

# Policy Brief: Collection, Use and Governance of Sociodemographic Data in Ontario

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Wellesley Institute advances population health and reduces health inequities by driving change on the social determinants of health through applied research, effective policy solutions, knowledge mobilization and innovation.

### **About this document**

This policy brief reflects the findings of two research reports by Wellesley Institute entitled 1) “Best Practices to Use Sociodemographic Data to Improve Access and Outcomes of Health Services for Equity-Deserving Populations” and 2) “Existing Models of Community Governance and Health Data.”

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### **Acknowledgment of Traditional Land**

We wish to acknowledge this land on which Wellesley Institute operates. For thousands of years, it has been the traditional land of the Huron-Wendat, the Seneca and the Mississaugas of the Credit. Today, this meeting place is still the home to many Indigenous people from across Turtle Island and we are grateful to have the opportunity to work on this land.

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## Introduction

Sociodemographic data can be an essential tool for research and policy development in healthcare. It can help researchers and decision-makers assess population- and community-level health and well-being through examining the connections between health outcomes and social determinants of health. Social

determinants of health include housing, income, employment and education. Data can also help identify disparities between and within population groups to support the development of policies and programs that improve healthcare services and supports for equity-deserving populations. However, while there has been a growing focus on the use of data to inform policy and program decision-making, there continue to be concerns around the collection, use and governance of sociodemographic data.

**"Sociodemographic data can be an essential tool for research and policy development in healthcare."**

Two recent literature reviews led by Wellesley Institute brought together evidence and best practices for service providers on effective strategies for the systematic use of sociodemographic data and models of community data governance. These strategies can support government, healthcare providers and community organizations that collect and use data to effectively engage communities, conduct data analysis, and advance health system change.

This policy brief provides recommendations for the Ministry of Health, Ontario Health, and other key actors on how to action the findings from the literature reviews and ensure the ethical collection, use and governance of sociodemographic data to advance health equity.

## Key Considerations

### Status of sociodemographic data collection in Ontario

Through the Anti-Racism Act<sup>1</sup>, Ontario currently mandates the collection of standardized race-based data in some public sector organizations including correctional services, child and youth services and education. The Act does not, however, mandate providers of health services, including public health units, to collect the same data. During the pandemic, the collection of race-based data through public health units was critical in informing the creation of equity-based COVID-19 interventions that reduced infection rates and hospitalizations<sup>2</sup>.

Mechanisms to collect race-based and sociodemographic data should be continued and integrated across the health system to advance equity.

Currently, there is also no specific guidance or standards for the collection and use of sociodemographic data in Ontario. And while the collection of sociodemographic data is a good start, it is also important to enable mechanisms that support the transparent and timely analysis and application of that data. Ensuring data can be integrated and compared across communities and the broader population will be essential to improving healthcare delivery and will lead to more equitable health outcomes.

## **Importance of community engagement and data governance**

Evidence shows the collection and use of sociodemographic data can raise concerns about data privacy, particularly among Black, Indigenous and other racialized communities<sup>3,4</sup>. Prominent work on best practices for the collection and use of sociodemographic data point to the importance of community engagement to acknowledge communities' sovereignty over their health data, including in determining and defining a clear purpose behind the use of the data. This was further reflected in the findings of the literature reviews, in which 11 of the 23 documents analyzed identified engagement as a key step in sociodemographic data use. These documents highlighted that engagement should be used to benefit equity-deserving communities, including through the provision of relevant information, knowledge generation and exchange with and among stakeholders.

Engaging with a diverse set of stakeholders, including healthcare professionals, community members, subject matter experts, community partners, policy implementers and other stakeholders was identified as ensuring the appropriateness and relevance of data collection and use efforts. Effective engagement with these stakeholders was also found to be critical, with factors such as equitable recruitment strategies and proactive engagement being highlighted.

The second literature review highlighted five models of community governance, each offering unique approaches to building community trust, ensuring equitable data systems, and building accountability mechanisms.

## Recommendations

Both literature reviews stressed the need for Ontario health system actors to develop and implement evidence-based strategies that incorporate meaningful community engagement and community data governance best practices in the collection and use of sociodemographic data.

Leadership from all levels of government and partnership and collaboration with community partners, community members, health professionals, agencies and others involved in health system planning and research will be critical to ensuring sociodemographic data is used to create equitable health outcomes.

The following recommendations are directed to Ontario's decision-makers and policymakers in the health system to support the integration of community engagement and data governance in the collection and use of sociodemographic data.


- The Ontario government should mandate the systematic collection of sociodemographic data, in line with other public sector organizations, through amending the Anti-Racism Act.
- The Ministry of Health should implement mechanisms to collect sociodemographic data in a standardized way, such as through voluntary identification through the OHIP issuance and renewal process.
- Ontario Health should coordinate with health service providers and lead the development of community data governance tables for each region initially, with a medium-term goal of coordinating at sub-regions such as Ontario Health Teams or as directed by community engagement. These tables should include a diverse set of stakeholders and community members that can inform the use of sociodemographic data that is tailored to regional needs.
- The Ontario government should create an independent Centre of Excellence on Sociodemographic Data, housed at an Ontario university, to bring together government, academics, community members and non-profit organizations to facilitate knowledge exchange and mobilization across sectors on the use of sociodemographic data to enable health system change. This should include a province-wide sociodemographic health data platform with the capacity to integrate with national data through Statistics Canada.

- In coordination with the Centre of Excellence, the Ontario government should fund the development and delivery of world-leading training for current and future healthcare service providers, researchers and health system planners, as well as community organizations and other relevant stakeholders, on how to ethically hold and use sociodemographic data.

## Conclusion

Sociodemographic data is essential for building knowledge and understanding the inequities in the health system. It can guide the development of the interventions needed to address these inequities. How this data is collected, analyzed and used can also greatly impact health equity.

Wellesley Institute's literature reviews demonstrate that best practices for the collection and use of sociodemographic data centre around meaningful community engagement and community data governance. The Ontario government can play a leading role in ensuring sociodemographic data is standardized, accessible and used to make a stronger, fairer and more equitable health system.



**“The Ontario government can play a leading role in ensuring sociodemographic data is standardized, accessible and used to make a stronger, fairer and more equitable health system.”**

## References

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