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Ethical Engagement and Management of HIV-Related Data and Biomaterials in Black, African, and Caribbean Canadian Communities

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Abstract

Focusing on African, Caribbean, and Black (ACB) communities in Canada, this research explored the ethical challenges of community-based HIV testing, highlighting participants' perspectives on consent, confidentiality, and the handling of HIV-related data and biospecimens. This research adopted a qualitative, community-based participatory approach (CBPR) to ensure African, Caribbean, and Black (ACB) community members were actively involved throughout the study. Thirty-three ACB individuals in Manitoba, Canada, participated in detailed qualitative interviews. Oversight and guidance were provided by a Community Guiding Circle, which contributed to shaping the study design, analyzing data, and interpreting findings. Participants were recruited through a combination of community organizations, social media outreach, and flyer distribution, with careful attention to capturing diversity in age, gender, sexual orientation, and geographic location. The collected data were examined using an iterative, inductive thematic analysis to identify emerging patterns and themes." Participants voiced deep concerns regarding the collection, sharing, and utilization of HIV-related data obtained during healthcare interactions, reflecting a pronounced mistrust of institutions such as the police, child welfare agencies, and immigration authorities having access to their personal health information. Their apprehensions focused on the management of biological samples, the potential for data misuse, violations of human rights, the criminalization of HIV, deportation risks, and threats to consent, privacy, and bodily autonomy. Although they expressed willingness to participate in medical research, participants consistently emphasized the need for greater transparency, robust informed consent processes, and enhanced control over any secondary use of their health data." The findings emphasize the necessity of culturally safe practices in HIV testing and ethical oversight within healthcare for African, Caribbean, and Black (ACB) communities. The study highlights the critical importance of empowering participants, maintaining transparency, upholding informed consent, and enforcing strong data protection measures to ensure that the management of HIV-related information aligns with the safeguarding of individual rights.

Keywords: Ethical, HIV-Related Data, Management, Biomaterials, African, Caribbean Canadian

Introduction

This study investigates the ethical dimensions of community-based HIV testing among African, Caribbean, and Black (ACB) populations in Canada, a group recognized as a priority in HIV-related research and policy [1–7]. Examining ethics in HIV testing for these communities requires attention to historical injustices, contemporary social dynamics, and foundational principles of equity, justice, and human rights [8]. Past abuses in healthcare—such as the Tuskegee study, forced sterilizations, and other unethical medical experiments—have contributed to deep-seated mistrust of medical research and HIV testing within Black populations [8, 9]. Understanding the ethics of community-based HIV testing must therefore be framed within the broader context of historical exploitation, ongoing anti-Black racism, and systemic inequities in healthcare access and treatment [9]. The concept of

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structural violence, as articulated by Paul Farmer [10, 11], helps illuminate how racialized social structures shape HIV testing experiences and outcomes in ACB communities, highlighting the intersection of ethical concerns and socio-structural inequities.

While prior research has identified ethical issues in HIV testing broadly [12–14], studies specifically exploring these issues within ACB populations remain limited. Common challenges documented in the literature include conflicts between mandatory reporting requirements and confidentiality [15], dilemmas for healthcare providers balancing individual rights with public health responsibilities [16], and complexities surrounding informed and voluntary consent [14, 17]. Despite this, the nuanced ethical challenges unique to community-based HIV testing for ACB populations remain underexplored and are often not adequately addressed by institutional ethics review boards in community settings.

In Canada, HIV test samples are processed at local or national laboratories, with results shared with healthcare providers and public health authorities [18]. Unlike opt-out testing models, most provinces require explicit informed consent for HIV testing [19]. The management of HIV-related data intersects with multiple regulatory frameworks, including privacy legislation, mandatory reporting, and public health surveillance requirements [19–21]. Positive HIV test results must legally be reported to public health agencies to monitor and control the epidemic, though the degree of identifiable data sharing differs across jurisdictions [3, 6, 18–21]. Access by non-health entities, including law enforcement, insurers, or immigration authorities, is less clearly defined, raising ethical concerns.

Emerging digital health systems have enhanced disease monitoring but also introduced risks of surveillance and privacy breaches, disproportionately affecting Black communities [20, 21]. Concerns include over-surveillance, unauthorized data use, and racial profiling [21, 22]. Secondary use of HIV surveillance data, such as in retrospective analyses, presents additional privacy and security challenges. Molecular surveillance techniques, increasingly used to trace genetically related HIV strains for outbreak management, offer efficient public health interventions but can exacerbate the surveillance of marginalized populations [23, 24]. Canada's legal landscape criminalizing HIV exposure, transmission, and non-disclosure further intensifies stigma and discrimination, particularly among marginalized groups such as migrants, sex workers, and people who use drugs, discouraging engagement with testing and care [24, 25]. Immigration-related concerns amplify these risks, as HIV-positive migrants may face stigma, discrimination, and the threat of deportation [26, 27].

The ethical governance of HIV-related biomaterials and associated data also remains underdeveloped. Transparent policies regarding consent, ownership, and secondary use are critical, as illustrated by high-profile Canadian cases highlighting misuse and privacy breaches [28–30]. Debates surrounding the secondary use of health data, including experiences during the COVID-19 pandemic, reflect concerns about potential commercialization or inappropriate application of patient information [31]. Scholars such as Molldrem and Smith [32] underscore the risks to privacy and consent in the re-use of clinical HIV data for public health purposes. While secondary use of patient data and biospecimens holds promise for biomedical research, precision medicine, and learning health systems [33, 34], the ethical implications specific to HIV remain insufficiently examined. Determining the scope of patient consent, and navigating the tension between future unknown uses and ethical obligations, continues to be a key area of debate among experts in ethics, healthcare, and patient advocacy [35–38].

This paper addresses these gaps by examining ethical considerations surrounding access to and secondary use of HIV-related data and biological samples. Centering the perspectives of ACB communities ensures that research practices uphold rigorous ethical standards while reflecting the needs, priorities, and lived experiences of those most affected, promoting a more just, community-centered approach to HIV data governance.

Materials and Methods

Study development and approach

The Ubuntu-Pamoja study drew inspiration from two African concepts: 'Ubuntu,' which emphasizes shared humanity, and 'Pamoja,' meaning together in Swahili. Central to this research was the Community Guiding Circle (CGC), a group of ten African, Caribbean, and Black (ACB) community members, which provided direction and insight throughout the study. The Ubuntu-Pamoja framework, created specifically for this project, was designed to embed collaborative and community-focused principles into the research process. From the initial planning stages through data analysis and validation, the CGC ensured that community voices were reflected in every step. Meetings were held regularly, both in person and online, to maintain continuous engagement and guidance. The study also prioritized building the CGC members' skills and knowledge in conducting HIV research and interventions. By employing a community-based research (CBR) approach, the study fostered meaningful collaboration between researchers and the CGC, enhancing both the design and the relevance of the study outcomes.

Participant recruitment and eligibility

Participants were brought into the study through a combination of outreach strategies, including announcements at local community organizations, recruitment by peers, and promotion on social media platforms. To be eligible, individuals had to meet three criteria: identify as Black African or Caribbean, be at least 18 years old, and reside in the province of Manitoba. The study was conducted under the approval of the University of Manitoba Research Ethics Board (protocol # HE2022-0264) and complied fully with institutional ethical guidelines. Prior to data collection, each participant provided informed consent both verbally and in writing, and all personal information was securely protected to maintain confidentiality.

Data collection and analyses

Each interview, conducted either in person or virtually, lasted approximately one hour, with participants receiving a $40 honorarium. The interviews were semi-structured and facilitated by a team of four female African, Caribbean, and Black (ACB) research assistants, including one PhD-level researcher and three Master's-level RAs, all extensively trained in qualitative methods. The discussions focused on participants' experiences with HIV testing, particularly access and related challenges, and were guided by questions specifically developed for this study.

Data were analyzed using a reflexive, inductive thematic approach [39]. Initially, the research team identified discrete units of meaning from the transcripts, which were then grouped into thematic statements and subsequently broader categories. Using MAXQDA software, transcripts were reviewed line by line, and initial codes were assigned based on careful interpretation of participants' responses. These codes were then iteratively examined to identify patterns, connections, and recurring concepts, which were clustered into preliminary categories.

Through ongoing reflexive discussions, the team evaluated how these categories reflected participants' perspectives and aligned with the study's goals. Prominent categories included concerns such as "mistrust in institutions," "risk of data misuse," "historical exploitation," and "desire for transparency and control." These captured specific anxieties, for example, about police or immigration access to personal health data, or the potential commercialization of biosamples. The categories were further synthesized into overarching themes that encompassed broader insights from the data. This process involved continuous reflection and refinement to ensure the resulting themes authentically represented participant voices.

The final themes were refined and named collaboratively. To enhance the reliability and trustworthiness of the findings, four members of the research team conducted the analysis, and consistency in coding and interpretation was verified through three team meetings and four Community Guiding Circle (CGC) sessions.

Sample characteristics

A total of 33 members of Manitoba's African, Caribbean, and Black communities took part in the study. Participants ranged in age from 18 to 50, with the average age being 34. Of the group, 20 self-identified as women and 13 as men. Regarding sexual identity, most (25) reported being heterosexual, while the remaining eight identified as part of LGBTQIA+ communities.

Although Winnipeg was the primary place of residence for most participants, two additional Manitoba cities—Brandon and Steinbach—were also represented. Educational backgrounds varied: 27 individuals had completed some level of college or university training, while six participants held a high school diploma as their highest credential.

Employment status also differed across the sample. Twenty-two people were working at the time of the study, two were enrolled as international students, and three were unemployed. Immigration and citizenship categories included 19 permanent residents, two individuals with study permits, three with work permits, seven refugees, and two Canadian citizens.

Among participants who had immigrated or arrived as refugees, the length of time spent in Canada ranged widely—from six months to 30 years—and averaged approximately 9.8 years.

Findings

Participants in the study described deep skepticism toward institutions such as law enforcement, child protective services, and immigration authorities having access to their health information. They worried about potential misuse of their data, the risk of being criminalized, and the long history of Black communities being exploited in medical research. Although some individuals were open to providing samples to support scientific progress, they strongly insisted on increased openness and personal control over how their health data is handled. They highlighted the importance of informed consent, straightforward explanations of how samples will be used, and ethical practices such as offering compensation if their samples contribute to future research.

Concerns about how institutions might access and misuse HIV-related information.

Most participants in the study expressed significant distrust toward institutions such as the police, child welfare agencies, and immigration services, fearing these bodies could access and misuse their health information. Many felt that they were not given enough detail about what happens to their biological samples or how their HIV test results might be shared, including the possibility that immigration officials could access this information:

“I don’t think they give enough details. They only explain the basics—why the tests are being done and, if it’s positive, how to get connected to care. No one really describes the path your sample takes or who gets to see your results… I’m unsure whether they might refuse me permanent residency because of my HIV status… They might deny residency or citizenship” (28-year-old Caribbean man).

This comment reflects widespread anxiety that health data could affect immigration outcomes. The fear points to a broader issue of limited transparency surrounding who can access health information, which can discourage individuals from pursuing important testing.

Several participants also raised concerns that child and family services could become involved, drawing on a long history of systemic injustices affecting Black communities:

“There isn’t enough clarity around this, especially related to immigration, the police, and child and family services. Some people might think, ‘They’re going to take my children.’ They weren’t provided with sufficient information about the process or what it means to give samples and receive results” (34-year-old African man).

This perspective shows how fears grounded in historical discrimination influence present attitudes toward health data sharing. It also highlights the urgent need for clear communication to address concerns about how personal health information may circulate across institutions.

Another participant referred to a recent Canadian media story involving an HIV criminalization case in which a refugee with HIV was deported: “Media too—I remember a case where someone who was HIV-positive was deported… and people still bring it up today. I think that’s a reason to be afraid” (40-year-old African man). This example illustrates how publicized incidents can intensify fears of criminalization and deportation, discouraging individuals from getting tested due to potential stigma and legal consequences.

Many participants described concerns that their health data could be accessed by multiple institutions, increasing the risk of criminalization and reinforcing hesitancy around testing:

“People who think they might be HIV-positive don’t want to get tested to confirm it. If one institution has my result, another can also look it up… Clinics, hospitals, and other health organizations share information. So regarding criminalization, how can I prove that I pose no risk when my results are shared everywhere?” (33-year-old African man).

This comment demonstrates the deep mistrust participants felt, worrying that broad access to test results could violate their privacy and potentially expose them to punitive measures and stigma.

Participants also expressed anxiety about how HIV testing might affect their health insurance: “People in the community worry that it could impact their insurance premiums because of the number of medical bills. I think community members will have concerns about who can access their sample and their results” (30-year-old Caribbean woman). This reflects the fear that sharing health data might lead to financial consequences, such as increased insurance costs, shaping individuals’ decisions about testing. It highlights the perceived link between medical testing and broader socio-economic risks.

Uncertainty regarding the future use of HIV data and biosamples

A central theme among participants in this study was uncertainty about how their HIV samples might be used in the future. One participant reflected on this ambiguity, stating that while such samples could contribute to medical advancements, there was little control or understanding of their potential uses, leaving them unsure about participation (36-year-old African woman).

Several participants referenced the historical exploitation of Black communities in medical research as a factor shaping their apprehensions:

“Considering the history of testing on Black people and its outcomes, I understand why Black individuals might be hesitant… Past examples show how this information has been used against Black people, so these concerns are legitimate” (29-year-old Caribbean woman).

Similarly, another participant noted: “Historically, the Black community has been treated as Guinea pigs in research, so that memory persists… I can certainly see why community members are concerned about the future use of their blood samples” (42-year-old African man).

Participants also expressed worries about contemporary misuse of biological samples, highlighting ongoing concerns about exploitation:

“There have been instances historically where people took it upon themselves to exploit our samples, DNA, and related materials, so I do have concerns about what might happen with my samples in the future” (36-year-old African woman).

These statements underscore fears grounded in both historical precedent and present-day risks, emphasizing the importance of informed consent and transparent policies regarding the storage and use of biological samples.

While some participants were willing to allow their health information or blood samples to contribute to research—demonstrating some trust in the medical field—concerns arose regarding who might access their results, particularly non-medical personnel such as social workers or public health officials. Many participants preferred to be informed and included in decisions if their information were accessed for non-medical purposes:

“I’m fine with doctors seeing my information in the future, but if, for example, a social worker or other public health officer wants access for any reason, I’d like to be notified and given the choice of whether they can see it or not” (27-year-old African woman).

This reflects that participants may trust medical professionals but feel uncomfortable with non-medical access without consent.

Ethical considerations regarding the future use of biomaterials were also highlighted:

“If what I give helps more people… maybe finding a cure, that’s ethical and good. But if it could be used negatively, causing stigma, then I have major concerns. We need assurance that the sample won’t create fear, stigmatize the community, or be used as a weapon” (45-year-old Caribbean man).

Another participant emphasized personal control over their sample:

“Is it destroyed once I get my results, or what happens to it? I’d like to see my results first, and if I believe it could help science, I’d allow them to keep it… After receiving my results, I’d want the ability to sign for either permission to retain it for research or to destroy it immediately” (33-year-old African woman).

Participants consistently stressed the need for transparency and clear information about how their samples are handled:

“Explain to the community exactly where the sample goes… show a path. Even use a diagram… a visual of where their sample travels. Be very straightforward and informative before they consent” (28-year-old Caribbean woman).

Concerns also extended to long-term use of samples. Some participants wanted ongoing communication if their samples were retained for future research:

“When they do this… after maybe three or four years… will they come back to inform me? They can use my sample, but I don’t want to hear about it after, say, ten years” (24-year-old African man).

Some participants were wary of the commercialization of their information:

“I don’t want my information sold; I don’t know who it could be sold to. People worry about that a lot. I want it treated ethically” (31-year-old Caribbean woman).

Lastly, several participants emphasized that future use of their samples should involve consent and potentially compensation, reflecting both the value of their contribution and the need for reciprocal respect:

“If researchers want to use my sample in the future, there should be consent and probably some form of compensation” (37-year-old African woman).

Results and Discussion

This study sheds light on the concerns voiced by ACB communities regarding the collection, storage, and use of HIV-related biomaterials and personal health data, highlighting broader patterns of structural violence [10, 11]. Participants’ apprehensions, grounded in fears of human rights violations such as breaches of privacy and loss of control over their bodies, point to the existing power imbalances embedded in healthcare systems. These issues resonate with Farmer's [10, 11] concept of structural violence, illustrating how systemic inequities and racialized barriers within healthcare generate complex ethical challenges. The findings underscore the importance of critically examining healthcare practices to ensure that Black communities experience care that is both equitable and just.

Consistent with previous research on ethical concerns in HIV testing, participants raised issues related to confidentiality, privacy, informed consent, discrimination, and mandatory reporting [14-17]. The study reinforces prior literature describing the structural vulnerabilities of ACB populations in relation to HIV [1, 2, 4-7]. Whereas past studies often focused on structural influences such as gendered power relations, economic hardship, limited access to information, educational disparities, and inadequate socio-economic infrastructure [40-42], this research expands understanding by showing how historical socio-structural inequities and systemic racism specifically create barriers to HIV testing, carrying important ethical ramifications.

The findings further highlight the need to contextualize HIV testing within the cultural and historical experiences of ACB communities. Participants reported deep mistrust in healthcare systems, reflecting the lingering effects of structural violence [10, 11] and the influence of historical power dynamics on healthcare policies and procedures. The study underscores the necessity for transparent communication in HIV testing, including information on sample management, interpretation of results, and protections for patient privacy. While Canadian regulations exist to safeguard data privacy, mandate reporting, and limit the sharing of health information, these guidelines are not consistently communicated to patients. For instance, regulations specify when HIV data can be shared with public health authorities but often do not extend to non-health entities such as insurers, law enforcement agencies, or immigration officials. Clearly communicating these rules could help reduce mistrust and alleviate fears of data misuse. Additionally, inconsistencies in data-sharing policies across provinces and territories indicate opportunities for reform to strengthen patient protections and foster trust. Emphasizing informed consent and privacy safeguards addresses fairness concerns, particularly around the potential impact of HIV testing on immigration, insurance, or legal status. Ethical issues regarding discrimination and stigma [41] further highlight the need for anti-racist healthcare environments, equitable testing, and redress for historical injustices [5, 43].

Concerns about the sharing of HIV test results and potential criminalization reinforce the centrality of confidentiality in encouraging HIV testing [24, 25]. Healthcare providers must adhere to strict protocols to prevent unauthorized disclosure of HIV status. Worries about immigration and insurance implications point to the necessity of anti-oppressive, migrant-affirming HIV testing environments [26]. Viewed through a structural violence lens [10, 11], these vulnerabilities demonstrate how marginalized communities remain at risk of punitive actions. Even when participants were not directly exposed to immigration-related consequences, perceptions of possible harm may discourage engagement with testing due to fear of stigma, deportation, or discrimination.

Participants' perspectives also emphasize the ethical principles of beneficence and non-maleficence, highlighting the need to conduct testing in ways that minimize harm, including fears of discrimination or deportation. Respecting autonomy and promoting informed decision-making are critical, enabling participants to retain control over their testing and data usage [43]. Maintaining confidentiality while supporting public health objectives is equally important: while privacy must be preserved, de-identified data can still be utilized for surveillance purposes [44]. Clear policy guidelines and community involvement are necessary to uphold privacy rights while facilitating effective public health interventions [45].

The study further illustrates the ethical challenges associated with retrospective analyses of public health data. While these analyses can enhance understanding of health trends and improve interventions, attention to participant consent, anonymization, and transparency is essential. For ACB communities already experiencing systemic marginalization, retrospective use of data without explicit consent may intensify mistrust and fear of misuse. Findings highlight the importance of community-informed policies guiding retrospective data usage and of including ACB representation in decision-making to build trust and promote equitable public health practices.

Participants expressed particular anxiety about the future use of their bio-samples, revealing a tension between contributing to medical research and fearing loss of control over their samples. Ethical considerations involved balancing altruistic intentions with the potential for marginalization or stigma, underscoring the importance of transparent communication about sample utilization [28]. Concerns about sample management and personal health data reflected a desire for agency and reinforced the necessity of informed consent and clarity in healthcare practices.

The structural violence framework [10, 11] also highlights the potential for commercialization of HIV data within societal and economic systems. Participants expressed concern that financial incentives might override ethical obligations, leading to the commodification of sensitive health information. Situating these issues within structural violence underscores the need for policies that promote transparency and prevent exploitation. Discussions around commercialization of HIV data were framed in the context of neoliberal capitalism, highlighting ethical challenges arising from profit-driven motives. Advances in HIV research, including viral load mapping and strain-specific DNA sequencing [46, 47], can improve scientific precision but may also perpetuate systemic biases, exacerbate inequities, and reinforce stigma in racialized and economically marginalized populations. In response, Molldrem and Smith [32] propose “HIV data justice,” emphasizing community involvement and control over data as essential for addressing ethical concerns.

Overall, the study emphasizes the importance of fostering trust in HIV testing for ACB communities through culturally safe practices, informed consent, and recognition of historical exploitation. Community-based organizations and clinics are essential in providing safe, confidential, and stigma-free testing environments. Culturally sensitive approaches can improve the acceptability of testing and empower individuals to prioritize their health [3, 48]. Implementing decolonizing, anti-racist strategies is vital for creating HIV testing and healthcare systems that are both equitable and just.

Study limitations

A primary limitation of this research stems from the use of purposive sampling, which may have disproportionately reflected the experiences of ACB individuals already involved with HIV-related organizations. While this strategy facilitated recruitment within the community, it likely overlooked the perspectives of those less connected to such networks or who hold different views on HIV testing. The relatively small number of participants also restricted the range of experiences captured, limiting the overall diversity of voices. Although the study aimed to include a variety of perspectives, the findings may not fully represent ACB populations across Canada, especially since the research was concentrated in Manitoba. Variations in healthcare infrastructure, social dynamics, and regional contexts in other provinces suggest that the results may not be broadly generalizable. Future research could address these limitations by engaging larger and more heterogeneous participant groups across multiple regions, employing mixed-methods designs to strengthen findings, and exploring alternative recruitment approaches to include ACB individuals who are not currently linked to HIV services.

Conclusion

This research highlights the ethical dilemmas faced by ACB communities in Manitoba regarding HIV testing, particularly around issues such as privacy, consent, ownership of personal health data, and risks of misuse. The study illustrates how historical injustices, structural violence, and systemic racism combine to shape these communities’ experiences and apprehensions about HIV testing and the handling of sensitive information. Understanding these contextual influences is essential for creating healthcare spaces that are inclusive, culturally sensitive, and respectful of community concerns.

The results reveal a pressing need for healthcare policies that protect individual rights, ensuring confidentiality, informed consent, and control over personal health records. Participants expressed a strong demand for transparency, clear communication, and institutional accountability, especially concerning who has access to their data and the purposes for which it is used. To foster trust, it is crucial that healthcare systems actively involve ACB communities in designing and implementing data governance policies, particularly those preventing access by non-medical entities. Granting ACB individuals greater agency over their health information is vital to reducing stigma and improving participation in HIV testing programs.

Future studies should extend these insights by examining similar ethical concerns across other regions in Canada, engaging diverse ACB populations, and exploring a broader range of healthcare contexts. Such research can help guide the development of a more equitable and responsive healthcare system that fully acknowledges the historical experiences, rights, and specific needs of African and Caribbean communities.

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