RADY FACULTY OF HEALTH SCIENCES

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Key Considerations: Race, Ethnicity and Indigenous Identity Data Collection and Use

Background

The COVID-19 pandemic brought forth increasing calls to collect and report on race, ethnicity, and Indigenous (REI) based identity data. In healthcare, high-quality REI identity data is vital for identifying and measuring health disparities that stem from systemic racism, and can be used to bridge the gaps in health and health care quality experienced by racialized communities.[1]

The Black, Indigenous and People of Colour (BIPOC) Working Advisory Council was formed in the spring of 2020 to provide support to all aspects of the development and implementation of a process to collect REI identifiers during COVID-19 that would empower the disaggregation of COVID-19 data by REI identity. The BIPOC Working Advisory Council comprised a diverse group with expertise in critical race theory, the histories of race and racism, human rights, epidemiology, Indigenous health, health research and health leadership. Members of the group are almost exclusively from BIPOC communities but were not appointed by the communities they are members of. Throughout this process the BIPOC Working Advisory Council understood the complexity and prudence required to collect this data, and has held as a strong priority that disaggregated REI data be tightly governed to minimize the potential for data misuse.

In partnership with Service Delivery Organizations (SDOs), Ongomiizwin – Indigenous Institute of Health and Healing and the George and Fay Yee Centre for Healthcare Innovation (CHI), work has been ongoing to implement the broader collection of REI identity data within healthcare facilities and programs in Manitoba. This work has included engagement across the healthcare system, with BIPOC community leaders, national organizations and the provincial government to create a standard dataset, along with collection standards, staff training and data governance guidelines. While there is no one size fits all approach, it is essential that organizations considering the collection and use of REI identity data:

- Undergo thoughtful planning to mitigate the potential for data misuse and further harm towards racialized communities, and
- Consider a rights-based approach to foster sovereignty for Indigenous populations and BIPOC communities

Similar considerations should also be made by organizations considering the collection and use of other intersectional data (e.g., gender identity, religion, disability etc.).

To harmonize collection of high-quality REI identity data within Manitoba, the SDOs, Ongomiizwin and CHI will be collaboratively releasing guidance documents around use of this data for the healthcare system. These future resources can be adapted by researchers or other

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[1] Canadian Institute for Health Information. Race-based and Indigenous identity data [Product release]. Accessed September 22, 2022.

organizations looking to collect, access or use REI identity data to measure and rectify inequalities in programming and services access, quality, experience and outcomes.

This document was developed by the REI Governance Working Group[2] and outlines key considerations for organizations considering the collection, access or use of REI identity data for equity enhancing purposes where data governance is led by and with BIPOC communities.

Organization Readiness Assessment

Area 1: Anti-Racism and Equity

- What is your organization’s commitment to anti-racism?
- How is your REI project building on your organization’s strategic planning and commitment to anti-racism?
- How does collecting REI identity data realign your organization to the equity goals outlined in your strategic plan?

Area 2: Organization Expertise

- What is the expertise of your organization’s team?
- How has your organization built/acquired the expertise to collect and use REI identity data?
- Does your organization’s team have expertise in equity, social justice and anti-oppression, anti-racism, critical race theory, data cleaning and analysis, human rights and community engagement?

Area 3: Meaningful Engagement

- What education and training has your organization’s team members taken to further their understanding of systemic racism?
- What actions has your organization taken to dismantle systemic racism?
- Do you understand the distinction between the collection of Indigenous identity and race/ethnic identity?
- Does your organization have trust and meaningful engagement with racialized communities?
- Have you spoken to your privacy officer, research ethics board, etc. about your organization’s plan to collect REI identity data?
- What are your staff training and internal/external communication plans?

Area 4: Data Governance

- How will REI identity data be collected and what protections will be put in place to ensure the safe collection, storage and use of this information?
- Who within your organization will be able to access and use this data?
- What information sharing agreements are necessary for your organization and with whom?
- What are your data governance plans for this information?
- How will your organization use REI identity data to develop and implement changes to advance equity?

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[2] The REI Governance Working Group was established as part of ongoing efforts to systematically collect REI data in the healthcare system.