

**ENGAGEMENT, GOVERNANCE,**

**ACCESS, AND PROTECTION (EGAP)**

# **EGAP Framework**

## Consultation Report





# BACKGROUND



In spring 2020, the Black Health Equity Working Group, made up of Black health sector leaders and health equity experts, began developing a governance framework for health data collected from Black communities in Ontario. As part of the development process, the group carried out a series of consultations with Black community members, researchers and academics, public health professionals, and health system organizations in the province. The goals of this outreach process were as follows:

**A**

to gather feedback from a diverse list of stakeholders whose work will be impacted by the collection of race-based data in Ontario,

**B**

to strengthen and refine the framework,

**C**

to get buy-in and endorsement of the framework.



From August 12, 2020, to October 6, 2020, we held 30 stakeholder consultations, some of which included multiple participants. We gathered feedback through email, a Google Form, and virtual meetings using a set of core engagement questions:

**1-** Are there important additional issues or concerns that are not included in the framework concerning race-based/sociodemographic data use?

**2-** Are there any additional components you would like to see added to any section of EGAP?

**A. Engagement**

**B. Governance**

**C. Access**

**D. Protections**

**3-** Is there any language or framing within EGAP that you feel could be potentially problematic for the communities you work with?

**4-** Are there aspects of this framework that are unclear or that you would need further clarification on?

**5-** Does this framework pose any challenges to how your organization collects, analyzes, and utilizes race-based/sociodemographic data? If yes, what are the points of tension and how could we begin to collaborate to address these barriers?

**6-** Are there any other issues that you would like to raise that have not been covered by these questions?

**Overall, respondents indicated strong commitment to the goals and principles of the EGAP Framework.**

**“It is an excellent contribution to the evolving developments to embed equity principles in data.”**

**“The E-GAP framework represents an important advancement to establish ethical and equitable data practices and structures. Most critically, it helps to enable a more democratic approach to data access, including control and ownership of data in order to advance racial equity in healthcare.”**

**“This initiative is timely and essential. It will contribute immensely to governance and practices related to collecting, using, disseminating, and sharing data in the best interests of Black communities.”**



# THEMES

## Recognize the divergence of views on race-based data

Respondents noted that members of Black communities have different views on race-based data and how data from Black communities should be collected, managed, and used.

**“Diverging perspectives within academia and in community on whether data on Black communities should be collected by the state and other organizations not housed in community.”**

**“We know that calls/support for data collection are not unanimous.”**

## Learn from other models and communities

Respondents affirmed the importance of learning from other models, including the OCAP® principles,<sup>1</sup> the CARE principles,<sup>2</sup> and the Jane and Finch Community Research Partnership Principles.<sup>3</sup> They also pointed to work that has been done by other communities.

**“Lots to learn here from research that occurs in partnership with Indigenous communities.”**

**“Look at experiences in other marginalized communities in taking ownership of data. For example, HIV/AIDS and the early experiences with the observational database”.**

<sup>1</sup> The First Nations Information Governance Centre. (2020). *Ownership, Control, Access and Possession (OCAP™): The path to First Nations information governance*.

[https://fnigc.ca/wp-content/uploads/2020/09/5776c4ee9387f966e6771aa93a04f389\\_ocap\\_path\\_to\\_fn\\_information\\_governance\\_en\\_final.pdf](https://fnigc.ca/wp-content/uploads/2020/09/5776c4ee9387f966e6771aa93a04f389_ocap_path_to_fn_information_governance_en_final.pdf)

<sup>2</sup> Research Data Alliance International Indigenous Data Sovereignty Interest Group. (2019). *CARE principles for Indigenous data governance*. Global Indigenous Data Alliance. <https://www.gida-global.org>

<sup>3</sup> The Jane Finch Community Research Partnership. (2020). *Principles for conducting research in the Jane Finch community*. <https://janefinchresearch.ca/research-principles>.



## Ensure inclusion and intersectionality

Respondents emphasized the need for inclusion and intersectionality, particularly in relation to Community Governance Tables, to ensure representation of different experiences and layers of identity. They noted the importance of adapting the framework for different contexts, such as urban and rural.

“Emphasis should be placed on finding ways to incorporate the perspectives of diversity within the Black community (e.g., Francophone, immigrants, Canadian-born Black people and others as part of the governance table).”

“Really important for this governance table to have representation from immigrants from the Caribbean, West Africa, East Africa, Canadian-born Black community members, and others—essentially a recognition of the diversity of the Black community. A small number of Black people are often expected to speak for the entire Black community.”

## Call for funding to build community capacity and infrastructure

Investments in training, capacity building, and infrastructure are required to realize the EGAP Framework. Respondents pointed in particular to the Ministry of Health's responsibility to fund and support this work.

“As data stewards, they [Ministry of Health]—and other bureaucrats—play a significant role in “getting things off the ground.”

“What should be the expectations and roles of stakeholders with existing structures for racialized data, like MOH, CIHI, ICES? What training and capacity building will be required? What will they need to do differently?”

“Explicit naming of the need of financial commitment from the Government of Ontario to support the development and maintenance of this infrastructure.”

## Facilitate community access to all data from Black communities

Noting that data from Black communities is held in a variety of places, including government and government bodies, agencies that carry out work for government, and other institutions and organizations, respondents said that data access issues need to be addressed.

**“Data need to be curated in such a way that that can be available to Black research and policy stakeholders; otherwise, over time, they represent a wasted opportunity for achieving equity and justice related to health and well-being.”**

**“Holding our data at ICES or some institutions is a barrier. Data should be freely accessible to community governance tables.”**

## Consider accountability measures

Respondents highlighted that moving forward, consideration of accountability measures to address violations of framework principles and agreements is needed

**“If there is accountability to communities, the community members need to have some kind of power over the institutions.”**

**“How will decision-makers be held accountable? How will monitoring for misuse and disciplinary action be handled?”**

**“Address the protection of personal privacy and the resulting accountabilities for ensuring it as well as any breaches.”**





# THANK YOU

**We thank all the respondents who took the time to engage with the initial framework draft and provide critical comments that allowed us to refine and strengthen it. Your insights were invaluable in advancing the EGAP Framework.**

