

ENGAGEMENT, GOVERNANCE,

ACCESS, AND PROTECTION (EGAP)

A Data Governance Framework for Health Data Collected from Black Communities in Ontario

EGAP





LOCATING **OURSELVES**

This report was written on the traditional lands of Indigenous Peoples. Much of its development took place in what is now known as Ontario, on the traditional territories of the Mississaugas of the Credit, the Anishnaabeg, the Chippewa, the Haudenosaunee, and the Wendat. We honour Indigenous Peoples as keepers of these lands and recognize the impact of ongoing colonial projects on their ways of life.

We locate ourselves on these lands as treaty people. Many of us are Black people, who have arrived on Turtle Island through various processes, including the transatlantic slave trade and the afterlives of colonization. We are grateful to live and work on these lands. We recognize and honour our role in upholding treaties and stand in solidarity with Indigenous Peoples.



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The Black Health Equity Working Group

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FOREWORD

Ideas about health data governance may not readily provoke interest for those not already immersed in them. Of more immediate concern for many Black communities are daily lived experiences of anti-Black racism, overt displays of violence, and discrimination within the health system. But data shapes all aspects of contemporary existence, informing policy development and determining what the world around us looks. Our aim here is to address where these two issues meet, for anti-Black racism runs through the realm of health data, with consequences for people's lives. The Engagement, Governance, Access, and Protection (EGAP) Framework seeks to ensure that data from Black communities is properly collected, protected, and used to promote equity.

Data is not just an academic tool or abstract entity. It's our information. Locally and globally, Black people have been quantified, analyzed, utilized, and discarded. We continue to be monitored, surveilled, targeted, and restricted. Data extraction, deployment, and manipulation have been used to justify and bolster slavery, violence, and anti-Black racism. White supremacy continues to flourish under existing information regimes that further entrench us in racial capitalism.

This is why we need control of our collective information. In today's digital world, data collection is pervasive, and all systems run on data. Data has real-world implications for Black lives and communities inside and outside the health system. Going forward, it must be used in ways that recognize our humanity and our lived experiences, never wavering from what should be the primary objective of collecting health data: to improve health outcomes.

We must continue to challenge what institutions and governments accept as evidence for change. Our voices, our stories, and our lived experiences are equally, if not more, valid than what can be quantified as evidence for action. We need race-based data that demonstrates how anti-Black racism is damaging the health of our communities—and even more importantly, that can be used to evaluate future interventions aimed at addressing racial inequities within and outside the health system that impact Black population health.

The decisions we make about data now will have generational impacts. The EGAP Framework is not a final iteration but rather another tool in a lineage of advocacy and resistance aimed at affirming, uplifting, and centering Black lives. It is one part of the journey towards liberation for Black communities.

We wish to thank all those who contributed to the production of the framework, especially the respondents who took the time to consider the initial draft. Your critical comments and insights guided us in strengthening and refining this document. There are many voices and ideas still to be heard, many considerations to be addressed, and we encourage Black communities and those working in health to continue the conversation.

– Black Health Equity Working Group



The graphic features a large orange circle on the left. Inside the circle, the word "EXECUTIVE" is written in a light teal, sans-serif font, and "SUMMARY" is written in a larger, bold, dark teal, sans-serif font. To the left of the orange circle is a smaller, solid teal circle. Below the orange circle is a teal curved line. To the right of the orange circle is a grid of 18 small teal dots arranged in three rows and six columns.

EXECUTIVE SUMMARY

Advocates have long called for the collection and responsible use of race-based data in Ontario's health system. When collected and used in accordance with best practices, race-based data in health can be used to dismantle structural racism:

- by uncovering inequities,
- by developing policy and practice to tackle these inequities,
- by monitoring and evaluating the effectiveness of interventions,
- by holding authorities accountable for improving outcomes, and
- ultimately by eliminating structural racism from systems.

The COVID-19 pandemic has amplified existing inequities resulting from anti-Black racism and disproportionately impacted Black communities in Ontario. Black communities experience higher infection rates, worse health outcomes, and more financial distress as a result of layoffs and reduced work hours.¹ Ontario has mandated the collection of race-based data for COVID-19 cases,² and as part of its data collection strategy it has engaged in community consultations. However, Black communities have identified significant concerns with the process as well as who is able to access and use the data.

The Black Health Equity Working Group, made up of Black health sector leaders and health equity experts, began meeting early in the

pandemic to develop a governance framework for health data collected from Black communities in Ontario. The objective was to address concerns from Black communities about the continued extraction of data from them without the return of tangible benefits.

After creating a draft framework, the working group carried out a series of stakeholder consultations with Black community members, researchers and academics, public health professionals, and health system organizations in Ontario to gather critical feedback and inform revisions. This report introduces the Engagement, Governance, Access, and Protection (EGAP) Framework, which outlines guiding principles in four areas of focus:



E

ENGAGEMENT

Genuine, cyclical, accessible consultation with communities regarding data collection, management, analysis, and use.



G

GOVERNANCE

Community decision-making about engagement processes and data collection, management, analysis, and use, achieved through the establishment of Community Governance Tables.



A

ACCESS

The right of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right.



P

PROTECTION

The safeguarding of all individual rights and types of data, including identifiable, de-identified, and anonymized data.

The EGAP Framework envisages Black communities gaining control over their collective data. Key to this is the establishment of Community Governance Tables, decision-making bodies on the front lines of building accountability. Community Governance Tables representative of local communities must be developed in various locations across the province. External parties will be required to present plans for community engagement, data collection, data management, data analysis, and data use to the relevant Community Governance Table, which will approve or reject them. Only with approval can the external party proceed with the work. Thus, data stewards and users will be answerable to Black communities through the Community Governance Tables, which can be developed and adapted for different circumstances and organizations.

The principles in the EGAP Framework have relevance beyond the COVID-19 pandemic, and the framework will continue to evolve as a living document. This report outlines steps that are required to implement the framework. It is offered as a starting point for anyone involved in the collection, management, analysis, and use of race-based data for health purposes, including governments and related agencies, health system organizations, research

institutes, and community-led organizations. It is also intended for Black community members, who are directly affected by the issues, questions, and recommendations for action raised here.

The collection of race-based data should never be the end goal: it must be used to create pathways for dismantling structural racism and advancing health equity.



INTRODUCTION



“Data is currently being collected, but it’s not being used to actually improve Black people’s lives.”

“Data collection is inescapable in this age of big data. We have to be a player at the table. The tables will meet even without us. But we are deeply concerned about the stories that may be told without us.”



This report introduces the Engagement, Governance, Access, and Protection (EGAP) Framework, developed by Black health sector leaders and health equity experts in Ontario to guide the collection, management, analysis, and use of race-based data from Black communities in ways that advance health equity.

Health equity is achieved when everyone can reach their full potential and are not disadvantaged by oppressive systems (e.g., social, economic, political, cultural) and conditions.
- World Health Organization



This framework is offered as a starting point for anyone involved in the collection, management, analysis, and use of race-based data for health purposes. Governments and related agencies, health system organizations, research institutes, and community-led organizations are encouraged to consider this guidance and to use and adapt the framework for their own contexts. This document is also intended for Black community members, who are directly affected by the issues, questions, and recommendations for action raised here.

Data comes in many different modes, including research, monitoring and surveillance, surveys, statistics, cultural knowledge, and more. Race-based data is collected or included in health-related information in a number of ways. It can come through collection of patient-level data in research projects directly targeted at Black communities; through research projects that collect patient-level data from people of a variety of races in order to make comparisons; through ongoing patient-level data collection by institutions and government (e.g., COVID-19, hospital, and Community Health Centre data collection); through linkage of health-related data to other data with race variables (e.g., census or citizenship and immigration data); and through use of community identifiers (e.g., neighbourhoods with Black populations). These forms of race-based data will be dealt with differently when applying the framework.

What must remain consistent is the centering of improved health outcomes for Black communities. Ontario is home to a diversity of Black communities, and the needs of a community in any given geographic area will vary with context and location. Community needs must be defined by the people who live in that community.

Data sovereignty entails the right to govern data collection, management, analysis, and use. It is a key part of self-determination.



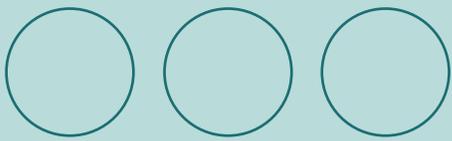
Driving the EGAP Framework is a desire for data sovereignty, where Black communities have full ownership and control over their collective data. This framework moves Black communities closer to data sovereignty through guiding principles in four areas of focus:

- **Engagement**—genuine, cyclical, accessible consultation with communities regarding data collection, management, analysis, and use;
- **Governance**—community decision-making about engagement processes and data collection, management, analysis, and use, achieved through the establishment of Community Governance Tables;
- **Access**—the right of communities to access their collective data and to determine who else can access it, along with the capacity building required to enable this right; and
- **Protection**—the safeguarding of all individual rights and types of data, including identifiable, de-identified, and anonymized data.

Race-based data must be collected to illuminate and measure the effects of structural racism on all areas of health. But then, crucially, action must follow, with the aim of dismantling anti-Black racism and producing health equity for communities. Without effective action to address health and other social needs, data collection, surveillance, and commodification in service of institutions becomes an example of anti-Black racism in and of itself.



Anti-Black Racism and Health



Centuries of anti-Black racism have harmed Black communities worldwide. Seeded in the transatlantic slave trade and ongoing European colonial projects, this type of racism has entrenched conditions of inequality for Black populations across Turtle Island. Despite national discourse to the contrary, Canada was both a colonial endeavour and a site of slavery,³ and racism is a lived reality for Black communities throughout the country.

“Anti-Black racism is a system of inequities in power, resources, and opportunities that discriminates against people of African descent. Discrimination against Black people is deeply entrenched and normalized in Canadian institutions, policies, and practices and is often invisible to those who do not feel its effects. This form of discrimination has a long history, uniquely rooted in European colonization in Africa and the legacy of the transatlantic slave trade.”⁴

Black communities experience anti-Black racism in many sectors, from education to employment and income, from policing to the criminal justice system. Health impacts follow in several ways.

FIRST

Experiences of racism and exposure to individual and structural violence⁵ add up; the cumulative effects can result in chronic stress and trauma, with repercussions for mental and physical well-being.⁶

SECOND

Access to material resources that contribute to health and well-being is restricted. For instance, racism in the labour market restricts employment opportunities,⁷ suppressing income levels in Black communities and engendering food⁸ and housing⁹ insecurity.

THIRD

Racism in the health system affects the treatment of Black individuals and can even discourage them from accessing services.¹⁰



In this way, anti-Black racism contributes to higher risks of illness, reduced access to quality health services, and worse health outcomes for Black communities.¹¹ These effects even reach across generations, through the perpetuation of poverty¹² and the impacts of chronic stress during pregnancy.¹³

Anti-Black racism has been recognized as a public health crisis by several high-level health institutions, including the Pan American Health Organization and Organization of American States.¹⁴ It has also been recognized as a health issue particular to Canada by the city of Toronto,¹⁵ the National Collaborating Centre for Determinants of Health,¹⁶ the Public Health Agency of Canada,¹⁷ and the United Nations Working Group of Experts on People of African Descent.¹⁸

Race is a social construct that grew out of European colonization to justify the domination of a “white race” over others. The idea of race has no scientific foundation. The main way that people perceive race is through physical features that provide little to no significant information about an individual’s biology or genetics. Racial categories shift over time and from place to place, reflecting societal configurations of power.



An important tool for challenging health inequities is the collection and use of sociodemographic data, which captures individual characteristics such as race, income, education, age, gender, and language. This allows data to be analyzed by subcategory, such as race, which can aid in identifying inequities and implementing interventions to address them.

Sociodemographic data in the health system is routinely collected in many countries, including the United Kingdom and United States, and the World Health Organization has called for the implementation of “national and global health equity surveillance systems with routine collection of data on social determinants and health inequity.”¹⁹ Canada notably trails when it comes to the availability of sociodemographic data with which to measure health equity.²⁰

Race-based data is a type of sociodemographic data. In Ontario, the Anti-Racism Act²¹ mandates standardized race-based data collection in several sectors, including education, child and youth services, and the prison justice system. Crucially, however, the Act does not mandate race-based data collection in health. Similarly, the province’s Anti-Racism Directorate has produced *Data Standards for the Identification and Monitoring of Systemic Racism*,²² covering the collection, management, and use of race-based data, including personal information, but it has not produced specific standards for the health sector.

Guidance for the health sector is essential. Adding further urgency is the COVID-19 crisis, which has amplified existing inequities resulting from anti-Black racism, with devastating

impacts on Black communities. Several regional public health units, including Peel, Middlesex-London, Toronto, Sudbury, and Ottawa, independently initiated collection of race-based data in relation to COVID-19.²³ The Ontario Ministry of Health later amended the Health Protection and Promotion Act (Paragraph 11, Section 5)²⁴ to mandate collection of information on race, income level, household size, and language for individuals who test positive for COVID-19 or any other new coronavirus. According to the ministry, collection of this data for COVID-19 cases is necessary to:

- A** Ensure a more complete picture of data collection related to COVID-19.
- B** Reduce inconsistencies in data collection efforts.
- C** Inform effective public health practices and interventions in response to COVID-19.²⁵



Black communities have not responded uniformly to these changes. Data collection is both supported and opposed. Among community members in support, even those who have long advocated for the collection and use of race-based data, the province-wide implementation does not come without reservations. The exclusion of Black communities in critical framing, planning, and implementation discussions is problematic. Concerns continue to be raised about historic and current processes wherein data and knowledge are extracted from Black people but that collective information is neither owned by nor accessible to Black communities. Other issues relate to historical misuse of data, surveillance, and privacy.²⁶

Additionally, Black communities point out that data must be used ethically and appropriately to create pathways for advancing health equity. Thus far, despite the collection of data illustrating the severity of the COVID-19 crisis for Black communities in places like Ottawa²⁷ and Toronto,²⁸ resource redistribution to hard-hit communities has been inconsistent. As a result, improvements in health outcomes for Black communities are not consistent across the board.





Race-based Data: Benefits and Best Practices



Race-based data in health should be used to measure the effects of racism on communities and to monitor the effectiveness of solutions being implemented to transform health systems.



When collected and used in accordance with best practices, race-based data in health can be used to dismantle structural racism:

- by uncovering inequities,
- by developing policy and practice to tackle these inequities, by monitoring and evaluating the effectiveness of interventions,
- by holding authorities accountable for improving outcomes, and
- ultimately by eliminating structural racism from systems.

From the outset, communities should be involved in plans to collect race-based data connected to them. Data collection needs to be tied to a meaningful and deliberate plan for acting on identified inequities, and this plan should be informed and endorsed by the communities it will directly impact.

Individuals need to understand why they are being asked for information about race in order to be able to provide informed consent or refusal. Without a fulsome explanation, they may think the collected information will lead to discrimination in their immediate medical care.²⁹ Data collectors must be trained to explain the importance of the data for reducing health inequities—namely, to ensure the best possible health services and outcomes, regardless of race—where and how the data will be stored, who will see the data, and what protections will be in place. They should also provide individuals with additional resources that clearly explain the benefits of the data and answer questions about data collection, use, and storage. These resources should be independent of the institution or facility where data collection occurs.



Illness does not naturally result from racial differences, because race is an idea with no biological basis. But race still has an impact on health because of racism, a major cause of inequities and social determinant of health.³⁰

The collection of self-reported data, where individuals define their racial and other demographic identities, is a best practice. Clarification about what information is being requested (i.e., what is meant by “race”) and accommodation of mixed or multiple racial identities is recommended.³¹ However, a person’s identity does not necessarily align with how they are seen. In health, as in other systems, people tend to be treated according to how close to or far from whiteness they are perceived to be. Therefore, it may also make sense to collect data about socially assigned race, which reflects how society categorizes a person; it is “the ‘race’ to which individual people and institutions in our society react, the on-the-street race that is automatically registered by people socialized in our race-conscious society and that operates in our daily lives to either constrain or facilitate opportunity.”³²

Data collectors should strive to ensure that individuals feel safe disclosing information. They should never challenge or deny a person’s identity,³³ nor should they assign a racial identity to a person. In formulating racial categories for reporting the data, researchers should work with communities to ensure their relevance. For example, “Black” alone may not suffice, whereas including the examples of African, Afro-Caribbean, and African Canadian descent may more fully capture the ways people identify.³⁴

Individuals have indicated they would prefer not to be asked for sociodemographic data at each medical visit, especially given that identities like race are not likely to change.³⁵ Therefore, where this data has already been recorded, collection does not need to reoccur. Further, the Black Health Equity Working Group has recommended that this information be collected during OHIP registration or renewal, which could lay the foundation for high-quality, representative data to measure inequities at the population level.³⁶ This would ensure the greatest opportunity for individuals to self-identify while facilitating analyses that can provide direction to health systems for improving care and reducing inequities.



Intersectionality refers to the multiple and overlapping identities that each individual has. These lead to unique experiences, opportunities, and challenges for different groups. Anti-Black racism is experienced differently depending on gender, immigration status, sexual orientation, age, disability, ethnicity, and more.

Collection of race-based data in health is just one step of the process. It can surface inequitable health outcomes, as well as inequalities in access to quality health services, that may otherwise remain hidden from public view. Analysts must have considerable knowledge and skills when working with the data. Having related expertise, including lived experience or a critical theoretical background (such as in critical race theory), and an intersectional approach can better equip analysts to interpret the data. Consulting with affected communities during data analysis can also provide a clearer picture of associated and causal factors related to specific inequities, helping avoid reductionist findings that suggest Black people are naturally more likely to fall ill by surfacing explanatory variables such as socioeconomic status, housing conditions, neighbourhood environment, and types of employment.

In conducting any analysis, the purpose of the data in advancing equity must be kept front and centre. The data should be used to assess health systems and institutions “and their progress towards social inclusion and cultural safety.... We're not measuring inherent deficiencies in different groups: we're measuring the negative impacts of longstanding structural

racism and social exclusion.”³⁷ What the data provides is a picture of the effects of structural racism—not race—on Black communities.

Once inequities are made visible, understanding and action are needed to truly reap the benefits of the data. Race-based data can help shape the health system to truly serve Black communities by informing the creation of programs targeting health inequities, the development of services tailored to the needs of communities, and resource allocation within health systems. Interventions can be assessed through subsequent data collection to determine if they have met their goals. Race-based data can also be used to combat racist accounts, fight for change, and promote transparency in government and other institutions: “Only through regular reporting can we hold the health system accountable for improving access and outcomes for racialized communities.”³⁸

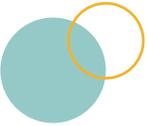
Through race-based data, researchers can understand and evaluate communities' health service needs, access to health services, and health outcomes. Working to eliminate structural anti-Black racism can prevent health inequities, improve quality of life, and save lives.



Race-based Data: Issues and Concerns



Without an explicit focus on dismantling structural racism, the collection and reporting of race-based data can be detrimental to Black communities.



Historically, data extraction from Black communities has not led to improved health outcomes. In some cases, structural violence has simply been reproduced.

Used unethically and improperly, race-based data can be wielded in support of inaccurate and stigmatizing portrayals of communities. Narratives that focus on blaming Black individuals or communities for problems that actually stem from structural anti-Black racism do harm and lead to further inequities. Black community members continue to express concerns about data misuse that contributes to the pathologizing of their communities and takes the place of anti-racist action.³⁹ A historical tendency in the analysis of race-based data has been to associate inequities with scientifically baseless genetic theories. This has occurred during COVID-19, where even health officials in Canada have stated that the higher rates of infection afflicting particular communities could be related to genetics rather than structural factors.⁴⁰

Concerns that data may be used against Black communities also stem from a lack of transparency about how data will be used. In Ontario, insufficient community engagement by all levels of government has raised concerns about accountability to those who will be impacted by the analysis, reporting, and responses to the data collected during COVID-19. These concerns have been heightened by the province's recent non-compliance with existing privacy regulations, which have been overruled by the enactment of the Emergency Management and Civil Protection Act.⁴¹

From April until mid-August in 2020, police were given access to a database with information about who had tested positive for the novel coronavirus,⁴² which the government said would protect first responders and the public.⁴³ Experts questioned the efficacy of this health intervention as well as the ethics of providing police with access to the data.⁴⁴

Community members expressed apprehension about the ongoing surveillance of Black communities predating enslavement and continuing to the current time,⁴⁵ and voiced concern that this development amplified discrimination faced by Black communities as they found themselves caught in the juncture of racism and COVID-19 stigma.⁴⁶ Access to the database was rescinded only after a legal challenge was filed.⁴⁷

Collecting data and then allowing it to languish is another problem. Ontario's health administrative data sets have not been effectively used and remain inaccessible to communities capable of conducting research and analyses to better understand the nuances within the data. The failure to include impacted populations in the data analysis process has led to

the implementation of ineffective interventions that do not consider the layered barriers faced by Black communities. Notable exceptions exist at specific organizations, including hospitals and Community Health Centres in Toronto, Ontario, which have used equity data to improve health outcomes for communities they serve.⁴⁸ However, overwhelmingly, data has not been put to use in identifying the systemic roots of health inequities and the role played by institutions in producing those inequities. In addition, community members have pointed to the inaccessibility of research results, including the incomprehensibility of the academic language used, the release of reports in formats of limited utility for communities, and even a lack of reporting back to communities.



Data sets become anonymized when they are stripped of personally identifying information, such as people’s names and dates of birth, to the extent that they can no longer be connected to particular individuals. Done effectively, anonymization protects individual privacy. Significant care must be taken, however, given the amount of personal information available online today that can be linked back to data and expose individuals’ identities.

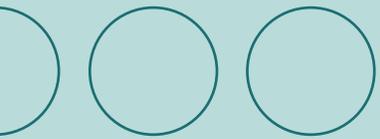


The digital age has spurred serious concerns about data security and the repurposing, selling, and monetizing of data. Health records are big business. The transition to electronic medical records in Ontario opened the door to the mass sale of patient files, where doctors or clinics have sold anonymized patient data to corporations without patient knowledge.⁴⁹ Among many problems related to practices like this is the risk of re-identification, where de-identified or anonymized data can be linked to other available information and reveal who it belongs to—which, for Black communities, could lead to enhanced discrimination.

These issues have led to divergent perspectives in Black communities on the collection and use of race-based data. Some people believe the risk of harm outweighs the potential health benefits. The Black Health Equity Working Group encourages engagement with these critical perspectives and the continuance of discussions about the collection and use of race-based data in Ontario's health system. Solutions that address community concerns must be sought and implemented.



EGAP Framework





Framework Development

Advocates have long called for the collection and responsible use of race-based data in Ontario's health system.

In January 2020, the second Black Experiences in Health Care Symposium convened in Toronto, Ontario, continuing discussions about the necessity of collecting and applying race-based data to address the ongoing poor health outcomes experienced in Black communities. The final symposium report put forward several recommendations, noting that the application of race-based data in the formulation of a Black health strategy is imperative to improving provincial health.⁵⁰ The following April, after the global emergence of COVID-19, close to 200 organizations endorsed an open letter to Ontario's Minister of Health calling for the collection of such data.⁵¹ The Black Health Equity Working Group also sent a letter to the province, reiterating the urgency of race-based data collection and outlining steps to promptly implement it.⁵²

The provincial government announced in May that it planned to begin collecting race-based data to inform health system responses to COVID-19.⁵³ Meanwhile, the Black Health Equity Working Group was meeting to begin development of a governance framework based on community ownership of race-based health data collected from Black communities.

Data ownership is distinct from data possession. The holders of the data are not necessarily the owners of the data. Ownership is about the relationship between the data and the people it came from. Communities should have ownership of the data they create.

The working group was inspired by other models such as the OCAP® principles (ownership, control, access, possession) pioneered by the First Nations Information Governance Centre,⁵⁴ the CARE principles (collective benefit, authority to control, responsibility, and ethics) published by the Global Indigenous Data Alliance,⁵⁵ and the Jane and Finch Community Research Partnership Principles,⁵⁶ which outline expectations regarding respectful and ethical behaviour by researchers working in community.

The Black Health Equity Working Group also grappled with the elements required for an effective data governance framework as outlined in a review conducted by the National Collaborating Centre for Determinants of Health:

- 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;
- And reinforces the necessity for data to be used for action related to addressing structural and systemic inequities.⁵⁷

After drafting a framework based on the concerns and needs of Black communities, the working group carried out a series of stakeholder consultations with Black community members, researchers and academics, public health professionals, and health system organizations in Ontario. The goals of this outreach process were to gather feedback from a diverse list of stakeholders whose work will be impacted by the collection of race-based health data in Ontario, to strengthen and refine the framework, and to get buy-in and endorsement of the framework.

Employing a set of core engagement questions (see Appendix) and a variety of methods, including a Google Form, email, and virtual meetings, the working group held 30 stakeholder consultations, some of which included multiple participants. This process informed the next iteration of the framework and provided an opportunity to describe the level of agreement across stakeholders. Overall, respondents indicated strong commitment to the goals and principles of the EGAP Framework.

The Black Health Equity Working Group is committed to ensuring that the collection and use of race-based data does not further exacerbate the inequities and structural harm endured by Black people in Ontario. The working group aims to hold government officials and health system leaders accountable to Black communities and ensuring good governance and accountability in data collection, management, analysis, and use. The ethical use of race-based data is essential to advancing health equity in Black communities.

Framework Principles



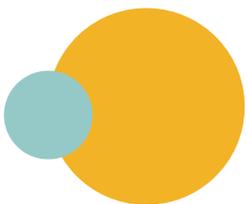
Harnessed for equity, race-based data can make a difference. Because it can provide a potent tool for improving the health of Black communities, a new governance framework for health data collected from Black communities in Ontario is proposed here: the EGAP Framework.

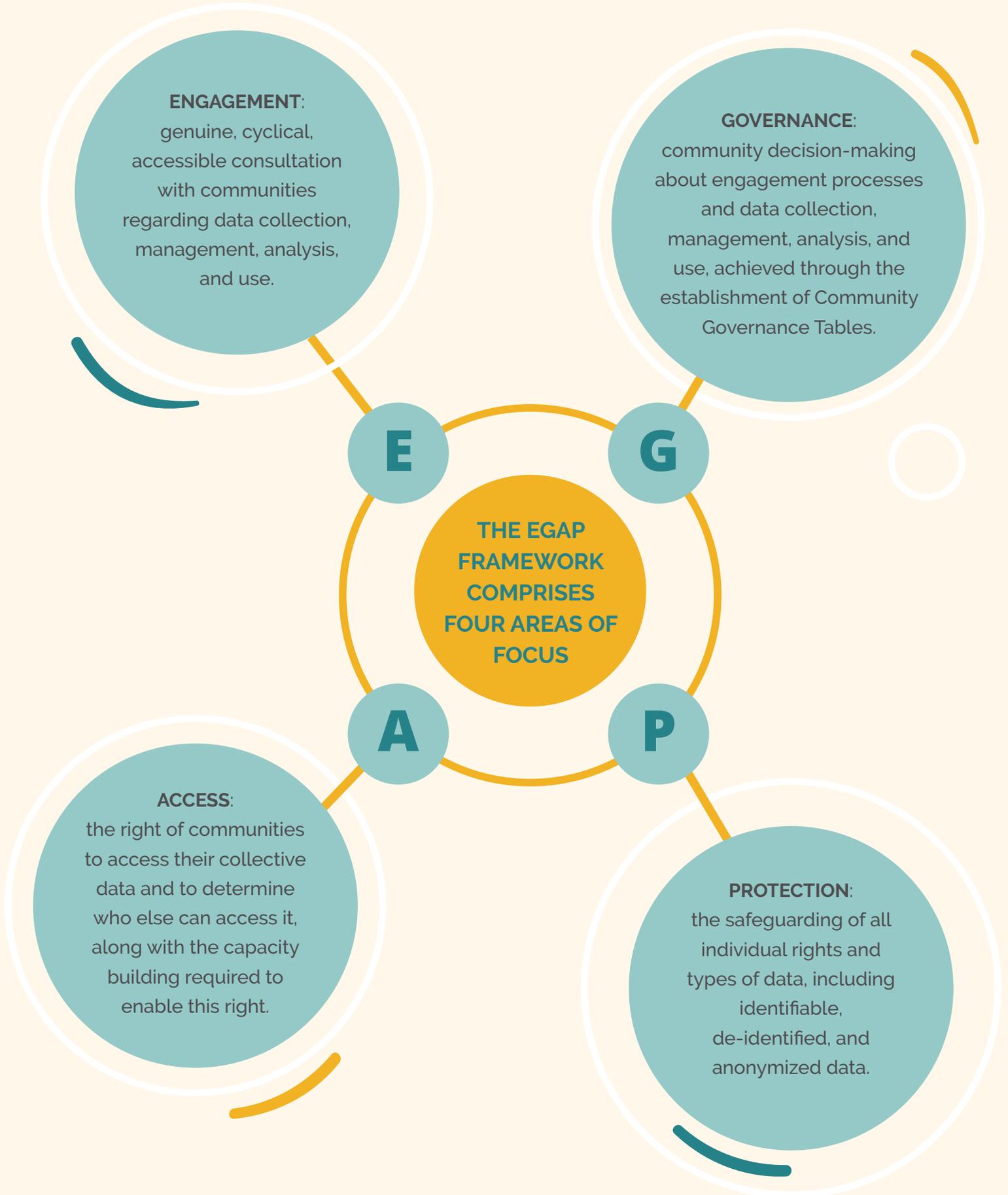
Data stewards hold or possess the data. They may or may not be the data owners.

Currently, individual patients technically own their data, but Ontario's Ministry of Health, Ministry of Long-Term Care, public health units, and all other agencies collecting data currently act as the data stewards.

The preferred longer-term strategy is for community-based Black-led and Black-serving health organizations to become both the owners and the stewards of the data. This would not negate individuals' ownership of their data, nor would it mean the removal of Black people's data from universal data sets. What community ownership and stewardship would do is reduce harms to affected communities and enable better use of data for systemic change.

At the heart of the EGAP Framework is a desire for data sovereignty for Black communities. Derived from the overarching right of self-determination, data sovereignty entails the right to govern data collection, management, analysis, and use. It means communities can decide what data is collected, who can access it, and how it can be used. By providing Black communities with greater control over their collective data, the principles outlined in the EGAP Framework bring these communities a step closer to data sovereignty.







ENGAGEMENT



An engagement process that involves broad consultation with Black community members, leaders, and organizations is essential. Any community groups with an interest in the issue should have the opportunity to play a role in the process. The aim is not simply to listen to people, but to ensure that projects reflect what is meaningful for communities and further health equity in ways that work for community members.

This means the engagement process must move well beyond the typical consultative approach, where limited input is sought from stakeholders, and government or organizations retain all decision-making power. Oftentimes in the health system, engagement is not participatory, it follows schedules and timelines that are convenient for institutions, and decisions are predetermined. Performative or self-serving forms of engagement and consultation will only deepen existing fissures between communities and institutions.

Processes that allow participation from only a select few individuals of a particular class or privilege, that ignore participants after initial planning with no accountability,⁵⁸ and that produce no meaningful outcomes are unacceptable. Likewise, a lengthy engagement process that serves only to stall vital action should be avoided.

Co-design is a participatory process in which stakeholders are an integral part of project planning to ensure established outcomes will meet community needs.



An authentic engagement process actually shifts power relations. A high engagement model, such as a co-design process, where communities develop their own processes and government or organizations provide the necessary support and resources, is recommended. Community-based research protocols, such as those configured for Toronto's Jane and Finch community,⁵⁹ may be considered in the development of effective engagement models.

Engagement should be cyclical and accessible, opening up space for participation from all parts of a community, including the most marginalized, in order to gather a diversity of Black perspectives. Provincial projects must ensure that strategies are in place to facilitate community engagement at regional levels to accurately capture differences that may exist between communities.





GOVERNANCE



The EGAP Framework envisages Black communities gaining control over their collective data. Key to this is the establishment of Community Governance Tables, which could be adapted for different circumstances and organizations. These decision-making bodies would be on the front lines of building accountability, and data stewards and users would be answerable to Black communities through them.

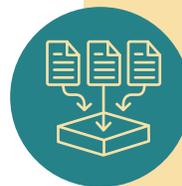
External parties would be required to present plans for community engagement, data collection, data management, data analysis, and data use to the relevant Community Governance Table, which would approve or reject such plans. Only with approval could the external party proceed with the work. Here are examples of topics to be addressed for each area:

COMMUNITY ENGAGEMENT



- regional outreach and engagement strategies
- achievement of adequate community representation
- recognition and addressing of concerns
- plans for continued community involvement in all stages of research

DATA COLLECTION



- collection tools and methods
- explanations of data use and storage for participants
- guarantee that participation will be voluntary and based on informed consent

DATA MANAGEMENT



- data storage and security
- privacy protections
- explicit agreement not to repurpose, share, or sell data

DATA ANALYSIS



- modes of data interpretation for focusing on inequities and their remedies
- application of intersectional approach (e.g., considerations of race, ethnicity, gender, sexual orientation, income, employment, household structure)
- formulation of categories
- decisions about data disclosure and suppression
- avoidance of harm to communities

DATA USE



- accountability to communities
- accessibility of reporting (e.g., considerations about language, report formats, individuals with disabilities)
- capacity building, training for emerging Black researchers, and resources to facilitate community-led research
- support for community priorities and responses
- targets for addressing health inequities and progress monitoring

Community Governance Tables must be developed in various locations across the province. Forming a Community Governance Table that reflects the heterogeneity of Black community members in a given region is important. This entails doing the work of understanding what the community in the area looks like, keeping in mind that Black people and communities self-define, and applying an intersectional approach to ensure adequate representation of the multiple experiences and layers of identity of community members. This may mean ensuring, for example, participation from Black migrants from the Caribbean and regions of Africa, along with Canadian-born Black community members. Community Governance Tables would also benefit from the inclusion of health equity professionals with technical expertise in areas such as sociodemographic data, community-based research, health system operations, health and personal health information policy, and data and artificial intelligence.

Decisions about the number and structure of these tables, along with their scope, must be determined and defined by communities.



ACCESS

Data access comprises two key aspects for Black communities: the right to access their collective data and the right to determine who else can access it.

Transparent pathways for communities to access their data without barriers must be established. Capacity and infrastructure needs must also be addressed. These may focus on building data literacy, providing training on accessing and analyzing data, and connecting with the requisite technology, especially in light of a digital divide that follows socioeconomic lines. Fully enabled data access can bring benefits to communities by informing the construction of new community priorities and providing evidence for use in advocacy efforts.

The EGAP Framework also requires a process by which communities can permit or deny access to external researchers or organizations. This should apply to existing data and new collection endeavours. The aim is to establish adequate protections and accountability from external parties without creating unreasonable impediments to accessing and working with the data.



Community Governance Tables would establish a set of criteria reflective of their community's needs and make determinations on applications for data access. Similar to the process of a research ethics board, external parties seeking access to the data would have to show their project meets standards such as the following:

- The research priorities centre the needs of Black communities.
- The research focuses on solutions and improvements in health outcomes.
- The research recognizes and addresses structural and social determinants at the root of health inequities.
- The research meets and aligns with the principles established in Ontario's *Data Standards for the Identification and Monitoring of Systemic Racism*.⁶⁰
- Research protocols are developed in consultation with communities, who are kept informed during implementation.

- Communities are involved in conducting the research, with the additional purpose of building capacity.
- Drafts of research reports, figures, tables, and other material are distributed to communities in advance to receive comment, identify divergent views, and refine any pieces requiring more nuance.
- Data is not repurposed, sold, or shared, including with government and government agencies.



One way that communities could access and share data is a community data trust, a mechanism for sharing data in a fair way that may involve infrastructure or platforms that allow members to upload and access data. Another option is a data partnership, where two or more partners with mutual data needs decide to share access to a specific set of data with an agreed-upon plan for how to use and protect the data. This partnership should involve co-governance and reciprocity. The Community Governance Tables would oversee the establishment of partnerships. Data stewards, such as the Ministry of Health and public health units, should not share data owned by Black communities without consent.



PROTECTION



All individual rights and data—including identifiable, de-identified, and anonymized data—must be protected.

Individuals' right to informed consent and refusal must be safeguarded. Data collectors must explain why they are asking for race-based data, what the data will be used for, how it will be stored, and who will have access to it. Consent to provide data must be offered freely, and individuals must be made aware of their right to withdraw their data at any point during collection. It must be made clear that patients are not required to give this information in order to receive care, and refusal to do so should not impact their quality of care. This becomes particularly important for people who may not feel safe disclosing information, such as individuals with precarious immigration status.

In order to protect the privacy of individuals, re-identification risks must be assessed carefully. Community Governance Tables may stipulate that under certain circumstances some data cannot be disclosed. This could apply, for example, to geographic areas with small Black populations, where data disclosure could present high risks of identifying the individuals to whom the data belongs.

When approving applications for data access, Community Governance Tables will build in mechanisms for transferring the data and terminating agreements in order to ensure appropriate data use throughout a research timeline.

As communities move towards data sovereignty, Community Governance Tables should have a focus on developing the specific protections needed to prevent data misuse. A subsection of the Community Governance Table should be devoted to developing the infrastructure needed to support this component of the work.

Ultimately, data sovereignty would provide the most significant protection of data. To this end, the province should work with Black communities to create and maintain a community data management system that tracks where data is collected and stored, helping communities monitor and influence the use of existing data resources.

All data collected provincially must reside in Canada to protect the privacy of individuals and comply with provincial privacy regulations.

RECOMMENDATIONS FOR IMPLEMENTATION



This section maps the primary areas in which action is needed to realize the EGAP Framework. The Ontario government and organizations of relevance looking to apply the framework should provide sustainable funding for Community Governance Tables along with any necessary training, capacity building, and infrastructure.

1

Education

The EGAP Framework must be promoted online, through media, and through health system channels with articulations of its rationale and development. As well, alternative community-based forms of data management and ways to leverage them should be explored.

Engagement processes must also include education about the origins of the EGAP Framework and its goals.

2

Community engagement

Provincial government, regional public health units, and other involved parties must implement a continual and long-term strategy for effective collaboration with community-based organizations, leaders, and members on current and future race-based data collection initiatives.

3

Community Governance Tables

Community governance tables with decision-making powers must be established in various locations in the province, with Black communities in those areas guiding their development. The governance tables will provide oversight of engagement processes and data collection, management, analysis, and use. They will also make determinations on applications for data access.

4

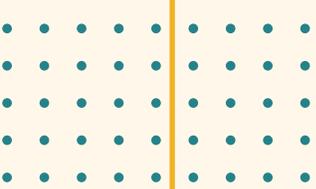
Stakeholder engagement

Provincial, regional, and local (e.g., Ontario Health Teams) health system agencies with mandates to improve population health outcomes must be involved in the collection and application of race-based data. Engagement should include clinicians, health professionals, health service providers, researchers, academics, and more.

5

Community engagement

Any legislative amendments necessary to break down barriers to Black communities possessing their own data should be made. Legislative changes should also focus on strengthening privacy protections and preventing the sale of patient information. All changes should be made in a transparent manner and communicated to the public.



6

Community data management and 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. The province should begin working with Black communities to establish timelines and milestones for creating and maintaining a community data management system that tracks where data is collected and stored. In cases where data is held by external entities, including government, the creation of data sharing agreements by Community Governance Tables will assist in monitoring data sharing.

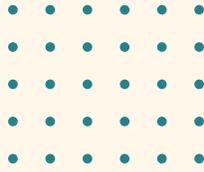
7

Data stewardship

A timeline should be set with the provincial and federal ministries of health, as well as other sectors and institutions that hold data connected to Black communities (e.g., CIHI, ICES, Health Canada, Statistics Canada) to adopt the principles outlined in the EGAP Framework. While processes for transferring data stewardship to Black community-based organizations are being determined and implemented, Black communities must have access to their data, irrespective of where it is held.



CONCLUSION



Race-based data in health can be a catalyst for powerful change. But the collection of such data is not an end in itself. Data must be used in service of equity needs with the explicit goal of improving the health of communities.

Current data processes pose many threats to Black communities by failing to focus on their health, their experiences, and their lives. The EGAP Framework offers a starting point for redress and the building of community trust by providing Black communities with greater control over their collective data. This is a fundamental requirement for a shifting province like Ontario. Though this framework was formalized amid the COVID-19 crisis and the absence of effective data collection and application to address the impacts of the virus on Black communities, the principles in EGAP have relevance beyond the current pandemic.

We embarked on this journey to begin a dialogue about what we would like to see and how we would like to see our data used. The legacies of anti-Black racism will not end with EGAP. We must envision and strive for a future of liberation, where Black communities achieve data sovereignty and the best health outcomes possible.





GLOSSARY



Anonymization

Data sets become anonymized when they are irreversibly stripped of personally identifying information to the extent that they can no longer be connected to particular individuals. Done effectively, anonymization protects individual privacy.

Anti-Black racism

Anti-Black racism “is a system of inequities in power, resources, and opportunities that discriminates against people of African descent. Discrimination against Black people is deeply entrenched and normalized in Canadian institutions, policies, and practices and is often invisible to those who do not feel its effects. This form of discrimination has a long history, uniquely rooted in European colonization in Africa and the legacy of the transatlantic slave trade.”⁶¹

Co-design

In a co-design process, stakeholders are an integral part of project planning to ensure established outcomes will meet community needs.

Data

Data comes in many different modes, including research, monitoring and surveillance, surveys, statistics, cultural knowledge, and more. In a digital age, many kinds of data are collected from individuals and communities, sometimes without their knowledge.

Data ownership

Data ownership is distinct from data possession. The holders of the data are not necessarily the owners of the data. Ownership is about the relationship between the data and the people it came from. Communities should have ownership of the data they create.

Data partnership

A data partnership involves two or more partners with mutual data needs who decide to share access to a specific set of data with an agreed-upon plan for how to use and protect the data.

Data sovereignty

As a key part of self-determination, data sovereignty entails the right to govern data collection, management, analysis, and use.

Data steward

Data stewards hold or possess the data. Sometimes they are referred to as data custodians. They may or may not be the data owners.

Data trust

A data trust is a mechanism for sharing data in a fair way that may involve infrastructure or platforms that allow members to upload and access data.

De-identification

De-identified data has been stripped of obviously identifying information, such as names. This data is not necessarily anonymized and, in many cases, can still be linked back to the individual.

Health equity

Health equity is achieved when everyone has access to quality care and the chance to attain the best health possible, regardless of factors like race, ethnicity, age, gender, income, or sexual orientation.

Health system

A health system “consists of all organizations, people and actions whose primary intent is to promote, restore or maintain health. This includes efforts to influence determinants of health as well as more direct health-improving activities.”⁶²

Informed consent

Informed consent in data collection occurs when a person freely agrees to participate after being presented with all relevant information such as the purpose, risks, and benefits of providing the data. The person

must understand the explanations, have the capacity to make decisions, and voluntarily agree without feeling any coercion.

Informed refusal

Informed refusal in data collection occurs when a person freely declines to participate after being presented with all relevant information such as the purpose, risks, and benefits of providing the data.

Intersectionality

Every individual has multiple and overlapping identities. These lead to unique experiences, opportunities, and challenges for different groups. Anti-Black racism is experienced differently depending on gender, immigration status, sexual orientation, age, disability, ethnicity, and more.

Race

Race is a social construct that grew out of European colonization to justify the domination of a “white race” over others. The idea of race has no scientific foundation. The main way that people perceive race is through physical features that actually provide little to no information about an individual's biology or genetics. Racial categories shift over time and from place to place, reflecting societal configurations of power.

Race-based data

Race-based data is a kind of sociodemographic data. In the health sector, race-based data allows for analyses of health inequities linked to racism.

Racial capitalism

Racial capitalism is the idea that racialized exploitation and capital accumulation are mutually constitutive. Through slavery, colonialism, and genocide, racial capitalism formed the basis of the modern world system; as “the development, organization, and expansion of capitalist society pursued essentially racial directions so too did social ideology.”⁶³

Re-identification

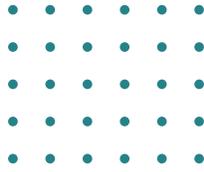
When personal indicators can be found in de-identified or anonymized data and linked back to the individual, re-identification has occurred. This often happens because of the huge amount of data about individuals that can be found by searching online.

Sociodemographic data

Sociodemographic data captures individual characteristics such as race, income, education, age, gender identity, and language. This allows analysis of data by subcategory and identification of inequalities between groups.



APPENDIX: 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?



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