GILEAD

Summary Report - May 2024

Partering for
Equity in Healthcare

Leading the charge on equitable healthcare:

Canada's opportunity to drive systemic change in HIV and Cancer Care

Executive Summary

Canada's universal healthcare system has been recognized globally for offering free access to medically necessary care to millions of Canadians each year. As Canada's population grows and becomes more diverse, meeting the unique needs of all Canadians within this framework is a challenge that has yet to be fully addressed.

Although Canada's healthcare system is described as 'universal', one of the key issues we continue to face is the persistence of healthcare inequities, especially for marginalized populations. The result is a system that is less efficient, less effective for some, and more costly. Health inequities cost Canada's healthcare system at least $6.2 billion each year[i].

The Rio Political Declaration on Social Determinants of Health reaffirmed Canada's commitment to addressing these gaps and improving health equity. Progress on these commitments in Canada through initiatives such as the monitoring of socioeconomic health inequalities, research and best-practice sharing were reported on in 2015[ii], yet, disparities continue, particularly in areas like virology and oncology, where Black, Indigenous, rural, and remote populations are disproportionately affected.

During a joint ideation session with experts and advocates across Oncology and HIV, facilitated by Gilead Sciences Canada, the urgent need to implement two specific, tangible solutions to improve the system were identified:

1. **Shared voices for shared solutions:** While governments often conduct consultations, there is an opportunity to make these processes more inclusive. Involving Indigenous, Black, and rural communities directly in decision-making ensures healthcare solutions are both culturally relevant and effective. Establishing multi-year advisory boards with representatives from these groups will help refine policies and healthcare programs. To enhance current efforts, governments should aim for broader representation both internally and through external committees, increase engagement opportunities, and provide transparent reports on consultation outcomes. These actions align to recommendations 1 and 6 from the Public Health Agency of Canada's Key Health Inequalities report.

2. **Turning data into policy:** Inconsistencies in collecting race-based data across disease states hinder a full understanding of health disparities. Mandating uniform race-based data collection through public health dashboards will allow for a more accurate measure of progress toward equity goals. These actions directly support recommendations 2 and 7 of the Public Health Agency of Canada's Key Health Inequalities report.

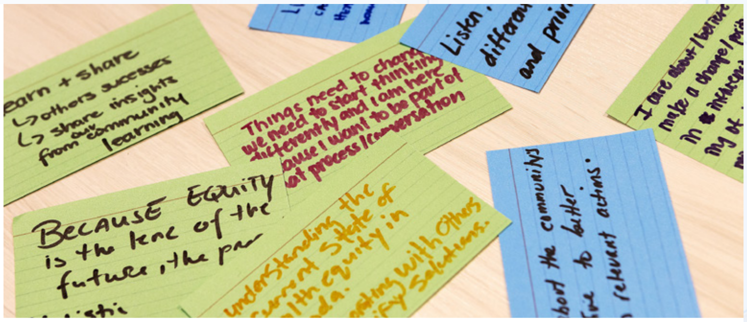
Rethink Breast Cancer recently launched the #MakeMeCount campaign, highlighting the need for complete and harmonized data to improve health equity and outcomes for all people diagnosed with cancer and accelerate the implementation of the 2023 pan-Canadian Cancer Data Strategy released by the Canadian Partnership Against Cancer and the Canadian Cancer Society. This strategy would support a more detailed understanding of who is included in broad cancer statistics, identify high-risk populations, gaps in care, and opportunities to improve outcomes.

Introduction

To tackle systemic healthcare inequities, Gilead Sciences Canada hosted its second annual *Partnering for Equity in Healthcare* event in May 2024. The event provided a platform to identify factors driving healthcare system inequities and propose solutions.

Bringing together patients, community members, policymakers, advocates, healthcare professionals, and thought leaders, the day's discussions focused on key areas within public health, virology, and oncology. A special emphasis was placed on HIV and breast cancer, two areas where historically marginalized communities, including Black, Indigenous, and rural populations, experience disproportionate healthcare burdens. Though the similarities within HIV and breast cancer may not seem immediately obvious, these communities share many common barriers to equitable and timely care.

Health equity was examined through the lens of geography, race, and culture—three critical social determinants of health. To sustain the conversation beyond the event, this paper outlines the key areas of inequity and presents actionable strategies for driving positive change.



Understanding Care Inequities by Population

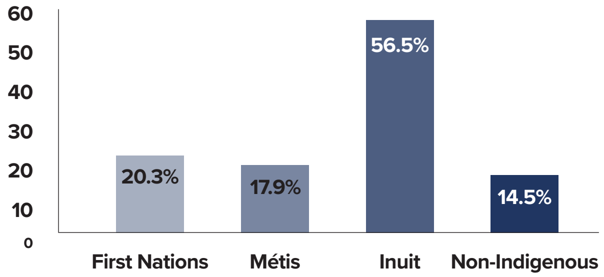
Healthcare inequities have profound effects that extend far beyond the individual patients who experience them, ultimately impacting entire communities and the healthcare system at large. When marginalized populations encounter barriers to receiving appropriate, timely, and high-quality care, the consequences are multi-layered, affecting both their personal well-being and the sustainability and efficiency of the broader healthcare infrastructure.

Indigenous People

Indigenous peoples of Canada continue to face profound and disproportionate healthcare challenges rooted in centuries of historical and ongoing colonial trauma and systemic racism, coupled with a long-standing mistrust of Western healthcare systems. They also experience disproportionately poorer health outcomes, including higher rates of chronic diseases, mental health issues, and a life expectancy that is 10 years below the national average compared to non-Indigenous Canadians.[iii] These challenges are compounded by the marginalization of Indigenous voices in healthcare policy, decision-making, and practice.

Despite making up **more than 5%**[iv] of Canada's population, **less than 1%** of the country's physicians identify as Indigenous.[v]

First Nations people living off reserve, Métis and Inuit across Canada are more likely to report being without a regular healthcare provider, compared to their non-Indigenous counterparts.[1]



[1] Canadian Medical Association. Indigenous Health. Accessed October 2 2024.

Indigenous Canadians...

- Are more likely not to have a family doctor and to live in northern or remote areas of Canada[vi] where there is decreased access to healthcare facilities.
- Have the highest rates of HIV in Canada – representing 10.3% of all those living with an HIV infection.[vii]
- Have the highest rates of HIV among Indigenous peoples in the US, New Zealand and Australia.[viii]
- Experience lower success in viral suppression rates, with only 54% achieving viral suppression compared to 95% of the general population.[ix]

Doris Peltier has dedicated her life's work to advocating for the wellbeing of Indigenous women living with HIV/AIDS. The 68-year-old Anishinaabe mother, grandmother and great-grandmother started working in the field in 2010 after she was diagnosed with HIV. Peltier says it's important to focus on the well-being of Indigenous women rather than illness.

> "For far too long a lot of the focus has been on our trauma and the regurgitation of that trauma. You're essentially spinning the tires and regurgitating the trauma of the women that you're working with."

While some Indigenous communities are advanced in their understanding, acceptance, and how they disseminate information, stigma, fear and misunderstanding still exist in others which results in barriers for people living with HIV. In provinces like Quebec where culturally-relevant support is limited for Indigenous women, this can lead to lateral violence, isolation and exclusion.

Image submitted by Doris Peltier, courtesy of CBC.ca/news

> "We talk about having Indigenous values. We talk about rekindling those Indigenous values but where's our Indigenous values around kinship when it comes to certain populations? The kinship system was strong and we need to bring that back because within the kinship systems that we've had, there's nobody left out of the circle."

- Excerpt from CBC Aboriginal AIDS Awareness Week article, 2019

Rural and Remote Patients

For many Canadians living in rural or remote areas, the scarcity of nearby healthcare facilities poses substantial barriers to timely and effective medical treatment.

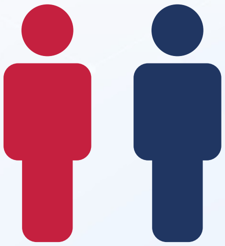
Traveling long distances to access health services not only involves significant time and inconvenience, but also leads to substantial travel-related costs. These travel-related costs disproportionately impact lower socio-economic groups, especially the “working poor” who earn too much to qualify for income support. These disparities are further compounded for rural residents, who typically have lower incomes, are less likely to have private health insurance, and experience poorer health and more chronic conditions compared to their urban counterparts. As a result, the need to travel long distances for routine or emergency care not only causes delays in receiving essential treatments, but also exacerbates existing health conditions.

When diagnosed with advanced blood cancer, Rod Delaney, a resident of rural Newfoundland, moved to Nova Scotia for several months to receive a bone marrow transplant. He was accompanied by his wife Joanne Wells and two dogs. When initial treatment options failed, they travelled cross-country to Ottawa to access CAR T-cell therapy. At the time, this life-saving treatment was not available in the Atlantic provinces and remains unavailable in his home province Newfoundland. Though his cancer is in remission today, Rod and his family still feel the financial and emotional impacts of the lack of access to treatments close to home. Their retirement plans have now been postponed indefinitely until they recover from the financial losses caused by Rod’s out-of-province treatments.

Black Women

Black communities are disproportionately affected by certain health conditions. For example, Black women face an almost three-fold increased risk of triple negative breast cancers compared to other women.[x] According to 2022 provincial data, 29.8% of first-time HIV diagnoses in Ontario were among African, Caribbean and Black people.[xi]

Compounding this inequity, people of colour, particularly Black women, face unique healthcare challenges that stem from intersectional discrimination and racism within the healthcare system. Black women often encounter biases, stereotypes, and a lack of culturally responsive care, which contribute to higher rates of maternal mortality, untreated chronic conditions, and other health disparities compared to their counterparts. Cultural competency is critically lacking, as shown by the fact that one in two Black individuals aged 15 to 40 years has faced racial discrimination in healthcare settings.



1 in 2

Black individuals aged 15 to 40 years have experienced **major racial discrimination in healthcare** settings.[2]

Dianne Bissessar is a Pickering, Ontario-based triple-negative metastatic breast cancer patient. In the midst of her cancer diagnosis, she felt unheard as a woman of colour with breast cancer and had to advocate for herself to find a healthcare provider that listened to her needs. Similarly, she says that more needs to be done for women of colour to have opportunities to support each other through their diagnosis and treatment.

> “Women of colour want to learn from each other about the best way to handle the news of diagnosis and the best decisions regarding treatment. A lot of the support groups did not represent my journey and my culture, and I really looked to find a support group that represented that. It was not easy to find, but once I found a support group that had culturally relevant resources and representation, they rallied around me.”

Dianne also says that ensuring women of colour are included in research about breast cancer is crucial to ensuring that they feel seen and included in the treatment outcomes.

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[2] Cénat, JM, Dromer, E, Darius WP, et al. Incidence, factors, and disparities related to cancer among Black individuals in Canada: A scoping review. Cancer. 2023; 129(3): 335-355.

Economic Impact

Socioeconomic inequalities cost Canada's healthcare system at least $6.2 billion annually.[xii] Barriers to care, such as geographic isolation, long wait times, or discriminatory practices, contribute to reduced preventative or routine care and often lead to delays in diagnosis and treatment. This results in more advanced, complex, and costly health conditions by the time care is finally accessed.

Access to primary care is another challenge with downstream impacts. It has been documented that because Black women have less access to regular or primary care, their cancers are diagnosed at a later stage, which results in poorer outcomes.[xiii]

Social Impact and Healthcare System Strain

At the individual level, patients who face healthcare inequities often experience significant stress, anxiety, and feelings of helplessness as they navigate a system that they feel is not designed to meet their needs. This emotional toll is compounded by the sense of alienation and exclusion many marginalized individuals feel when they encounter implicit bias or overt discrimination within healthcare settings. These experiences can have a lasting impact on mental health, leading to higher rates of depression, anxiety disorders, and other mental health challenges, particularly among populations already vulnerable to socio-economic hardship.

The psycho-social strain is not limited to individuals; it permeates entire communities. For families and caregivers, the responsibility of providing support to loved ones who cannot access appropriate care often leads to additional emotional, financial, and physical stress[xiv]. This creates cycles of distress that perpetuate disadvantages, as community members become more focused on caregiving and coping with healthcare challenges rather than on broader aspects of social and economic well-being. The social cohesion of communities weakens under the weight of these disparities, exacerbating feelings of isolation and distrust, especially in historically marginalized groups.

> “Rod's cancer became like a job to me. I was 100-per-cent focused on it from the time I woke up in the morning to the time I went to bed. As a caregiver, I did endless research, joined every relevant Facebook group and reached out to every organization I could think of for help.”
>
> – ***Joanne Wells**, wife and caregiver to Rod Delaney*

Cultural Competency and Individual Impact

One of the most critical challenges contributing to healthcare inequities is the pervasive lack of cultural competency. For many marginalized groups, the healthcare environment can be unwelcoming or dismissive of their cultural beliefs, practices, and values, with research showing that 17% of Indigenous adults diagnosed with cancer felt that their care was not culturally appropriate.[xv]

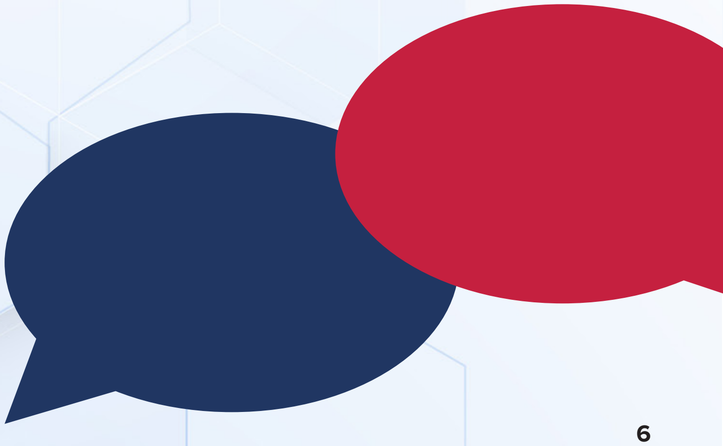
This disconnect can lead to a lack of trust in healthcare providers and systems, causing patients to avoid seeking care until their health conditions worsen.

Providers who are not trained or equipped to understand the cultural contexts of their patients are more likely to make incorrect assumptions or deliver care that is not aligned with patients' needs or preferences. This can lead to misdiagnoses, inappropriate treatments, and a general reduction in the effectiveness of care. Additionally, the absence of culturally competent care contributes to healthcare disparities by creating an environment where marginalized patients do not feel safe or respected, further deepening mistrust in the system.

> “As a women of colour, throughout my experience with breast cancer, I believe that we could better serve the community by providing greater access to resources, such as support groups that can speak to our unique challenges and cultural nuances. The Black community can be suspicious of medical care and have deep rooted concerns that they are not going to receive the best care.”
>
> – ***Dianne**, living with metastatic breast cancer*

44.5%

of recent foreign-born Canadian immigrants reported **discrimination and unfair treatment** due to language barriers.[3]



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[3] *Zghal, A, El-Masri, M, McMurphy, S, and Pfaff, K. Exploring the Impact of Health Care Provider Cultural Competence on New Immigrant Health-Related Quality of Life: A Cross-Sectional Study of Canadian Newcomers. J Transcult Nurs. 2020 Oct 23; 32(5): 508-517.*

Possible Solutions

Case studies

Culture in healthcare delivery: Māori Care

Culturally Competent Care Models: Successful healthcare systems in New Zealand, which integrate Maori cultural practices into care delivery, have significantly improved health outcomes for Indigenous populations. This model could serve as a benchmark for creating culturally competent care in Canada.

> **Insights:** Involving communities in decision-making processes ensures that healthcare services are tailored to meet the specific cultural and social needs of marginalized populations.

Race-Based Data Collection: UK National Health Service

The UK has pioneered race-based data collection initiatives that inform healthcare policy and interventions. These programs have allowed for more precise tracking of health outcomes among marginalized communities, providing a data-driven foundation for policy decisions.

> **Insights:** Implementing similar models in Canada could enable better-targeted interventions for populations at risk.

Reaching marginalized populations The Blue Door

The Blue Door Clinic in Regent Park, Toronto, provides short-term HIV treatment, ongoing community support and referrals to community and health services for people living with HIV who are precariously insured or uninsured in Ontario. The program then seeks to connect them to ongoing HIV primary care through a network of providers in the community. The program also provides support and education to service providers (e.g., primary care providers) to build knowledge of the needs of precariously insured or uninsured people living with HIV and build capacity to deliver services to this population. The Blue Door Clinic is supported by 11 collaborating partner organizations in Toronto: the Black Coalition for AIDS Prevention, Casey House, the Committee for Accessible AIDS Treatment (CAAT), Fife House, the Hassle Free Clinic, the Ontario HIV Treatment Network (OHTN), the Parkdale Queen West Community Health Centre (CHC), the Regent Park Community Health Centre, Sherbourne Health, The Centre for Spanish Speaking Peoples and the Toronto People With AIDS Foundation.

> **Insights:** Reaching marginalized populations requires collaboration between partners to ensure those who may not have access to the traditional healthcare system are still able to access treatment. This program can be replicated in other urban markets with large populations of new residents.

Enhancing training for rural HCPs: Rural Cancer Hubs

Dr Kristin Campbell at the University of British Columbia and Dr Sarah Neil-Sztramko at McMaster University have launched innovative training hubs to ensure that rural patients can access high-quality, evidence-based supportive cancer care. With support from a Canadian Cancer Society Challenge grant, a team led by Drs Campbell and Neil-Sztramko have launched training hubs where healthcare providers who are not located in cities can access mentoring, training and guidance specific to supporting breast cancer survivors in their local communities. The researchers hope their project will ultimately enhance the overall health and well-being of people living with and beyond cancer.

> **Insights:** Providing resources and training to healthcare professionals already working in communities can help provide an immediate bridge to enhanced care for patients in rural communities, and an expansion of these hubs can create further opportunities to improve care within these communities so that patients don't need to travel for treatment.

Building a Path Forward: Recommendations for Driving Systemic Change

Based on the insights from the data and discussion, this white paper proposes two key recommendations to begin to address healthcare inequities in Canada. The excellent work being done by the participants in Partnering for Equity in Healthcare points the way – we need to continue to build on their efforts to make equitable healthcare reach across the country to all who need it.

1. Consistently integrating community wisdom and insights into healthcare decision-making

> **Rationale:** Community engagement is critical for ensuring that healthcare interventions are culturally relevant and effective. Involving Indigenous, Black, and rural and remote communities in to decision-making processes will ensure that healthcare services are responsive to their specific needs.
>
> **Action Steps:** Elevate existing models for the integration of community feedback into design and delivery at all levels of healthcare, drawing on best practices. Identify gaps in community engagement and establish formal advisory boards composed of representatives from marginalized communities where needed.

2. Healthcare outcome tracking through race-based data collection

> **Rationale:** Collection of race-based data will allow for better informed health policy decisions and interventions. Mandating race-based data collection through public health dashboards that regularly report on health disparities will allow Canada to track progress made toward equity goals. Draw on projects and best practices such as those established by Dr. Notisha Massaquoi and the Black Health Equity Lab at the University of Toronto eg. Black Women and HIV Research Data Governance project.
>
> **Action Steps:** Advocate for continued investment of resources in projects such as those underway by Dr. Massaquoi and others, and sharing the findings widely in order to drive healthcare system changes needed to address inequities.

Discussion

1. **How can we better leverage the patient voice in private and public sector decision making across Virology & Oncology?**
2. **What programs already exist that can be levered/improved/better funded?**
3. **How do we create the opportunity for more Indigenous-led healthcare policy solutions?**

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[i] *The Direct Economic Burden of Socio-Economic Health Inequalities in Canada. Accessed Oct 31 2024.*

[ii] *Rio Political Declaration on Social Determinants of Health: A Snapshot of Canadian Actions 2015. Accessed Oct 31 2024.*

[iii] *The future of health in Canada. Healthcare reimagined. Deloitte. Public Health Agency of Canada. Estimates of HIV incidence, prevalence and Canada's progress on meeting the 90-90-90 HIV targets, 2020.*

[iv] *Stats Canada. Statistics on Indigenous peoples. Accessed Oct 1 2024.*

[v] *Canadian Medical Association. Indigenous Health. Accessed October 2 2024.*

[vi] *Stats Canada. Study: Access to primary healthcare among First Nations people living off reserve, Métis and Inuit, 2017 to 2020. Accessed on October 4 2024.*

[vii] *The epidemiology of HIV in Canada. CATIE. Accessed Dec 12 2024.*

[viii] *Koehn, Katrina, et al. Rates of new HIV diagnoses among Indigenous peoples in Canada, Australia, New Zealand, and the United States: 2009-2017. AIDS. 2021 Aug 1;35(10):1683-1687.*

[ix] *Palmer, Alexis, et al. Viral suppression and viral rebound among young adults living with HIV in Canada. Medicine (Baltimore). 2018 Jun 1;97(22):e10562.*

[x] *McCarthy, Anne Mare et al. Relationship of established risk factors with breast cancer subtypes. Cancer Medicine. 31 August 2021. Accessed Oct 31, 2024.*

[xi] *Rio Political Declaration on Social Determinants of Health: A Snapshot of Canadian Actions 2015. Accessed Oct 31 2024.*

[xii] *The Direct Economic Burden of Socio-Economic Health Inequalities in Canada. Public Health Agency of Canada. Accessed Oct 31 2024.*

[xiii] *Dunne, Caitlin. Black Women's Health Matters. BC Medical Journal. BCMJ, vol. 62, No. 6, July August 2020. Accessed Oct 31 2024.*

[xiv] *Cancer Caregiving in the U.S. Accessed Oct 31 2024.*

[xv] *Canadian Medical Association. Indigenous Health. Accessed October 2 2024.*

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