



June 5, 2026

Executive Lead – Committee
Office of the Chief Coroner
Occ.deathreviewcommittees@ontario.ca

Dear Obstetrical and Perinatal Death Review Committee (OPDRC):

Re: inclusion of race-based data in the QuinC investigation database

Further to our response to the OPDRC Coroner’s Report submitted on October 17, 2025, we are writing regarding the planned inclusion of race-based data in the QuinC investigation database. As noted in your December 2024 report, the OPDRC has begun tracking racial identity to better understand how these factors influence health outcomes. The Association of Ontario Midwives (AOM) acknowledges the value of race-based data in identifying the impacts of structural racism. However, there are significant considerations for the handling of this data that warrant careful attention.

Our Health-Care Equity, Quality and Human Rights team has identified concerns about how race-based data will be interpreted in cases under review. There is a long history of such data being used in ways that reinforce, rather than dismantle, structural violence towards First Nations, Inuit, Metis (FNIM) and racialized communities. For example, in our response to the Coroner on June 3, 2019, we noted that the 2017 Coroner’s Report included stigmatizing details unrelated to outcomes, such as references to race or substance-use history. There have also been cases that note an absence of substance use history in cases involving FNIM patients, as if this is anomalous. These practices reinforce bias rather than utilizing data to support the Ontario Human Rights Commission mandate to “monitor discrimination, remove systemic barriers, address historical disadvantages, and promotive substantive equality”.¹

A critical first step in considering the use and collection of race-based data is in determining how this data will directly benefit the population it is intended to serve, and whether such data has historically improved outcomes for marginalized equity deserving populations. Evidence from the Black Health Equity Working Group (BHEWG) shows that inequities and anti-Black racism persist

¹ Ontario Human Rights Commission. *Racism and racial discrimination: Data collection (fact sheet)*. Available from: www3.ohrc.on.ca/en/racism-and-racial-discrimination-data-collection-fact-sheet

in jurisdictions where race-based data is collected.² Data is routinely extracted from Black, First Nations, Inuit and Metis communities without measurable improvements in outcomes or return of benefit.²

Persistent disparities in health outcomes experienced by FNIM and racialized communities constitute a form of structural racism. While the collection and utilization of race-based data is often proposed as a strategy to address inequities, data collection alone is insufficient. To be ethical and effective, the data must meaningfully contribute to dismantling racism and advancing health equity, principals embedded in community-developed data governance systems such as the “Ownership, control, access and possession” (OCAP) framework and “Engagement, governance, access and protection” (EGAP) framework. This requires engagement with affected communities, recognition of their data ownership and governance rights, and adequate organizational resources to comply with existing standards.

The AOM requests that the OPDRC provide clarity on the framework guiding the collection, maintenance, and use of race-based data. This framework should align with existing guidance from FNIM and other racialized communities. This guidance is readily available through organizations like the First Nations Information Governance Center (FNIGC), the Black Health Equity Working Group (BHEWG), and the Canadian Institute for Health Information (CIHI) in their *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada*. Without adherence to a transparent, equitable, community-informed framework, there remains significant risk of harm.³

To support this process, the OPDRC can actively seek out relevant expertise for the committee, including lived experience, a critical theoretical background, and an intersectional understanding of the data under review. Committee members should be trained in trauma-informed and culturally safe perspectives, particularly with respect to FNIM communities and the impact of the well-founded mistrust of settler institutions.

² Black Health Equity Working Group. *Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities*. 2021. p. 20. Available from: blackhealthequity.ca

³ Canadian Institute for Health Information. *Guidance on the use of standards for race-based and Indigenous identity data collection and health reporting in Canada*. Ottawa (ON): Canadian Institute for Health Information; 2022. Available from: www.cihi.ca/sites/default/files/document/guidance-and-standards-for-race-based-and-indigenous-identity-data-en.pdf

This commitment to transparency and equity in the management and use of race-based data is essential to achieving the committee's stated goal of understanding how and why health systems fail FNIM and racialized people. Transparent processes and meaningful collaboration with the communities represented are crucial to building trust and mitigating the risk of harm.

Thank you for your attention to these concerns. The AOM welcomes continued dialogue and collaboration with the OPDRC on this critical issue.

Yours in partnership for quality and safety,



Juana Berinstein, AOM, Co-CEO



Ellen Blais (Jun 11, 2026 14:12:34 EDT)

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