



# BLACK EXPERIENCES IN HEALTH CARE SYMPOSIUM:

Bringing together community and health  
systems for improved health outcomes

Executive Summary



# LETTER FROM BLACK EXPERIENCES IN HEALTHCARE SYMPOSIUM PLANNING COMMITTEE

## A CALL FOR JUSTICE: RACE-BASED DATA COLLECTION IN THE COVID-19 CONTEXT

April 29, 2020

Continuing to bring attention to the disproportionately poor health outcomes facing Black populations in Ontario, and the importance of collecting race- and ethnicity-based health data, the Black Experiences in Health Care Symposium's second iteration occurred in January 2020. This convening emphasized the need for health systems and communities to partner to improve health outcomes. When we began this work, we could not have anticipated that we would soon be in the throes of a global emergency, exacerbating existing social, economic and racial justice issues in Canada.

Alarming trends from the United States and the United Kingdom indicate that Black and other racialized populations experience disproportionately higher negative outcomes related to COVID-19 than non-racialized populations. Data from Illinois shows that [43 percent of people who have died](#) from the disease and [28 percent of those who have tested positive](#) are African Americans, who make up just [15 percent of the state's population](#). Despite making up only 14% of the population, one study indicates that Black, Asian and Minority Ethnic groups account for a [third of critically ill coronavirus patients](#) in UK hospitals. In the UK, of 53 known NHS staff who have died in the pandemic thus far [68% who have died are racialized](#).

The underlying causes of these disparate outcomes are not unique to the COVID-19 context. The novel coronavirus has laid bare already existing rampant inequality, poverty, food and housing insecurity, and difficulties accessing appropriate health and social services that afflict Black populations in Canada and elsewhere. Mantras of us being "All in this together" are proving to be false as we are not hearing about how Black, Brown and Indigenous lives are being impacted by this virus; and it assumes that there was equity in our socio-economic and health status pre-COVID-19.

As it stands now, COVID-19 is affecting our communities; however, we do not have the means to understand the full scope and impact on our communities. This is why, more than ever, the collection of disaggregated race- and ethnicity-based health data is vital.

The time to act is now. The call for race- and ethnicity-based data is a call for justice within our province to adequately and accurately understand who is suffering, how, and why and thus make visible our lives and health status during this pandemic. Race- and ethnicity based data can provide a real time, fulsome picture of how to target support and resources to our communities for the best outcomes.

In the attached report, *Black Experiences in Health Care Symposium: Bringing Together Community and Health Systems for Improved Health Outcomes*, we've highlighted a few key recommendations that emerged from the Black Experiences in Health Care Symposium 2020 that can prove even more impactful to Black health outcomes in Ontario during the COVID-19 public health crisis. We also acknowledge that COVID-19 will have long lasting impacts and our communities will be faced with new sets of challenges post-pandemic. We want to ensure that the structures, policies and responses take an equitable approach towards healing and factor in the needs of our communities in a post-COVID-19 environment.

*Sincerely, The Black Experiences in Health Care Symposium Planning Committee*

Camille Orridge	Lydia-Joi Marshall
Corey Bernard	Paul Bailey
Gideon Quaison	Ryan Hinds

# FOREWORD

Since 2000, Black Health Alliance has been working in partnership with Black communities, health and social service providers, and governments to improve the health and well being of Black populations.

Health disparities have a profoundly negative impact on the health and well being of Black populations, the true scope and scale of which we do not know, because in Ontario socio-demographic health data is not collected.


We know that there are multiple factors which contribute to these gaps in health, including social determinants of health, institutional practices, and anti-Black racism. While these issues are complex and interconnected, we know that they can be addressed.

In partnering with the Health Commons Solutions Lab and Sinai Health our goal was to build off of the work of many health system leaders, and push forward actions to work together to support sustainable change in addressing these disparities.

The 2020 iteration of the Black Experiences in Healthcare Symposium represents a continuation of this work, and we look forward to continuing to work with the broad range of stakeholders that we will take to drive improvements to the health and well being of Black populations.

**Paul Bailey**  
President  
Black Health Alliance

**Lydia-Joi Marshall**  
Vice President  
Black Health Alliance



**“A health system that routinely fails entire communities simply isn’t good enough.”**

Equity and understanding the lived experience of different people in Ontario is the driving force behind Health Commons. We believe that health is defined by community life and that by working together, health partners and communities can powerfully reshape the experience of health and health outcomes.

Working alongside the Black Health Alliance and Sinai Health to plan the day, we knew that the Black Experiences in Health Care Symposium would be a rare opportunity to bring together a large group of current and future Black leaders to reimagine health in the community and begin to come together around specific recommendations for action. Our organization took on a supporting role, often in the background, but we benefited hugely from the wisdom and insight into the unique challenges, systemic barriers, and opportunities to deliver better care to Black Ontarians.

A health system that routinely fails entire communities simply isn’t good enough. Black health *is* the health of Ontario. Understanding the shortcomings of care, consultation, and service delivery is the only way to address and improve the system.

Health Commons wants to be part of the solution. As an organization that has long advocated for collection of race-based data as a foundational principle of health equity, we have a lot to learn. We will take the lessons and stories from this day into every part of our work - with OHTs and with agencies in particular - as an advocate for change. We are always available to offer our support in designing a strategy, understanding and analyzing data, and documenting and sharing learnings so that the entire Ontario health system can improve.

Please get in touch for support,

**Sophia Ikura**

Executive Director, Health Commons Solutions Lab

# EXECUTIVE SUMMARY

The 2020 Black Experiences in Health Care Symposium (BEHCS) was organized by the BEHCS Planning Committee which included representatives from the Black Health Alliance, Health Commons Solutions Lab with support from the Toronto Central LHIN, Mississauga Halton LHIN, and hosted by Sinai Health.

The Symposium aimed to:

- ▶ Surface opportunities and barriers to true partnership between Black communities and the health system
- ▶ Educate attendees on the history and current state of race-based data collection
- ▶ Spotlight organizations successfully collecting and applying race-based data to improve experiences and outcomes for Black Ontarians
- ▶ Identify actionable, sustainable, and measurable next steps

The Symposium was held on January 30, 2020 bringing together over 120 attendees to discuss how we access care and improve care outcomes (see Appendix A). Led by respected speakers from multiple disciplines, the day allowed for wide-ranging conversation on the Black experience with the current healthcare system - from academia, to government, to frontline care.

Building on the work accomplished at the [Black Experiences in Health Care Symposium in 2017](#), the 2020 event renewed focus on engaging and informing health system partners and creating collaboration opportunities to advance Black health in Ontario. One priority area identified was the need for race-based data collection and its application for Black Ontarians.

**The event covered a wide variety of topics, grounded by the need for race-based data collection. Key themes that emerged included:**

- ▶ Anti-Black racism has an ongoing, negative impact on how Black communities receive care, and can impede how they care for their communities
- ▶ Race-based data collection - and its application - must be mandated across the health care system. This must be done in partnership with Black communities in order to truly understand the depth and breadth of these outcomes
- ▶ Black communities must have ownership of and access to all data collected to prevent the repetition of historical, contemporary, and potential future misuse of data
- ▶ Black representation in leadership and at decision making tables is needed at all levels - in government, in academia, and among providers
- ▶ Ontario's health system agencies have a responsibility for holding provider organizations and leaders accountable for funding, governing, designing, and providing health care that meets the needs of Black communities
- ▶ Building solidarity and forming coalitions with other communities experiencing marginalization are necessary to advance collective goals in the health system and across sectors

The availability of socio-demographic and race-based data is essential to draw attention to differences in illnesses, access to services and health outcomes. This is true not only for the Black community but for all communities marginalized by factors like race, language, sexual orientation or immigration status. [Ontario's Anti-Racism Act](#) established in 2017, set out requirements for standards for the collection, use, and management of information, including personal information, by public sector organizations to identify and monitor systemic racism and racial disparities. Despite this, data is not routinely collected provincially, and local initiatives have proven difficult to sustain. Health information custodians like hospitals and other providers (which were not covered under the Act) have not prioritized the issue and few have introduced tools to better understand differences in care based on race or socio-economic factors. Only through regular reporting can we hold the health system accountable for improving access and outcomes for racialized communities. While the current restructuring underway in Ontario healthcare may afford new opportunities, we will need a persistent and coordinated voice to keep equity on the agenda and deliver much needed changes in how we collect, use and share data.

## Racism, Racialization and Health

- ▶ Recent research on racism, discrimination, and health in Canada points to health disparities and inequities in health care access and delivery for racialized Canadians
- ▶ Black Canadians are the third largest minority group in the country and there is a lack of health research specific to Black Canadian women, specifically around breast/cervical cancer (Nnorom, Findlay, Lee-Foon, Jain, Ziefler, Scott & Lofters 2019)
- ▶ Men who self-identify as Black are twice as likely to report poor health as those who self identify as Arab or Asian (Levy, Ansara & Stover, 2013)





# RECOMMENDATIONS

This report provides an overview of the core themes, challenges and recommendations that emerged from the Symposium. It highlights the importance of participants' personal lived experience as Black people working in and/or engaging with the health care system, and it signals the dire need for a more equitable health system going forward. These recommendations were developed by the BEHCS Planning Committee and our advisory table based on the rich discussion and a wealth of input generated throughout the Symposium. Together they summarize the key themes of the day and point to future directions and actions over the coming weeks and months.

- 1** Require all publicly funded government agencies and health service providers (including Ontario Health and Ontario Health Teams) to be held accountable for:
  - Collection and application of race-based data
  - Measuring, improving and publicly reporting on care and outcomes of Black Ontarians
  - Including Black leadership at all levels including governance, senior and middle management, and advisory committees.

- 2** Ensure race-based data collection spans across the continuum of care, not just in hospitals and Community Health Centres, to improve data quality, analysis, and the opportunity to positively impact the lives and outcomes of Black communities accessing care.

- 3** Partner with large health data and information entities like the Canadian Institute for Health Information (CIHI) and Institute for Clinical Evaluative Sciences (IC/ES) to help support race-based data collection and utilization.

- 4** Standardize and mandate anti-Black racism, anti-oppression, and decolonization training for health care providers, professionals, leaders, and health system planners.

- 5** Create accessible and culturally competent mental health services throughout the province for all Black people and their communities.

- 6** Expand funding to create more integrated services that support the families and loved ones of Black people experiencing mental illness.

- 7** Establish a mechanism to routinely monitor and assess diversity in health system leadership throughout the province.

- 8** Improve communication with Black communities on the purpose and use of the data that is being collected from them.

- 9** Create paid positions and roles for community trust builders in health provider organizations who help navigate the relationships between the community and health system. These trust builders need to be recognized and provided fair compensation for their participation from beginning to end of all engagements.

- 10** Develop a Black-led strategy for identifying Black representatives for provincial/regional community engagement opportunities in health care, and develop engagement practices and methods that reflect the diversity within Black communities.

**11** Prior to engaging with Black communities, conduct an environmental scan of existing reports, opinion papers and community gatherings hosted by Black communities to understand what has already been stated on these issues and where work in the system is already occurring.

**12** Support, resource, and fund platforms that are building solidarity amongst racialized communities. For example, the work being done by the [National Collaborating Centre for Determinants of Health](#) and the [San'yas Indigenous Cultural Safety Training program](#) to explore Indigenous and Black People's Solidarity in Health.

**13** Increase accountability measures for universities and other research institutions around transparency and intended data use when engaging with Black communities.

**14** Identify and support those already conducting research within/for Black communities. Promote research focusing on the relationship between data analytics and social justice, also referred to as Data Justice.

**15** Identify ways to encourage, foster, and support multi-generational ways of knowing to inform data collection, analysis, and interpretation.

**16** The collection and use of race-based data to drive improvements and the development of a Black health strategy is integral to delivering on the vision for a healthy Ontario that meets the needs of ALL Ontarians.





# NEXT STEPS

During the Symposium, a number of potential partnerships and actions were proposed in order to bring together health systems and communities for collaboration on next steps:

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## CIRCULATE THE SYMPOSIUM REPORT, HIGHLIGHT KEY FINDINGS, AND PROMOTE ONGOING INITIATIVES

Along with this report, the source material and documents from the Black Health Symposium 2020 will be made available through the Black Health Alliance. This report summarizes the ideas, insights, and recommendations of over 120 participants and we encourage other members of the public to get in touch for further analysis, interpretation, and research on the participant generated content.

### Practical strategies discussed at the Symposium:

- ▶ Share your experience of attending the Symposium with Health Commons Solutions Lab/Black Health Alliance and help validate the content within this report to inform future engagements.
- ▶ Review the [Black Experiences in Health Care Symposium](#) report from 2017.
- ▶ Connect with speakers and facilitators on their research who attended the Symposium. (Appendix B)

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## DEVELOPMENT OF A BLACK-LED STRATEGY THAT IS AIMED AT IMPROVING THE HEALTH AND EXPERIENCES OF BLACK ONTARIANS

There are many examples of work that benefits Black Ontarians happening within communities across the province. However, this work often takes place within individual organizations or at a program level with little or no coordination across geographies or sectors of care. In order to amplify this work a set of shared priorities, goals and values need to be documented and shared to establish and advance a provincial agenda focused on improving Black health experiences and outcomes.

### Practical strategies discussed at the Symposium:

- ▶ Convene a list of key health system stakeholders to share recommendations with to guide current and future strategies around how Black and other racialized communities receive care.
- ▶ Coordinate with Ontario Health to share the priorities and recommendations from Black communities to inform the ongoing and future development of teams and strategies.
- ▶ Craft an action plan with timelines, resources and roles to execute the collectively identified priorities within an agenda developed by a coalition.

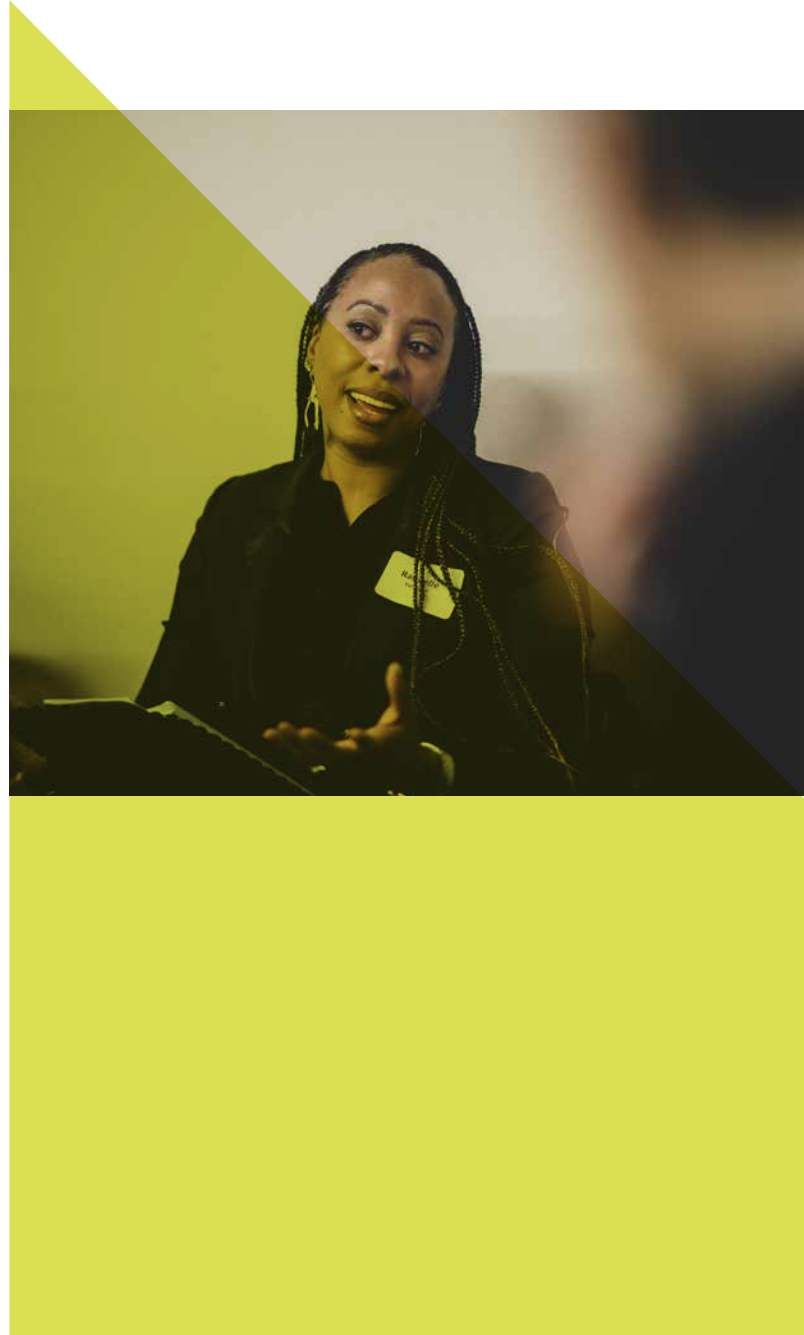
We encourage readers of this report to get in touch with the people leading existing work for Black communities and finding ways to partner and advance these projects.

## BUILDING ALIGNMENT AND SOLIDARITY WITH OTHER RACIALIZED COMMUNITIES

The Black Experiences in Health Care Symposium provided a space for Black communities, leaders and professionals within the health system, and many more individuals to share their experiences in health. Platforms like this are important for building solidarity amongst communities, in unearthing the root causes of poorer health outcomes in Black communities, naming and confronting anti-Black racism, creating action to dismantle inequitable practices in the health care system, and supporting Black Liberation. Organizations and leaders in all sectors are encouraged to develop programming or educational opportunities to bring together stakeholders, further understand issues, and devise strategies for transformational change.

### Practical strategies discussed at the Symposium:

- ▶ Create a list of organizations willing to partner to continue mobilizing around the needs and priorities of Black communities in Ontario.
- ▶ Develop a coalition or group of multi-sectoral advocates who are capable of partnering with Black communities to represent, advocate, and advance the priorities identified by Black communities.
- ▶ Identify other racialized communities who have similar needs, challenges, and priorities to collaborate towards collective asks that improve equity outcomes across the health care system.
- ▶ Plan, convene, and organize future engagement opportunities with racialized groups to identify commonalities and create shared agendas with collective asks that improve health outcomes.



# ACKNOWLEDGEMENTS

This Symposium represented a strong example of collaboration between community and the formal health care system. A special thank you goes to the advisors, speakers, and panelists who shared their valuable time and input to make the Black Experience in Health Care Symposium 2020 possible.

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Toronto Central LHIN  
Wellesley Institute

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