



We Can't Breathe

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

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LOCATING OURSELVES

Acknowledgement

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

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.”

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.

Statement of Positionality

As someone who occupies multiple roles in the HIV and health sector in Ontario and Canada, I chose to occupy this space to help end a system in which anti-Black racism and colonialism continue to exist. It is important, in the desire to bring about real change, to speak truth to power. However, Speaking Truth to Power does not bring about any sustainable change. I am an example of what happens when a Black person – a Black woman – individually speaks truth to power, they get bullied, harassed, canceled, expelled, and silenced.

I choose to occupy a different space, a radical, crazy, nonsensical space of those rendered non-existent by and through a violent, colonial, and oppressive system. In my Blackness I choose to occupy and embrace this space that has been forsaken by the colonial and anti-Black racist and misogynoir-ist systems and to relish and embrace my right to refusal (Harney & Moten, 2013).

I urge other Black people to join me on a path of refusal, a space where we have a right to refuse that which has been offered to us. Let us recognize (and embrace) that there is power in refusal because most times, in a system that is so institutionalized Black people are only offered two choices, yes or no and most times, both choices are damning.

We should embrace the right to refuse that which we are offered, especially when offered without consultation or involvement. Refusal of what's offered is a call to action. It means we refuse the call to order; we refuse to accept without question, to be tokenized, or controlled. In refusing, we create dissonance, and more importantly, we allow dissonance to continue even after us (Harney & Moten, 2013); we must refuse mandates in recognition of the Black experiences of violence, knowledge, and truth. This space I occupy today is not a space of critique, rebellion, or opposition. I occupy this space because it is always here. I hope we will use this space to end a system that continues to oppress, abuse, and

discriminate against Black people and to utilize our right to refuse that which we are offered ~Maureen Owino, 2022

BACKGROUND AND CONTEXT

About Us, and how we got to this point

“[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 an Ad-hoc Committee on HIV in Black communities in Canada. This Committee comprises Black researchers, activists, scholars, people living with HIV, and frontline workers who have come together to collectively initiate a Manifesto for research, policy, programs, and community engagement to change the trajectory of HIV among Black communities in Canada. In respect of the work that precedes this Manifesto and in recognition of Black leaders who continue to advocate for Black diasporic communities, we will take a step back and also explore the evolution of the HIV movement/activism in Canada and the work that has happened before.

We acknowledge the advocacy, compassion, passion, and leadership of Black activists and leaders who took on these battles throughout many decades and made it possible for some of us to be here today and to be able to do this work. 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.

This Ad hoc Committee acknowledges that our group and this Manifesto is not the only voice speaking to the issue of dismantling anti-Black racism in social and health services in Canada. We recognize and build on the work done or being done by other Black leaders across Canada.

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-based in name only.

In 2020, Ontario accounted for about three-quarters of HIV cases among people identified as Black in Canadian HIV data. As Black community stakeholders competed for legitimacy and funding over the years, decision-making elites gradually took control of our agenda. Furthermore, there has been a regrettable degradation in the quality of leadership from the Ontario Black agency entrusted with leading implementation, monitoring, and evaluation of the strategy on HIV for Black communities in Ontario. This is especially troubling as we are living with and through multiple pandemics (Bain et al., 2020).

In the early to mid-1990s, Black community members and service providers in Toronto, especially from Black LGBTQ networks, originated programs, services, and community engagement activities to care for members of our community who contracted HIV and 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, and 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 framework with no 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.

Today, 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, people living with HIV, and change agents to create and invest in new, hopefully more effective, interventions in support of our Black lives.

Over the past ten years, Black HIV researchers, activists, frontline staff, and community members working in the HIV have called for the establishment of (perhaps more radical) principles and guidelines related to data management, policy development and implementation, and programming related to HIV in Black communities. Such a commitment would enable Black communities across Canada to assert a leadership role in research, policy, and programs for Black communities - including Black communities that asserted their existence during the 18th and 19th centuries (e.g., African Nova Scotian communities), and Black people living with HIV or AIDS (PHAs), across Canada.

In January 2022 an Ad-hoc Committee was established to initiate the development of this Manifesto and advocate for Black leadership of an approach to change the trajectory of HIV among Black communities.

HIV and Black people 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 influences 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).

In Ontario, ethno-racial background was missing for 37% of first-time HIV diagnoses in 2020 (OHESI, 2022). Based on their experience and knowledge, service providers and 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 Canadians up to 2019

By 2019, the number of new cases or diagnoses in Canada had been falling for the at least 10 years. This trend, in Canada as a whole and in Ontario, was due mainly to decreasing numbers of new diagnoses among white Canadians, especially white gay and bisexual men and other white men who have sex with men (white GBMSM). But there were no such hopeful signs for Black Canadians. 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 less than 5% of the national and provincial population (Haddad et al., 2021; Haddad et al. 2018; OHESI 2021).

To illustrate the seriousness of HIV among Black Canadians: while the share of diagnoses continues to tumble for white GBMSM, Black GBMSM are going in the opposite direction (OHESI 2021; 2022; PHAC, 2022; Haddad et al., 2021; Haddad et al. 2018).

In short, 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 shows 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, Black people account for one of every four new diagnoses year after year. The trend is similar in Ontario (OHESI, 2021).

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 in 2019 and 2020

Canada, 2019-2020

Black people account for 3.5% of Canada's total population. However, *in terms of HIV cases with known race or ethnicity*, the gross over-representation of Black people 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

Ontario, 2019-2020

Black people make up 4.5% of Ontario's total population. However, *among HIV cases with known race or ethnicity*, Black people were over-represented 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

Understanding the pattern in 2019 and 2020

The trend in new diagnoses *suggests* a noticeable decline in Black people's share of diagnoses in 2020 compared to 2019 and the previous 10 years, especially among women. However, events in 2022-2022 point to a different reality.

Among women in both Canada and Ontario, Black women's share of diagnoses fallen rather sharply from 2019 to 2020. Black women and white women had an

almost equal share of diagnoses in 2020 even though white women vastly outnumber Black women in the total Canadian and Ontario population. It is remarkable that the huge disparity between white and Black women persists even after a sharp drop in Black women's share of HIV diagnoses.

Among men, white men's share of diagnoses has been falling consistently for Canada and Ontario since 2015, while Black men continued to be over-represented. In other words, relative to white men, Black men fare quite badly in HIV diagnoses.

Under 'normal' conditions, there should not be such a steep decline in Black women's share of diagnoses in just one year (i.e., 2020). During COVID-19 in 2020-2021, STBBI services (such as HIV testing) were not readily available to the public. Understandably, the demand for services also fell (PHAC 2021). PHAC has warned that, because of COVID-19, HIV data for 2020 should be "interpreted with caution" (PHAC 2022). In Ontario, there were 26% fewer HIV tests in 2020 than in 2019. COVID also affected data collection activities to measure and assess new diagnoses.

Charting a new direction for Black Canadians

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 diasporic 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.

HIV among Black people in Canada does not stand in isolation from the intersecting spiral of our substantially lower income, higher rate of incarceration, poverty, food insecurity, gross over-representation in police street checks and carding, 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. 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. 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).

To shift 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/interventions, determine why these responses continue to fail Black people, and reimagine innovative interventions that will radically address anti-Black and structural disadvantages Black people encounter.

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 diasporic 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).

Whereas all research projects and organizations are mandated to have protocols, ethics, and policies within their organizations, these protocols and policies are framed for the protection of these institutions and not necessarily the affected communities (Bagele, 2013; Chilisa, 2019; Gaudry, 2011). Additionally, most of these policies, protocols and ethics do not consider the protection of communities or society from disrespect, marginalization, and psychological harm.

This Manifesto is a mechanism through which Black diasporic people individually and more broadly as a community will hold researchers, policymakers, and service providers accountable. It will provide an avenue for centering Black experiences and stakeholders 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.

Our Mission:

- inspire existing institutions, research apparatus, and service providers to dismantle anti-Black racism and address Black experiences in all aspects of their work

Our Vision:

To achieve justice and health equity through:

- engaging Black communities in critical reflection on HIV prevention, care and support
- demonstrating committed leadership of decision-making in research, policy, and programs/practice
- developing and applying interventions and practices that strengthen health and wellbeing especially in relation to HIV and emerging pandemics.

CHANGING THE CHANNEL - A TRANSFORMATIVE APPROACH

This Manifesto is a living document. The Manifesto provides guidelines for conducting Black-focussed HIV-related research and supporting effective policies and programs for Black diasporic people 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 is envisaged for Black community members who continuously navigate spaces and institutions that are generally not safe for Black individuals to speak up due to continuing anti-Black racism and intersecting forms of oppression and exclusion such as misogynoir and homophobia (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 provides a support and much needed, Black-focussed space for Black activists, scholars, service providers, and researchers. The Manifesto is a mechanism to support self-determination for Black stakeholders.

What we want

Developing a Black research and policy manifesto without addressing the issues of anti-Black racism would be to reproduce the harms we seek to address and undo. Anti-Black racism, whether personal or systemic, 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 informs determines how public resources are allotted. Black people continued experience of structural violence is explicitly overlooked by numerous state-funded institutions, leading to racial inequities related to income, employment, access to education and healthcare that continue to impact the health outcomes of Black people (Block & Galabuzi, 2011; Nestel 2012; Black Experiences in Healthcare, 2020).

Having a Black research, policy and service provision Manifesto shows agency on a matter of life and death. We must bring an anti-racism lens to this work – one that specifically identifies anti-Black racism, and its attendant structural violence.

While the torture and murder of Mr. George Floyd, an African American cis man, at the knee of a white policeman seemed shocking to many white people, for Black people it symbolized the cumulative trauma, anti-Black racism, and violence we continue to experience over and over (Barbot, 2020). Black people literally and figuratively have a knee on our neck on an ongoing basis due to systemic anti-Black racism. The murder of Mr. George Floyd, the death of Ms. Regis Korchinski-Paquette (Doradea, 2020), Mr. Tony McDade (Mahoney, 2021) and others (Robertson et al., 2020) triggered various responses from Black Lives Matter (BlacklivesmatterTO, 2018), Not Another Black Life (notanotherblacklife, 2019), and Movement for Black Lives, to name a few (CBC, 2020; Khan, 2020).

In the wake of massive popular support for decisive action to address anti-Black racism, 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; Husbands & Owino, 2020; Leitch et al., 2021; McKenzie, 2020b). This should have happened sooner, especially since the United Nations declared 2015-2024 the International Decade of People of African Descent (United Nations, 2001).³

In recognising the UN's International Decade for People of African Descent, the Canadian government also publicised its commitment to a better future for "Black Canadians."⁴ However, Canada continues to lag other countries that are taking tangible action in recognition of this decade, such as undertaking concrete measures to improve the human rights situation of people of African descent.⁵ These developments raise serious questions about the extent or depth of Canada's commitment to a better future for "Black Canadians" (McKenzie, 2020a)?

Simple statements of solidarity are not enough and are no longer accepted. Non-Black racialized people and white people must take direction for Black diasporic communities and effectively support transformational change by disrupting the continuing reproduction of whiteness, white supremacy, and white logics of research. To work with us they must acknowledge the role of whiteness and white supremacy in these oppressive, and systemically excluding policies and structures, including how they are individually supporting or benefitting from this harm.

These actions must include equitable and meaningful collaborations with Black diasporic peoples, who are best equipped to provide recommendations for meaningful and transformative change to address the issues we have raised above. We have a specific note for CIHR, other funding agencies (public and private), academic institutions and community organizations. Now is the time to create and enforce policies and protocols that requires that all researchers applying to conduct research with Black diasporic people (in Canada or internationally) observe and abide by the Black Health Equity Working Group's document, Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities (Black Health Equity Working Group, 2021).

These key strategic possibilities represent the basis of a new framework that acknowledges and supports the health and wellness of Black diasporic 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 at all levels, WE DEMAND IT!

Our Demands

We recommend and support the following transformative actions or direction:

1. This manifesto urges researchers, policymakers, and service providers interested in working with Black people to meaningfully **engage in processes and actions geared toward dismantling anti-Black racism** by:

- Acknowledging the existence of anti-Black racism in their systems
- committing to sustainable and meaningful change towards social justice and equity
- Ensuring that Black people are meaningfully engaged in developing frameworks for implementing and monitoring these processes and activities
- Designating appropriate resources to Black communities to implement structures and systems to support Black research, mentorship, policy analysis and services
- Implementing compulsory, enforceable and ongoing anti-oppression, anti-racism, and decolonization training for all researchers, policymakers, and public service employees

2. Emancipation: The current research protocols set up by research funding institutions and academic institutions perpetuate colonial systems of domination that will never amount to any change. These protocols have been set up without consultation or engagement with Black people. In contrast, any research conducted within Black populations must be committed to and focused on emancipation. Black communities continue to be pathologized, stigmatized, tokenized, and surveilled through research and service provision. Historically research has been used for medical surveillance, and Black people's bodies have been expropriated for the benefit of science and scientists with little benefit for Black communities (Bogart et al., 2021; Wasserman et al., 2007). Researchers must acknowledge the history of anti-Black systemic racism and the trauma it has caused Black communities; and explain how the research they

are conducting will assist in the dismantling of these harms. Researchers conducting HIV-related research in Black communities continue to use methods that dominate, suppress, problematize, and control Black people; they also use standards of whiteness as the measure of success (Yancy, 2016). Black people are experts in our lives and possess the ability to design and develop solutions and interventions that serve their communities. We can collectively inspire transformation by taking leadership to create new action around health and HIV. Funders, researchers, and policymakers must support Black people to exercise leadership in knowledge production, governance, and service provision. This will ensure that the knowledge produced contributes to the overall wellbeing of Black people and their communities. Researchers must also acknowledge the social, historical, and political contexts that shape Black experiences. Black leadership in policy and research for Black communities must be rooted in and be responsive to Black communities. All agencies or institutions that are leading a local, provincial, or federal response to HIV in Black communities should be guided by the wisdom and expertise that circulates among those communities. Investments must be made in the development of models of community engagement that inform and support community leadership in their agenda for health and wellbeing. Additionally, we must discard the exceptionalism that has typified the response to HIV since the start of the epidemic. We must rethink how to describe the Black population; rather than using language that infers blame, we should use language that describes the structural deficits/disadvantages that increase Black people's vulnerability to HIV, and the strength or potential to effect change for the better. We must use approaches that incorporate health and wellbeing rather than the HIV-stigmatizing approaches. Collective and collaborative work is critical in developing result-oriented perspectives, initiatives, and strategies that are robustly grounded in a shared principle of justice to strengthen health and wellbeing rather than merely responding to HIV.

3. Research is key in providing evidence that can be used to develop strategies and interventions. Without proper data on Black people, our issues are unacknowledged, erased and ignored. We emphasize the need for more Black research by Black scholars to better understand the specific role of structural violence in vulnerability to HIV and poor health outcomes among Black communities. Concurrently, there is evidence from other jurisdictions (and even in Canada, too) that new technologies to curtail HIV transmission may not be equitably available to Black communities, or their effects among Black

communities may be attenuated (Nelson et al., 2019). Research is needed to develop and test evidence-based interventions that secure Black people's access to healthcare and other systems that promote wellbeing. These interventions must be structured to address anti-Black racism and the attendant inequities that imperil Black life. For example, Black people who have been diagnosed with HIV often have serious difficulty accessing and maintaining care and treatment, which means that they are unable to achieve virological suppression. There is a clear disparity between how white PLHIVs benefit from the care cascade and how Black people tend to fall off the cascade. 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 decolonizing methods and analyses. Non-Black researchers conducting research with Black people must meaningfully engage with the Black community. Also, , researchers who are not from Black communities but want to conduct research among Black communities, must partner with Black stakeholders on research projects and data governance in our communities. Furthermore, we recommend that future research on Black populations must be housed in among community stakeholders in community institutions.

4. Self Determination: Research, policy, and practice: It is imperative that we examine how we produce and interact with knowledge, evidence, and data. 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 “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.

5. Funding: 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-oriented 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 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.

6. 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.

7. Institutional policies and structures: Many institutional policies for research, including funding policies, research lead policies, and research

involvement policies, are destructive to the involvement of Black people in research and especially Black researchers, academics, or community organizations. Examples of these policies include and are not limited to conflict-of-interest policies and institution affiliation policies. We are already aware that Black people are under-represented in decision-making positions in policy and governance bodies. The few who make it to those tables are barred from accessing research or other funding, taking leadership or any other role in funded research, or being involved in any way in the funded studies. Black people are then forced to make the difficult decisions of what, where, and how they can be involved in decision-making or funding applications, reinforcing the narrative that we are not qualified. 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.

8. Meaningful and equitable engagement: Researchers, policy makers and service providers must ensure meaningful engagement through collaborations and ongoing consultations with Black communities at all stages. This includes identifying needs, development of research questions, policy, and program development. Similarly, Black community stakeholders must be involved as equal partners in any research, policy or program-related discussions pertaining to the health and wellbeing of Black communities. All institutions must support leadership by Black stakeholders, and otherwise engage equitable, meaningful

and accountable collaboration with Black stakeholders. meaningful, and accountable.

9. 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 conceptual 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.

10. 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 developed by the Black communities. This should be implemented to ensure accountability and enforcement where there is conflict. Researchers interested in doing research with Black communities must commit to doing good research; the key to doing good research involves engaging in anti-oppressive research and anti-Black racism research that draws on social justice. Doing good research does not just include developing anti-Black racism and anti-oppression frameworks or 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.

[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>

[3] <http://www.un.org/en/events/africandescentdecade/>

[4] <https://pm.gc.ca/en/news/news-releases/2018/01/30/prime-minister-announces-government-canada-will-officially-recognize>

[5] <https://www.un.org/en/observances/decade-people-african-descent/actions-taken>

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