



A Manifesto for transformative action on HIV among Black communities in Canada

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Abstract

Black communities bear a hugely disproportionate share of Canada's HIV epidemic. Black persons annually represent up to one quarter of new diagnoses, while in contrast, diagnoses have been falling among white Canadians for the past two decades. There has been a notable lack of urgency and serious debate about why the trend persists and what to do about it. For too long, public institutions have reproduced hegemonic white supremacy and profoundly mischaracterized Black life. Consequently, Black communities suffer policies and programs that buttress systemic anti-Black racism, socio-economically disenfranchise Black communities, and in the process marginalize knowledgeable, experienced, and creative Black stakeholders. The Interim Committee on HIV among Black Canadian Communities (ICHBCC) is a group of Black researchers, service providers, and community advocates who came together in early 2022 to interject urgency to the HIV crisis facing Black communities. Specifically, the ICHBCC advocates for self-determined community leadership of research, policies, and programs, backed by access to appropriate resources, to change the trajectory of HIV among Black Canadian communities. In this article, we introduce the wider community to the Black HIV Manifesto that we developed in 2022.

Résumé

Les communautés noires constituent une part très disproportionnée de l'épidémie de VIH du Canada. Les personnes noires représentent annuellement jusqu'au quart des nouveaux diagnostics, tandis que les diagnostics diminuent chez les Canadiennes et les Canadiens de race blanche depuis 20 ans. Il y a une absence notable d'urgence et de débat sérieux sur la raison de la persistance de ces tendances et sur ce qu'il faudrait y faire. Pendant trop longtemps, les institutions publiques ont reproduit l'hégémonie de la suprématie blanche et extrêmement mal caractérisé les vies noires. Par conséquent, les communautés noires souffrent de politiques et de programmes qui soutiennent le racisme anti-Noirs systémique, privent les

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communautés noires de leurs droits socioéconomiques et marginalisent ainsi les connaissances, l'expérience et la créativité des parties prenantes noires. Le comité intérimaire sur le VIH dans les communautés noires du Canada (ICHBCC) est un groupe de chercheurs et de chercheuses, de prestataires de services et de porte-parole communautaires de race noire qui se sont regroupés au début de 2022 pour mettre l'accent sur le caractère urgent de la crise du VIH dans les communautés noires. Plus précisément, l'ICHBCC plaide en faveur d'un leadership communautaire autodéterminé de la recherche, des politiques et des programmes, appuyé par un accès aux ressources nécessaires, pour changer la trajectoire du VIH dans les communautés noires du Canada. Dans cet article, nous présentons à l'ensemble de la communauté le « manifeste noir sur le VIH » que nous avons élaboré en 2022.

Keywords HIV · Black communities in Canada · Systemic anti-Black racism · Black HIV Manifesto

Mots-clés VIH · communautés noires au Canada · racisme anti-Noirs systémique · « manifeste noir sur le VIH »

The problem

HIV transmission has been declining in Canada over the last 15 years at least, but this trend masks a disturbing reality. Black communities bear a hugely disproportionate burden of the epidemic, while declining transmission is limited to white Canadians (especially white gay men).

Canada's Black population accounts for approximately 5% of the country's total population, but in 2019, Black women and men accounted for 42% and 18% of reported new HIV cases among all women and men respectively (Haddad et al., 2021). Overall, Black people annually account for one of every four new diagnoses, and Black people living with HIV have a higher mortality than their white counterparts (Tjepkema et al., 2023).

Available data may underestimate the burden of HIV that has fallen on Black communities. As late as 2019, race and ethnicity identifiers were available for only 42% of new HIV cases (Haddad et al., 2021). Then, in 2020, COVID-19 interrupted HIV monitoring programs to such an extent that race and ethnicity data were unreliable (PHAC, 2023). Moreover, even though the care or engagement cascade may be effective for monitoring progress toward eliminating HIV transmission (NCCID, 2017), cascade representations are generally unavailable for Black Canadian communities. Consequently, there is no clear picture of the extent to which Black people who are living with HIV are achieving virologic suppression, which is a key marker of future trends in HIV transmission.

Canadian responses to HIV over the past 40 years appear to have benefitted the country's white population while Black communities languish from policies and programs that may be underfunded or inappropriate relative to the systemic inequities they face. In short, public health authorities and institutions reproduce a regime of systemic anti-Black racism and elide their responsibility to Black Canadians.

Why the problem persists

In 2020–2022, COVID-19 erupted among Black Canadian communities in a similar way to the emergence of HIV among those communities over the past four decades (Ezizeka et al., 2023). Clearly, public health authorities seemed to have learned nothing from the inequities of health and well-being that HIV had already exposed.

The grossly disproportionate burden of HIV among Black communities, just like COVID-19 more recently, is a specific and predictable outcome of anti-Black processes that reproduce systemic inequalities. For example, we note the federal government's conspicuous silence about Black people in its Action Plan on STBBIs (PHAC, 2019), even though Black communities are overwhelmingly burdened by Canada's HIV epidemic. This silence eliminates the need for action, which helps to perpetuate the conditions that produce inequitable health outcomes. While the public health response is lacking, Black people have been disproportionately subjected to criminal prosecution for "HIV non-disclosure" (Mykhalovskiy et al., 2016), which invokes the stereotype of Black people's alleged lawlessness. In short, anti-Black racism does not arise spontaneously, but is produced and reproduced institutionally, including through public health institutions and systems. Anti-Black racism reconfigures the social determinants of health as markers of systemic inequality.

The disproportionate impact of HIV on Black communities is consistent with the intersecting spiral of our substantially lower income, higher unemployment, chronic food insecurity, and other inequities (Abdillahi & Shaw, 2020; James et al., 2010; Uppal, 2023). For example, anti-Black racism is associated with Black people's diminished access to the healthcare system (Husbands et al., 2022), which then disproportionately exposes them to poor health outcomes. In short, anti-Black racism incubates in and through our public health and social care systems.

Canadian public institutions have a history of either accommodating anti-Blackness through benign neglect or unconscious bias, or actively supporting anti-Blackness through their policies and programs. These institutions privilege white decision-makers to exercise authority for managing HIV in Black communities, with limited critical awareness of how systemic anti-Black racism undermines Black people's well-being. Therefore, instead of exercising responsibility for Black people's health, public institutions fail to substantively address anti-Black racism and the systemic, intersecting inequities that Black communities face. In other words, the infrastructure that constitutes Canada's response to HIV accommodates or reproduces anti-Black racism instead of meaningfully engaging Black communities to change the course of the epidemic, or inoculating Black communities against emerging epidemics (Dryden & Nnorom, 2021; Nelson et al., 2019). Predominant Canadian responses to HIV frame Black people as irresponsible, unruly, and non-compliant, and obscure the structural violence that undermines Black people's health and well-being (Husbands et al., 2020; Mykhalovskiy et al., 2016). Black communities experience the burden of HIV diagnoses and death as an outcome of the incapacity of public health systems to disrupt anti-Black racism and structural disadvantage.

Toward a framework for ending HIV transmission in Black communities

Shifting the current trajectory of HIV in Black communities requires a transformative response to the epidemic that supports effective prevention, treatment, support, and care. Fundamentally, we need to reimagine innovative and creative interventions that will effectively disrupt systemic anti-Black racism, address structural disadvantage, and strengthen community health and well-being. Black communities must take the lead to institute inclusive decision-making processes in research, policy, programming, and resource allocation (Black Experiences in Healthcare, 2020). This will help to ensure that Black communities benefit from their accumulated knowledge, experience, creativity, and enthusiasm.

Black leadership in decision-making also extends to stewardship in collecting and using data to effect change. These issues include how, why, and what data gets collected; what counts as "evidence" to inform policy and programs; and how data are managed and utilized, who has access to it, and under what conditions. This form of stewardship will help to centre Black people's representation, concerns, and interventions in policy, programs, and resource allocation (Black Health Equity Working Group, 2021).

The Black HIV Manifesto

In January 2022, a group of Black scholars, activists, and service providers established an Ad Hoc Committee on HIV in Black Canadian Communities. The Committee's initial purpose was to develop a Manifesto on HIV in Black communities (Interim Committee, 2022) and engage their Black colleagues around Canada on the merits of Manifesto.

The Manifesto is a framework for (a) prioritizing Black people's needs, strengths, potential, and challenges related to addressing HIV and promoting health; (b) supporting Black leadership of the response to HIV among Black communities; (c) holding researchers, policymakers, and service providers accountable to their Black communities; and (d) monitoring progress in addressing HIV. It provides an avenue to centre Black experiences and leadership in all aspects of research, policy, and practice that affect the health and well-being of Black communities.

The Ad Hoc Committee organized a special session for Black stakeholders at the 2022 conference of the Canadian Association for HIV Research (CAHR), where they workshoped and discussed the draft Manifesto with 70 participants. The Manifesto outlines a set of values and demands geared toward dismantling anti-Black racism and changing the trajectory of HIV among Black Canadians, which may be summarized as follows: institutional policies that oppose anti-Black racism, value Black life, promote emancipation, and promote social justice; dedicated funding for Black scholars, practitioners, research, and interventions commensurate with the magnitude of the challenge HIV poses for Black communities; community leadership in decision-making about national, provincial, and municipal plans and strategies to address HIV; and community stewardship of systems to monitor HIV (i.e., so-called surveillance systems) to ensure that these systems meet the needs of Black stakeholders and communities.

Black stakeholders subsequently established a national steering committee in mid-2023 (now called the Interim Committee on HIV in Black Canadian Communities, or ICHBCC) to oversee further development and dissemination of the Manifesto, and design and implement engagement and advocacy for transformative action. This intervention portends a new framework through which our stakeholders and constituents assert our leadership, expertise, skills, and community engagement practices for a transformative response to HIV.

To date, the ICHBCC has (a) advocated to national health agencies and research and knowledge dissemination organizations to adopt the Manifesto and explore new relationships and initiatives with Black stakeholders and communities, and (b) disseminated the Manifesto to health and HIV-related organizations and individuals across Canada. For

example, the ICHBCC advocated for a Black Expert Working Group (BEWG) to work collaboratively with PHAC on strengthening how HIV is monitored to enhance understanding and decision-making among Black communities.¹

Conclusion

Current trends indicate that, overall, Canada appears to be heading toward zero HIV transmission over the next decade or two. In reality, this trend is restricted to white Canadians. Black communities in Canada continue to be disproportionately burdened by the country's epidemic. A similar pattern of inequity emerges across several markers of well-being. Black Canadians are structurally disadvantaged through anti-Black racism.

Black scholars, service providers, and community advocates established the ICHBCC to advocate for a transformative action on HIV affecting Black communities. Our Manifesto is a framework for such action. We will continue to engage Black stakeholders, health authorities and policy-makers, research funders, and research institutions to recognize that business as usual only guarantees inequitable health outcomes for Black Canadians, and to encourage and lead approaches that are beneficial to Black people's health and well-being in the short and long term.

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References

- Abdillahi, I., & Shaw, A. (2020). *Social determinants and inequities in health for Black Canadians: A snapshot*. Public Health Agency of Canada. <https://www.canada.ca/en/public-health/services/health-promotion/population-health/what-determines-health/social-determinants-inequities-black-canadians-snapshot.html>. Accessed 18 Dec 2023.
- Black Experiences in Healthcare. (2020). *Symposium report*. Sinai Health System. Human Rights and Health Equity Office.
- Black Health Equity Working Group. (2021). *Engagement, Governance, Access, and Protection (EGAP): A data governance framework for health data collected from Black communities*. <https://blackhealthequity.ca>. Accessed 7 Dec 2023.
- Dryden, O., & Nnorom, O. (2021). Time to dismantle systemic anti-Black racism in medicine in Canada. *CMAJ*, 193(2), E55–E57.
- Ezizeka, O., Girmay, B., Mengistu, M., & Barrett, K. (2023). What is the health impact of COVID-19 among Black communities in Canada. *Canadian Journal of Public Health*, 114, 62–71. <https://doi.org/10.17269/s41997-022-00725-6>
- Haddad, N., Weeks, A., Robert, A., & Totten, S. (2021). HIV in Canada—Surveillance report, 2019. *Canada Communicable Disease Report*, 47(1), 77–86. <https://doi.org/10.14745/ccdr.v47i01a11>
- Husbands, W., Oakes, W., Mbulaheni, T., Ongoïba, F., Pierre-Pierre, V., & Luyombya, H. (2020). Resourceful masculinities: Exploring heterosexual Black men's vulnerability to HIV in Ontario, Canada. *Ethnicity & Health*, 25(2), 17–33. <https://doi.org/10.1080/13557858.2017.1395817>
- Husbands, W., Lawson, D., Etowa, E., Mbuagbaw, L., Baidoobonso, S., Tharao, W., Yaya, S., Nelson, L., Aden, M., & Etowa, J. (2022). Black Canadians' exposure to everyday racism: implications for health system access and health promotion among urban Black communities. *Journal of Urban Health*, 99, 829–841. <https://link.springer.com/article/10.1007/s11524-022-00676-w>.
- Interim Committee on HIV in Black Canadian Communities. (2022). *We can't breathe: A Manifesto for transformative action to address HIV among Black Canadian communities*. <https://blackmanifestohiv.ca/manifesto/>. Accessed 18 Dec 2023.
- James, C., Este, D., Thomas Bernard, W., Benjamin, A., Lloyd, B., & Turner, T. (2010). *Race and well-being: The lives, hopes and activism of African Canadians*. Fernwood Publishing.
- Mykhalovskiy, E., Hastings, C., Sanders, C., Hayman, M., & Bisaillon, L. (2016). 'Callous, cold and deliberately duplicitous': Racialization, immigration and the representation of HIV criminalization in Canadian mainstream newspapers. A report funded by a grant from the Canadian Institutes of Health Research Centre for Social Research in HIV Prevention. https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2874409. Accessed 1 Nov 2023.
- NCCID (National Collaborating Centre for Infectious Diseases). (2017). *Reflections on the development of the HIV Cascade measures: Meeting proceedings*. Rady Faculty of Health Sciences, University of Manitoba. <https://nccid.ca/publications/reflections-development-hiv-cascade-measures-meeting-proceedings/>. Accessed 7 Dec 2023.
- Nelson, L. E., James, L., Coleman, T., Etowa, J., Husbands, W., Lofters, A., Mitchell, M. O., Nguemo, J. D., Nnorom, O., Oraka, C., Rana, J., Siddiqi, A., & Wilson, C. L. (2019). A recipe for increasing

¹ We use the concept of “monitoring HIV” in place of the epidemiologically familiar term “HIV surveillance”. In relation to Black Canadians, “surveillance” is a concept that references enslavement, colonialism, and systemic anti-Black racism, thereby hindering the important work of meaningfully engaging Black communities about health and well-being.

racial and gender disparities in HIV infection: A critical analysis of the Canadian guideline on pre-exposure prophylaxis and nonoccupational post-exposure prophylaxis' responsiveness to the HIV epidemics among women and Black communities. *The Canadian Journal of Human Sexuality*, 28(1), 1–4. <https://doi.org/10.3138/cjhs.2018-0043>

- PHAC (Public Health Agency of Canada). (2023). *HIV in Canada: Surveillance report to December 31, 2020*. Ministry of Health, Ottawa. <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/hiv-canada-surveillance-report-december-31-2020.html>. Accessed 7 Nov 2023.
- PHAC. (2019). *Accelerating our response: Government of Canada Five-Year Action Plan on sexually transmitted and blood-borne infections*. Government of Canada. <https://www.canada.ca/en/public-health/services/reports-publications/accelerating-our-response-five-year-action-plan-sexually-transmitted-blood-borne-infections.html>. Accessed 15 Dec 2023.
- Tjepkema, M., Christidis, T., Olaniyan, T., & Hwee, J. (2023). *Mortality inequalities of Black adults in Canada*. Health Reports. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/82-003-x/2023002/article/00001-eng.pdf>. Accessed 15 Dec 2023.
- Uppal, S. (2023). *Food insecurity among Canadian families*. Insights on Canadian Society. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/75-006-x/2023001/article/00013-eng.htm>. Accessed 18 Dec 2023.

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