

Wellesley Institute Submission in Response to the Proposed Regulation under the *Anti-Racism Act* on Data Standards for the Identification and Monitoring of Systemic Racism



Proposal Number: 18-ARD002

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Wellesley Institute congratulates the Anti-Racism Directorate (ARD) on the release of the Draft Data Standards for the Identification and Monitoring of Systemic Racism. The Draft Standards are an important step forward towards the *Anti-Racism Act's* goal of supporting the identification and monitoring racial disparities and inequities, and enabling remedial action towards the elimination of systemic racism and advancing racial equity.

Wellesley Institute wholeheartedly supports these goals. Our mission is to advance population health and reduce health inequities through applied research, effective policy solutions, knowledge mobilization and innovation. We have long advocated for socio-demographic data collection, including on issues related to race and racism. In our view, socio-demographic data collection is an indispensable tool for identifying and addressing inequities that lead to health disparities. We appreciate the opportunity to comment on the Draft Standards, and draw on our expertise in this area.

This submission is substantially based on Wellesley Institute's 2017 paper, *Socio-demographic data and equity in health services in Ontario: building on strong foundations*.¹

That report was a contribution to the current discussions in Ontario about socio-demographic data and health services. It included a literature review, a policy scan, and the results of discussions with a range of persons knowledgeable about and interested in socio-demographic data collection in Ontario. It identified nine guiding principles and best practices for implementing initiatives to strengthen socio-demographic data collection in Ontario:

1. Collecting data for appropriate purposes,
2. Privacy and protection of data,
3. Informed consent,
4. Transparent data collection,
5. Opt-in/opt-out framework,
6. High-quality data,
7. Standardized data,
8. Self-reported data, and
9. Trained staff.

These principles and best practices form the foundation of this submission.

Wellesley Institute has strong concerns about the omission of health services from the scope of data collection under the *Anti-Racism Act*. We recognize that this is beyond the scope of the Draft Standards, but it is important that it be raised in this context. Without such data, the Government of Ontario's commitments to the elimination of systemic racism, and to the achievement of health equity as outlined in the *Patients First Act*, cannot be realized. We urge the Anti-Racism Directorate, and the Government of Ontario more broadly, to re-visit section 6(7) of the *Anti-Racism Act*, which excludes health information custodians from the data collection requirements.²

There is much to applaud in the Draft Standards. They show careful consideration of theoretical and methodological concerns. They are strong in the following general matters:

- **Principles:** The six principles that guide organizations in interpreting and applying the Standards address the core concerns of privacy, quality, accountability and integrity, and are well-aligned with the principles identified through Wellesley Institute’s research and consultations.
- **Indigenous communities:** The identification of the particular rights, concerns and needs of Indigenous communities is essential.
- **Collection Methods:** The emphasis on direct collection of data reflects the gold standard approach for this type of data collection, and the guidance offered for indirect collection is clear and helpful.
- **Race questions and categories:** The clear recognition of race as a social construct, together with the collection of race-related personal information on religion and ethnicity, is, in our view, an appropriate general approach to these complex and sensitive questions.

A general concern is ensuring that the data collected is a basis for action, and that such action is based in a clear understanding of the realities and operation of systemic racism. This concern should inform modifications to the Draft Standards and the work of the ARD in general. The collection of race-based data is important, justifiable, and ethical when it used to eliminate systemic racism and advance racial equity. It is not necessarily justifiable and ethical if the results are not then used to inform action to address racial disparities. It is important that the Standards both protect against misuse of data and ensure that the data is put to effective use.

Based on the above, Wellesley Institute has identified five areas where the solid foundations of these Draft Standards can be strengthened:

- ensuring that those responsible for collecting data are properly equipped for this important task;
- ensuring appropriate use of the data collected;
- enhancing the questions;
- recognizing Indigenous rights and concerns; and
- ensuring that the standards provide sufficient methodological guidance.

These are detailed in the remainder of this submission.

1. Ensuring appropriate skills, training and understanding for those collecting data

The *Anti-Racism Act* clearly outlines the transformative purpose of data collection to eliminate systemic racism and advance racial equity. The Draft Standards include significant guidance to support Public Sector Organizations (PSOs) in collecting data, such as mandatory standardized questions regarding race and Indigenous identity. However, the guidance and minimum requirements provided by the Draft Standards can be further strengthened to ensure that PSOs are both supported and accountable to ensuring the data collection efforts contribute to this overarching purpose of advancing racial equity. Specifically, further attention can be given to ensuring that PSO staff have the training and support needed to implement data collection.

PSOs are being asked to collect data in the context of existing workloads and with varying levels of knowledge of systemic racism, racial inequities, and likely varying acceptance and buy-in regarding the

purpose and importance of data collection. Staff may also have conscious or unconscious biases that could affect the way in which data is collected, analyzed and employed, and unless such biases are addressed, data collection could inadvertently reinforce rather than address systemic racism. As well, PSOs will essentially be monitoring and measuring their own organizations for evidence of systemic racism, a potentially fraught task. Moreover, the requisite skill in quantitative methods is often in short supply. It is critical to ensure that PSO staff have the knowledge and skills to implement data collection in an inclusive and respectful way that advances the purpose of the Act. Data needs to be collected in a way that builds trust, particularly due to the personal nature of information and historic misuse of socio-demographic data.

Experience in Ontario and elsewhere shows that properly trained staff are essential for successful implementation of standardized socio-demographic data collection. High-quality training contributes to staff understanding and acceptance of data collection and its rationale and significance, which contributes to staff buy-in, comfort in answering clients' questions, and ultimately client trust.

The Standards indicate that staff training in most cases is necessary for good implementation of the Standards. Given the importance of this, we recommend that staff training be a mandatory requirement for all PSO staff involved in the collection, analysis, interpreting and use of data. Mandatory training should include:

- An emphasis on the purpose and importance of data collection to address systemic racism as articulated in the *Act*,
- Cultural safety and anti-oppression approaches to ensure that data is collected and used by PSOs in an inclusive and respectful way,
- Foundational skills in the collection and analysis of data.

While it is important that staff training be responsive to the organizational context and staff roles, standardized training materials from the Directorate would be beneficial to support mandatory training would enhance the consistency, quality of data collection across PSOs, and strengthen the capacity of PSOs to collect data.

Given varying levels of knowledge and buy-in and existing workloads, training and supports for those responsible for implementing data collection is critical to ensure data is collected and used in ways that advances the goals of the *Anti-Racism Act*.

2. Ensuring appropriate use of the data collected

The aim of data collection is to provide the information needed to support action to address systemic racism. The Draft Standards provide important guidance for analysis and reporting. However, in the context of the ARD's mandate it is important to ensure that data is transformed into change.

Given past examples of misuse of sensitive data, it is important to include strong mechanisms to ensure that data is analyzed and used in a way that advances racial equity, avoids racial stereotyping and is in

accord with the purposes and principles of the *Anti-Racism Act*. This includes ensuring that racialized and Indigenous communities have a say in how data is collected, analyzed, interpreted, and reported.

The Data Standards and related ARD activities should ensure that PSOs are accountable for acting on the disparities revealed by data collection. Recent examples from Ontario and British Columbia highlight the risk of failing to do this. In 2015, the Auditor General of British Columbia found that despite decades of data collection to reduce educational disparities, the Ministry of Education and school districts had not adequately analyzed and used data to address persistent education gaps for Aboriginal students.³ The Auditor General identified systemic barriers to Aboriginal student success and “racism of low expectations,” which had not be addressed, highlighted that “monitoring performance is only the first step in evidence-based decision making,” and recommended clearer accountability, analysis, interpretation, public reporting, and action on data. Likewise, in 2016, the Ontario Police Service asserted that disproportionately high rates of Black and Middle Eastern drivers experience traffic stops did not prove racial profiling. The Ontario Human Rights Commission responded that in the context of the lived experience of racialized and Indigenous populations, court and tribunal decisions on racial profiling, and historical police/community relations, the data provided clear evidence of racial profiling, and required action.⁴

The challenge of ensuring action raises issues that may go beyond the specific confines of the Draft Standard into other aspects of the ARDs mandate. It may be useful to create Guidelines or other tools to assist PSOs to create and publicly report on strategies in response to disparities revealed by data collection. Wellesley Institute recognizes that the *Anti-Racism Act* does mandate the creation and maintenance of a Government of Ontario anti-racism strategy, and appreciates this whole-of-government approach. However, the information revealed by data collection can and should also be the subject of PSO-specific responses.

Use of socio-economic data to inform and impel action will be fostered by involvement of the communities affected, and by mechanisms for accountability and action.

Mandatory involvement of racialized and Indigenous communities: The Draft Standards highlight the value of input from racialized and Indigenous communities throughout data collection, analysis, interpretation and use. The First Nations OCAP (Ownership, Control, Access, Possession) principles make a clear and compelling case for mandatory involvement of Indigenous communities in data collection: similar principles and approaches can be valuable broadly in supporting strong involvement of racialized groups in data collection across Ontario. The existing provisions can be strengthened by mandatory, meaningful and transparent mechanisms for the involvement of racialized and Indigenous communities in collection, analysis, interpretation and reporting of data, and in development of action plans to redress inequities. The Standards could, for example, require mandatory community advisory committees for data collection and interpretation at PSOs.

3. Enhancing the questions

The creation of the Data Standards is an ideal opportunity to consider the categories of population groups that are being used, and whether the sociodemographic categories currently employed reflect the growing

diversity of Canadian communities. Researchers have emphasized the importance of data categories that are specific, reflect population diversity, and enable the development of targeted interventions.⁵ Without more complex categories to reflect the socio-demographic characteristics of racialized communities, our understanding of issues, service use and unmet needs, and our ability to address those issues remains fragmented. The language and choices of the sociodemographic groups of the Draft Standards should reflect our communities.

For example, it may be helpful, in light of current demographic trends, to include as part of the standardized questions further disaggregation of the race category of “Black”. The sub-category of “African” is broad and embraces a wide range of experiences, so that it may be helpful to specify West African and East African, as one suggestion. Expanding on the recognition of the racialization of religion, it may be useful to consider a question that collects information about visible markers of religious observance, particularly in light of incidents of violence and discrimination experienced by individuals wearing items like the hijab.

4. Recognizing Indigenous rights and concerns

The Draft Standards recognize that there are specific challenges and considerations in the collection of Indigenous health-based data. Wellesley Institute recognizes that the health and well-being of First Nations, Metis and Inuit populations is linked to broader determinants that stem from historic, legal, political and social conditions in Canada, and in collecting Indigenous health data, it is essential to recognize the fundamental role that colonization, racism and barriers to self-determination have played in the disparities in their health outcomes. Non-Indigenous approaches to data collection can be alienating to Indigenous communities and work to further marginalize them in the system.

Wellesley Institute supports recommendations on data collection made by the Ontario Federation of Indigenous Friendship Centres (OFIFC), and the First Nations Information Governance Centre, including in particular the recommendations made in the OCAP Principles and the OFIFC’s Submission to the Ministry of Health and Long-Term Care on Patients First. These point to ensuring that the approaches to standards and collection of Indigenous health-based data should be rooted in Indigenous perspectives and voices, and respectful of the right of Indigenous communities to control and manage information. The OCAP principles are foundational⁶. Considerations to Indigenous data collection could include⁷:

Mechanisms for accountability and action: The Draft Standards could be strengthened to enhance the realization of Principle 2, Organizational Commitments and Accountability: “Organizations are committed to and accountable for employing the data standards to help eliminate systemic racism and advance equity.” Accountability mechanisms should be required for PSOs to ensure data is collected, analysed and interpreted, reported, and then acted on, in a way that is proactive, transparent and thorough. In addition to reporting results of analysis, public reporting should include mandatory reporting on interpretation of results and an organizational action plan for reducing any identified disparities. This points to a need for protocols for action, as a follow-up to the Draft Standards.

- Training of those collecting Indigenous-specific data in cultural safety and competency;
- Inclusion of Indigenous communities in the planning, consultation, delivery and evaluation of data; and

- Attention to the specific needs of Indigenous populations in urban settings, as well as those living on reserves.

5. Methodological concerns

The Draft Standards should be lauded for the level of guidance that they provide on how to measure, analyze, and report data on systemic racism. There are three specific areas where clarification or additional information would be helpful.

Describing and analyzing gaps: The Draft Standards emphasize that thresholds should be “reasonable, set in good faith, and reflect engagements with affected communities”. However, as communities are setting their thresholds, they should be mindful that moderate or even small gaps could still point to important inequities that require action. The Draft Standards offer an example of an organization that sets a threshold of 2.0 as a meaningful threshold for ‘notable racial disproportionality’ (p. 36), but does not include the rationale that this organization may have for setting this threshold. Without this, it is unclear why it is not ‘of concern’ that one group is 1.3 times as likely to drop out of high school, compared to another. This is important to emphasize because some differences may still represent systemic inequalities or discrimination even if the gaps are not large, and therefore be important to report and discuss.

Multivariate analysis: The Draft Standards advocate for multivariate analysis to “assess the extent to which other factors” explain race gaps. Such an analysis is valuable, but requires considerable technical sophistication and time. Poorly-specified multivariate analysis might mis-estimate the size of race gaps, potentially in the direction of under-estimating gaps. It would therefore be helpful to provide additional guidance or resources to assist public sector organizations with gathering data in carrying out this task.

Minimum sample sizes: The Draft Standards recommend minimum sample sizes for statistical analysis (p. 30, 36). As there are numerous statistical methods (such as Fisher’s exact test) for analyzing small samples, it would be helpful to clarify the rationale for these particular cut-offs. Relaxing these constraints could also assist PSOs when they wish to report gaps within aggregate groups. For instance, if a report wishes to compare West African and East African populations, as described above, this could result in small sample sizes in many datasets. PSOs should therefore have further guidance on how to speak about gaps when the number of individuals is small, in order to identify specific groups facing the greatest challenges.

Conclusion

Wellesley Institute strongly supports the work of the Anti-Racism Directorate and the collection of data as a means of identifying and addressing systemic racism. The Draft Standards provide a strong foundation for this work. This submission outlines six specific areas in which that foundation could be enhanced. We would be pleased to provide further information or to discuss the content of the discussion, should that be of assistance to you.

Endnotes

- 1 Wellesley Institute, *Socio-demographic data and equity in health services in Ontario: building on strong foundations* (Toronto: October 2017), <http://www.wellesleyinstitute.com/publications/socio-demographic-data-and-equity-in-health-services-in-ontario/>
- 2 *Anti-Racism Act*, S.O. 2017, c. 15, s 6(7).
- 3 Auditor General of British Columbia. (2015). An Audit of the Education of Aboriginal Students in the B.C. Public School System. Retrieved from http://www.bcauditor.com/sites/default/files/publications/reports/OAGBC%20Aboriginal%20Education%20Report_FINAL.pdf
- 4 Ontario Human Rights Commission. (2016). OHRC Response to the Race Data and Traffic Stops in Ottawa Report. Retrieved from <http://www.ohrc.on.ca/en/ohrc-response-race-data-and-traffic-stops-ottawa-report>
- 5 Bierman, A.S., Lurie N., Collins, K.S., and Eisenberg J.M., “Addressing Racial and Ethnic Barriers to Effective Health Care: The Need for Better Data”. *Health Affairs* 21, no 3 (2002): 91-102.
- 6 First Nations Information Governance Centre. *OCAP Principles*. <http://fnigc.ca/ocap.html>
- 7 Ontario Federation of Indigenous Friendship Centres. (2017). Submission on MOHLTC’s Patients First – A Proposal to Strengthen Patient-Centred Health Care in Ontario.