

We Can't Breathe

A Manifesto for Transformative Action to address HIV
among Black Canadian Communities

Revised

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INTRODUCTION

Canada's HIV epidemic has affected Black communities more than any other, a situation that is getting worse. Current trends indicate that HIV transmission is falling among white Canadians, which is consistent with the expectation that Canada can end HIV as a major public health threat over the next decade or two. This raises the prospects that Black Canadians will be left behind, while decision-makers move the resources elsewhere to fight other emerging threats. This is the likely outcome of business as usual where, despite claims to the contrary, institutional policies and strategies reproduce anti-Black racism and undermine Black people's wellbeing and livelihoods.

This Black HIV Manifesto rejects business as usual (i.e., the past 40 years of Canadian responses to HIV), and proposes instead a new transformative basis for addressing the grossly disproportionate burden of HIV among Black communities in Canada. It is a call for equity and justice. It is addressed as much to public institutions and governments as to our Black colleagues across the country. It is a demand for governments and their institutions to reject the anti-Black foundations of their systems and structures. But it is also an instrument to inspire Black communities to pursue a quality of understanding and leadership that rejects elitism and foregrounds our struggle for justice among all segments of our Black communities.

LOCATING OURSELVES

Acknowledgement

With thanks, we have adopted the Land Acknowledgement developed by the **Black Health Education Collaborative** (<https://www.bhec.ca/>).

We acknowledge with gratitude the Indigenous Peoples across Turtle Island who continue to thrive and resist colonial violence while striving for self-determination and decolonial futures. We live, work and play in various territories including the lands of the Huron-Wendat, Haudenosaunee and Mississauga's of the Credit River; Cree, Oji-Cree, Dakota and Dene peoples, the Anishinaabe, and on the homeland of the Métis Nation; Kanien:keha'ka and Mi'kmaq.

We remember our ancestors, forcibly displaced Africans, brought to Turtle Island through the Trans-Atlantic Slave Trade and the histories and legacies of colonialism and

neo-colonialism which continue to impact African Peoples and the descendants of the Black diaspora across the world.

We recognize that racial colonial violence harm Black and Indigenous Peoples through both common and distinct logics and actions. We recognize our responsibility and obligations as African Peoples to be good guests on these lands. We offer thanks to our elders and communities from whom we learn. May your wisdom inform our actions towards a more just future.

We honour Indigenous and Black people who continue to be here, who continue to be in relation with one another in spite of the pervasiveness of anti-Indigenous and anti-Black racism, and who together fight against genocide and the after lives of slavery. We honour Indigenous and Black people including those who were (back in the day) and are (in the present day) queer, trans, genderqueer, and two-spirit. We stand committed to reconciliation and reparations, and remain engaged in anti-colonialism, and continued disruptions of anti-Black racism.”¹

We recognize that HIV disproportionately impacts Indigenous, Black, and Afri-Indigenous people across Turtle Island due to the continuing impacts of colonialism, slavery, and anti-Black racism. We stand together to continue our fight against colonialism and anti-Black racism towards ending HIV/AIDS in our communities – locally, nationally, and globally.

We also acknowledge the efforts of Black people across Canada who have engaged the struggle for justice and health equity, especially those who have mobilized Black communities to implement a community-based response to HIV.

Who we are

“[T]o articulate Blackness is to consider how we embody, are marked as, negotiate, and sometimes resist endogenous and exogenous constructions of ourselves as Black people, as Black scholars, and activists, and, importantly, as Black individuals.” (Ibrahim et al., 2022).

We are the Interim Committee on HIV in Black communities in Canada (ICHBCC). We comprise Black researchers, activists, scholars, people living with HIV, community-based service providers, and healthcare professionals who have come together to collectively develop and disseminate a Manifesto for research, policy, programs, and community engagement to change the trajectory of HIV among Black communities in Canada.

However, in doing this work, we acknowledge leaders of our movement who paved the way for us and continue to advocate for Black communities. We acknowledge the advocacy, compassion, passion, and leadership of Black activists and leaders who organized and struggled on our behalf throughout many decades and made it possible for some of us to further the cause. We remember those of us who died of AIDS and through their death highlighted how the pandemic continues to impact Black people and Black communities today.

We also acknowledge that the ICHBCC and this Manifesto are not the only voices speaking to the issue of dismantling anti-Black racism in in Canada. We recognize and build on the work of other Black leaders across Canada.

We initially came together early in 2022 as an ad hoc committee to explore transformative perspectives to address the hugely disproportionate burden of Canada’s HIV epidemic among Black communities. We agreed to develop and disseminate a Black HIV Manifesto to support and encourage fresh community-engaged perspectives on understanding and addressing HIV. With support from the Canadian Association for HIV Research (CAHR), we organized a session at the Canadian HIV conference in April 2022 for our Black colleagues to debate and discuss the draft Manifesto. Two months later, we organized a working meeting to revise the Manifesto and expand our membership as the ICHBCC.

Since 2022, we have been advocating to national and provincial health agencies for transformative ways of supporting Black stakeholders and their communities to change the trajectory of HIV among Black communities.

BACKGROUND AND CONTEXT

Missed opportunity and a new beginning - an Ontario Example

We recognize and acknowledge that Black communities initially demonstrated leadership to meet the challenges of HIV. However, today the Black response to HIV has become community-engaged in name only, and policy decision-makers still keep us at arm’s length.

In the early to mid-1990s, Black community members in Toronto, especially from Black LGBTQ networks, originated programs, services, and community engagement activities to care for members of our community who contracted HIV or were dying

from AIDS, and to organize against the spread of HIV/AIDS in Black communities. For example, the Black Coalition for AIDS Prevention (Black CAP) pioneered and modelled Black people's investment in health and wellbeing by focussing on HIV. Simultaneously, continental African communities in Toronto launched initiatives and organizations that eventually evolved into Africans in Partnership Against AIDS (APAA). These organizations lead the way for Black-led interventions across the country.

By the late 1990s, Black service providers and community members in Toronto and Ottawa were experiencing burgeoning demand for their services. In response, the leading stakeholders established a provincial task force which partnered with municipal and provincial policymakers to develop Ontario's first strategy on HIV in Black communities in 2003 (ACCHO 2003).

In 2005, the task force was dissolved to launch the strategy under the aegis of a new network – the African and Caribbean Council on HIV/AIDS in Ontario (ACCHO) – to coordinate, monitor and evaluate the implementation of the strategy. This achievement demonstrates collective self-determination and the power of community mobilization and leadership in identifying a problem and taking steps to resolve it. It also attests to the exceptional quality of creativity, critical thinking, analysis that the stakeholders mobilized in response to the challenge of HIV (ACCHO 2003). Over the next few years, ACCHO constructively pushed the boundaries of its work through initiatives to engage its constituents, build service providers' capacity to work with Black communities, set research priorities to generate knowledge that was needed to inform policy and practice to improve the HIV response.

However, in response to the emerging Black leadership, provincial decision-makers instituted a strategy that may have diverted the leaders from their cause. With hardly any input or discussion with ACCHO, provincial bureaucrats decided to fund community-based agencies throughout Ontario to work on HIV prevention among Black communities within the Strategy but without oversight or direct involvement from ACCHO about the work those agencies would do. In other words, the provincial government was now subsidizing predominately white focussed and staffed agencies (i.e., agencies that had not demonstrated any particular interest in Black life) to prevent HIV from spreading among Black communities.

A few of these predominately white agencies now have Black leadership that are making a difference to Black communities. However, that leadership is provisional since those agencies are not accountable to Black communities.

It is vital to note that the network of funded agencies have private and separate agreements with the provincial government and Black people have only a residual influence on the agencies (e.g., helping them strengthen their “capacity” to work with Black communities). In short, in exchange for provincial government funding, Black stakeholders found themselves subsidizing white agencies to work among Black communities on issues Black people were already qualified and motivated to address.

As HIV continues to spread in Black communities, Black stakeholders and communities have been relegated to a secondary or supportive role in Canadian responses to HIV among Black communities. For this reason, we are leveraging the expertise, creativity, and commitment of Black service providers, researchers, scholars, and people living with HIV to create and invest in new, hopefully more effective, interventions in support of our Black lives.

Over the past 20 years at least, Black HIV researchers, activists, community-based service providers, and community members working in the HIV have called for a leadership role in decision-making related to Black people’s health. Historically, decision-making about our health and wellbeing was the preserve of agencies and agents that had no substantive commitment to, or involvement in, Black communities. This Manifesto is written in the spirit of, and reinforces, the demand for a leadership role in decisions about our health and wellbeing.

HIV and Black communities in Canada: What is the problem?

Tracking the HIV epidemic affecting Black Canadians – a story of neglect

Black communities are poorly served by the processes and methods that government agencies use to assess, track and communicate trends in diagnoses.

It is well known that Black communities are grossly over-represent in HIV diagnoses; however, the precise magnitude is shrouded by health authorities’ lack of urgency to report on “race” and ethnicity. Since data on HIV influence support for

policy and programs, the lack of more precise data allows health authorities to shirk their responsibility to Black Canadians.

It should be considered a scandal that, even in 2020 two large provinces (BC and Quebec) did not submit to PHAC an ethno-racial breakdown of new HIV cases; in addition, two other provinces (New Brunswick and Saskatchewan) provided data that recognised only First Nation or other (PHAC, 2022). Furthermore, in 2022, neither Manitoba nor Nova Scotia included race and ethnicity in their “surveillance” data submitted to the federal (PHAC 2024). The outcome of this failure to collect and share data is that, by 2022, “race” or ethnicity was available for less than half of the new HIV cases in PHAC’s “surveillance” report (PHAC 2024). Black communities have no say in how, or what, data about them gets collected or used, or how their data are curated or shared. In short, Canadian governments and public institutions are addicted to colonial practices well into the 21st century, which continue to undermine Black health and wellbeing.

In Ontario, ethno-racial background was missing for one-third of first-time HIV diagnoses in 2022 (OHESI, 2022; 2024). Based on their experience and knowledge, service providers, community advocates and some policy makers believe that Black people may be over-represented among the cases that do not have a confirmed racial or ethnic designation. In other words, it is quite likely that the burden of HIV among Black people in Ontario and Canada may be even more severe than the available data show.

Public health authorities in Canada also release data about Black people without any notable consultation or follow-up with the agencies, researchers and stakeholders who are on the front lines of mobilizing Black communities in response to HIV. This is a serious flaw that hampers the efforts of Black stakeholders to mount an informed community response to HIV.

The increasing burden of the Canadian epidemic among Black communities up to 2019

By 2019, the share of new diagnoses among the white population of Canada and Ontario had been falling steadily for the past 10 years at least, principally among white gay, bisexual and other white men who have sex with men (i.e., white gbMSM). But there were no such hopeful signs among the Black population. Instead, year after year Black people accounted for one of every four new cases or diagnoses in Canada as a whole and in Ontario, even though Black people make up

just about 5% and 6% of the respective national and provincial population (Haddad et al., 2021; Haddad et al. 2018; OHESI 2021).

Those trends suggest that, by 2019, there were at least two vastly different HIV epidemics in Canada. For example, even though Black people account for roughly 4% of the country's population, 2019 data show that Black women and men accounted for 42% and 18% of reported cases among all women and men respectively. In comparison, white women and men make up 14% and 38%, respectively, of new diagnoses (Haddad et al. 2021). Overall, as stated above, Black people account for one of every four new diagnoses year after year for Canada, and the trend is similar in Ontario up to 2019 (OHESI, 2021). Added to this, for at least the two decades ending in 2019, Black Canadians were much more likely to die of AIDS than their white counterparts (Tjepkema et al. 2023).

It is clear to us that the epidemic among Black communities requires a transformative and vastly different approach than the business-as-usual that has benefitted white Canadians.

Black people and annual HIV diagnoses, 2019 to 2022

Canada

Black people account for 4% of Canada's total population. However, *in terms of HIV cases with known race or ethnicity*, the gross over-representation of Black people in 2019 (Haddad et al. 2021) and 2020 (PHAC 2023), is as follows:

- Black women made up 42% of the 280 new cases among women in 2019, and 19.6% of the 158 new cases in 2020
- Black men accounted 17.7% of the 598 new cases among men, and 15.7% of the 443 new cases in 2020
- On the whole, Black people's share of new cases decreased from 25.5% in 2019 to 16.7% in 2020

But this apparently steep decrease from 2019 to 2020 is deceptive. PHAC (2022) advised that the data for 2020 should be "interpreted with caution" because the outbreak of COVID-19 and the public health mandates to address it restricted people's access to HIV testing facilities and their willingness to present for testing.

As COVID-19 continued into 2021, Black people's share of new first-time cases declined further in 2021 to 15.4% (i.e., down from 16.7% in the previous year). However, as COVID-19 retreated in 2022 and the public health mandates were being eased or eliminated, Black people's share of new cases rose to 18% in 2022 (PHAC 2023; 2024). **The evidence suggests that Black people's over-representation will return or even surpass the pre-COVID level of one in every four new cases. In short, there is no dispute that Black communities are disproportionately burdened with Canada's HIV epidemic.**

Ontario

More than half of Canada's Black population resides in Ontario. Therefore, HIV trends among Ontario's Black population provide a window for understanding the trends in Canada as a whole.

Black people make up 5% of Ontario's total population. However, *among HIV cases with known race or ethnicity*, Black people were over-represented in 2019 (OHESI 2021) and 2020 (OHESI 2022) as follows:

- Black women comprised 59% of the 86 new first-time diagnoses among women in 2019, and 44.4% of the 54 new first-time diagnoses among women in 2020
- Black men comprised 18% of the 365 new first-time diagnoses among men in 2019, and 19.6% of the 271 new first-time diagnoses among men in 2020
- Overall, Black people accounted for 25.9% of new diagnoses in 2019, with a slight decline to 23.7% in 2020

Following the small dip in Black people's share of new first-time diagnoses in 2020 (i.e., during COVID), their share rose again in 2021 (24.3%) and 2022 (28.6%) (OHESI 2024). **This shows that, unlike the diminishing trend among white gbMSM, Black people in Ontario are falling further behind in the provincial response to HIV, just like the trend for Canada as a whole.**

CHARTING A NEW DIRECTION FOR BLACK COMMUNITIES

To understand why Black Canadians have been inequitably served by provincial and federal strategies to address HIV, we must first recognize and acknowledge the ubiquitous structural violence that impacts the HIV response in Black communities. We need to understand HIV as a specific outcome of an anti-Black process that reproduces and entrenches systemic inequality. Anti-Black racism does not arise in isolation or merely by chance but is produced and reproduced institutionally. As a form of structural violence, anti-Black racism makes the social determinants of health generally inaccessible to Black Canadians – the social determinants emerge instead as indicators of structural disadvantage.

HIV among Black people in Canada emerges along with the inter-related indicators of structural disadvantage: substantially lower income, higher rate of incarceration, poverty, food insecurity; shockingly higher likelihood of being victims of deadly force by the police, and other inequities (Abdillahi & Shaw, 2020; Bain et al., 2020; Hartman, 2008; Maynard, 2017).

Decision-makers in elite positions continue to position Black people as irresponsible, unruly, ignorant, and non-compliant (Mykhalovskiy et al., 2016; Husbands et al, 2020). These anti-Black narratives obscure how ongoing structural violence undermines Black people's health and wellbeing. Therefore, HIV joins a list of other inequities inflicted on Black communities by the white supremacist social order (Crichlow, 2014; Hastings et al., 2017; Maynard, 2017).

Structural anti-Black violence also informs and embodies the relationship between public health institutions and Black diasporic communities. Anti-Black racism incubates in and through public institutions. In Ontario, health and policy institutions have declared Black people a HIV priority population while pursuing a culture of discourse and decision-making that often stifles Black voices and subordinates' Black stakeholders (OACHA, 2016; Robinson et al., 2006). As such, how, or under what circumstances, will the HIV epidemic end for Black Canadians (Katz et al., 2020; Nelson et al., 2019; Timothy, 2018)?

Predominately white decision-makers in federal and provincial governments and AIDS agencies, have done little to address the intersectional disparities faced by Black communities and more specifically, address how anti-Black racism remains a

deciding factor in our health disparities. In other words, the Black HIV/AIDS epidemic underwrites the personal and professional advancement of white researchers, bureaucrats, and service providers, and the authority and prominence of public institutions that proclaim otherwise. The infrastructure that constitutes Canada's response to HIV reflects and reproduces white privilege/supremacy and does nothing substantive in changing the course of the epidemic in Black communities (Dryden & Nnorom, 2021; Nelson et al., 2019).

Shifting the current trajectory of HIV in Black diasporic communities in Canada mandates a radical and transformative response. It is an approach that both inspires and guarantees effective prevention, treatment, support, and care for those living with and at risk of HIV in Black diasporic communities. To succeed, we must examine the current HIV response, determine why these responses continue to fail Black people, and reimagine innovative interventions that will radically address anti-Black and structural disadvantages that stalk Black communities.

We must also institute inclusive decision-making processes in research, policy, programming, and resource allocation which will ensure that Black people, specifically those affected by HIV, are part of the decision-making bodies (Black Experiences in Healthcare Symposium, 2020).

This radical transformation will insist that we creatively and innovatively rethink programming and interventions and ensure that anti-Black racism and structural barriers are interrupted and disrupted. By centring Black people, including those living with HIV, we will redesign decision-making process and bodies. In addition, working with a Black-focused process that identifies and disrupts anti-Black racism, we will create meaningful and equitable participation in decision-making around data collection, including what data gets collected and how, what constitutes evidence, determining who produces evidence/data, how data are managed and utilized, and who will be the drivers in policy and program development and resource allocation (Damba et al, 2020; Black Health Equity Working Group, 2021; Husbands & Owino, 2020).

This Manifesto is a mechanism through which Black communities will hold researchers, policymakers, and service providers accountable. It will provide an avenue for centering Black experiences and expertise in all aspects of research, policy, and practice that affect the health and wellbeing of Black communities. And it will also be a framework for monitoring our progress in those spheres, and the outcomes for health and wellbeing.

A TRANSFORMATIVE APPROACH

This Manifesto outlines the policy-related values and directions to effectively address HIV among Black communities in Canada. It has been developed to inspire and provide guidance for Black HIV researchers, policymakers, funders, community-based organizations, and others. Additionally, the Manifesto will inspire Black community members to articulate their needs and perspectives in spaces and institutions that are generally not safe for Black individuals to speak up against anti-Black racism and intersecting forms of oppression and exclusion (Bailey, 2021).

Black researchers, scholars, students, activists, and community members are working in institutions and within systems that historically oppress, silence, and penalize them. We acknowledge that many Black people involved in research, service provision, policy work, advocacy, or speaking out on social justice are continuously putting themselves at risk of punishment, surveillance, job loss, or being labelled as unprofessional and unruly (Chambers, 2018; Chambers et al. 2018). This is how anti-Black racism works and is wielded. The Manifesto is a mechanism to support self-determination for Black stakeholders.

But developing a Black HIV Manifesto without addressing the issues of anti-Black racism would be to reproduce the harms we seek to address and undo. Anti-Black racism is a form of structural violence that informs how public health and other institutions marginalize and exclude Black people and their interests. This structural violence reproduces the inequities that emerge as the so-called social determinants of health (Block & Galabuzi, 2011; Nestel 2012; Black Experiences in Healthcare, 2020).

In the wake of massive popular support for decisive action to address anti-Black racism in 2020, and also in response to the UN's International Decade for People of African Descent (United Nations 2001), institutions and governments started to release statements in support of Black life and against systemic anti-Black racism (Boisvert, 2020; Ontario, 2017).²

Some of these responses included declaring anti-Black racism a public health crisis and commitment to collecting race-based data to understand and address the systemic barriers which disproportionately affect Black communities (Boisvert, 2020; Leitch et al., 2021; McKenzie, 2020a; 2020b).

However, simple statements of solidarity are not enough and are no longer accepted. Hence this Black HIV Manifesto outlines an actionable pathway to equity and justice. These key strategic possibilities represent the basis of a new framework that acknowledges and supports the health and wellness of Black communities in Canada. The well-being and survival of Black people demand that our stakeholders and constituents, including people who are living with HIV, assert our leadership, expertise, and skills in response to HIV. As Black people not only are we entitled to equitable support from governments and public institutions at all levels, WE DEMAND IT!

OUR DEMANDS

Dominant frameworks and protocols for research and policy development disseminated in/through academic and public institutions perpetuate colonial systems of privilege. These protocols and frameworks benefit the institutions but alienate, marginalize, and oppress Black stakeholders and their communities. Therefore, we are calling for frameworks, protocols and modes of engagement that promote Black emancipation (i.e., foreground Black people's wellbeing and self-determination to achieve equity and justice) (Husbands et al. 2025).

We recommend and support the following transformative values and directions:

Institutional policies and structures: Researchers, policy decision-makers, and service providers will strengthen their ability to work with Black communities by meaningfully engaging in processes and actions geared toward dismantling anti-Black racism. This involves:

- acknowledging the existence of anti-Black racism in their institutions and systems
- committing to sustainable and meaningful change towards social justice and equity
- supporting Black stakeholders and communities to exercise leadership in developing, implementing and monitoring:
 - initiatives to understand and address anti-Black racism
 - structures and systems to support Black scholarship, mentorship, policy development and analysis, program development, and service delivery

- programs to encourage and support critical awareness of anti-racism, decolonization, equity and social justice in their respective areas of responsibility
- Committing appropriate resources to support the directions outlined above.

By and large, institutional policies undermine the involvement and aspirations of Black people in senior decision-making roles. In public institutions, decisions are made about Black people's health without us being in the room. Even when we are allowed in, discussions take place as though we are not there. For example, many Black community members or leaders who have the expertise having worked in and been involved in multiple successful interventions, programming, and research, are barred from accessing research funding and resources because they have no affiliation with an academic institution. The belief that research and researchers belong only be in the academy is not respectful of communities that continue to face social injustices and inequity. Academia is historically structured to impose Eurocentric worldviews and enforce colonial and oppressive rules and policies that systematically discriminate against Black people. Many Black people then get disqualified from academic careers, while academic institutions promote themselves and their limited expertise as more worthy than community-based institutions, lived experience, and practical expertise. How do we decide what knowledge is valuable and who has the expertise to generate this knowledge? We ask funders and resource holders to examine what equity means and review their policies and practices to ensure equitable representation. We insist that the academy, research funding institutions, and policymakers demonstrate their willingness to meet and work with community-based researchers regardless of institutional affiliations.

In short, Black communities must press institutions to ensure that Black people have leadership roles in decision about Black people's health. All institutions must support leadership by Black stakeholders, and otherwise engage equitable, meaningful and accountable collaboration with Black stakeholders.

Research: Funders and policymakers must support Black people to exercise leadership in all aspects of knowledge production, data governance, and knowledge exchange. This will ensure that the knowledge produced contributes to the overall wellbeing of Black people and their communities.

Research is key in providing evidence that can be used to develop strategies and interventions to address HIV. Without proper data, or access to data about us, our issues are unacknowledged, erased and ignored. We emphasize the need for more

Black research by Black scholars, with appropriate support from research funding agencies, to:

- better understand the specific role of structural violence in vulnerability to HIV and poor health outcomes among Black communities.
- generate nuanced understanding of HIV among Black communities
- identify and harness community knowledge, outlooks and resources that are instrumental to health and wellbeing
- inform and support interventions that engage communities in implementing critical responses to HIV

Our research and advocacy must force decision-makers to surrender their neoliberal inclinations and support people to access the best care and treatment that is available. Additionally, research conducted with Black communities must implement and utilize methods and forms of analyses that respect our intellectual traditions, are attuned to the issues under consideration, and support emancipation.

Research generates data, and Black communities must have a leadership role in decisions about data stewardship, access, use and dissemination.

Evidence: Researchers and scholars produce and/or disseminate knowledge that enhances how we understand HIV and informs how we develop and design policy and programs to address it. However, the status of “**research evidence**” depends on how it is produced and who produced it. The Canadian system of knowledge production impedes, devalues, and invalidates the contributions of Black researchers, scholars, and other stakeholders (Chambers et al., 2018; Hale, 2008; Nabudere, 2011; Wilson, 2015; Wilson et al., 2016). Every graduate student in public health will be familiar with white scholarship, which is mostly outdated and is expected to shape how we understand health and wellbeing (e.g., Michel Foucault and Pierre Bourdieu, among others). On the contrary, we have several brilliant Black scholars with both lived and academic expertise on Black issues who rarely get cited or appropriately centred in university curricula. Black people are still made to believe that we are incapable of contributing to the intellectual life of Canada.

A particular concern around evidence is the lack of race-based data to strengthen understanding of racism in Black lives and the dispossession of Black people in relation to the social determinants of health. The lack of data also masks the ways in which structural violence produces inequitable health outcomes. We must examine the collection, stewardship of, and access to “race-based” data to

understand inequity and promote wellbeing. White scholars continue to benefit from the extraction of Black intellectual property and Black people's stories for their own private and professional gain. We recommend the creation of a Black scholars/researchers collective to exert some degree of control or leadership over data collection, management, access, and use, to ensure that Black people have access to their own data to address our needs and aspirations. As Black people, we must assert our interests and authority among the public institutions and networks that are accustomed to disregarding our legitimacy. We propose the establishment of a transparent, accountable strategy to disrupt the way that research funding agencies, research agencies, and research ethics boards (where Black voices are seldom heard) have exerted ownership over anything to do with research data (Bain et al., 2020; Damba, et al., 2020; Husbands & Owino, 2020; McKenzie, 2020b; Prescod et al., 2020; Wilson et al., 2016). Data must serve a useful purpose of helping Black communities to understand how they are being disenfranchised and to develop the dialogues, policies, and programs that will ensure a prosperous self-determined future. Why should we continue to allow government-supported agencies to collect our data and treat it like their private property but then are incapable of implementing interventions to support Black people's health? We also demand that research funding institutions and government provide funding, structural and mentorship support, as well as opportunities for professional growth to support Black students, researchers, and community members.

Funding: The burden of Canada's HIV epidemic has fallen on Black communities precisely because the strategies to address HIV in Canada were never designed to accommodate us. Quite frankly, we have been regarded as a nuisance, people without discipline who deserved to be managed or disciplined. Therefore, we have been underfunded relative to the magnitude of the inequity we face. Research and programs to address HIV among Black communities need substantially more funding than is currently available. Ensuring the availability of equitable funding and resources for Black community-focussed research and programs is critical. Black researchers are woefully under-represented relative to the disparities and inequities that Black communities endure. Therefore, research funding should ensure a supply of Black talent relative to the magnitude of the effort required to address current and future inequities. In other words, there is a need for a separate funding stream designated for Black researchers doing Black research, for supporting more Black scholars in university graduate and post-doctoral programs and hiring more Black scholars in research institutions. Currently, Black people who are already engaged in research careers must compete with all others for funding. This is an inefficient and inequitable way to allocate resources and support, given

the entrenched inequities and disparities that affect Black livelihood. Funding bodies need to restructure how research and program funding is distributed or allocated and underscore the importance of funding that supports epidemiological evidence, promotes health, and supports innovation. For funding to be equitable, we need funding models that respond to the needs of the community; for example, it would make sense that since Black people routinely account for one-quarter of diagnoses, least 25% of the HIV and health research funding should support knowledge development by Black scholars. Also, funding needs to be allocated to incentivize action on rights and equity.

Black communities have also subsidized the cost of programs for support, care and capacity building from their own meagre resources. Black people who work on the frontlines of HIV service provision earn very small incomes, and their agencies are insufficiently funded. Yet, for the past 40 years, Black service providers, PLHIVs, and researchers have mounted an enormous community effort to address HIV. In other words, federal and provincial governments have underfunded the response to HIV among Black communities. This is a gross inequity. We call for alternative funding models that support our stakeholders and incentivise innovation.

Public health authorities fund a wide range of programs and services to address HIV. However, this funding is too often driven by the prejudices and power of the funders rather than any overriding concern with need, results, or justice. Often, Black stakeholders feel pressured to accept certain levels, types, or timelines for fear of being stigmatized or punished. This commoditization of Black life exacerbates the inequities that we experience as Black people. Black program and service practitioners also compete with one another, which increases their exposure to the whims or moods of those who are disbursing funds. Clearly, community leaders and practitioners need to collaboratively develop and articulate their shared perspectives, grounded in available evidence to challenge the power of the bureaucrats.

Culturally appropriate and relevant research, policy, and practice: Policy and services for Black communities should be culturally inclusive. One of the critical elements of colonialism, slavery and anti-Black racism was the use of cultural genocide to suppress and dominate Black people. This genocide was characterized by processes aimed at detaching Black people from their worldviews, cultures, beliefs, religion, practices, and values by either criminalizing or obliteration. Unfortunately, decision-makers in research and policy continue this practice by undermining or disregarding Black people's cultural richness or diversity (Nestel

2012; Walcott, 2019). Research and policy to address Black people's health and wellbeing is still framed and driven through the white gaze. This allows decisions about research, policy and programs that do not respect the knowledge, worldviews, diversity, and cultural expertise of Black communities. Black bodies thus become either invisible or criminal. We stress the need for researchers, service providers and policymakers to engage in practices that respect and validate Blackness in all its diversity. They must ensure that the programs, policies, and services they create or develop are culturally appropriate and accessible for diverse populations of Black people.

Equity, social justice, and anti-Black racism frameworks: All research, practice and policy must be aligned with and developed using equity, social justice and anti-racism frameworks that Black communities support. Doing good research or making good policy and programs does not just include developing a written commitment to social justice. It must include actionable processes that foster anti-oppression and anti-racism and work towards shifting power relations and dismantling structural violence. To dismantle structural injustices requires that one be intricately aware of and acknowledge that injustices exist.

DIVERSITY, INTERSECTIONALITY, AND CLASS

Canada's Black population is as diverse as any other in ordinary socio-demographic terms – age, income, family status and structure, gender, national origin, ethnicity, culture, sexual orientation, place of residence, immigration and settlement histories, and so on. However, since the 16th century, we have shared generally similar experiences of colonization, racism, and displacement. Yet, despite our common histories of anti-Blackness, how racism manifests and affects us (in terms of our sense of self, health, and livelihoods), as well as how we survive or resist, varies across our intersectional identities and across time and space. We share a similar narrative, but not necessarily the same stories. Our struggle requires us to foreground the fullness of Black lives.

As Black people, our lives and livelihoods have been expropriated as raw material for capitalism, which emerged as a global system at our expense. But we cannot pretend that we are all disenfranchised in the same way or to the same extent. Our struggle for racial justice is also a struggle within capitalism. But our journey demands the discipline of “constructive politics” (Táíwò 2022) to realize our just rewards.

[1] Borrowed, with permission, from Dr. OmiSoore Dryden.

[2] <https://pm.gc.ca/en/photos/2020/06/05/prime-minister-trudeau-and-minister-hussen-participate-anti-black-racism-protest>

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