

Health Equity Report

March 2023

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About the Author

Amie Archibald-Varley is a thought leader and advocate for health equity. In her role as Health Equity Specialist at Niagara Health, Amie provides leadership, advice and strategic consultation to embed anti-racism and equity into the culture, policies and practices of this large health system, with a specific focus on promoting respect for equity-deserving groups. She has previously advised Health Canada, the Canadian Institute of Health Research and the federal government on topics ranging from nursing to health equity, anti-Black racism, mental health and poverty.

Amie is also a noted international speaker with the National Speakers' Bureau, media contributor, freelance journalist with the CBC, podcaster and author. As co-host, she can be heard on the Gritty Nurse Podcast. Her book, *The Wisdom of Nurses*, is forthcoming from Harper Collins (April 2024).

About the Report

Niagara Health commissioned this report to advance health equity across the organization as part of the next step in its Strategic Plan. The author was asked to provide a current state analysis and to craft a plan, including recommendations, that would satisfy this objective.

Executive Summary

Health inequities and poor health outcomes occur across Canada. Despite having a publicly funded healthcare system, there is growing evidence to suggest that the gap is widening in health disparities and inequities for racialized groups. Factors such as income, housing, socio-cultural and environmental conditions contribute to health inequities. Differential access to health, primary care and preventative services and racial and ethnic differences in the quality of care delivered also contribute to health disparities. Although race is a social construct with no biological basis, racism and its effects on healthcare are very real.

While COVID-19 has affected the entire world, the health risks, burdens, experiences, and outcomes are not equal for everyone. “Through the collection of race-based data, it was found that overall, the COVID-19 mortality rate was significantly higher for racialized populations (31 deaths per 100,000 population) compared to the non-racialized and non-Indigenous population (22 deaths per 100,000 population)” (Government of Canada, 2021). Thus, the benefits of improved care for racialized and Indigenous communities may be substantially more than for others. Covid-19 has pulled back the veil on systemic inequities in healthcare, which started national conversations on equitable access to care, quality of care and population health.

In most provinces and territories race-based- ethnic data is not collected, creating a gap in achieving health equity. Although we do not collect race-based data, the stories and experiences of patients and families highlight widespread inequities in Canada. We need to look no further than the experiences of Joyce Echaquan, Brian Sinclair, John River, and Heather Winterstien. My own mother, Shirley Archibald, was a victim of racism in healthcare. We can and must do better.

“Racism affects communities at both interpersonal and systemic levels; directly producing health inequities. Studies show links between racism and increased risk of poor health outcomes, including negative impacts connected to encountering racism (such as increased stress and declining mental health), underutilization of health services, mistrust of health systems, and higher rates of chronic disease” (Ontario Health, 2020).

Racism in healthcare must be dismantled through conversations, policy and practice changes. This transformative change must start with honest conversations and assessments of our systems structures.

Health equity is a priority at Niagara Health. Achieving health equity requires the examination of current policies and practices, thought processes, and evidence-based research to reduce unnecessary and avoidable differences. Health equity means ensuring access to opportunities to attain a higher level of healthcare through timely, appropriate and high-quality, comprehensive care, free from discrimination and independent of social, economic, and demographic status. Niagara Health needs to make continuous efforts to reduce disparities.

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The purpose of this report is to examine health inequities disparities as it relates to clinical service delivery/clinical practice, and identify changes in clinical practices to reduce disparities. To this end, this report provides:

1. A current state analysis of health equity at Niagara Health through (meta-analysis of research, evidence-based practices that supports health equity strategies, collaboration with staff/community engagement)
2. Uses evidence from a variety of sources to identify clinical practice recommendations for Niagara Health to reduce health inequities of all equity-deserving groups. Some recommendations require community partnership/engagement or are provincial in nature, and have been identified as such in this document.

The following guiding principles helped define this body of work, given the focus on health equity in a clinical hospital setting:

- We are here, first and foremost, for the health and well-being of patients.
- Ontario Health Equity, Inclusion, Diversity and Anti-Racism Framework, as identified in the Strategic Plan, will serve as the framework for this work.
- The equity plan resulting from this work will be developed in the spirit of learning and mobilizing change to improve the quality and safety of care for patients.
- The plan will focus on health equity within the hospital.

Historically, healthcare leaders have not backed down from addressing complex issues. The COVID-19 pandemic is an example of how efficiently and effectively leaders globally worked to reduce the number of deaths and harm. In a matter of weeks, many organizations dramatically revised operations and planning, shifted to remote work where possible, deployed telehealth, reimagined research protocols and productivity, and even in some cases—crowdsourced personal protective equipment. A similar all-hands-on-deck approach is needed to health inequities and address racism in healthcare. This is a moral and ethical obligation.

Methods

To inform this work, I conducted a meta-analysis of health equity literature (examined evidence-based practices that support health equity strategies) and interviewed six NH leaders and engaged several community health partners: Positive Living Niagara, Niagara Public Health, Niagara Region, Ontario Native Women's Association and Folk Arts Multicultural Centre. I also conducted benchmarking with healthcare organizations working to improve health equity in their communities. The hospitals that responded included: Peterborough Regional Health Centre, Brockville General Hospital, Chatham Kent Health Alliance, Windsor Regional Hospital, Hamilton Health Sciences, North Bay Regional Health Centre and Oak Valley Health. The results presented in this document provide guidance and recommendations to inform the implementation of this plan for a multi-year project on how Niagara Health can begin its journey to reduce health disparities and improve health equity in the community it serves.

Key themes

The key themes emerged from meaningful patterns across the three data sources (research, leadership interviews, and hospital benchmark data). The themes demonstrate that key issues the health system is grappling with to improve care from a health equity perspective. These themes included:

1. Health Equity as a strategic priority utilizing Ontario Health's Equity, Inclusion, Diversity and Anti-Racism Framework.
2. Collection of race-based/ethnic-based data/upgrading the Health Informatics System
3. Deploy strategies to address the multiple determinants of health of equity-deserving groups on which healthcare organizations can directly impact healthcare services, socioeconomic status, physical environment, and healthy behaviours.
4. Creation & development of structural processes to integrate and support health equity work.
5. Decrease institutional racism within the organization; and
6. Develop partnerships with community organizations to improve health and equity.

Recommendations

The table below summarizes the clinical recommendations resulting from this body of work as a starting point to improve health equity.

| | Niagara Health (NH) | Niagara Ontario Health Teams (NOHT) | Ontario Health (OHW)West/Ontario Health (OH) |
|---|--|--|--|
| Kidney Care | <ul style="list-style-type: none"> Remove race as a modifier for eGFR function testing. Collect socio-ethnic/race-based data in relation to kidney care outcomes for equity-deserving groups. Create a plan to discuss changes with clients and plan for impact of patients who cross into this new threshold in the Niagara region. | | <ul style="list-style-type: none"> Revisit clinical care standard. Implement “waiting time adjustment” for kidney transplant candidates affected by race-based calculation (as proposed by the Organ Procurement and Transplantation Network in 2023). |
| HIV | <ul style="list-style-type: none"> Educate Niagara Health staff related to HIV treatment/care to reduce stigma Examine how Niagara Health can deliver HIV care/treatment (outreach worker, nurse, social worker etc.) so patients can access care closer to home (with a focus on equity-deserving communities). Collect socio-ethnic/race-based data in relation to HIV for equity-deserving groups to improve healthcare outcomes/reduce risk of infection. | <ul style="list-style-type: none"> Examine how they may be able to provide appropriate mental health services, education, treatment, and follow-up, planning and services that will achieve health equity for patients with an HIV diagnosis. Educate community re: HIV (prevention, lifespan, treatment, peer-to-peer program, reduce transmission rates and improve health outcomes through early detection, treatment and support). | |
| Limb Amputation, Wound Care/ Patient Experience, Stigma, Delay in Care | <ul style="list-style-type: none"> Collect socio-ethnic/race-based data in relation to limb amputations/wound | <ul style="list-style-type: none"> Creates targeted strategies and policies required to serve communities with high amputation rates to reduce these disparities. Review current regional data related to wounds and wound care, ischemia and limb amputations. | <ul style="list-style-type: none"> Creation of actionable policies and quality metrics to reduce the incidence of critical limb ischemia and enhance the delivery of optimal care are needed. |

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| | | | |
|----------------------------------|--|---|--|
| | | <ul style="list-style-type: none"> • Improve patient relations in the community & collaboration with public health agencies in relation to wound care and critical ischemia. | |
| Screening for Cancer Care | <ul style="list-style-type: none"> • Collect socio-ethnic/race-based data in relation to Breast Cancer & Colorectal Cancer Screening rates. | <ul style="list-style-type: none"> • Design a campaign targeting equity-deserving groups using WCH and Health Partners Minnesota as a model. | <ul style="list-style-type: none"> • Targeted resources to support equity-deserving groups who are disproportionately impacted. |
| Maternal/Neonatal Care | <ul style="list-style-type: none"> • Collect socio-ethnic/race-based data in relation to Maternal/Neonatal mortality & morbidity for equity-deserving groups to improve health • Collaborate with hospital organizations that have begun this work. | | |
| Gender Affirming Care | <ul style="list-style-type: none"> • Integrate gender-affirming care into the new Health Information System build. • Create an interim solution in relation to patient identification, including pronouns and chosen name to provide gender-affirming care for transgender patients and non-binary patients. | | |
| Migrant Workers | | <ul style="list-style-type: none"> • Collect data in relation to this specific patient population to improve the overall care given to migrant workers in the Niagara region. | |
| Mental Health | <ul style="list-style-type: none"> • Examine how Niagara Health might provide culturally affirming care to racialized populations. | <ul style="list-style-type: none"> • Collect data to support patients experiencing mental health and addictions as this is a priority of the OHT. | |

In addition, the following general recommendations can be applied to all health service providers:

- Focus on Anti-Indigenous and Anti-Black Racism.
- Include and Engage Key Voices. Listen to the staff and communities and include their ideas and feedback into the design, delivery and evaluation of programs and services
- Invest in Implementation. Apply the financial and people resources needed for success and ongoing sustainability. Specific funding and resource allocation to Health Equity to engage in activities that impact the patients, workforce and community.
- Represent and Reflect Ontarians. Strive for all levels of the organization to reflect the communities served.
- Address and reduce implicit and racial bias in a timely manner in the work environment.
- Reduce disparities by using data and best practices to establish standards, identify disparities and implement corrective action through a focus on access, experience and outcomes for the population.
- Identify and address discriminatory practices and procedures in all forms and all levels using targeted approaches (HIV, Kidney Care, Cancer Screening, Mental Health, Maternal/Neonatal health etc.)
- Contribute to Population Health. Work with other arms of government and agencies in planning services to improve the health of the population. Aligning with services across regions and Ontario Health Teams (OHTs)
- Report and Evaluate to Drive Improvement. Publish Framework metrics publicly with all reports, including an equity analysis.

Health Equity: A Moral and Ethical Obligation to Achieve Health for All

In healthcare, the goal is to improve the health of individuals, communities and populations. Having access to healthcare is not enough to reduce inequities. An intersectional health focus is required—examining the impact or “intersections” of the social determinants of health. Various health equity frameworks were examined (Ontario Health’s Equity, Inclusion Diversity and Anti-Racism Framework, The Petal Framework, and the IHI framework). The framework chosen for this work is Ontario Health’s Equity, Inclusion, Diversity and Anti-Racism Framework. To achieve health equity, a systems-level approach is required to reduce health disparities and improve healthcare outcomes. Health equity must be prioritized by all leaders and at all levels of our organization. This is a significant change to how we work and deliver healthcare services. Health equity requires substantial commitment, including financial resources. This work cannot be done “off the side of our desk.” It requires dedicated resources, support and dedication.

“A high-quality health care system starts with a culture that promotes equity and reduces disparities” -Ontario Health’s Equity, Inclusion, Diversity and Anti-racism Framework.

Ontario Health's Equity, Inclusion, Diversity and Anti-Racism Framework

With a focus on addressing anti-Indigenous and anti-Black racism

11 Areas of Action

- Collect Equity Data**
Set up systems and supports to collect, analyze, and use equity data to report findings and inform future decisions
- Embed in Strategic Plan**
Ensure efforts to address equity, inclusion, diversity, anti-Indigenous and anti-Black racism are at the highest priority for the organization
- Partner to Advance Indigenous Health Equity**
Recognize that strong relationships with Indigenous leadership and communities – founded on respect, reciprocity, and open communication – are critical in ensuring that the new health care system in Ontario reflects and addresses the needs of Indigenous peoples.
- Invest in Implementation**
Apply the financial and people resources needed for success and ongoing sustainability
- Identify Clear Accountability**
Establish and assign “who” is responsible for “what”
- Represent and Reflect Ontarians**
Strive for all levels of the organization to reflect the communities served
- Include and Engage Key Voices**
Listen to the staff and communities and include their ideas and feedback into the design, delivery and evaluation of programs and services
- Address Racism** Focus on Anti-Indigenous and Anti-Black Racism
Identify and address discriminatory practices and procedures in all forms and all levels using targeted approaches.
- Reduce Disparities**
Use data and best practices to establish standards, identify disparities and implement corrective action through a focus on access, experience and outcomes for the population
- Contribute to Population Health**
Work with other arms of government and agencies in planning services to improve the health of the population
- Report and Evaluate to Drive Improvement**
Publish Framework metrics publicly with all reports including an equity analysis

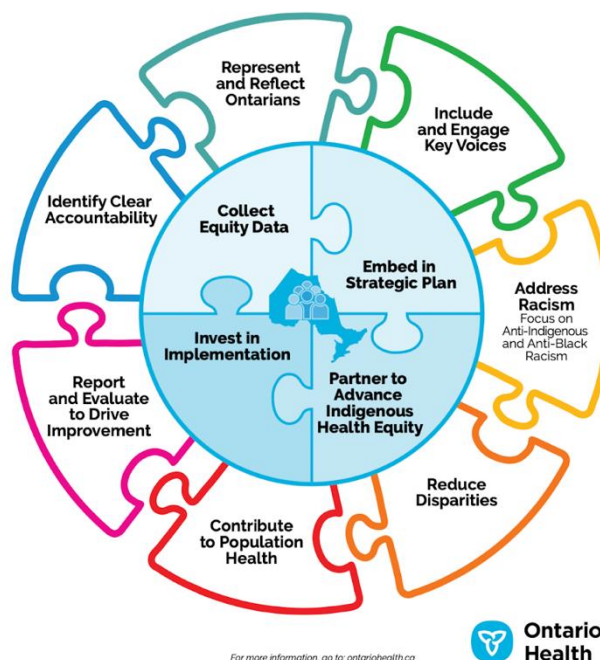


Figure 1: Ontario Health’s Equity, Inclusion, Diversity and Anti-Racism Framework ⁴⁴

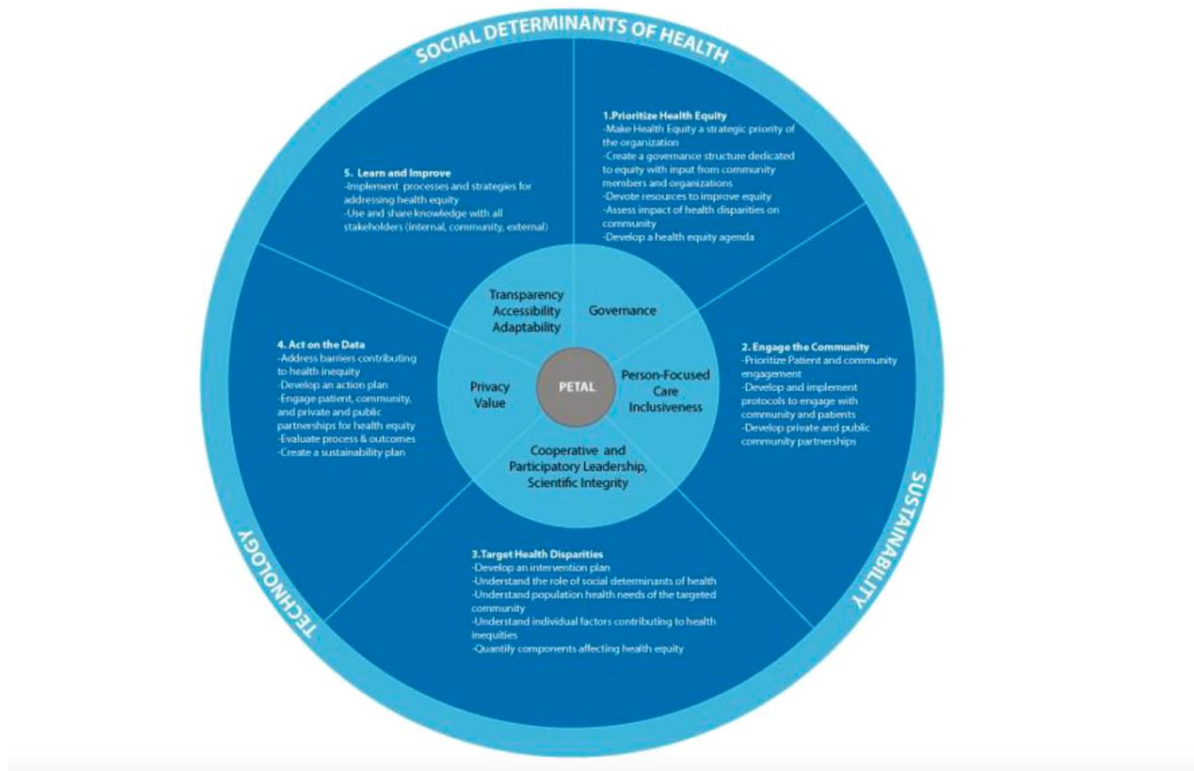


Figure 2: PETAL framework ¹¹

Figure 3. A Framework for Health Care Organizations to Achieve Health Equity

| | | |
|----|---|--|
| 1. | Make health equity a strategic priority | <ul style="list-style-type: none"> • Demonstrate leadership commitment to improving equity at all levels of the organization • Secure sustainable funding through new payment models |
| 2. | Develop structure and processes to support health equity work | <ul style="list-style-type: none"> • Establish a governance committee to oversee and manage equity work across the organization • Dedicate resources in the budget to support equity work |
| 3. | Deploy specific strategies to address the multiple determinants of health on which health care organizations can have a direct impact | <ul style="list-style-type: none"> • Health care services • Socioeconomic status • Physical environment • Healthy behaviors |
| 4. | Decrease institutional racism within the organization | <ul style="list-style-type: none"> • Physical space: Buildings and design • Health insurance plans accepted by the organization • Reduce implicit bias within organizational policies, structures, and norms, and in patient care |
| 5. | Develop partnerships with community organizations | <ul style="list-style-type: none"> • Leverage community assets to work together on community issues related to improving health and equity |

Figure 3: IHI Framework: A framework for Healthcare Organizations to achieve Health Equity

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Data Collection & Strategies

More broadly, Canada has been slow to acknowledge the role that structural racism plays in our society and how that racism serves to generate and perpetuate inequalities, including in health. As a result of Canada not collecting race-based healthcare data, the information available is limited. What little is available demonstrates racial and ethnic inequalities in several outcomes in Canada, including cardiovascular disease, cancer and diabetes. It should be noted that much of the current research centers on immigrant populations whose experiences are distinct and sometimes overlap with the experiences of Canadian-born non-white people. At best, the available data provides an incomplete picture of the inequities faced by non-white people. To effectively address current inequalities, we need to increase the quantity and quality of research substantially. The dearth of effective research is a critical barrier that makes it impossible to research and redress the effects of racism on healthcare.

“We don't know what we don't collect...”

“...we are at the infancy stages of researching things...trying to get our leaders in healthcare to see the role we play...”

“I interact with colleagues across the province, and I'm going to say this topic never comes up...not sure if this is on people's radars fully.”

An environmental scan was conducted amongst the leadership team at Niagara Health. Most respondents suggested that we have no specific examples of clinical and/or patient care activities to improve health equity because we do not measure it. In addition, it was not well understood what programs were available within Niagara Health that specifically targeted health equity.

“...race/ethnic-based data is not collected...we do not collect anything specifically targeting health equity”

Racism remains an enduring feature of Canadian society, undergirding inequity in healthcare systems. Despite perceptions that Canada is more equitable and less racist than the United States, several studies have found that these issues are similar to those in the US. Still, unlike the United States, they remain under-studied in Canada. Racism is a social determinant of health and Canadian health researchers need to start including this as a key component of their

research. Researchers need to acknowledge that concerns facing the immigrant population are not congruent with the very real concerns facing Canadian-born people who are not white.

“Staff and doctors have felt bias in their work environments here.”

Several hospital organizations stated that getting senior leadership on board with equity initiatives is a critical first step. Leadership must understand that these initiatives require time, resources and labour investments to be effective. It is also important that leaders understand that, once adopted, these initiatives do not have an end date; instead, they must become a part of the organization’s infrastructure. Several respondents also indicated there had been reluctance on the part of leadership to begin collecting race-based data and that doing so presents numerous challenges; however, these same respondents agree that this is a critical part of any equity initiative.

“not my comfort... well comfort comes from **exposure, experience, and embracing** ...you gotta get out there you've got to go into those uncomfortable waters you know and that's how you best learn...”

“...creating urgency for change will be a catalyst”

UHN: We Ask Because We Care

The University Health Network (UHN) is a strong proponent of responsibly collecting and researching population health survey data and noted that collecting ethnic/race-based data has been instrumental in helping identify and address many forms of inequalities.³⁹ UHN noted that collecting socio-demographic data is critical to the organization’s health equity initiatives.³⁹ UHN stated that “data collection is only a means to a bolder end: equity in health, represented in the absence of systematic disparities in health between groups with different levels of underlying social advantage/ disadvantage- that is, wealth, power, or prestige.”³⁹ This will be an integral step in Niagara Health’s journey to achieve health equity.

Addressing Racism in Healthcare

It is imperative for Niagara Health to address racism. Studies show links between racism and increased risk of poor health outcomes, including negative impacts connected to encountering racism (such as increased stress and declining mental health), underutilization of health services, mistrust of health systems, and higher rates of chronic disease.⁴⁴ Racism in healthcare must be dismantled through conversations, policy, and practice changes. This transformative change must start with honest conversations and assessments of our systems structures. Racial

bias is the tendency to view and treat members of a racial group positively or negatively. Biases about Black racialized and Indigenous people are mostly negative, as evident in stereotypes, prejudice and discriminatory treatment. We cannot take a “color-blind” approach to healthcare. This was also reflected in the comments that Niagara Health leaders made in relation to addressing racism and unconscious bias.

“Unconscious bias training should be more of a focus because it is “such a huge topic to tackle”

“...it (health equity) can’t be learned in a LERHN module”

Through conversations with Niagara Health leaders, many respondents stated the importance of creating psychologically safe environments for this work. It was also discussed that they feel like those systems & mechanisms for psychological safety in relation to racism are not fully in place. A discussion surrounding how discrimination is handled occurred. There were concerns surrounding equity in relation to discipline, follow-up, investigating and acting on racism and discrimination that occurs at Niagara Health. Racism affects communities at both interpersonal and systemic levels; directly producing health inequities.

“the staff aren’t even thinking about that they are there to take care of a very acute thing they just don't have the tools of how to deal with that other stuff that comes up”

It is recommended that NH:

- Focus on Anti-Indigenous and Anti-Black Racism.
- Identify and address discriminatory practices and procedures in all forms and all levels using targeted approaches (HIV, Kidney Care, Cancer Screening, Mental Health, Maternal/Neonatal health etc.)
- Address and reduce Implicit and Racial Bias in a timely manner in the work environment.

“We need to learn more surrounding social determinants of health and marginalization and stigma related to certain communities and diagnosis, bias and antiracism”

Kidney Care & Kidney Transplant

Even though race is a social, not a biological construct, the current estimated glomerular filtration rate (eGFR) equation includes age, sex, body weight and race as modifiers^{14, 17, 33, 36}. A person's eGFR is a critical diagnostic method for detecting and managing kidney diseases. The presidents of the American Society of Nephrology (ASN) and the National Kidney Foundation (NKF) instructed all their members to cease including race as a modifier in the equations used to estimate kidney function.^{14, 17, 33, 36} Instead, they provided their members with a more accurate and representative equation that excluded race-based considerations from the data. In addition, they clarified that "the use of race in clinical algorithms normalizes and reinforces misconceptions of racial determinants of health and disease."^{14, 17, 33, 36} We must move beyond this to address the racism and racial disparities that impede the care of people with kidney disease." Currently, at Niagara Health, we still use race as a modifier.

It is important to note that although Black people are approximately four times more likely to be diagnosed with renal failure than white people, they are often diagnosed later, and it takes longer to get on transplant lists.^{14, 17, 33, 36} The antiquated and unscientific inclusion of race-based modifiers in eGFR leads diagnosticians to overestimate the kidney functions in Black patients, masking the severity of their kidney disease.^{14, 17, 33, 36} This then results in late diagnosis and delayed transplant referrals. The eGFR test has drawn scrutiny from experts in recent years. In the summer of 2021, the Organ Procurement and Transplantation Network board, responsible for linking transplant centers together and developing policies, prohibited the use of the calculation.^{14, 17, 33, 36} Moreover, the Organ Procurement and Transplantation Network board attempted to remediate the harms caused by these systems by approving adjustments in the waiting times for Black organ transplant candidates.^{14, 17, 33, 36} Many experts consider these to be unprecedented efforts to correct systemic imbalances that cause significant harm. Dr. Martha Pavlakis, a nephrologist and a chair of the kidney transplantation committee at the transplantation network, stated that it's a "restorative justice project in medicine."^{14, 17, 33, 36}

It is perhaps most surprising that the inclusion of race as a modifier in the eGFR equation has only recently been called into question because it has been known and accepted for a long time that race is a social construct. It has also been known that the Black people who participated in the original studies that helped develop the test were likely exposed to exogenous factors, such as medications or differences in diet, that impacted their creatinine levels.^{14, 17, 33, 36} Rather than attribute these differences to non-biological factors to account for these differences, scientists at the time concluded that Black people "had more "muscle mass" and a higher baseline level of creatinine." Race as a modifier in eGFR calculations must be removed from Kidney Function tests.^{14, 17, 33, 36}

It is recommended that NH:

- Remove race as a modifier for eGFR function testing.
- Collect socio-ethnic/race-based data in relation to kidney care outcomes for equity-deserving groups.

- Create a plan to discuss changes with clients and plan for impact of patients who cross into this new threshold in the Niagara region.

It is recommended that OH/OH West:

- Review Clinical Standard
- Implement “waiting time adjustment” for kidney transplant candidates affected by race-based calculation (as proposed by the Organ Procurement and Transplantation Network in 2023).

HIV

Although HIV is an easily treatable disease, disparities continue to persist. HIV is still a highly stigmatized and discriminated disease.²⁴ There are numerous barriers in the Niagara Region in relation to accessing care for HIV services. These barriers include lack of access, stigma, structural racism, discrimination and homophobia. There is much stigma and discrimination surrounding treatment, diagnosis and follow-up care. In Canada, Black women and men accounted for 42% and 18%, respectively, of reported cases among all women and men. In comparison, white women and men make up 14% and 38%, respectively, of new diagnoses.^{24,45} Many systemic factors also lead to increased infection amongst Indigenous women.^{24,45} Indigenous women account for 11% of new HIV infections.⁴⁵ Transwomen also experience higher rates of HIV.^{24,45} Ontario has no up-to-date statistics, but a study in 2012 showed Trans women were 10 times more likely to report having been diagnosed with HIV than Ontarians overall.⁴⁵

Data taken from the Ontario HIV Epidemiology and Surveillance Initiative (OHESI), as well as public health, identify that there are known 384 people living with HIV in the region. However, these numbers may actually be closer to 500 and based on information from the Special Immunology Services (SIS) clinic in Hamilton Health Sciences. If clients need HIV-specific care, (lab work, medication) clients must travel to Hamilton to receive these treatments. Patients in this clinic have been “turned away for care” from physicians in the region- citing that “this is not their expertise” even when treatable issues such as bronchitis are apparent. Fear surrounding correct PPE was discussed. It was identified that there is a lack of comprehensive sexual health education amongst care providers in the region in relation to HIV disease diagnosis, treatment and transmission.

The Positive Living Niagara clinic services 120 individuals living with HIV. This includes folks who use drugs, gay men, and men who have sex with men. The clinic provides care to clients in homes, shelters or wherever they client may be living. The clinic provides transportation to and from HHS for medical care for HIV specific care because it's not available in Niagara. The organization was identified as “supporting folks who might be living at some intersections– new immigrants to the community,...folks who need a little *more help navigating HIV services and those affected by poverty*”. These patients are often in the early HIV diagnosis stages. Many have many other “*intersecting oppressions.*” These intersecting oppressions are associated with, “*determinants of health, sexism, racism, and transphobia. HIV-stigma is*

*compounded by intersecting stigma, discrimination and oppression rooted in sexism, racism, and transphobia”.*⁴⁵

“60% of their clients identify as male. Approximately half of those identify as gay men or men who are having sex with men. 33% of our clients are women. 35% of our clients are African-Caribbean Black and the majority of those clients are women. 7% of our clients are from other racialized communities. Approximately 23% of clients use substances. 12% are well supported and able to manage their use while approximately 11% struggle with addiction and the complexity surrounding an HIV diagnosis.”~Positive Living Niagara”

This is deeply disturbing to see the trends in the Niagara Region in relation to HIV care and treatment. A particular focus for Niagara should be examining the impact of Black & Indigenous Women, newcomers to the Niagara Region, Transwomen and people who use drugs. It is imperative to have access to appropriate services and resources for individuals affected by HIV in Niagara.

It is recommended that NH:

- Examine how Niagara Health can deliver HIV care/treatment (outreach worker, nurse, social worker etc.) so patients can access care closer to home (with a focus on equity-deserving communities).
- Collect socio-ethnic/race-based data in relation to HIV for equity-deserving groups to improve healthcare outcomes/reduce risk of infection.
- Educate Niagara Health staff related to HIV treatment/care to reduce stigma

It is recommended that NOHT:

- Examine how they may be able to provide appropriate mental health services, education, treatment, and follow-up, planning and services that will achieve health equity for patients with an HIV diagnosis.
- Educate community re: HIV (prevention, lifespan, treatment, peer-to-peer program, reduce transmission rates and improve health outcomes through early detection, treatment and support).

Limb/Amputations/Wound Care & Patient Experience/Stigma/Delay in Care

Discussions highlighted concerns surrounding the increased prevalence of wound care issues, lower leg ischemia and limb preservation in Niagara. Health disparities regarding amputation and wound care have been well documented in both Canadian and American studies.^[8,14,26] The social determinants of health, and the intersections of sex, gender, race and ethnicity demonstrate the essential relationships at play as important cofactors for those population disparities.

When an individual needs to have a lower limb amputated as a result of uncontrolled ischemia that occurs secondary to diabetes mellitus or peripheral arterial disease, it is truly unfortunate. These types of amputations are even more tragic because they are largely preventable with proper follow-up care and treatment. Management and treatment of lower limb ischemia should not vary by socioeconomic factors, however, evidence demonstrates that racialized individuals, low income and people who are unhoused experienced poorer health outcomes.^[8,14,26]

Another disturbing revelation was made in relation to this finding. It was noted that a sizable amount of the population is resistant to accessing services at Niagara Health because of service-related issues (discrimination and poor overall treatment). Residents in the region have described horrible experiences and interactions with staff while receiving service at Niagara Health. Some residents said hearing about others' experiences made them avoid seeking care. Others are concerned that they will experience stigma from the staff at Niagara Health. For instance, one client with cellulitis refused to return to Niagara Health because *“he was like I was just tossed around and treated poorly like just considered drug seeking.”* Another client who had broken his femur *“felt that his care was so lacking and so poor that he would rather just sit in a hotel room and try and heal on his own.”* Issues like these have become common that staff at one public health facility have made a concerted effort to do *“bit of a better job at keeping track of how many times people are coming to us with health concerns that they're just refusing to go to the hospital Niagara Falls.”*

They also indicated that they know of *“folks who have lost both limbs from the knee down due to mistreatment, hesitation and stigma.”* One client went *“from like a very small wound on one foot that is clearly infected and needed care to within two weeks having a double amputation.”* Many of these concerns regarding clients delaying getting health care are directly related to stigma. The fear of being stigmatized leads people to delay getting treated when antibiotics would be effective before it escalates to amputation. An interviewee stated that *“we see folks of all ages right now with amputations either I've just interacted with another client in the past two years she went from loose having her toe amputated to having from below her knee amputated and then having a hip replacement that didn't take and now she's just unable to walk in as wheelchair bound.”* They concluded by stating, *“I don't think I've seen that as heavily*

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in other communities where amputations tend to be caused by blood-based infections, not related to disease processes like diabetes and due to a lack of treatment and follow-up care” which they are seeing at Niagara Health.

Evidence related to Limb Ischemia

When researchers divided their data by age and racial group, it became abundantly clear that Black patients experienced higher amputation rates, which increased with age. ^[8,14,26]

Researchers tried to determine whether these disparities were the result of inequitable management strategies on the part of physicians, which provoked significant debate and controversy. ^[8,14,26] It is still unclear whether these regional disparities are being driven by the biases of physicians administering care, or whether there are other explanations. ^[8,14,26]

“Previous studies have demonstrated that within African American populations, regardless of geographic region, there is a higher incidence of amputations compared to white populations (5.0-6.5 per 10,000 individuals versus 1.2-2.5 per 10,000). Furthermore, African American persons are not only more likely to undergo limb amputation but also the amputations are more significant, with a higher risk of above-the-knee amputations.” ^[14]

Limb amputation can be delayed and or prevented by timely and aggressive treatment.

It is recommended that NH:

- Collect socio-ethnic/race-based data in relation to limb amputations/wound care.
- Improve patient relations in the community & collaboration with public health agencies in relation to wound care and critical ischemia.

It is recommended that NOHT:

- Create targeted strategies and policies required to serve communities with high amputation rates to reduce these disparities.
- Review current regional data related to wounds and wound care, ischemia and limb amputations.
- Improve patient relations in the community & collaboration with public health agencies in relation to wound care and critical ischemia.

It is recommended that OH/OH West:

- Creation of actionable policies and quality metrics to reduce the incidence of critical limb ischemia and enhance the delivery of optimal care are needed.

Colorectal Cancer & Breast Cancer Care/Screening

Although Ontario does not currently collect ethnic or race-based data, data collected in the United States indicated that Black women were approximately 40% more likely to die from

breast cancer than white women.⁴⁶ The reasons for this disparity are multifactorial. In the Toronto Star article, *What one Toronto hospital is doing to ramp up screening for breast cancer — and to make sure no one gets left behind*, Dawn Barke, a Black woman and cancer survivor, stated, “The obstacles that Black women face are not limited to the anxiety and the mistrust of doctors, there’s a fear of being judged, social supports, child-care issues, transportation.⁴⁷ Other challenges could be financial, being a one-parent home and worrying about caring for their child if they have a health crisis.” Black women and other women of colour also tend to falsely believe that breast cancer is a disease that primarily afflicts white women because many survivors who speak publicly are white. As a result, when non-white women are diagnosed, many feel alone and isolated “because they don’t see themselves reflected in any of those materials, campaigns, education, etc.”^{46, 47.}

In June 2022, Women’s College Hospital in Toronto noted 300,000 people overdue for mammograms.^{46, 47} Many of these people were from groups, like Black women, that have been historically under screened.^{46, 47} Women’s College Hospital is committed to closing the gaps impacting Black women by offering a screening event specifically designed for Black women.^{46, 47} During these events, participants over 50 years of age were able to get Pap smears and/or mammograms. The hospital also provided anyone who qualified to attend with taxi chits, free parking and TTC tokens if they needed assistance with transportation. Transgender patients were also identified as a population with less screening. Gender-affirming care and strategies must be deployed to ensure the screening of this population.

Another example of how targeted screening reduces inequities is listed in the figure below. HealthPartners in Minnesota reduced screening gaps for breast cancer by “4 percent between racial groups and by 5 percent between insurance types, and they reduced screening gaps for colorectal cancer by 13 percent between racial groups and by 2 percent between insurance types.”⁴³



Figure 4: Reducing the Gap Colorectal & Breast Cancer Screening⁴³

It is recommended that NH:

- Collect socio-ethnic/race-based data in relation to Breast Cancer & Colorectal Cancer Screening rates.

It is recommended NOHT:

- Design a campaign targeting equity-deserving groups using WCH and Health Partners Minnesota as a model.

It is recommended that OH/OH West:

- Targeted resources to support equity-deserving groups who are disproportionately impacted.

Maternal & Morbidity & Mortality

Black women historically have the highest maternal mortality rates. The risk of Black women dying due to complications during pregnancy, childbirth and postpartum is three times higher than for white women.^{5,6,28} According to the U.S. Centers for Disease Control and Prevention (CDC), this gap has continued to widen. Disturbingly, the vast majority of pregnancy-related deaths are deemed preventable.^{5,6,28} According to CDC researchers, over 80% of these deaths were caused by overlooking cardiac issues or infections and neglecting to diagnose mental health crises that result in deaths by suicide or overdose.^{5,6,28} The continued undermining of Black women’s experiences, stories, and truths is a known effect that produces these devastating health outcomes.^{5,6,28} Black maternal morbidity and mortality has no boundaries; wealth and fame do not stop its deleterious effects. After a difficult birth, Serena Williams stated, “I know those statistics [around Black maternal mortality] would be different if the medical establishment listened to every Black woman’s experience.”^{5,6,28} The National Birth

Equity Collaborative, a non-profit organization in Louisiana and Washington, D.,C. attempts to address these disparities of black maternal mortality through legislative advocacy, community partnerships and research efforts. ^{25,26,48}

Ample research demonstrates that pain experienced by Black patients is more likely to be dismissed by healthcare workers, which results in Black patients receiving fewer interventions, such as prescriptions for pain.⁵⁰ These biases and discriminatory treatment are seen in medical students and other health professionals and crop up partly due to false beliefs about biological differences” between Black and white patients.⁵⁰ These beliefs influence these individuals’ behaviours even though they have ready access to information that refutes them. According to the University of Virginia researchers, the impacts of these biased beliefs are especially severe for Black women.⁵⁰ We need to look no further than the stories of Anarcha, Besty and Lucy, three enslaved women of 1840’s also known as the “Mothers of Modern Gynecology,” to understand the abhorrent ideas about pain management and the inhumane treatment of Black women’s bodies.⁵⁰

Neonatal Morbidity & Mortality

Researchers have determined that the disparities in preterm and very preterm birth rates between Black and white women in Canada mirrored those in the United States.^{5,6,28} A study by McGill University in 2016 found in 8.9% of Black women gave birth to pre-term babies, compared to 5.9% of their white peers, examining singleton live births for 2004 through 2006.^{5,6,28,48}

March of Dimes identified the leading causes of infant death in the United States include: birth defects; prematurity/low birthweight; sudden infant death syndrome; maternal complications of pregnancy and respiratory distress syndrome.⁴⁹

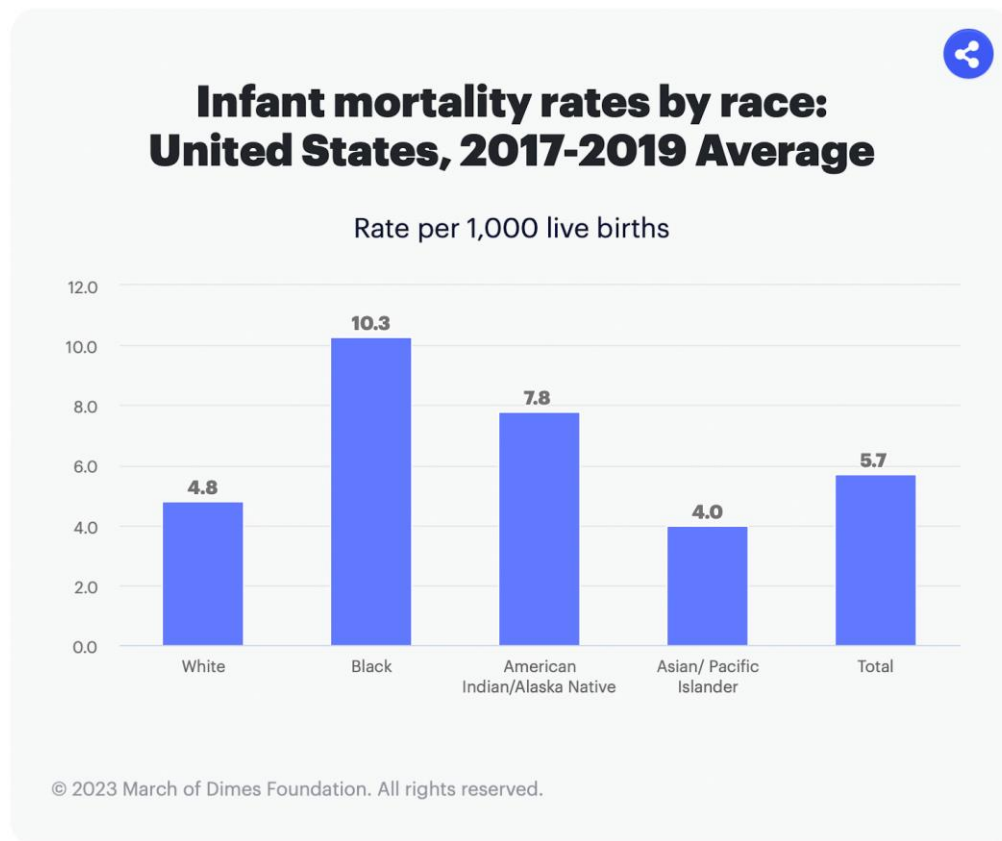


Figure 5: Infant Mortality rates by race

“During 2017-2019 (average), the infant mortality rate (per 1,000 live births) in the United States was highest for black infants (10.3), followed by American Indian/Alaska Natives (7.8), Whites (4.8) and Asian/Pacific Islanders (4.0). Black infants (10.3) were about 3 times as likely as Asian/Pacific Islander infants (4.0) to die during the first year of life during 2017-2019” (average).⁴⁹

It is recommended that NH:

- Collect socio-ethnic/race-based data in relation to Maternal/Neonatal mortality & morbidity for equity-deserving groups to improve health.
- Collaborate with hospital organizations that have begun this work.

Gender Affirming Care

During Niagara Health leadership interviews, it was noted that the Health Informatics System (HIS) does not allow a Transgender or non-binary patient to be called by their chosen name. Their “dead name” appears as (name on their health card). Niagara Health needs to put a system in place (until a new HIS system is available) to provide genders affirming care—so the patient can be called by their chosen name and preferred pronoun.

“looking at that language and if I'm somebody in the community from an equity-deserving population, do I look at that criteria and say they don't want me”

It is recommended that NH:

- Integrate gender-affirming care into the new Health Information System build.
- Create an interim solution in relation to patient identification, including pronouns and chosen name to provide gender-affirming care for transgender patients and non-binary patients.

Migrant Workers

Niagara Health is improving mental health access for Migrant Workers: “Migrant workers are Ontarians that live and work in our province on a temporary work authorization permit.²¹ Migrant workers grow our food, build our roads, work in restaurants and factories, and care for children, the sick and the elderly.²¹ These groups of individuals tend to be racialized, and many come from lower-income families. Niagara Health, in partnership with the Government of Ontario, has provided Migrant Workers with psychological support if required, increasing access and reducing barriers to receiving care. Much more work still needs to be done to ensure that quality and equitable care is being delivered to this patient population.

It is recommended that NOHT:

- Collects data in relation to this specific patient population to improve the overall care given to migrant workers in the Niagara region.

Mental Health and Addictions

There were several suggestions that Niagara Health must focus on mental health and addictions from a culturally affirming and intersectional lens to improve access to mental health resources and care.

“Exploring patient experiences by different socio-demographic variables can uncover gaps in care and inform tailored programs and services to support an equitable care experience for all patients.”

It is recommended that Niagara Health:

- Examine how Niagara Health might provide culturally affirming care to racialized populations.

It is recommended that NOHT:

- Collect data to support patients experiencing mental health and addictions

Conclusion

How we think about people, including the assumptions and stereotypes we assign them, has devastating effects, especially in healthcare. A structural approach to health equity is a priority at Niagara Health and requires examining current policies, practices, thought processes, and evidence-based research to reduce health inequities. Health equity means ensuring people in our communities have access to opportunities to attain a higher level of healthcare through timely, appropriate, high-quality, comprehensive care, free from discrimination and independent of considerations of social, economic, and demographic status. Data will be a powerful catalyst for action as we move forward. To accomplish our goals, it is critical to strengthen our process with respect to the collection and use of data, using evidence to measure inequities and formulating effective interventions. Our researchers and academic partners can play a vital role in developing and translating research into practice.

We cannot forget the importance of communication. Effective communication within our organization and communities will determine our success. Effective communication uses health literacy principles to inform and educate the public. Putting health literacy principles into action advances health equity, which seeks to attain the highest level of health for all people. When people can access and understand the information we want to convey, they can act on it; however, this may not be enough to spur action.

Niagara Health must continue to work toward improving health equity. This report and recommendations will help inform the strategic priorities of the organization. We must ensure that leaders understand the work required for health equity requires an entire system change, dedication and commitment, perseverance, financial support and resources to make health equity sustainable.

General Recommendations for Niagara Health:

- **Collect Equity Data.** To understand where disparities exist, we must set up systems and supports to collect, analyze, and use equity data to report findings and inform future decisions. This must be a part of the new Health Information System build. We need this information to understand where and how people are most impacted so that we can take public health action to serve those people better. To address this, it is recommended to use the “We Ask Because We Care” approach. No one is protected until we are all protected.
- **Include and Engage Key Voices.** Listen to the staff and communities and include their ideas and feedback into the design, delivery and evaluation of programs and services
- **Invest in Implementation.** Apply the financial and people resources needed for success and ongoing sustainability. Specific funding and resource allocation to Health Equity to engage in activities that impact the patients, workforce and community.
- **Represent and Reflect Ontarians.** Strive for all levels of the organization to reflect the communities served.

- **Reduce Disparities** Use data and best practices to establish standards, identify disparities and implement corrective action through a focus on access, experience and outcomes for the population.
- **Contribute to Population Health.** Work with other arms of government and agencies in planning services to improve the health of the population. Aligning with services such as: Niagara Public health and Positive Living Niagara as starting points.
- **Report and Evaluate to Drive Improvement.** Publish Framework metrics publicly with all reports, including an equity analysis.

Appendix A: Recommendations

Address Racism

Racism affects communities at both interpersonal and systemic levels; directly producing health inequities. Studies show links between racism and increased risk of poor health outcomes, including negative impacts connected to encountering racism (such as increased stress and declining mental health), underutilization of health services, mistrust of health systems, and higher rates of chronic disease” (Ontario Health, 2020). Racism in healthcare must be dismantled through conversations, policy and practice changes. This transformative change must start with honest conversations and assessments of our systems structures. Racial bias is the tendency to view and treat members of a racial group positively or negatively. Biases about Black, racialized, and Indigenous people are mostly negative, as evident in stereotypes, prejudice and discriminatory treatment. We cannot take a “color-blind” approach to healthcare.

It is recommended that Niagara Health:

- Focus on Anti-Indigenous and Anti-Black Racism.
- Identify and address discriminatory practices and procedures in all forms and all levels using targeted approaches (HIV, Kidney Care, Cancer Screening, Mental Health, Maternal/Neonatal health etc.)
- Address and reduce Implicit and Racial Bias in a timely manner in the work environment.

Collect Equity Data

To understand where disparities exist, we must set up systems and supports to collect, analyze, and use equity data to report findings and inform future decisions. This must be a part of the new Health Information System build. We need this information to understand where and how people are most impacted so that we can take public health action to serve those people better. No one is protected until we are all protected.

It is recommended that Niagara Health:

- Use “We Ask Because We Care” framework developed by UHN
- Integrate collecting of data in new HIS system

Kidney Care & Kidney Organ Transplant

It is recommended that Niagara Health:

- Remove race as a modifier for eGFR function testing.
- Collect socio-ethnic/race-based data in relation to kidney care outcomes for equity-deserving groups.
- Create a plan to discuss changes with clients and plan for impact of patients who cross into this new threshold in the Niagara region.

Provincial Recommendation:

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- Implement “waiting time adjustment” for kidney transplant candidates affected by race-based calculation (as proposed by the Organ Procurement and Transplantation Network in 2023).

HIV

It is recommended that Niagara Health:

- Examine how they may be able to provide appropriate mental health services, education, treatment, and follow-up, planning and services that will achieve health equity for patients with an HIV diagnosis.
- Examine how Niagara Health can deliver HIV care/treatment (outreach worker, nurse, social worker etc.) so patients can access care closer to home (with a focus on equity-deserving communities).
- Collect socio-ethnic/race-based data in relation to HIV for equity-deserving groups to improve healthcare outcomes/reduce risk of infection.
- Educate Niagara Health staff related to HIV treatment/care to reduce stigma
- Examine how they may be able to provide appropriate mental health services, education, treatment and follow-up, planning and services that will achieve health equity for patients with an HIV diagnosis.

It is recommended that Niagara Health Collaborate (Community):

- Educate community re: HIV (prevention, lifespan, treatment, peer-to-peer program, reduce transmission rates and improve health outcomes through early detection, treatment and support).

Wound Care & Limb Preservation

It is recommended that Niagara Health:

- Creates targeted strategies and policies required to serve communities with high amputation rates to reduce these disparities.
- Review current regional data related to wounds and wound care, ischemia and limb amputations.
- Collect socio-ethnic/race-based data in relation to limb amputations/wound care.
- Creation of actionable policies and quality metrics to reduce the incidence of critical limb ischemia and enhance the delivery of optimal care are needed.
- Improve patient relations in the community & collaboration with public health agencies in relation to wound care and critical ischemia.

It is recommended that Niagara Health Collaborate (Community):

- Improve patient relations in the community & collaboration with public health agencies in relation to wound care and critical ischemia.

Screening for Cancer Care

It is recommended that Niagara Health:

- Collect socio-ethnic/race-based data in relation to Breast Cancer & Colorectal Cancer Screening rates.
- Targeted resources to support equity-deserving groups who are disproportionately impacted.

It is recommended that Niagara Health Collaborate (Community):

- Design a campaign targeting equity-deserving groups using WCH and Health Partners Minnesota as a model.

Maternal/Neonatal Care

It is recommended that Niagara Health:

- Collect socio-ethnic/race-based data in relation to Maternal/Neonatal mortality & morbidity for equity-deserving groups to improve health.
- Collaborate with hospital organizations that have begun this work.

It is recommended that Niagara Health Collaborate (Community):

- Collaborate with hospital organizations that have begun this work.

Gender Affirming Care

It is recommended that Niagara Health:

- Integrate gender-affirming care into the new Health Information System build.
- Create an interim solution in relation to patient identification, including pronouns and chosen name to provide gender-affirming care for transgender patients and non-binary patients.

Migrant Workers

It is recommended that Niagara Health:

- Collects data in relation to this specific patient population to improve the overall care given to migrant workers in the Niagara region.

Mental Health

It is recommended that Niagara Health:

- We collect data to support patients experiencing mental health and addictions and examine how Niagara Health might provide culturally affirming care to racialized populations.

General Recommendations for Niagara Health and others

- Include and Engage Key Voices. Listen to the staff and communities and include their ideas and feedback into the design, delivery and evaluation of programs and services
- Invest in Implementation. Apply the financial and people resources needed for success and ongoing sustainability. Specific funding and resource allocation to Health Equity to engage in activities that impact the patients, workforce and community.

- Represent and Reflect Ontarians. Strive for all levels of the organization to reflect the communities served.
- Reduce Disparities Use data and best practices to establish standards, identify disparities and implement corrective action through a focus on access, experience and outcomes for the population.
- Contribute to Population Health. Work with other arms of government and agencies in planning services to improve the health of the population. Aligning with services such as: Niagara Public health and Positive Living Niagara as starting points.
- Report and Evaluate to Drive Improvement. Publish Framework metrics publicly with all reports, including an equity analysis.

Appendix B: Interviews with the Leadership Team at Niagara Health

At Niagara Health, we are beginning our journey to understand better how to achieve health equity. This begins with conversations. I started by interviewing a few people from the leadership team to get a sense of what people know and understand about health equity from a community standpoint. Six questions were asked in total to understand what individuals knew about health equity.

“The single biggest problem in communication is the illusion that it has taken place,” ~George Bernard.

1. Do you have examples of clinical and/or patient care initiatives or activities undertaken to improve health equity at NH?

An environmental scan was conducted amongst the leadership team at Niagara health. Most respondents suggested that we have no specific examples of clinical and/or patient care activities to improve health equity because we do not measure it. In addition, it was not well understood what programs were available within Niagara Health that specifically targeted health equity.

“...race/ethnic-based data is not collected...we do not collect anything specifically targeting health equity”

“We know about it, I don’t know how much of it is in the forefront in how we deal with it”.

“We are just new on this journey—lots for us to start doing—”

“Health equity... I think that’s a gap for us”

“Staff and doctors have felt bias in their work environments here.”

Some respondents discussed work ongoing in the emergency department such as, the **Familiar Faces Program** which involves working with the community to understand and provide support to folks who are “familiar faces in the emergency room”.

Niagara Health is working toward improving Indigenous Health and Reconciliation by strengthening relationships with the Indigenous communities in Niagara. The Aboriginal Patient Navigator Program supports patients and their families and assists in accessing the healthcare system and traditional healing and wellness practices. An external review of the Emergency Department is underway to improve patient care and experiences for Indigenous Peoples.

Niagara Health is improving mental health access for Migrant Workers: “Migrant workers are Ontarians that live and work in our province on a temporary work authorization permit.²⁰ Migrant workers grow our food, build our roads, work in restaurants and factories, and care for children, the sick and the elderly.²⁰ These groups of individuals tend to be racialized, and many come from lower-income families.²⁰ Niagara Health, in partnership with the Government of Ontario, have provided Migrant Workers with psychological support if required, increasing access and reducing barriers to receiving care. Much more work still needs to be done to ensure that quality and equitable care is being delivered to this patient population.

It is recommended that Niagara Health:

Collects data in relation to this specific patient population to improve the overall care given to migrant workers in the Niagara region.

2. Are you aware of examples from research literature, other organizations and conferences of hospital-based initiatives that improve health equity?

Many respondents were unaware of examples from research and could not provide examples of specific health equity work occurring elsewhere in Canada. Discussions around prenatal care, maternal/neonatal care, interpreter service use, Transgender/Gender Affirming care arose, but no conclusions can be drawn specifically because we do not measure socio-ethnic/race-based data. The UHN framework for ethnic/race base data and the Health Equity Report from Hamilton Health Sciences was mentioned. The main theme of all respondents was that Canadian healthcare organizations were just at a starting point when examining health equity.

“...we are at the infancy stages of researching things...trying to get our leaders in healthcare to see the role we play....”

“I interact with colleagues across the province, and I'm going to say this topic never comes up...not sure if this is on people's radars fully.”

Some respondents discussed interventions to partner with South East Asians for better cardiac and renal health (dietary needs) but could not provide specific details about these programs. The rest of the responses came from work established in the United Kingdom (UK) and the United States (US). The following are examples listed by respondents:

- The Health Equity: Prioritization, Perception, and Progress IHI 2021 Pulse Report.

- UK's statutory responsibilities around equalities and health inequalities and the national NHS programmes
- Roswell Park in Buffalo

3. Where do you think there are opportunities to improve health equity at Niagara Health?

Several respondents indicated that education is critical to improving health equity at Niagara Health. Most respondents have discussed the overall examination of policies, procedures and criteria that may include or exclude communities from an equity-deserving lens.

"...many "of our people/staff are amazed at what you don't know."

"unconscious bias training should be more of a focus because it is "such a huge topic to tackle"

"...it (health equity) can't be learned in a LERHN module"

"We need to learn more surrounding social determinants of health and marginalization and stigma related to certain communities and diagnosis, bias and antiracism"

"We need to learn from stories...how do we know we are providing quality care? (from a health equity lens)"

Creating Safe Spaces: Many respondents stated that it is important to create psychologically safe environments for this work to occur and feel like those systems are not fully in place. A discussion surrounding how discrimination is handled occurred. There were concerns surrounding equity in relation to discipline, follow-up, investigating and acting on racism and discrimination that occurs at Niagara Health.

"the staff aren't even thinking about that they are there to take care of a very acute thing they just don't have the tools of how to deal with that other stuff that comes up"

"...ensure that people understand the importance of it"

"If we don't get it, our staff won't get it" leaders need to be comfortable addressing inappropriate language and situations.

“treatment/cultural preferences and what that looks like when someone wants care in a different way – being open to doing things in a different way”

Communication broadly: In addition to creating a safe environment to discuss these complex topics, several respondents suggested that front-line staff and community members should be engaged and invited to talk about health equity. It was identified that the external website could do more to reflect the importance placed on Health Equity.

Safe and Quality Care: Respondents discussed the impact of patient relations data and how that may inform our way forward with care and health equity. One respondent discussed examining patient-reported outcome measures or experience measures as it is a quality improvement metric that examines patient experience (CIHI).

Measuring/Research/Collecting Data: Respondents indicated that Niagara Health’s research should focus on “*hitting marginalized areas.*”

“...how do we get out to those people [in marginalized areas] to get their follow-ups done?”

“how do we ensure they are in our system, tracking and bringing them back.”

“We don't know what we don't collect...”

Gender Affirming Care: It was noted that the Health Informatics System (HIS) does not allow for a Transgender or non-binary patient to be called by their chosen name. Their “dead name” appears as (name on their health card). Niagara Health needs to put a system in place (until a new HIS system is available) to provide genders affirming care—so the patient can be called by their chosen name and preferred pronoun.

“looking at that language and if I'm somebody in the community from an equity-deserving population do I look at that criteria and say they don't want me”

Mental Health and Addictions: There were several suggestions that Niagara Health must focus on mental health and addictions from a culturally affirming lens and intersectional lens to improve access to mental health resources and care.

“addressing patients’ specific needs and involving them in decisions about their care and treatment can help reduce health inequalities and lead to better outcomes.”

“exploring patient experiences by different socio-demographic variables can uncover gaps in care and inform tailored programs and services to support an equitable care experience for all patients.”

Time/Resources: There were several concerns surrounding time management and time allotted to learn more about health equity.

“...leadership team should create the space and time for learning because, currently, staff are expected to do online modules while they are at work.

“Expecting them to learn without giving them the time and tools to learn is not fair.”

4. From your experience, do you have any lessons learned about enablers and barriers to implementing health equity initiatives?

Enablers:

- Informatics and collecting data can help drive/manage/track change
 - Leadership commitment and building on commitments from our strategic plan
 - How we prepare people on the team
 - Messaging and transparency in the approach to health equity initiatives (normalization/familiarization with health equity)
 - An engaged team
 - Partnering by getting out and building relationships (listening and learning) about the struggles and gaps in healthcare faced by members of the community.
 - Having productive conversations about unconscious bias and the importance of listening and learning.
 - A knowledgeable and dedicated health equity department, so Niagara Health has the right people at the table.
 - Ongoing education of staff members concerning health equity trends globally.
-

“...creating urgency for change will be a catalyst”

- Guidance from the ministry of health.
- Funding this work properly to ensure it is completed appropriately.
- Leveraging the knowledge and experience of communities and programs who might have started this work.

“Without robust measurement we aren’t able to successfully track or implement and I think one of the biggest things will be the ability to measure pre-post data so having that robust infrastructure then to be able to say hey this is how we’re doing right now and this is our intended future state and I think obviously without robust measurement were not able to successfully implement your track successful implementation.”

Barriers:

- Not digging into the data (ie) IRS related to discrimination and doing something about them. Who follows up with it? How do we address it?
- Doing too much all at once. Niagara Health needs to make changes tangible
- Not demonstrating impact or providing feedback to the team
- Not creating a psychologically safe workforce
- Not freeing time to learn about health equity/anti-racism. This work must be interactive.

5. What’s your advice on how best to reach out to your colleagues and other leaders to get their thoughts on these topics?

“not my comfort... well comfort comes from exposure, experience, and embracing ...you gotta get out there, you've got to go into those uncomfortable waters you know and and that's how you best learn”

“Leveraging evidence right now would be really impactful like I had said before, but actually showing the empirical literature that suggests that there are you know these gross inequities that exist within outcomes.”

Respondents also suggested:

- One-on-one conversations
- Workshops
- Webinars
- Travelling roadshows
- Pop up booths

- Health equity office
- Focus groups
- Use a “trickle-down approach”
- Define what health equity and get everyone to the same level/page regarding what it is by using:
 - Sourcenet
 - Huddles
 - Fireside chats
 - Surveys
 - Leadership forums
- Keep the conversation going by making health equity a part of the fabric of what it means to Niagara Health (building it into the organizational design, onboarding etc)
- Health equity signage
- Health equity benchmarks should be a part of Accreditation.
- Ensuring our workforce is diverse. different perspectives and experiences to the table

Appendix C: Comparing Health Equity Work: Hospital Benchmarking

Understanding and acknowledging that a single hospital system, or even the broader health sector, will not have all the answers to achieving health equity is important. Reducing silos amongst organizations and creating a community of practice in the health sector will have an optimal impact. We must work together with other sectors to improve the health and healthcare experience of our patients. The same questions asked of the leadership team at Niagara were asked of the community hospitals. A total of seven hospitals (Peterborough Regional Health Centre, Brockville General Hospital, Chatham Kent Health Alliance, Windsor Regional Hospital, Hamilton Health Sciences, North Bay Regional Health Centre and Oak Valley Health) responded through a Microsoft forms document.

1. What work is underway at your organization to improve health equity?

Health equity initiatives at almost all the organizations surveyed are still in their infancy. However, these nascent programs have begun incorporating health equity initiatives in various ways. It is important to note that some organizations have undertaken more comprehensive steps to incorporate these initiatives, while others have not. Only three of the organization surveyed have committed to developing health equity programs. Most of the others have started to incorporate Diversity, Equity and Inclusion (DEI) initiatives into their organization. There is high variability in commitment and approach across all of these organizations.

Several Health Systems began the process of developing EDI programs by conducting needs analyses that generated reports and recommendations. Others started by creating DEI Committees, while others have created departments dedicated to researching and deploying DEI principles. Despite this variability, most organizations have begun incorporating DEI courses into their mandatory training programs for staff and have included healthy equity initiatives in their strategic plans. The type of training varies, with some organizations bringing in DEI experts to facilitate the initial training programs, while others are training programs are delivered exclusively through online modules. Some organizations chose to deploy the initial rounds of training to hospital board members and organizational leadership before deploying the training across the organization.

Several organizations have started to review their existing policies and procedures through an EDI lens. This work is often completed by the EDI committee or by an EDI department. Interestingly, several organizations have also committed to gathering race-based data to measure healthy equity outcomes across different demographic groups. Often, the organizations that have committed to health equity also commit to gathering race-based data (Oak Valley Health, Hamilton Health Sciences).

2. At Niagara Health, we are using the Ontario Health Equity, Inclusion, Diversity and Anti-Racism Framework. Is your organization using a particular framework? If so, which one?

All but one of the organizations surveyed indicated that they are using the Ontario Health Equity, Inclusion, Diversity and Anti-Racism Framework. The other organization is in the process of determining which framework it will be using.

3. Do you have examples of clinical and/or patient care initiatives or activities undertaken at your organization to improve health equity that you can share?

Two organizations are focusing their efforts on expanding interpreter services for clients. Additionally, several organizations have deployed cultural awareness training for staff and developed reporting mechanisms for people (clients and staff) to report discrimination and harassment. Two organizations also focused on creating gender-affirming care and training and reviewing processes to help improve preferred names and pronouns in their systems. Others focused on developing programs incorporating indigenous clients into the hospitals' processes. One organization focuses on incorporating an indigenous health navigator into the cancer care program. The other organization has been working on creating a smudging policy and educational plan.

4. From your experience, do you have any lessons learned about enablers and barriers to implementing health equity initiatives?

Several organizations stated that getting senior leadership on board with equity initiatives is a critical first step in the process. Leadership must understand that these initiatives require time, resources and labour investments to be effective. It is also important that leaders understand that, once adopted, these initiatives do not have an end date; instead, they must become a part of the organization's infrastructure. Several respondents also indicated there had been reluctance on the part of leadership to begin collecting race-based data and that doing so presents numerous challenges; however, these same respondents agree that this is a critical part of any equity initiative.

5. Are you aware of examples from research literature, other organization and conferences of hospital-based initiatives that improve health equity?

Several respondents indicated that there are numerous helpful resources available. The following were recommended:

- The Institute for Healthcare Improvement's annual IHI Forum Conference (2023)
- SickKids
- UHN's Social Medicine Program
- Seattle Children's Hospital
- Michigan Medicine
- HEC Montréal
- The Canadian College of Health Leaders (CCHL)
- Canadian Chronic Disease Indicators (CCDI)

Appendix D: Connecting our Community Partners

Over the course of 6 months, I discussed health equity and quality improvement strategies with the following community health groups: Niagara Public Health & Emergency Services

Niagara Region, Positive Living Niagara, Ontario Women's Native Association and the Niagara Folk Arts Multicultural Centre. The identification and communication of public health gaps must be examined from an equity-deserving lens. This section highlights key issues related to health inequities in the community. We must examine the gaps in public health as they apply to our hospital sector and understand the needs of the public and community allies. To achieve success in health equity outcomes for our community, it will be paramount for our organization to understand the unique expertise and experience of patients, families and the community. Data collection also was a theme in conversations with community partners from a public health perspective.

HIV

Although HIV is an easily treatable disease, disparities continue to persist. HIV is still a highly stigmatized and discriminated disease. There are numerous barriers in the Niagara Region in relation to accessing care for HIV services. These barriers include lack of access, stigma, structural racism, discrimination and Homophobia. There is much stigma and discrimination surrounding treatment, diagnosis and follow-up care. In Canada, Black women and men accounted for 42% and 18%, respectively, of reported cases among all women and men. In comparison, white women and men make up 14% and 38%, respectively, of new diagnoses (Haddad et al., 2021). Many systemic factors also lead to increased infection amongst Indigenous women. Indigenous women account for 11% of new HIV infections (OHESI, 2021). Transwomen also experience higher rates of HIV. Ontario has no up-to-date statistics, but a study in 2012 showed Trans women were 10 times more likely to report having been diagnosed with HIV than Ontarians overall (OHESI, 2021).

Data taken from the Ontario HIV Epidemiology and Surveillance Initiative (OHESI), as well as public health, identifies that there are a known 384 people living with HIV in the region. However, these numbers may actually be closer to 500 and based on information from the Special Immunology Services (SIS) clinic in Hamilton Health Sciences. If clients need HIV specific care, (lab work, medication) clients must travel to Hamilton to receive these treatments. Patients in this clinic have been "turned away for care" from physicians in the region- citing that "this is not their expertise" even when treatable issues such as bronchitis are apparent. Fear surrounding correct PPE was discussed. It was identified that there is a lack of comprehensive sexual health education amongst care providers in the region in relation to HIV disease diagnosis, treatment and transmission.

The Positive Living Niagara clinic services 120 individuals living with HIV. This includes folks who use drugs, gay men, and men who have sex with men. The clinic provides care to clients in homes, shelters or wherever they client may be living. The clinic provides transportation to and

from HHS for medical care for HIV specific care because it's not available in Niagara. It was identified that the organization is “*supporting folks who might be living at some intersections—new immigrants to the community,...folks who need a little bit more help navigating HIV services and those affected by poverty*”. These patients are often in early HIV diagnosis stages. Many have many other “*intersecting oppressions*”. These intersecting oppressions are associated with, “*determinants of health, sexism, racism, and transphobia. HIV-stigma is compounded by intersecting stigma, discrimination and oppression rooted in sexism, racism, and transphobia*” (OHESI, 2021).

“60% of their clients identify as male. Approximately half of those identify as gay men or men who are having sex with men. 33% of our clients are women. 35% of our clients are African-Caribbean Black and the majority of those clients are women. 7% of our clients are from other racialized communities. Approximately 23% of clients use substances. 12% are well supported and able to manage their use while approximately 11% struggle with addiction and the complexity surrounding an HIV diagnosis. -Positive Living Niagara”

This is deeply disturbing to see the trends in the Niagara Region in relation to HIV care and treatment. Of particular focus for Niagara should be examining the impact of Black & Indigenous Women, newcomers to the Niagara Region, Transwomen and people who use drugs. It is imperative to have access to appropriate services and resources for individuals affected by HIV in Niagara.

It is recommended that Niagara Health:

- Examine how they may be able to provide appropriate mental health services, education, treatment, and follow-up, planning and services that will achieve health equity for patients with an HIV diagnosis.
- Examine how Niagara Health can deliver HIV care/treatment (outreach worker, nurse, social worker etc) so patients can access care closer to home (with a focus on equity-deserving communities)
- Collect socio-ethnic/race-based data in relation to HIV for equity-deserving groups to improve healthcare outcomes/reduce risk of infection.
- Educate Niagara Health staff related to HIV treatment/care to reduce stigma
- Educate community re: HIV (prevention, lifespan, treatment, peer-to-peer program, reduce transmission rates and improve health outcomes through early detection, treatment and support)
- Examine how they may be able to provide appropriate mental health services, education, treatment and follow-up, planning and services that will achieve health equity for patients with an HIV diagnosis.

Patient Experience/Stigma/Delay in Care /Limb/Amputations/Wound Care

Through discussions, concerns were highlighted surrounding the increased prevalence of wound care issues, lower leg ischemia and limb preservation in Niagara. Health disparities regarding amputation and wound care have been well-documented in both Canadian and American studies. The social determinants of health and the intersections of sex, gender, race and ethnicity demonstrate the essential relationships at play as important cofactors for those population disparities.

When an individual needs to have a lower limb amputated as a result of uncontrolled ischemia that occurs secondary to diabetes mellitus or peripheral arterial disease, it is truly unfortunate. These types of amputations are even more tragic because they are largely preventable with proper follow-up care and treatment. Management and treatment of lower limb ischemia should not vary by socioeconomic factors, however, evidence demonstrates that racialized individuals, low income and people who are unhoused experienced poorer health outcomes.

Another disturbing revelation was made in relation to this finding. It was noted that a sizable amount of the population is resistant to accessing services at Niagara Health because of service-related issues (discrimination and poor overall treatment). Residents in the region have described horrible experiences and interactions with staff while receiving service at Niagara Health. Some residents said hearing about others' experiences made them avoid seeking care. Others are concerned that they will experience stigma from the staff at Niagara Health. For instance, one client with cellulitis refused to return to Niagara Health because *“he was like I was just tossed around and treated poorly like just considered drug seeking.”* Another client who had broken his femur *“felt that his care was so lacking and so poor that he would rather just sit in a hotel room and try and heal on his own.”* Issues like these have become common that staff at one public health facility have made a concerted effort to do *“bit of a better job at keeping track of how many times people are coming to us with health concerns that they're just refusing to go to the hospital Niagara Falls.”*

They also indicated that they know of *“folks who have lost both limbs from the knee down due to mistreatment, hesitation and stigma.”* One client went *“from like a very small wound on one foot that is clearly infected and needed care to within two weeks having a double amputation.”* Many of these concerns regarding clients delaying getting health care are directly related to stigma. The fear of being stigmatized leads people to delay getting treated when antibiotics would be effective before it escalates to amputation. An interviewee stated that *“we see folks of all ages right now with amputations either I've just interacted with another client in the past two years she went from loose having her toe amputated to having from below her knee amputated and then having a hip replacement that didn't take and now she's just unable to walk in as wheelchair bound.”* They concluded by stating, *“I don't think I've seen that as heavily in other communities where amputations tend to be caused by blood-based infections, not related to disease processes like diabetes and due to a lack of treatment and follow-up care”* which they are seeing at Niagara Health.

Evidence related to Limb Ischemia

When researchers divided their data by age and racial group, it became abundantly clear that Black patients experienced higher amputation rates, which increased with age. Researchers tried to determine whether these disparities were the result of inequitable management strategies on the part of physicians, which provoked significant debate and controversy. It is still unclear whether these regional disparities are being driven by the biases of physicians administering care, or whether there are other explanations.

“Previous studies have demonstrated that within African American populations, regardless of geographic region, there is a higher incidence of amputations compared to white populations (5.0-6.5 per 10,000 individuals versus 1.2-2.5 per 10,000). Furthermore, African American persons are not only more likely to undergo limb amputation but also the amputations are more significant, with a higher risk of above-the-knee amputations.”

Limb amputation can be delayed and or prevented by timely and aggressive treatment. If indeed, Niagara Health’s Limb amputation rate is higher than its regional peers; it is recommended that Niagara Health:

- creates targeted strategies and policies required to serve communities with high amputation rates to reduce these disparities.
- Review current regional data related to wounds and wound care, ischemia and limb amputations.
- Collect socio-ethnic/race-based data in relation to limb amputations/wound care.
- Creation of actionable policies and quality metrics to reduce the incidence of critical limb ischemia and enhance the delivery of optimal care are needed-
- Improve patient relations in the community & collaboration with public health agencies in relation to wound care and critical ischemia.

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