleagues.

While evolving IDSov principles and frameworks provide a strong foundation for handling and using Indigenous data, they cannot be applied wholesale to other populations in Canada. Other systemically marginalised populations do not have the sovereign rights of Indigenous Nations and Peoples. Given this, we have kept our work on IDEA separate from work supporting Indigenous data sovereignty, while acknowledging that there is some overlap in the principles and practices related to both, and are learning from this continually evolving work as we further develop tools and processes to protect systemically marginalised populations within data access and use.

Together, our knowledge and engagement with IDEA across organisational and data equity domains provided a foundation and informed which questions could be and needed to be answered related to IDEA activities across the network.

Methods

The IDEA Team conducted a collaborative environmental scan in 2022/2023 to collect information and identify research and operational activities related to IDEA among member organisations. The objectives of the scan was to understand: 1) How activity promoting and embedding IDEA is organised and supported across the network; 2) What resources currently exist that can be leveraged, adopted, and adapted by other organisations; and 3) Where the IDEA Team should focus its attention and prioritise resources.

Environmental scan design

An environmental scan was used for gathering information on different areas of IDEA implementation across HDRN Canada. A survey format was chosen for collecting this information, recognising that the answers to the questions asked about broad organisational and data research topics might be held within multiple staff members' responsibilities. To allow coordination and connection of diverse experts within an organisation, a survey was developed by a subgroup of the IDEA Team (Amy Freier, Amédé Gogovor, Jessica Duris, John Riley, Mamata Pandey). Questions were developed given our collective scope of academic knowledge about organisational IDEA and data equity and institutional knowledge about the broad activities of member organisations. Question validation was done insofar as the questions were deemed to help us achieve our objectives and were appropriate to the varied states of IDEA across organisations.

Frameworks that guided survey development

Environmental scans conducted in academic contexts aligned closely with IDEA in organisational practices sources and helped to inform questions in sections 2, 3, 5, and 6 of the scan [3, 47]. These applied examples helped to refine focus on operational concerns, specifically relating to budgets, policies, and the collection of personal information to measure the diversity of staff and researchers. Resources specific to IDEA in organisations outside of academia were also formative [48]. In particular, the Global Diversity and Inclusion Benchmarks [49] is an internationally recognised tool and their companion document, Diversity, Equity & Inclusion Approaches Insight and Impact Worksheet (DEI Approaches Framework) [50] helped to guide our focus on education, policies, and reflection of IDEA within organisational strategies.

Several data equity frameworks further informed questions in section 4 and 6 of the scan and were complimentary to the academic sources on QuantCrit and data justice. The "Data Equity Framework" developed by We All Count [51], informed our thinking across the data research cycle, including funding, analysis, interpretation, and data sourcing. The BC Office of the Human Rights Commissioner's report on disaggregated data shaped our questions related to the collection and use of disaggregated data, specifically towards purpose, process, and tools [34]. Finally, we were inspired by the "Toolkit for Centering Racial Equity Throughout Data Integration," which at the time had been recently developed by the Actionable Institute for Social Policy [52].

While these frameworks informed the focus areas of our scan, we had to adapt them to the context of a distributed data research network in Canada. Questions were highly tailored to understand the local contexts of the data centres; for example, the relative lack of disaggregated data that was routinely collected across provinces and territories informed the depth of questions that could be asked about demographic data collection and use. Additionally, the relative placement of many data centres, which are nested within larger organisational governance systems, and jurisdictional practices informed questions about budgets, policy autonomy, and resources that could be shared across the network.

Survey Content and Administration

The survey was comprised of six sections, including: organisational profile, IDEA Team, employment and organisational policies, data processes, education, and priorities (Table 1). The environmental scan focused on organisational aspects of member organisations rather than the organisational aspects of the network operations.

Data analysis

First, we summarised the data using descriptive statistics and narrative synthesis. Second, we sought feedback from members of the IDEA Team and broader HDRN Canada IDEA Community of Practice which includes at least one representative from all HDRN Canada working groups and teams as well as one representative from each member organisation through two review sessions. Finally, we

Table 1: Sections and brief descriptions of the environmental scan survey

Survey section	Description
Organisational Profile IDEA Team	Organisation name, contact information, and affiliation Description of (if applicable) local IDEA Team including information on members, key roles, and budgets.
Employment and Organisational Policies Data Processes	Presence and nature of IDEA-related policies and strategies, including internal collection and use of identity data for employees and vendors. IDEA-informed process for collecting administering data, access, and use. Data use questions pertained to whether researchers were required to incorporate concepts of IDEA into data analysis and overall research process.
Education Priorities	Administration of IDEA-related learning. Organisation's prioritisation of IDEA-informed actions. The curated list of priorities covering organisation and data research activities was initially established by the IDEA Team members (Amédé Gogovor, Amy Freier, John Riley, Mamata Pandey) and refined by HDRN Canada members from across all Working Groups, Teams, and member organisations with an interest in furthering IDEA. Each priority was identified and scored as: Level 1(3 points) – an action that was in progress or planned for the next six months; Level 2 (2 points) – activities planned for the next year; Level 3 (1 point) – activities as part of a long-term plan; Not applicable (0 points); or Complete (4 points). The score for each item was obtained by summing the values. Items with a larger value were determined to be a higher priority.

HDRN Canada had 19 member organisations at the time of the environmental scan. The survey was sent to a designated staff member at each member organisation, who would then seek out answers if it went beyond the scope of their role. For this same reason a follow-up interview was not scheduled since the breadth of questions went far beyond the scope of an individual role.

incorporated their insights to refine our analysis and ensure the findings were valid and actionable.

Results

Survey responses were collected from 18 units between December 1, 2022, and February 28, 2023, with one member organisation unable to respond.

Organisational profiles

Among the survey respondents there was one independent organisation, two national organisations, four organisations affiliated with a health authority or hospital, and eleven organisations affiliated with a university.

IDEA teams

Eleven of the 18 responding organisations had a formal group or team to help organise and support local IDEA initiatives. While there were an estimated 100 distinct individuals involved with local IDEA teams across the network, the vast majority were people volunteering their time with their work on IDEA teams. IDEA implementation was not formally recognised in these individuals' job descriptions, duties, or performance reviews. Across the network, only 5.25 full-time equivalents (FTEs) were dedicated to carrying out work to further IDEA initiatives.

Despite the voluntary nature of most local IDEA committees, they are often tasked with substantial and substantive work. Most commonly, local IDEA teams were

largely involved with "Providing advice and input into organisational strategy" and "Coordinating education and training." Less commonly, local IDEA teams were tasked with conducting inclusion surveys, conducting outreach, and performing research.

Employment and organisational policies

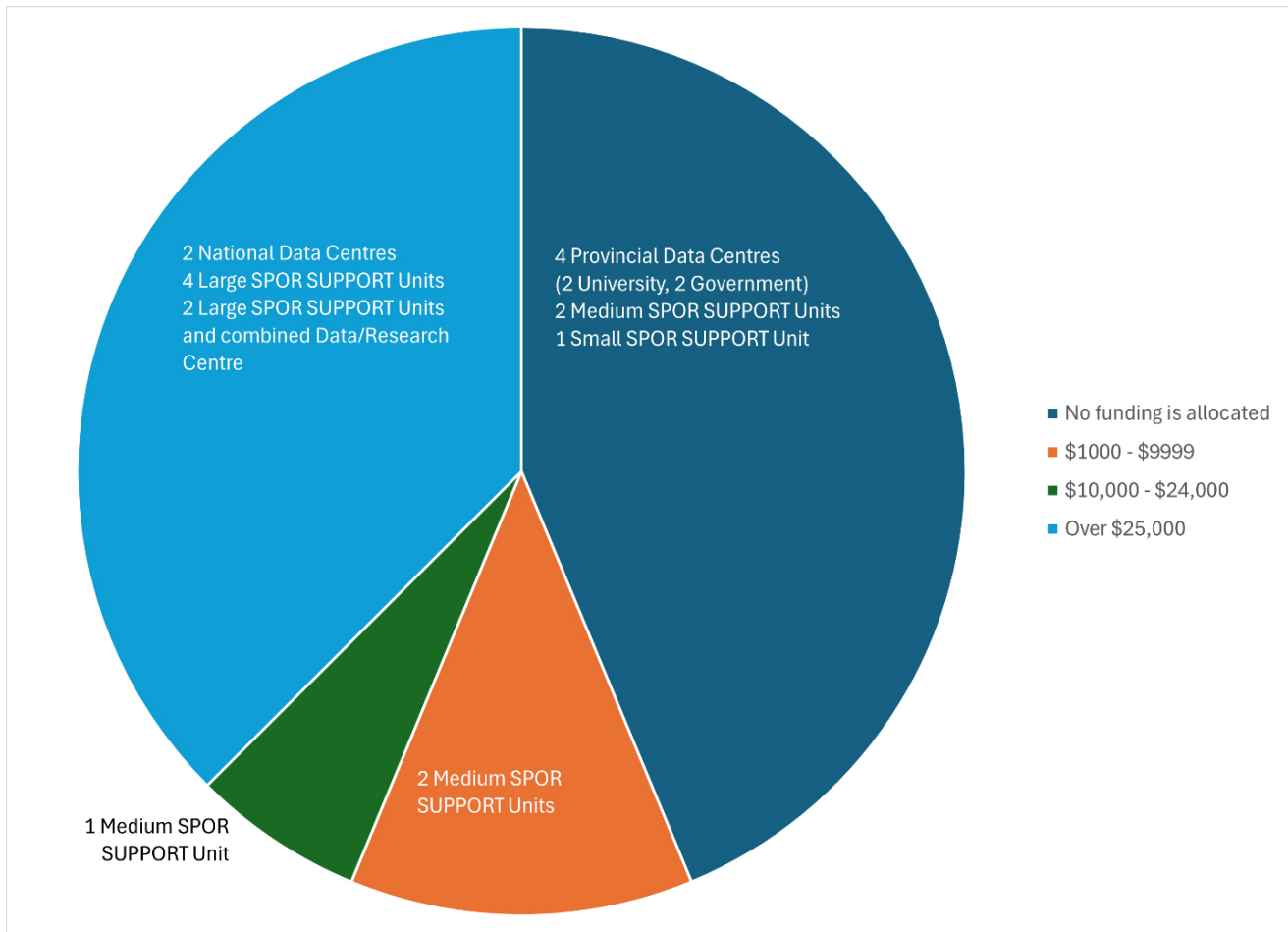
Ten organisations had policies directly relating to diversity and equity, and nine had blanket policies directly related to inclusion and accessibility. Adjacent to Inclusion, Diversity, Equity, and Accessibility, 10 of the 18 member organisations had policies relating to non-discrimination, 9 on sexism, and 8 had policies on anti-racism. Five of the 18 organisations had specific policies related to anti-oppression, transphobia, homophobia, and religious biases. Four of the 18 organisations had no policies relating to any of these topics.

Across member organisations there were large gaps when it came to financial resources (beyond FTEs) dedicated to furthering IDEA, with over a third having no dedicated budget, and a third having more than \$25,000 dedicated to IDEA work (Figure 1).

Fourteen organisations collected self-identified demographic data from employees; of those, 10 indicated this occurred during onboarding of new employees or the start of new contracts. Within sites collecting this data, 11 collected data on sex; 10 collected data on age, disability, and Indigenous identity; nine on gender identity or expression; eight on race; seven on immigration status; six on language; and five on sexual orientation.

Notably, eight member organisations collected self-identified data on service users, students, or researchers.

Figure 1: Breakdown of IDEA budget allocation across the 18 member organisations



Of those sites, seven collected data on gender identity or expression and Indigenous identity; six collected data on race and disability; five collected data on age, sex, sexual orientation, and immigration status; and one collected data on language.

Data processes

Member organisations were asked to identify any tools or guidance their organisation provides for researchers working in the administrative data environment. A number of examples were provided covering key tasks of data centres, including appropriate use of disaggregated data, health equity and social determinants of health, IDEA in study team composition, research question development, variable identification, community or public engagement, and knowledge translation.

As HDRN Canada member organisations largely provide services related to the use of already collected data, questions about data collection were omitted.

The scan demonstrated most traction within the realm of disaggregated data. The term “disaggregated data” represents the concept of collecting sociodemographic equity data to facilitate the disaggregation of results from whole populations to systemically marginalised populations. Across respondents, five organisations indicated that they had formal mechanisms to ensure disaggregated data are considered within data

research project design and interpretation (for both internal and external researchers). A further four had informal processes that were recommended but not required.

No organisations reported having any tools/methods to adequately track whether data about systemically marginalised populations were being used to inform health or health systems in their respective provinces.

Education

Respondents identified education as a priority to further awareness of concepts of IDEA. Most commonly, 11 respondents used webinars to provide education; eight respondents indicated that guest speakers, conferences, and E-learning modules were used to provide education; six sites relied on workshops and orientation training; four used toolkits, and mentorship; and six organisations employed some other mechanism to increase learning and awareness of IDEA.

Priorities

Member organisations were asked to indicate what priorities existed in their organisation related to IDEA from a curated list covering organisation and data research activities. Results indicated that cultivating support from management or advisory boards, dedicating time for staff to learn

about concepts of IDEA, and incorporating IDEA into the organisation's mission, vision, or strategic plan were their top three priorities (Table 2).

Discussion

Data from the environmental scan falls into three overarching themes: building competency, being in compliance, and building the organisation [50]. Notably, the majority of responding units are affiliated with a government department or university, thus limiting their independence in setting policies, priorities, and collecting certain information from staff. In most cases, IDEA activities are driven by the host institutions and may be constrained by jurisdictional data governance policies and practices.

Building competence – education

Building competence focuses on improving the effectiveness of interactions among individuals [50]. Across North America, organisations are heavily investing limited IDEA resources into training and education. Similarly, in HDRN Canada organisations, webinars, guest speakers, and workshops were popular mechanisms to learn about embedding IDEA in operational and data research practices. Research shows the most impactful IDEA training derives from multi-session programmes that build upon knowledge, skills, and organisational capacity [53]. However, many organisations still rely on one-off unconscious bias training sessions, which are shown to be unhelpful and often harmful [53].

At HDRN Canada, staff often access IDEA-related education through their host institutions, where content remains conceptual rather than applied to data research. This scan did not ask whether the training provided was mandatory for staff and leadership. As a distributed network, HDRN Canada could strengthen organisation-level priorities by providing coordinated, cumulative, and skills-based training to all its members and member organisations.

While building knowledge and capacity in IDEA is essential for change, training rarely results in measurable behavioural changes [54]. Future education initiatives should be tied explicitly to learning outcomes, and subsequent environmental scans should examine changes in behaviour, operations, and attitudes as a result of training.

Being in compliance – policies

Being in compliance refers to rules, legislation and any other regulatory requirements [50]. Organisations are obligated to enact policies that reduce discrimination and harassment [55]. Implementing IDEA-focused policies is foundational to advancing positive change and needs to be supported by training to promote awareness and accountability in the workplace [56]. A scan of Canadian universities found significant variation in IDEA-related policies [2], which is mirrored across HDRN Canada member organisations. These differences reflect how institutions understood, internalised, and operationalised concepts, with diversity and equity as the most digested and actioned concepts in organisational policies.

Survey respondents indicated that IDEA concepts are often embedded within broad anti-discrimination/harassment policies. While broad policies encompass all forms of discrimination targeted policies are also necessary to enact specific and timely responses [57]. Equity impact assessments, aimed at uncovering structural biases and gaps within policies, have become popular tools to address these limitations [58].

A significant yet unintended finding of the environmental scan revealed a lack of awareness regarding where policies were located within the host organisations. Many member organisations indicated that no individuals were assigned to track updates to institutional policies or roll out new policies, particularly prevalent in data centres affiliated with governments or universities. Discussion showed that gaps in knowledge were leading to gaps in application and timely access to resolution or justice.

Overall, the wide variation in policies reflected a lack of established mechanisms to deal with equity issues. Within a distributed network, this finding has implications for how IDEA issues are addressed (e.g., when staff are hosted at two separate institutions and thus governed by different policies). At the time of the environmental scan, HDRN Canada did not have guidance on how to navigate such policy issues.

Being in compliance – employee diversity

While there are few agreed upon standards related to the demographic diversity of staff members, demographic data is often seen as one of the most tangible measures of IDEA within a workforce and is reflected within Canada's Employment Equity Act [59]. The Government of Canada has created the 50-30 challenge to achieve gender parity and increase representation of systemically marginalised groups on boards and senior management [60], or research appointments, for example Canada Research Chairs [61]. However, these programmes have limitations. Pursuing 50-50 gender parity while recognising gender is not a binary is potentially harmful. Further, measuring diversity through a thirty percent indicator may flatten many other aspects of diversity and intersectionality (religion, language, worldview, SES, disability).

Within academic or government institutions, data centres or departments often lack direct control over which demographic data is collected from employees during onboarding or at different times throughout employment. Even in cases where demographic data were collected from employees, most organisations did not have access to this data to analyse the diversity of data centre staff as stipulated within the Employment Equity Act [59]. Anonymous staff, vendor, and product-user surveys and scans were also rarely resourced or prioritised.

HDRN Canada's distributed structure adds complexity. Staff are typically hired by local institutions bound to prescribed hiring procedures, making additional diversity requirements not feasible at this time. Moreover, assignments to HDRN Canada work are dependent on local skills and capacity. Nonetheless, understanding staff diversity is important to obtain a baseline measure and to identify specific gaps in experiences and perspectives.

Table 2: Top 5 ranked IDEA-related Activities/Areas (n = 18)

Rank	Activity/Area	Complete	L1	L2	L3	N/A
1	Cultivating support from management or board	6	5	6	1	0
2	Dedicating time for staff to learn about IDEA	1	8	7	1	1
3	Incorporating IDEA into your organisation's mission, vision, or strategic plan	5	3	4	4	2
4	Developing an IDEA Team, Employee Resource Group, etc.	4	4	3	5	2
5	Creating an IDEA Strategy, framework, policy, etc.	3	5	4	4	2

Developing organisations – local IDEA teams

Developing the organisation includes systemically improving performance [50]. Most organisations had a team to help support local IDEA initiatives, often relying on employee volunteers and individual dedication. As in line with other organisations, this work was typically done outside of job descriptions, was unevaluated, and added to regular job requirements [62].

Volunteerism has both positive and negative aspects. Volunteering demonstrates genuine buy-in and dedication from staff. However, reliance on volunteers can be tenuous, especially when formal duties recognised in job descriptions take precedence, when employees leave the organisation, or when burnout happens amongst volunteers [63]. As IDEA becomes central within organisational strategies, increasingly more critical planning and decision-making is placed on employees who may not be appropriately compensated, are pressured to undertake this emotionally-taxing work alongside their regular responsibilities and are often members of systemically marginalised groups advocating for their own rights [63–66].

Developing the organisation – budget

Advancing of IDEA requires a dedicated budget [67], yet these budgets are often the first cut during financial adversity [68, 69]. This runs counter to the fact that recessions impact systemically marginalised groups the earliest and the hardest [70–72]. As a distributed network of federal, provincial, and academic units, understanding the current financial resources dedicated to IDEA within each of the member organisations was important for HDRN Canada as a first step to coordinating and sharing resources across the network.

Significant funding gaps exist across member organisations. Some academic respondents' institutions reported zero IDEA budget since IDEA budgets sit with central administration or faculty rather than local units. The lack of agency within academic units speaks to the fact that in most cases IDEA initiatives are top-down and are disconnected from members' specific needs.

Since inclusion represents how people feel, the perception of no dedicated resources may signal whether IDEA is valued [73]. However, the IDEA Team hesitated to set a minimum standard for IDEA budgets, understanding that funding decisions outside of a data centre's control could become exclusionary. These disparities demonstrate an equity issue. Notably, the organisations with the highest budgets were often SPOR Support for People and Patient-Oriented Research and Trials (SUPPORT) Units funded by Canada's health

funding agency, CIHR, and local partners, whose mandates identify equity, diversity and inclusion (EDI). Their examples show how IDEA can be embedded in operations, something newer for data centres, yet crucial to sustainability of IDEA.

Developing the organisation – data processes

Data centres within HDRN Canada are stewards of administrative data, registries, and survey data; they provide access to data once ethics, privacy, and permissions requirements have been met. Data centres can instruct researchers who are part of their unit to follow best practices in incorporating IDEA concepts into their research, but they are unable to impose requirements and processes onto external researchers beyond what is required in data sharing agreements.

When the environmental scan was conducted, knowledge of how to consider equity in data processes (including curation, cleaning, linkage, analytics, and interpretation) was limited across the network. Instead of asking an overwhelming amount of specific questions, which might have limited survey responses, we decided to ask overarching questions in the hopes that diverse processes would be revealed.

Despite the limited disaggregated data being collected across Canada at the time of the survey, responses showed high interest in best practices [34, 52, 74–76]. However, the treatment of disaggregated data was not cohesive across the network and very few organisations had adopted tools that address disaggregated data explicitly. HDRN Canada has an opportunity to fill this gap as an access hub for researchers across the country. The desire for, as well as caution towards, the collection and use of disaggregated data from systemically marginalised groups is clear [76–78]. Guiding documents in the collection and use of this data are being released from governments and institutions across the country and HDRN Canada can provide a platform for sharing these documents with all researchers who access data through the HDRN Canada website.

While there is a call to ensure that disaggregated data is specifically used to improve equity [34], there were currently no mechanisms developed to ensure use of disaggregated data was tied to equity initiatives in policy or system improvement. As a first step toward creating an HDRN Canada IDEA Strategy, the lack of coordinated and consistent data processes to further IDEA is a foundational discovery, providing an opportunity to move this work forward across jurisdictions by leveraging existing guidance and resources.

Limitations and lessons learned

The results of our scan highlight first steps for a distributed network to harmonise and elevate IDEA work across sites. The questions posed in this environmental scan were neither comprehensive nor exhaustive. In part, we learned that devising questions in a networked environment walked a very thin line, especially with the knowledge that some member organisations were further along in their IDEA work than others. Questions had to be broad enough to be inclusive, while succinct enough to avoid item ambiguity. Admittedly, we did not avoid item ambiguity, which is unsurprising given that responses came from across 13 regions of a vast country. For member organisations nested within universities or provincial governments, more information about the distribution between resources at an institutional level versus the unit level could have better informed interpretation of resource discrepancies. Discussion with the HDRN Canada IDEA Team indicated that further granularity about budgets and budget sources (e.g.: operating funds, grants, or other avenues) would have been informative and could have avoided some ambiguity. Particularly, more utility would have come from specification of budget spent to further IDEA within a specific unit, rather than across an entire institution. In this networked environment, we found that more specific information about educational topics and outcomes, core competencies, and efficacy of learning was needed to distinguish baseline information about IDEA from applied information about IDEA in a data research environment.

We found that while there are many excellent theoretical and practical frameworks to apply in data research environments, none had been applied intentionally. As we strove to build an inclusive network, we made our best efforts to ensure that we were not evaluating member organisations against an unknown or impractical measure, while still gaining a solid understanding of activities across the network. We were also limited based on the type of data organisations held. For example, we knew when starting the survey that most member organisations had limited robust disaggregated data, if any. To reduce burden, some detailed process questions were not asked knowing that they could not be answered.

Ultimately, we do not recommend other organisations repeat the very specific and tailored environmental scan we devised. We do, however, highly recommend asking questions about both organisational processes and data research processes. The level of detail will be dependent on the scale of the organisation or network. For example, questions about budgets could be tailored to independent units, national organisations, or member organisations nested within universities. Questions about disaggregated data could similarly depend on whether data is primarily collected or secondarily used, along with context about legal responsibilities and data sharing agreements.

We encourage other organisations, especially networked organisations wherein resources and practices are distributed, to undertake their own environmental scan. The decision not to share our tailored design was made with the knowledge that the data systems, cultures, and organisations have their own intricacies. Exercises deciding which questions will be helpful in planning future strategic actions comprise as much of the work as interpreting the information gathered.

Conclusion

An environmental scan of HDRN Canada was beneficial in understanding the opportunities and challenges in promoting IDEA in organisational practice and data equity within a network. While organisations may be quick to establish IDEA programmes in response to external or internal pressures [79–81], it is essential that strengths and limitations are assessed to ensure meaningful and impactful implementation.

In the current state, IDEA is broadly supported by leadership but unevenly applied, often confined to the traditional realm of human resources. We are seeing barriers to progress in data equity in part because there are few examples of how to apply IDEA concepts in the data research space, let alone the distributed data centre space. Efforts to improve IDEA in research design must be coupled with efforts to improve IDEA in research practice. Assuming we can focus on research design without considering the environment in which the research is being done perpetuates the notion that research, and data, exist in a neutral or objective zone. Considering the learning environment, the people, and the data centre processes that support data research are steps towards data equity, particularly understanding who has access to the data and what practices surround its use.

The scan led to a number of recommendations, divided between actions for HDRN Canada and actions for HDRN Canada member organisations. Importantly, it helped to clarify how HDRN Canada can support IDEA initiatives without duplicating member organisation's efforts. Highlighting opportunities and areas of need, the environmental scan helped make a case to develop a network wide IDEA Strategy and Action Plan (forthcoming in a future article).

By including detailed methodology and a description of the survey, we provide a roadmap for other networks or organisations to assess their own IDEA activities across organisational and data equity areas of inquiry. With greater knowledge of these activities, more informed actions can be taken to ensure we are creating inclusive organisations and equitable data research processes that advance health and health equity.

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Statement of conflict of interest

The authors have no conflicts of interest to declare.

Ethics statement

This study did not require ethical approval as it was used for quality improvement purposes and did not involve human participants as research subjects of the use of personal data.

Data availability statement

The data associated with this project is not available for public dissemination but will be made available upon reasonable request to the corresponding author.

AI disclosure statement

The authors used ChatGPT, version 4.1 for editing/reducing word count. The output was reviewed and verified by the authors

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