

Data Governance & Accountability Framework for the Collection and Use of Sociodemographic Data in Healthcare

Consultation document guiding development of protocols ensuring health equity for Black communities

Executive Summary

The COVID-19 pandemic has not affected all segments of the population equally. It has amplified existing disparities. These disparities are acutely felt by already marginalized and disenfranchised communities.¹ Over the course of the pandemic, the social determinants of health have interacted with public health interventions, changes in medical care, social policy and the economic downturn to increase inequities.

Ontario has initiated collection of health and sociodemographic data, including race based data, (sociodemographic is a multi-entity term, included markers such as geographic location, income, gender and sexual diversity, etc.) Ethically and appropriately used, data should create pathways advancing health equity. Disparate health outcomes at the population level cannot be fully analyzed and understood without data illuminating barriers to equitable care. However, collection of these data is not in itself the end goal. Data collected must be used to address inequities in healthcare.

This document has been developed in response to concerns outlined by Black communities in response to Ontario's proposed data collection strategy. The current provincial strategy replicates systemic and structural inequity. Specifically, Black people have raised alarms about extraction of data from Black communities without tangible reductions in health inequities.

This document introduces the *Engagement, Governance, Access and Protection Framework (E-GAP): a data governance and accountability framework* developed by health experts in Black communities. This draft framework highlights the necessity for a new way of governing data in relation to Black communities. This is a living consultation document, one that will be developed and finalized through extensive consultation with Black communities across the province.

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Background

Ontario's [Anti-Racism Act](#) (ARA)² highlights the systemic nature of racism in Ontario and its relationship to histories of exclusion, displacement and marginalization impacting Black, Indigenous and other racialized communities.

Sociodemographic based data collection is an important tool in challenging inequity linked to systemic racism. Disaggregated data is considered vital for identifying disparities, monitoring the impact of interventions and eliminating systemic racism. Sociodemographic data is routinely collected in many high-income countries, including the UK and USA, to help promote equity. The collection of sociodemographic and race based data is not an end in itself. It is one of many tools that may be used to promote health equity. The data needs to be appropriately analyzed as part of a clearly articulated plan for the development and implementation of equity focused interventions if it is to help reduce disparities.

Standardized race-based data collection in Ontario has been mandated by the ARA in several sectors including education, child and youth services and the prison justice system. Ontario's Anti-Racism Directorate produced data standards³ for the collection, use and management of information, including personal information. The Province of Ontario's [Data Standards for the Identification and Monitoring of Systemic Racism](#) provide consistent, effective practices for producing reliable information to support evidence-based decision-making and public accountability to help eliminate systemic racism and promote racial equity.

Crucially, the ARA does not mandate health sector race based data collection and Ontario's Anti-Racism Directorate has not produced specific guidance on the collection of race based data in health. There is a need for such guidance for the health sector, as collecting sociodemographic data is considered wise and promising practice in advancing health equity. Here the authors draw on the understanding of wise practices as used in Indigenous spaces to mean "locally appropriate actions, tools, principles or decisions that contribute significantly to the development of sustainable and equitable conditions".⁴

Implementation of data collection during the ongoing COVID-19 pandemic has added urgency to the current context. Several regional public health units across Ontario have initiated collection of sociodemographic and race based data in response the pandemic, including Peel Public Health, Middlesex-London Health Unit York Region and Toronto Public Health. The Ministry of Health has mandated provincial data collection to accurately document the impact of COVID-19 on marginalized communities. Data collected should inform and guide pandemic responses, with the goal of improving health outcomes and influencing post pandemic recovery planning.

According to the Ministry of Health, the collection of this data is important for cases of COVID-19 to:

- Ensure a more complete picture of data collection related to COVID-19
- Reduce inconsistencies in data collection; and
- Inform effective public health practices and interventions in response to COVID-19.

To facilitate data collection, the Ministry of Health has made amendments to [Regulation 569, Paragraph 11 of Section 5](#) of the Health Protection and Promotions Act.⁵ These amendments have been implemented to facilitate the collection of information on race, income level, language, and household size for individuals who test positive for a novel coronavirus including, COVID-19.

While communities have long advocated for the collection and responsible use of these data, implementation of province wide data collection does not come without reservations. Black communities continue to raise concerns about historic and current processes,⁶ wherein data and knowledge is extracted from Black people, while that data is neither owned by, nor accessible to Black communities.⁷ Additionally Black communities point out that ethically and appropriately used, data must create pathways advancing health equity for Black people. To date, even where data is currently collected, (such as data illustrating the severity of the COVID-19 crisis in Toronto's North West), the province has been slow to act and produce solutions that meaningfully improve health outcomes for marginalized populations.⁸

Finally, Black communities are sounding the alarm on the exclusion of key voices from implementation and strategy building tables. Specifically, the exclusion of Black communities in critical framing and planning discussions simply replicates systemic harm. Many concerns have been raised, including but not limited to historical misuse of data, surveillance, and privacy. It must also be noted that **Black communities are not homogenous in their responses to data collection. Data collection policies are both opposed and supported in equal measure.** Among groups where data collection is supported, concerns have been raised about data sovereignty and ownership. This framework aims to inform sociodemographic data collection in health, and support the sector in developing high quality processes and procedures.

This paper introduces the Engagement, Governance, Access and Protection Framework (E-GAP); a *data governance and accountability framework* developed by health experts in Black communities. Anti-Black racism has been recognized as a public health crisis by several public health institutions including the [Pan American Health Organization and World Health Organization](#)⁹. In Canada it has been recognized as an important issue by the Public Health Agency of Canada and the National Collaborating Centre for Determinants of Health.¹⁰

The legacies of anti-Black racism, systemic inequities and discrimination will not end with the COVID-19 pandemic. We must envision a future where Black, Indigenous and racialized communities redefine a “new normal” that prioritizes the health and wellbeing of historically marginalized communities. This framework is in alignment with long-term strategies that ensure Black communities play a central role in defining and determining governance of their own collective health.

The E-GAP Framework

A fundamental component of data collection for Black communities is the need to invest in the establishment of community data governance frameworks. Data is integral to developing a strong evidence base for improving health outcomes. When collected, analyzed and utilized, data can be the catalyst for effective change. However, appropriate protections are critical.

We propose a new framework for governments collecting race based data in Canada: the Engagement, Governance, Access and Protection Framework (E-GAP). It is based on the concerns and needs of Black communities and inspired by other data frameworks such as the OCAP principles,¹¹ the Jane and Finch Community Research Partnership Principles¹² and the myriad of calls for more transparency and control of data in the digital age. This document is in three parts and covers:

- The main issues in race based data governance;
- The Framework; and
- Implementation.

The Issues

Engagement

1. Lack of engagement and accountability

There has been insufficient community engagement by all levels of government in developing sociodemographic and race based data collection for health. As a result, some in our communities are concerned that there is a lack of accountability to the groups that will be impacted by the collection, analysis, reporting and subsequent responses to the data.

Governance

2. Unethical research reproducing harm

There continue to be concerns about research that contributes to stigmatization by pathologizing disenfranchised communities. The negative and inaccurate narratives that are

produced of Black, Indigenous and racialized communities lead to further inequities. Furthermore, impacted communities have identified critical issues relating to accessibility of the research results, including barriers relating to languages used to disseminate findings and release of reports in formats that produce limited utility for communities.

3. Inadequate analysis and misinterpretation of data

The analysis of sociodemographic and race based data requires researchers to have considerable awareness, knowledge and skills. Inexpert analysis reinforces harm to already marginalized and impacted communities. Researchers with expertise with lived experience or appropriate theoretical backgrounds, (such as critical race theory), may be less likely to misinterpret data or produce stigmatizing findings.

Including people with knowledge of systemic racism in the analysis and interpretation of data, can provide a clearer picture of associated/causal factors related to specific disparities. Unfortunately, for race-based health data, there is a historical tendency to associate disparities with genetic theories, which are unsupported by scientific evidence. Correlations such as these have been inaccurately used during COVID-19, most notably in Quebec, as well as in the U.S.A and U.K.

Access

4. Data inaccessibility and lack of access to health improvement

Historically, Black communities have been accessed to participate in numerous data collection exercises but have not had access to improved health outcomes as a consequence. Existing data has not been effectively used within provincial health administrative datasets and data that has been previously collected remains inaccessible to communities capable of doing research to better understand the nuances within the data. There are notable exceptions with specific organizations, including hospitals and several [Community Health Centre's](#) (CHCs), who have used equity data to improve health outcomes for racialized and marginalized communities they serve. However, overwhelmingly, data has not been used effectively to identify the systemic issues that bring about health disparities and the role institutions play in producing those disparities

Protection

5. Lack of trust, transparency and protections

There is a clear lack of trust; communities are concerned that data may be used against Black communities, repurposed, sold or monetized. These concerns stem in part from a lack of transparency at the provincial level in clarifying how data will be used. Concerns have been heightened by the province's recent deviations from compliance with existing privacy regulations, which have been overruled during the enactment of the *Emergency Management and Civil Protection Act*.¹³

The Framework

The integration of communities as partners in data collection and analysis for action improves the quality of the data and the effectiveness of any intervention. The E-GAP framework focuses on the COVID-19 data collection but it should be regarded as a foundational document for all race based and sociodemographic data collection. These data and information are collected in many different modes including research, monitoring and surveillance, surveys, statistics, cultural knowledge and more.

There is growing agreement that Black communities should own data being collected throughout and after this pandemic. The Ministry of Health, Ministry of Long Term Care, Public Health Units and all other agencies collecting sociodemographic data currently act as the data stewards. The preferred longer-term strategy for many would be Black communities to become the data owners and stewards in alignment with efforts to achieve data sovereignty.

The E-GAP model is structured around community needs and explicit partnerships. In an effort to better utilize findings from the data for systemic change and to reduce or eliminate additional harms towards the researched communities, data governance models prioritize community ownership.

The E-GAP framework does not directly comment on the principles that should be used for data collected on Indigenous peoples. The Province of Ontario should be in direct discussions with Indigenous populations about the collection and use of their COVID-19 data.

An effective data governance framework:

- Establishes and enforces standards, including definitions and technical standards
- Develops and enforces policies regarding the creation, collection, access, delivery, monitoring, measurement, management and auditing of data
- Sets out a data governance structure – defining the various roles, responsibilities and accountabilities
- Establishes an appropriate technological infrastructure, that allows for ease of access, cleaning, transformation, delivery and monitoring of data
- Reinforces the necessity for data to be used for action around addressing structural and systemic inequities

The E-GAP model relies on the development of a Community Governance Table as the structure to ensure continued engagement, adequate governance, improved access and better protections for Black communities.

Engagement

The first step should be that the Ministry of Health begin a province-wide community engagement process that involves broad consultation with community members, leaders and organizations. Meaningful engagement must focus on development of infrastructure that allows communities to collect, store, manage and analyze their own data.

- Additionally, strategies must be in place to facilitate community engagement at the regional level to accurately capture the nuances and differences in communities that may exist.
- This process must be documented, publicly and transparently reported.
- Community engagement must be continuously carried out in an accessible manner that allows broad input from key stakeholders.

Governance

The E-GAP model envisages the development of infrastructure that allows communities to collect, store, manage and analyze their own data. The Community Governance Table would be on the front line of building transparent accountability. As the data stewards, the Ministry of Health and Public Health Units are considered accountable to Black communities. Consultation with the Community Governance Table should be done prior to the release of all reports to ensure that reporting does not further stigmatize marginalized communities.

The Community Governance Table would have a number of functions:

- Building the individual and systemic capacity for continued respectful engagement in data collection, analysis and utilization through:
 - Professional development, training and tools,
 - Standards of excellence, and
 - Access to equitable funding

This table will advise the province and local public health units on:

- Community Engagement
 - Developing regional outreach and engagement strategies
 - Ensuring representation from various members within Black communities
 - Ensuring concerns are surfaced and addressed
- Data Collection
 - Training for staff implementing collection tools
 - Revisions to current tools
 - Information shared with respondents regarding data storage

- Ensuring participation is voluntary
- Methods to improve response rates
- Analysis
 - Disaggregated by race
 - Data suppression
 - Utilization of existing and new data to address inequities
 - Intersectional analysis of the data (race, ethnicity, gender, income, etc.)
- Reporting
 - Ensuring public reporting does not cause further harm to communities
 - Monitoring the effects of public reporting
 - Accessibility of reporting to people who identify as Black (language and accessibility for individuals with disabilities)
- Utilization
 - Ensuring the data collected is used to address systemic racism, structural inequities and improve health outcomes
 - Community-led research
 - Community-led responses
 - Limitations on access to the data for researchers affiliated with universities and private sector
 - Setting targets to address health disparities and monitoring progress
 - Monitoring of misuse of the data
- Management
 - Storage of data
 - Data sharing agreements
 - Approvals for research submissions
- All data collected should be exempt from ownership or access by private enterprises with interests in repurposing or selling the data without the express consent of communities
- The governance table will establish a set of approval criteria that permit or deny access to all data governed. Additionally, this table will determine criteria external researchers must adhere to.

Data partnerships

The Community Governance Table would oversee the establishment of “**Data partnerships**”¹⁴ - which adopt co-governance models:

- Involves parties with mutual data needs who interact on a horizontal level
- Requires perception of mutual benefit and confidence in the security, confidentiality and quality of data
- Leadership provides vision, guidance and resources required to facilitate data sharing
- Formal sharing arrangements and joint data governance structures facilitate well-functioning data partnerships

Community Data Trust

The Community Governance table would also promote “**Community Data Trust**” within a research community:

- May include shared infrastructure or platforms, allowing members to upload data that is compiled, archived and distributed
- Shared data sets retain a formal owner

Access

The E-GAP framework requires that capacity is built in communities to use their data. In addition there need to be transparent pathways for access to data. There will be a need to actively facilitate access to and the use of data by communities.

E-GAP framework also requires a process that permits or denies access by external researchers or organizations based on an approval criteria. Similar to the process of an REB, researchers or organizations seeking access to the data being gathered and managed by the Community Governance Table must ensure they meet the prerequisites needed to access the data. This will apply to existing data and new collection endeavors.

- All research initiatives must meet and align with the principles established in the [Data Standards for the Identification and Monitoring of Systemic Racism](#)
- Research priorities must center the needs of Black communities
- Research should focus on solutions and improvements in health
- Research must acknowledge and address the root causes of inequities, the structural inequities and systematic differences in social, economic and environmental resources and assets that affect health and well-being
- Communities must be consulted when developing research protocols and be kept informed during implementation.
- Communities must be involved in conducting the research, with the additional purpose of building capacity within community.

- Community consent to additional/secondary use of sample beyond the original project is required, together with agreement on storage and ultimate destruction of samples.
- Advance drafts of research reports should be distributed to the community to identify community views.

Protection

One of the major ways that communities can be protected is through the ownership of their data. Data sovereignty for Black communities is a way of facilitating protection. The Province should begin working with Black communities to establish timelines and milestones for an independent data management system that supports community ownership of data. It should also develop systems to help communities monitor and influence the use of existing data resources.

The Community Governance Table should have a focus on developing the specific protections that need to be in place to protect communities from the misuse of data in lieu of full data ownership. A subsection of this Governance Table will be devoted to specifically developing the infrastructure needed to support this component of the work beyond COVID-19

A function of the Community Governance Table will be to accept, review and make decisions on submissions from external entities or individuals seeking to access this data. Mechanisms for terminating the agreements and transferring the data to researchers or organizations will be built into approvals to ensure appropriate uses of data throughout the research initiative timeline.

The E-GAP framework suggests that all data collected provincially must reside in Canada to protect individual's private information and comply with provincial privacy regulations. Individuals must fully consent to sharing their data and be made aware of their rights to withdrawal their data at any point during the collection.

Implementation of E-GAP

There are a number of actions necessary for the E-GAP model to be realized. These are listed to help Government plan the implementation.

- Community Engagement
 - Provincial government and regional public health units must begin a continuous and long-term strategy for effective collaboration with community based organizations, leaders and members on current or future race based and SES data collection initiatives
- Stakeholder engagement

- Provincial, regional health and local (e.g. Ontario Health Teams) system agencies who have mandates to improve health outcomes for all populations, including Black communities, must be involved in collection and application of data
- Engagement should include clinicians, health professionals, health service providers, researchers, academics and more
- Education
 - Information must be made available online and through media that assists in articulating the rationale and development of this governance framework
 - Educating all key stakeholders who are consulted during the community engagement process on the origins of this governance framework, its goals and the other frameworks that have informed its development
 - Promoting and supporting discussions that seek to understand, strategize and leverage alternative community based forms of data management
- Legislation
 - Amendments to legislation can help address barriers related to Black communities holding their own data.
 - These legislative changes should focus on privacy laws, jurisdiction, capacity and access to information
- Establishing Community Governance Table
 - Creating a governance table to provide oversight on the collection, analysis, management and utilization of data
 - This governance table must be comprised of community leaders and health equity professionals with technical expertise in the areas of;
 - Sociodemographic data collection, analysis and use
 - Community-based research
 - Health system operations
 - Health policy and personal health information in the Canadian context
 - Data AI experts
- Change the Data Steward
 - Establishing a timeline with the Provincial and Federal Ministries of Health, as well as other sectors responsible for institutions that hold data related to Black and racialized groups, (e.g. CIHI, ICES, Health Canada, Statistics Canada), to adopt the guidelines around proper collection and use of Black and racialized data outlined in this framework
 - Access of this data to racialized communities should be permitted, irrespective of where the data is held.

- Transferring data to the stewardship of Black community based organizations
- Data Sharing Agreements
 - Until data sovereignty is achieved it is important that Black communities identify ways to protect and manage the way their data is shared or linked to other systems
 - In cases where Black communities' data is held by external entities- including government- the creation of data sharing agreements by the governance table will assist in monitoring data sharing

It is critical for the Ministry of Health, the Ministry of Long Term Care and the provincial government of Ontario to understand that the concerns, processes and strategies for organizing surfaced in this framework are non-negotiable. The data collection process that is currently being initiated poses many threats to Black communities and represents new potential harms to some of the most marginalized communities already dealing with the effects COVID-19. Many new ways of thinking have been spurred by COVID-19. This data governance and accountability framework may start now but is a fundamental requirement for a modern democratic Province striving for equity for its diverse population.

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E-GAP Framework Core Engagement Questions

August, 2020

This document contains a list of core engagement questions that will be used to gain feedback from stakeholders involved in the outreach strategy for the E-GAP Framework.

The goals of the outreach process and sharing of the draft framework is to:

- Gather feedback from a diverse list of stakeholders whose work will be impacted by the collection of race and sociodemographic data in Ontario
- Improve the E-GAP framework
- Get buy-in and endorsement of E-GAP framework

Questions:

1. Are there important additional issues or concerns that are not included in the framework concerning race-based/socio-demographic data use?
2. Are there any additional components you would like to see added to any section of E-GAP :
 - a. Engagement
 - b. Governance
 - c. Access
 - d. Protections
3. Is there any language or framing within the E-GAP 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/socio-demographic 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?

Let's talk about race based data collection



THE ISSUE:

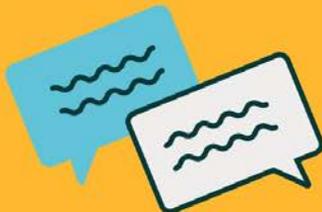
Ontario has started collecting health and sociodemographic data, including race based data, to understand how the COVID-19 pandemic is moving through our communities. Data collection is an important tool in challenging inequity. Ethically used, the data should create pathways to better health for all. If data collection doesn't lead to better health for impacted communities, these processes are not beneficial. The goal of data collection is to support data-driven action and accountability.

WHY THIS MATTERS:

Anti-Black racism, systemic inequities and discrimination will not end with the COVID-19 pandemic. Black communities are concerned about historic and current processes, [i] where data and knowledge is extracted from Black people, while that data is not owned by or accessible to Black communities. [ii] Many concerns have been raised, including historical misuse of data, surveillance, and privacy. Additionally Black communities say that even where data is currently collected, movement has been slow and there has been no meaningful improvement to Black life. Black communities don't have the same response to data collection. Data collection is both opposed and supported. Where collection is supported, discussions are taking place about data sovereignty and ownership.

A group of health equity experts and leaders in Black health have drafted a data governance and accountability framework called the **Engagement, Governance, Access and Protection Framework** or **E-GAP**. The framework's goal is to inform sociodemographic data collection in health, and support the sector in developing high quality processes and procedures.

JOIN THE CONVERSATION:



We envision a future where Black, Indigenous and racialized communities redefine a "new normal" that prioritizes the health and well-being of historically marginalized people.

This framework is in alignment with long-term strategies that ensure Black communities play a central role in defining and determining governance of their own collective health.

We want to hear from you. Are you interested in contributing to the development of E-Gap? Join the conversation, contact: rbdwg2020@gmail.com

[i] REDE 4 Black Lives. COVID Conversations (2020).

[ii] Black Public Health Collective (2020). Open Letter: Race Based Data is not Racial Justice.

BLACK PEOPLE MUST DEFINE HOW OUR HEALTH DATA IS GOVERNED AND USED.



Join the conversation. Email: rbdwg2020@gmail.com

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- ¹² The Jane Finch Community Research Partnership Principles outline expectations regarding respectful and ethical behaviour by researchers who work in the community. Read more: <https://janefinchresearch.ca/>
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