# BLACK EXPERIENCES IN HEALTH CARE SYMPOSIUM:

**Bringing together community and health systems for improved health outcomes**

BLACK HEALTH ALLIANCE

HEALTH COMMONS SOLUTIONS LAB

Sinai Health

# 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 |

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# INTRODUCTION

"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."

# 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:

## 1

## 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)

## 2

## 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.
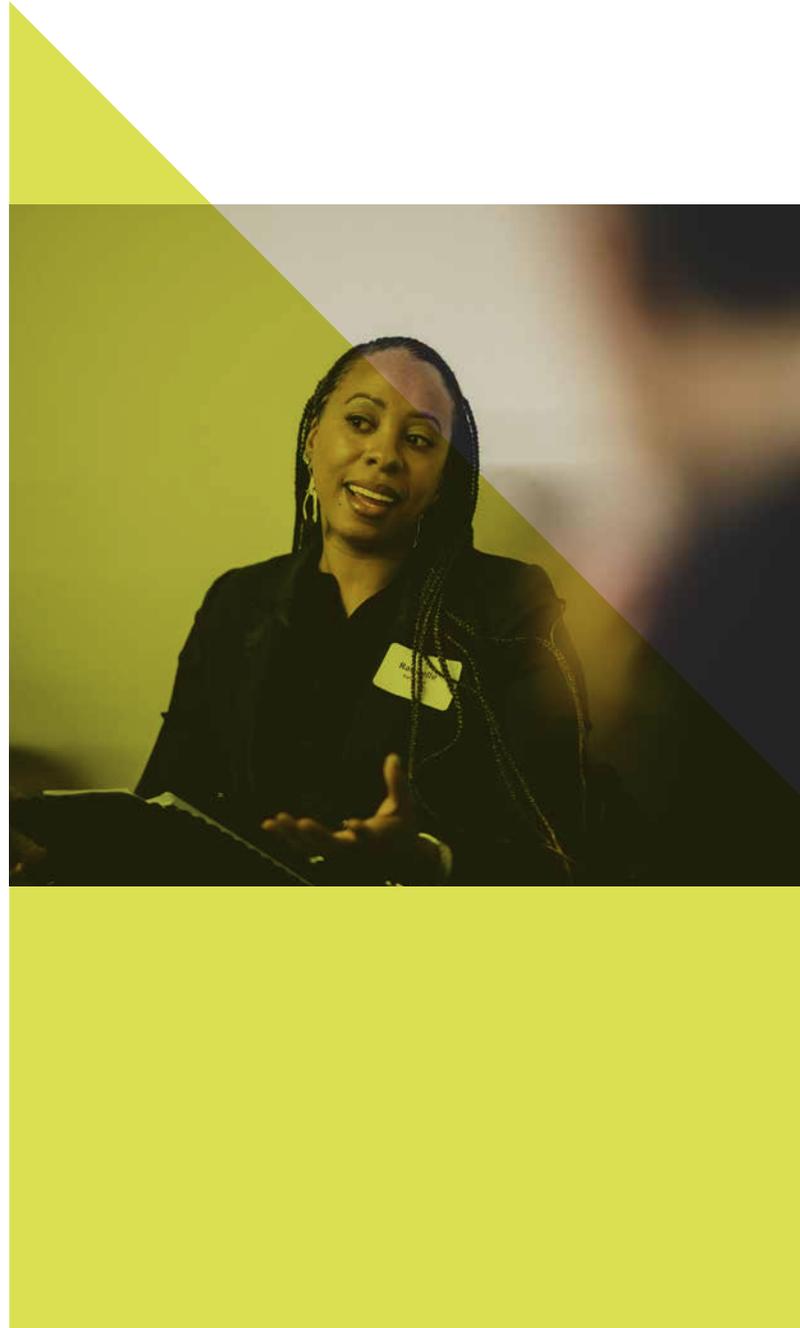
## 3

# 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.

# SYMPOSIUM SUMMARY

The day began with a land acknowledgement from Nenookaasi Ochyrm, Indigenous Mental Health and Outreach Worker from TAIBU Community Health Centre, signaling the importance and shared commitments to decolonization, partnering with Indigenous communities, and addressing white supremacy. The Black Health Alliance and Health Commons Solutions Lab welcomed attendees, emphasizing the rich knowledge in the room and opportunity for action throughout the day. Participants included representatives from health care, social services, not-for-profits, private sector, legal, education,

and government, in roles ranging from directors, CEOs, executive directors, presidents, and managers, to health care providers, researchers, and students.

**Dr. Gary Newton**, President and CEO of Sinai Health, welcomed attendees and spoke from his perspective as a physician and health system leader. He addressed the value of race-based data collection work in daily clinical interactions and more broadly at a population health level.

"The data sets we have are incomplete and they don't even come close to demonstrating the intersectionality of Blackness that exists in our local landscape. During this time of transformation, we need to take advantage of the system's willingness to change and support a shift that is geared toward better serving Black communities."
- Dr. Gary Newton, President and CEO of Sinai Health

In the context of an Ontario health system undergoing significant change, Dr. Newton indicated that this Symposium allows hospital leaders like himself to hear directly from Black communities to understand their priorities, recommendations, and ways to improve the health system to enhance the lives of Black people.

**Dr. Kwame McKenzie,** CEO of Wellesley Institute, called for a move to action and reinforced the priorities of race-based data collection, leadership and accountability.

"The system needs Black leadership... it will help the whole system if the leaders of the health system look like the people who are using the health system,"
- Dr. Kwame McKenzie, CEO of Wellesley Institute

Beyond collection, Dr. McKenzie called for a plan to use data to improve outcomes and the opportunity to take advantage of system changes by implementing models of care (i.e. access models, treatment models) in Ontario Health Teams and setting a new standard of care for Ontario Health.

Attendees heard from **Karen Dickson**, a patient partner, who grounded the day in her lived experiences navigating the Ontario health care system as a Black woman dealing with mental health issues and highlighting how significantly every aspect of her life was impacted by not having access to appropriate care and services.

**Camille Orridge** (Senior Fellow at the Wellesley Institute) provided a keynote on "Bringing Together Community and Health Systems to Improve Health Equity Outcomes" in which she provided the historical journey of socio-demographic data collection in Toronto and the current opportunities for change within the evolving health system.

**Dr. Onye Nnorom** (President of the Black Physicians' Association of Ontario) moderated a panel that consisted of **Notisha Massaquoi** (Principal, Nyanda Consulting), **Camille Orridge** (Senior Fellow, Wellesley Institute), **Caroline Bennett Abuayyash** (Assistant Professor, Dalla Lana School of Public Health, University of Toronto) and **Shawn Hercules** (Researcher, McMaster University).

The panel identified the politics of race-based data collection and called for race-based data collection to be mandated throughout the health care system as it is being collected and utilized in other sectors like education, in the child welfare system, and more.

Concurrent breakout sessions led participants through interactive and engaging sessions where they unpacked reshaping patient-centred approaches in healthcare, surfacing the value in race-based data collection and mobilizing coalitions for advocacy, and developing principles for collecting and acting on data for Black communities. For the full list of facilitators, please refer to Appendix B.

In the afternoon, attendees participated in a breakout session recap where they highlighted the most salient themes and ideas from their respective experiences. Attendees then formed small groups to identify the important considerations or action-oriented next steps in this work.

> **"We need to build data infrastructure that exists outside of formal healthcare institutions... This data needs to be collected, owned, and analyzed by Black Communities. "**
> - BEHCS 2020 Attendee

The closing keynote from **Angela Robertson**, "If Not Now, When: Leadership, Allyship & Action" united the discussions and ideas from throughout the day with a call to action. Drawing on her years of leadership experience in health care and social services, she asked each of us to think about our role in advancing Black health equity and race-based data collection, whether in our professional roles, in our communities, or as allies. Angela spoke about the importance of naming racism and using data to bring disparities to light, addressing biases towards patients, and taking action to build on the existing work in this space.

# KEYNOTES

"We live in a city that says diversity is its strength but we offer little access to necessary culturally responsive supports and services."

# EXPERIENCES NAVIGATING ONTARIO'S INEQUITABLE HEALTH CARE SYSTEM

## Karen Dickson
Patient Partner

**Karen Dickson** opened the day by sharing her story navigating the health care system as a Black person living with mental illness and schizophrenia. After building a successful career as a lawyer, lack of access to appropriate mental health care compounded her challenges - leading to precarious housing, losing custody of her child, and forcing her to move from jurisdiction to jurisdiction to seek care. Ultimately, her most successful and supportive care network was found in support from other members of Black communities, who coordinated and provided her with the comprehensive and culturally appropriate care she needed.

Now, Karen has reunited with her child and found suitable supportive housing that honours and balances her needs for independence and care. Her story navigating traditional care illuminates how the current system offers and denies access and how services, currently situated, fall short for many people, and especially Black Ontarians. Recounting the discrimination, anti-Black racism, and struggles she encountered before finally receiving the care she needed, Karen grounded the day in the lived experience of the patients most affected by system barriers, strategies, budgets, and decisions.

# WHAT DID WE LEARN?

**Racism is a Determinant of Health:** It's a reality that needs to be addressed in order for Black people to achieve good health. Approaching care from a comprehensive perspective that factors in the Social Determinants of Health is critical when providing care for marginalized communities experiencing racism in the health care system.

**Health impacts beyond physical health:** For many individuals in Black communities, not receiving or being able to access appropriate care can lead to substantial losses in many aspects of life: employment, housing, family, and more.

**Develop culturally-responsive care:** Accessible and culturally appropriate mental health services for Black people are needed throughout the province, as Black communities are not restricted to one geography and move and live throughout the province.

**Hiring Black practitioners is important and necessary:** Black and other racialized health care providers are critical for patients to feel safe, supported, and understood.

**History and context shape experiences:** Anti-Black racism has immediate and long-lasting negative impacts on the way Black communities access services, receive care, and engage with the health system and providers.

**Providing better care to Black communities is everyone's responsibility:** The commitment to improving Black experiences in health care is not solely the responsibility of Black health care professionals, but rather it is up to everyone in the health system to gain the knowledge, build the skills, and be trained on how best to meet the needs of Black people as they access health care services.

## TORONTO'S BLACK COMMUNITIES & MENTAL HEALTH

Dr. Kwame McKenzie, CEO of the Wellesley Institute unpacks the challenges that Black communities face when it comes to their mental health and the factors contributing in a recent Op Ed titled "Toronto's Black community faces far greater risk of having serious mental health problems".
Dr. McKenzie explains that mental health problems are the most common reasons for people missing work. Mental illness costs $13 billion a year to our local economy and people with mental health problems are more likely to live in poverty than others.

Dr. McKenzie highlights that there are primary care providers to help address mental health within Black communities, such as Women's Health in Women's Hand and TAIBU. There are also specialist mental health providers, such as Across Boundaries and CAMH's Substance Abuse Program for African and Caribbean Youth. But the truth is that mainstream services often do not meet the mental health needs of the Black population. We live in a city that says diversity is its strength but we offer little access to necessary culturally responsive supports and services.

# RECOMMENDATIONS

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

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

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

**Anti-Black racism** is policies and practices embedded in Canadian institutions that reflect and reinforce beliefs, attitudes, prejudice, stereotyping, and/or discrimination that is directed at people of African descent and is rooted in their unique history and experience of enslavement and colonization in Canada.
(Toronto Action Plan to Confront Anti-Black Racism, 2017)

**"The main point I would like to make is that your faces are important. Believe that your contacts and interactions make a difference to a person who is suffering. The Black experience in health care very much includes you."**

- Karen Dickson

## CULTURALLY APPROPRIATE, ACCESSIBLE, AND EFFECTIVE SUPPORTS

Black Torontonians continue to experience the impacts of Anti-Black racism on their health and well being. Compared to non-racialized people, Toronto's Black residents report higher rates of pain, discomfort, high blood pressure, and obesity. Limited access to effective health and community services remain a challenge for Black residents and families living in Toronto.

Recent recommendations have emerged from the five year (2018-2022) Toronto Action Plan to Confront Anti-Black Racism Strategy that call for improved quality and availability of City-programmed community mental health services for Black Torontonians. The actions associated with this call for City to Province collaboration to support training for community mental health and addiction treatment service providers using an Anti-Black Racism Analysis. Collaboration with Black communities and the Province was also recommended to leverage Black cultural knowledge to lead and provide more mental health services across the city for Torontonians of African descent. (Toronto Action Plan to Confront Anti-Black Racism, 2017)

# BRINGING TOGETHER COMMUNITY AND HEALTH SYSTEMS TO IMPROVE HEALTH EQUITY OUTCOMES

## Camille Orridge
Senior Fellow, Wellesley Institute

**Camille Orridge**, Senior Fellow at the Wellesley Institute brought expertise from her time in the Toronto Central LHIN and personal experiences navigating the health care system. She echoed that the health system needs transformation at the system level in order to provide equitable and effective care for all the communities it serves. Transformation must emerge from Black and other marginalized communities at all levels of the system, ranging from providing care to executive leadership and governance. To make that change a reality will require collecting and analyzing race-based data, real accountability, and advancing Black leadership.

For many years, Black communities have found ways to organize and coordinate care through programming and grassroots organizations to provide care for their communities. The current funding models that exist in health care do not provide enough resources for sustainable impacts and lack an equitable approach that factors in the intersectionalities and needs of a diverse Black population. In the current health care landscape, the collection of race-based data, reporting of accountability measures aimed to improve Black health, and diversity in leadership at decision making tables is needed to ensure a healthier Black community in Ontario.

# WHAT DID WE LEARN?

**Data is a tool:** We need to insist that race-based data is collected to make our case for better treatment and improved outcomes in health care. The collection of race-based data allows us to quantify the detrimental impacts of anti-Black racism, disproportionate rates of illnesses within our communities, and differential treatment when attempting to access care. The lack of will throughout the health care system to collect race-based data in itself is a form of racism and the mandatory collection/application of this information to improve Black experiences is needed.

## ONTARIO HUMAN RIGHTS COMMISSION

Ontario Human Rights Commission (OHRC) has pointed out that collecting and analyzing data that identifies individuals by their race, ethnicity, citizenship, sexual orientation, or similar factors can assist institutions or systems to protect and promote human rights. OHRC called on the Minister responsible for the Anti-Racism Directorate to strengthen requirements for race-based data collection, including in health care, in order to advance human rights. (Ontario Human Rights Commission, 2009)

**Accountability to our communities:** We need to organize (as a community and alongside other marginalized communities whose needs are not being met) so that the health system, current leadership, and mainstream organizations are held accountable. In a shifting health care landscape we must continue to push the equity mantle and surface priorities within Black communities so that the new configuration of regional bodies mandated to provide care are clear on how they can do so for Black communities.

**Black leadership must be prioritized:** We need a place at the decision making table so that Black voices are not rudimentarily consulted at the end of strategies that will directly impact Black lives. Black leadership is needed in identifying gaps, the engagement/consultation of Black communities, ideation of possible solutions, and the roll-out as well as evaluation of initiatives. Black leadership within health care and across different sectors provides the system with many merits and allows voices, perspectives, and experiences critical to improving everyone's health care outcomes to be brought to the foreground.

"We need services that speak directly to our health needs – cradle to grave. We need access that doesn't create barriers. And we need a system – and health system leaders – who are directly accountable to the communities they serve."

- Camille Orridge, Senior Fellow, Wellesley Institute

# RECOMMENDATIONS

**1** **Require all publicly funded government agencies and health service providers 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** **Establish a mechanism** to routinely view, monitor, and assess diversity at the health system leadership level throughout the province.

## HEALTH SYSTEM ACCOUNTABILITY & BLACK LEADERSHIP

Initiatives are needed to recruit, train, and hire members of diverse Black communities for leadership and governance roles in health and community organizations. The health care system's leadership locally, provincially, and nationally needs to better reflect the diversity within the communities it serves.

In 2016 the Stats Can census recorded 627,710 Black Ontarians living in the province. In Ontario, Black immigrants came from 150 different countries. Toronto has the largest Black population in the country, with 442,015 people or 36.9% of Canada's Black population. Black people represented 7.5% of Toronto's total population, the highest proportion among census metropolitan areas. Currently there is nowhere within the system to track that the diversity and intersectionalities of Black communities is accurately represented in the changing health care landscape and at governance tables. (Statistics Canada, 2016)

**Keynote Video**

https://www.youtube.com/watch?v=GTlZgUeUnqE

**Blog Post**

https://www.healthcommons.ca/blog/a-path-forward-to-improve-black-health-in-ontario-camille-orridge

# IF NOT NOW, WHEN: Leadership, Allyship & Action

## Angela Robertson
### Executive Director of the Parkdale Queen West Community Health Centre

**Angela Robertson's** keynote, "If Not Now, When: Leadership, Allyship & Action" united the discussions and ideas from throughout the day with a call to action. Drawing on her years of leadership experience in health care and social services, Angela asked each of us to think about our role in advancing Black health equity and race-based data collection, whether in our professional roles, in our communities, or as allies. Angela spoke about the importance of naming racism and using data to bring disparities to light, addressing biases towards patients, and taking action to build on the existing work in this space. These conversations have been taking place for many years. The system is ripe for change, and effective action must be taken now to ensure delivery on equity.
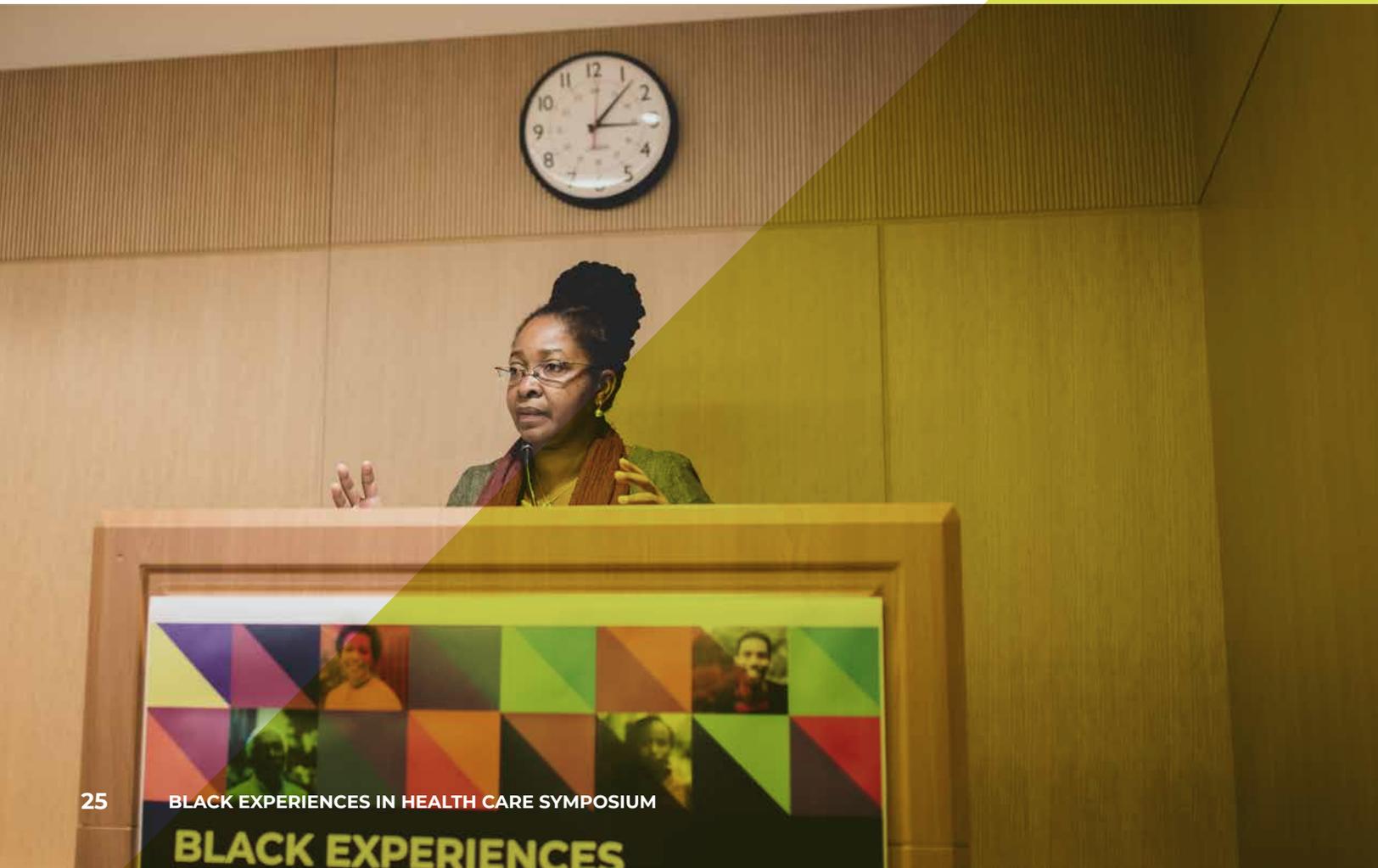
## WHAT DID WE LEARN?

**A focus on patient experiences must also include Black experiences:** We must ensure centring patient experiences is instrumental to any changes we make, and that the experiences of Black communities are included in that process.

**Data offers clarity:** Bring the nature of disparities to light by collecting data. You can't respond to a challenge until you can name it and identify what needs to change.

**The tools exist:** Evidence of the value of data collection is clear and there is recognition of the work that has been done, but we must figure out how to move that work forward.

**Black health needs to be a priority:** A healthy Ontario vision must include Black communities and a strategy for Black health. To progress on this, we need to know who the patients are.

**There is strength in partnerships:** The importance of allies and provisional alliances cannot be understated.

## RECOMMENDATIONS

**1** 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.

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

**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.

**Keynote Video**

https://www.youtube.com/watch?v=hkzi_3VDnnQ

**Blog Post**

https://www.healthcommons.ca/blog/legacy-of-strength-future-of-change-angela-robertson-behs-keynote

**"Good intentions aren't going to move us forward. Liberation, historically, is the word used. The work of liberation and writing wrongs is never done. Collecting race-based data is a tool we can use to address those sites of inequalities and wrongs. We must be relentless. We, in this room, our allies and communities, must be relentless in pursuing strategies that develop better health outcomes for Black communities."**

\- Angela Robertson
Executive Director of the Parkdale Queen West Community Health Centre

# PANEL DISCUSSION:
# Collecting Race-based Data and the Opportunities for Action

## Speakers

**Dr. Onye Nnorom**, President, Black Physicians' Association of Ontario (Moderator)

**Notisha Massaquoi**, Principal, Nyanda Consulting

**Camille Orridge**, Senior Fellow, Wellesley Institute

**Caroline Bennett Abuayyash**, Assistant Professor, Dalla Lana School of Public Health, University of Toronto

**Shawn Hercules**, Researcher, McMaster University



This session engaged attendees in a discussion about the history of race-based data in the Ontario health care system. The conversation explored the histories of this initiative in the province, the reasons race-based data needs to be collected, and how socio-demographic data collection is currently being used to improve client care in the health care system. Furthermore, this session explored the barriers, levers for change, and actions required to advance collection in a safe, community-led, and privacy respecting way.

# HISTORY OF RACE-BASED DATA COLLECTION

Race-based data provides timely and important findings for policy makers, service planners and practitioners who seek more equitable and effective ways to meet the diverse needs of populations in our health care system. But in Canada, there is a major gap in health data and research on diverse populations. Not enough standardized socio-demographic data is being collected and analyzed. (Khan, Kobayashi, Sharon & Vang, 2015)

In 2009, the Toronto Central Local Health Integration Network (Toronto Central LHIN) required hospitals to begin reporting on equity initiatives. In 2013, Toronto hospitals began collecting a standardized set of patient-level socio-demographic data in alignment with the "Measuring Health Equity in Toronto Central LHIN" mandate. Community Health Centres also joined the mandate in 2014. Variables that are currently collected are spoken language, Canadian-born, the length of residency in Canada, ethnicity/race, disability, gender, sexual orientation, income, and the number of people supported by income.

## ONTARIO'S ANTI-RACISM STANDARDS

The Data Standards for the Identification and Monitoring of Systemic Racism, also known as Ontario's Anti-Racism Data Standards were established to help identify and monitor systemic racism and racial disparities within the public sector. The Standards establish consistent, effective practices for producing reliable information to support evidence-based decision making and public accountability to help eliminate systemic racism and promote racial equity. The purpose of the Standards is to set out requirements for the collection, use, disclosure, de-identification, management, publication, and reporting of information, including personal information. They help enable public sector organizations to fulfil their obligations under the Anti-Racism Act, 2017 to identify and monitor racial disparities in order to eliminate systemic racism and advance racial equity.

## What is health equity?
Health equity allows people to reach their full health potential and receive high-quality care that is fair and appropriate to them and their needs, no matter where they live, what they have, or who they are. (Health Quality Ontario, 2016)

# WHAT DID WE LEARN?

**Reducing racial disparities in health care must be prioritized:** Health care was not included in the decision to make data collection mandatory in the Anti-Racism Act in 2017. There needs to be more will and commitment within the health care system to collect, analyze, and report on race-based data. Where it is currently collected, it is not adequately enforced.

**Wide-scale collection across all services is needed:** Black people access services across the continuum of care, and data collection needs to connect across the system, including among OHTs and

various funders to make collection mainstream and ensure large scale accountability.

**Learn from the experiences of others:** Many health service providers have been collecting demographic data for years, offering opportunity to learn from the experiences, successes, and challenges of the Toronto Central and Mississauga Halton LHINs.

**Data management is of vital importance:** As we advance data collection, we need to expand the conversation about data collection principles and use. We need an organization that can report on the data and engage the research community in pushing this forward.

**Understand and appreciate the politics of data collection:** Data collection is a political statement but too frequently people try to depoliticize it and make it a mechanical issue, rather than acknowledging that the decision not to collect this data is rooted in racism. Centring our experiences, and making a commitment to improve the lives and experiences of Black Ontarians is a political act that we must all undertake.
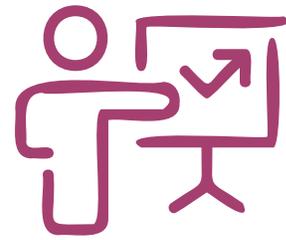
**"[Data is the] only way to get funding, engage in prevention, and get community to say, 'Hold on a second, there's something we need to actively engage in to figure out why rates are so high and what we can do.'"**

-Notisha Massaquoi, Principal, Nyanda Consulting
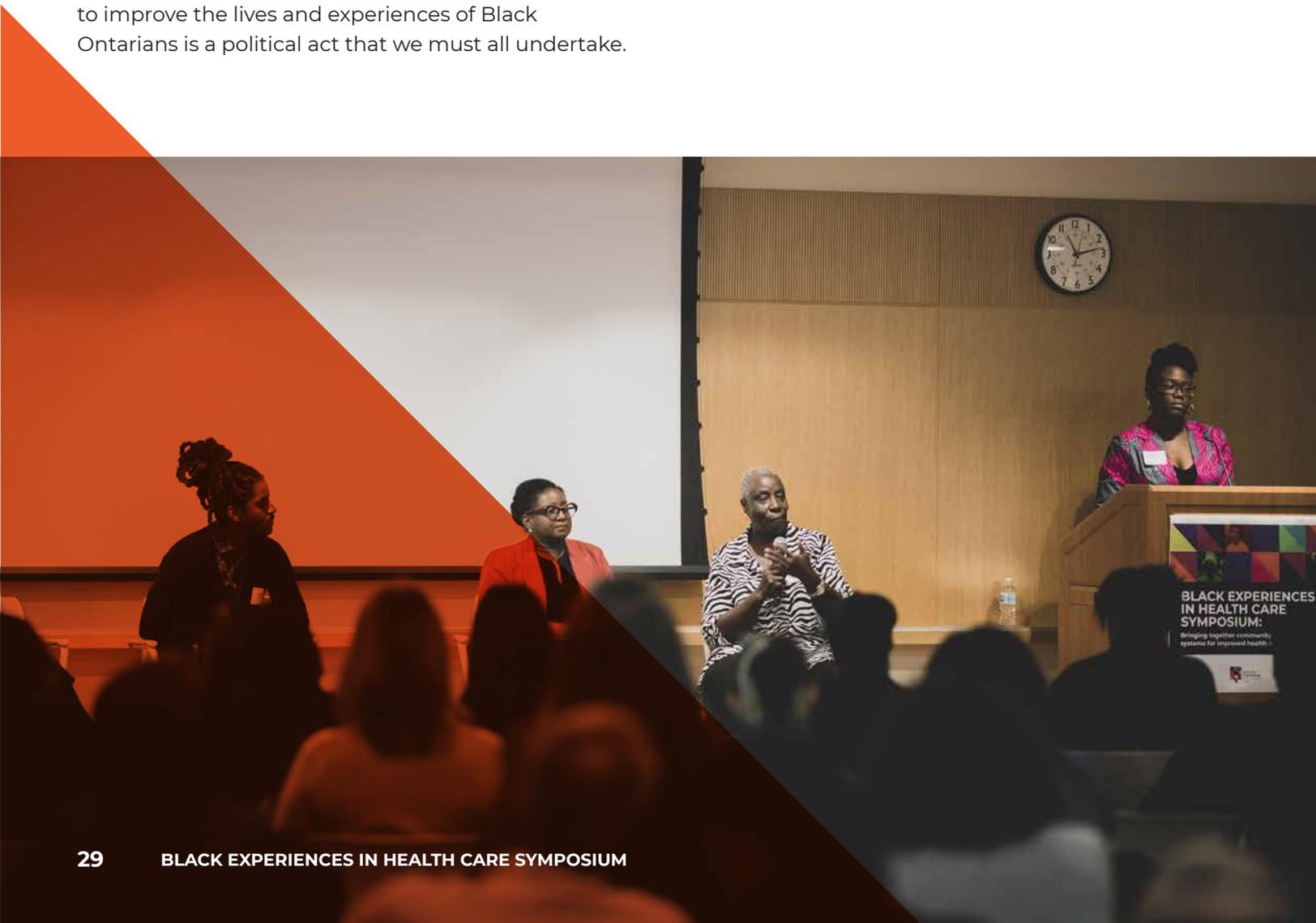
**"We want the data to be prepared – we know that Black patients experience poorer health outcomes – many want to say it's poverty and other things – it's racism"**

- Caroline Bennett Abuayyash, Assistant Professor, Dalla Lana School of Public Health, University of Toronto

## CIHI AND IC/ES

The Canadian Institute for Health Information (CIHI) is an independent, not-for-profit organization that provides essential information on Canada's health systems and the health of Canadians. They provide comparable and actionable data and information that are used to accelerate improvements in health care, health system performance, and population health across Canada.

CIHI has several tools and reports like The Pan-Canadian Dialogue to Advance the Measurement of Equity in Health Care devoted to analyzing data sets by equity stratifiers. For this work, they defined an equity stratifier as a variable that captures a demographic, social, economic, geographic or other characteristic and that

identifies population sub-groups that can be used to measure inequalities in health care access, quality, and outcomes.

The Institute for Clinical Evaluative Sciences (IC/ES) plays a central role in Ontario research aimed at identifying health inequities, and developing and evaluating health policy and services. IC/ES brings together research, data, and clinical experts to lead advanced studies that evaluate health care delivery and outcomes. An independent not-for-profit research institute, IC/ES receives its core funding from the Ministry of Health.

# RECOMMENDATIONS

**1** 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.



## RACE-BASED DATA COLLECTION & APPLICATION

Race-based data collection has been happening throughout the system and not just in health care. Many other sectors have begun to understand the importance of being able to identify inequities in how different communities within a population interact with a service or sector. For example, the One Vision One Voice: Changing the Ontario Child Welfare System To Better Serve African Canadians report published in 2016 made several recommendations to the Ontario Ministry of Children and Youth Services to create more equitable conditions for racialized children and youth navigating the system.

One of those recommendations stated mandatory requirements for the collection and annual reporting of disaggregated race-based data by child welfare agencies through the Child Protection Information Network (CPIN), Ontario Looking After Children (OnLAC), and Crown Ward Review. Mandatory requirements should stipulate that such data be used as a basis for strategic planning, program development, and service delivery related to the African Canadian community, and that child welfare agencies report annually on performance measures to both the Ministry of Children and Youth Services and the community. (Turner, 2016)
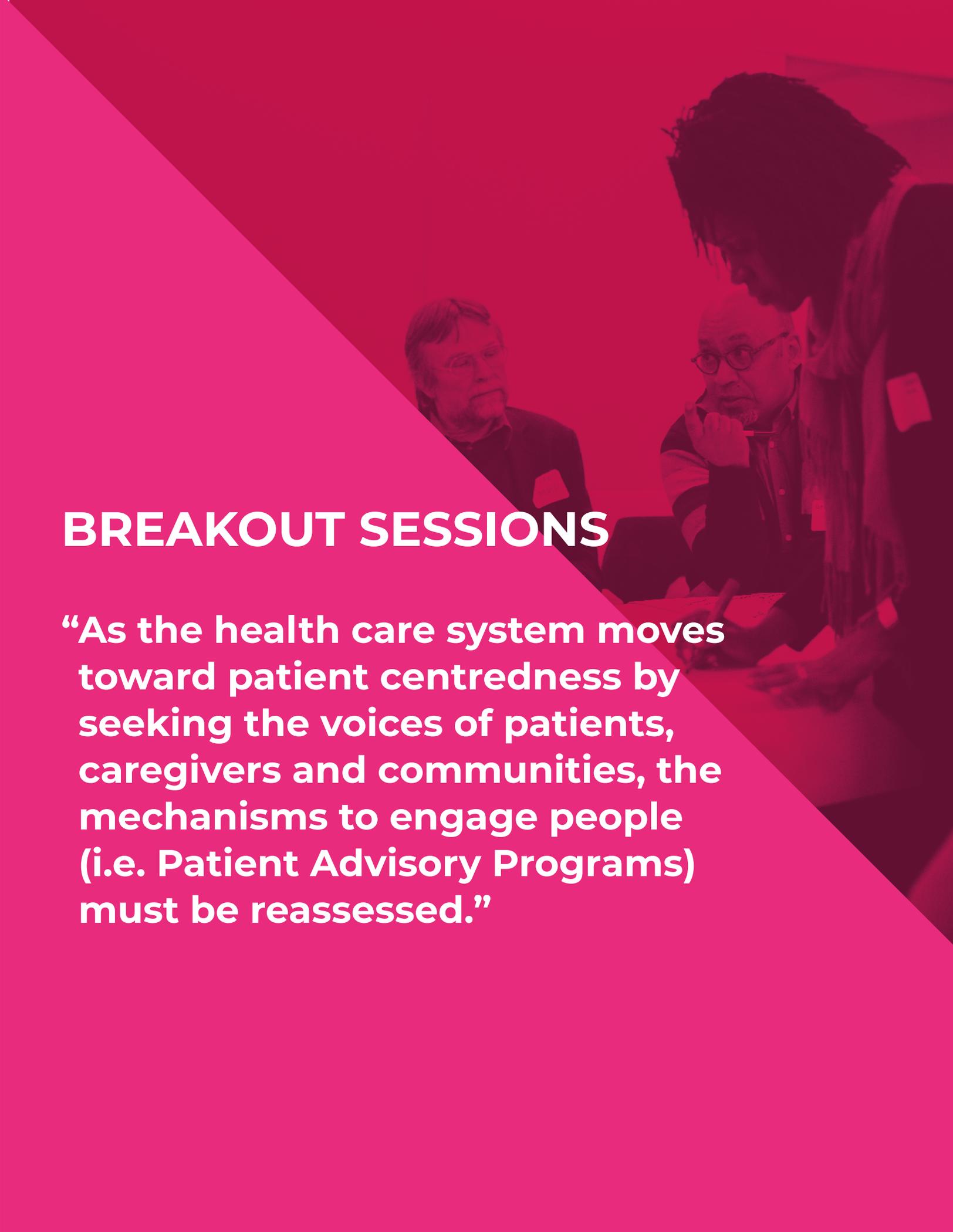
# BREAKOUT SESSIONS

"As the health care system moves toward patient centredness by seeking the voices of patients, caregivers and communities, the mechanisms to engage people (i.e. Patient Advisory Programs) must be reassessed."

# BREAKOUT SESSION 1: Reshaping patient-centred approaches to include Black experiences in health care

## Facilitators:

**Corey Bernard**, Manager, Patient Partnership, Community Outreach and Health Equity, Mississauga, Halton LHIN

**Venessa Downer**, Patient Partner

**Ryan Hinds**, Community Engagement Lead, Toronto Central LHIN

**Cian Knights**, Experience and Engagement Specialist, Unity Health

**Aman Sium**, Director, Client and Family Integrated Care, Holland Bloorview Kids Rehabilitation
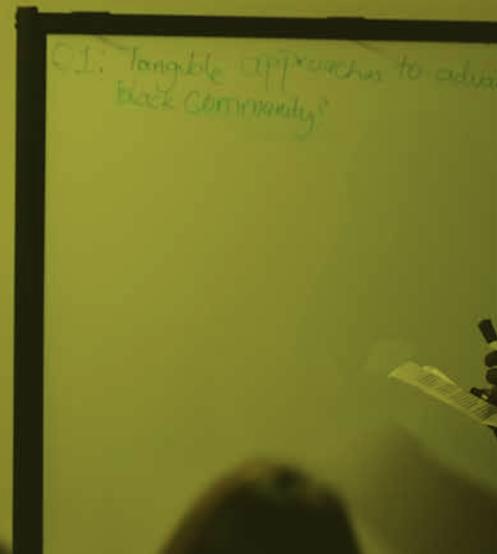
As the health care system moves toward patient centredness by seeking the voices of patients, caregivers and communities, the mechanisms to engage people (i.e. Patient Advisory Programs) must be reassessed. Many strategies do not reflect or implicitly include Black experiences. As a result, they can contribute to the erasure of needs, concerns, preferences and experiences of Black people, exacerbating disparity as decisions are made without the inclusion of Black voices. The disconnect between engagement opportunities and environments that create a sense of belonging, the necessity of pre-engagement work with peoples from Black communities, and the importance of employment equity for enabling and building trust were identified as a few current contributing factors.

This interactive session gave participants a chance to collectively discuss the challenges and create a set of recommendations for establishing a respectful and reciprocal partnership with Black communities that can be used to guide health care leaders, providers, Ontario Health Teams, and Ontario Health.

# WHAT DID WE LEARN?

**Politics, not just engagement:** A specific anti-racism policy around the engagement of Black people and health care experiences  is required to ensure that the ways we engage do not further perpetuate anti-Black racism, discrimination, and trauma within Black communities.

**Preparation and education prior to engagement:** Before engaging with communities, take time to read and learn about what that means specifically in the context of Black communities. This includes understanding needs, priorities, concerns, as well as solutions already being raised and identified within Black communities.

**Community-centred engagement:** Engagement needs to be empowering and be on the terms of those involved. We need multiple models of engagement that reflect diversity of needs. Health care has

developed a formula that often defaults to having people that identify as patients sitting on committees. This approach has proven unsuccessful in adequately or effectively engaging with Black communities, and most often ignores or dismisses issues of race and class in these committees. Institutions need to find ways to get more diverse voices into the conversation.

**Leadership buy-in and alignment with priorities:** All providers are required to serve all populations and many now have explicit mandates to make special efforts to serve underserved populations. With equity also being a focus, it is important that health system leadership understands the necessity and methods to continually engage Black communities to help guide care.

**Getting comfortable in the uncomfortable:** Many leaders experience discomfort in unpacking narratives of racism and discrimination broadly or within their organizations. Providers and leaders need to understand the importance of working through this discomfort with education and training, specifically Anti-oppressive training and Anti-racism training.

**Organizations need to be inclusive:** Communities need to see people in organizations who are from their communities and have a shared understanding of experiences and priorities. Black people at all levels throughout an organization who can do analysis and synthesis of data are important so that the core pieces of patient stories are not lost.

**Health equity and employment equity go hand in hand:** Patients need to see themselves reflected in hospital staff, physicians, and nurses. Everyone must invest in Black leadership and mentorship programs.

**Our stories matter:** Black people, families, and communities need to be listened to, acknowledged, and appropriately responded to. Stories that capture a range of experiences, intersectionalities and community solutions need to be valued and should not be manipulated into a broader narrative that may dismiss, exploit, or further discriminate against Black communities.

## PUBLIC HEALTH DISCOURSE AND IMPLICATIONS FOR TRANSFORMATIONAL CHANGE

The term 'Vulnerable groups' as Amy Katz describes is often vaguely defined or undefined is applied as a proxy for a wide range of groups with conditions and situations. These groups are often constituted as inherently vulnerable and regardless if policies or processes change, group vulnerability will remain. Unfortunately, populations and groups in power who are responsible for generating structural vulnerability are rarely examined with this framing. As a result, the term vulnerable is used to strategically attract resources, policy interest, and public concern but the vagueness associated with it also conceals the structural nature of public health problems obscuring power relations and limiting transformational change (Katz, Hardy, Firestone, Lofter & Morton-Ninomiya, 2019). This is an important message to hold for both health systems and racialized communities as 'Community/Patient Engagement' is continually being redefined.

**"Health care has a developed formula when it talks about engagement...The current engagement model is based on race and class. So even if you get a Black person in there, they may come from certain class that experiences issues differently. We need other engagement strategies that are not about further perpetuating inequities. Institutions need to find ways to get the right voices for communities into the conversation."**

- Cian Knights, Experience and Engagement Specialist, Unity Health

# RECOMMENDATIONS

**1** 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.

**2** 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.

**3** 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.

# BREAKOUT SESSION 2: Surfacing the value in race-based data collection & mobilizing coalitions for advocacy

## Facilitators and Speakers:

**Cynthia Damba**, Manager, Health Analytics, Toronto Central LHIN

**Gideon Quaison**, Data Analyst, Health Commons Solutions Lab

This session unpacked the value of equity and race-based data collection across the health care system in Ontario, and provided a brief overview of existing tools and resources. As a result, participants developed methods of shared advocacy and communication strategies around race-based data collection/application at the individual, organizational, community and system levels.

**Cynthia Damba**, Manager of the Health Analytics Team at the Toronto Central LHIN, opened the session with a presentation on 'Why Race-based Data Matters' that provided an overview of the current equity data collection landscape and discussed the impact and the implications of race-based data collection by presenting analyses and findings from health equity initiatives.

## WHAT DID WE LEARN?

**Existing data equity initiatives can be leveraged:** Tremendous work has gone into equity data collection initiatives in the Toronto Central LHIN. We can use that data to highlight inequities in care and outcomes for the Black community – such as *Black patients having the highest readmission to hospital rate after 30 days, compared to all other racial/ethnic groups.*

**Data revealed significant differences by race/ethnicity** in chronic conditions and comorbidity, Emergency Department use, inpatient hospitalizations and primary care access, that need to be considered when planning for services for the Black population.

**Differences in race/ethnicity may be masked** by looking at the whole groups as homogenous populations (both across other socio-demographic fields but also within the Black race category, as there may be variability based on cultural origin). It is important to analyze the intersectionality of correlated sociodemographic variables to identify subpopulations within categories that may be further marginalized.

**Gideon Quaison**, Health Commons Solutions Lab, guided participants through a series of activities designed to encourage understanding and empathy for different roles and perspectives across the health care system (e.g. patients, providers, program planners, administrators, and policy makers). To conclude, groups modelled coalition building to advance a collective ask at the system level.

# WHAT DID WE LEARN?

**The value of race-based data is tied to the impact that the data can/will have:** The value of data collection is not clear to everyone and there is a risk in assuming that the value is shared equally by all groups. Taking time to sit with a new perspective builds a deeper sense of empathy and a more fulsome understanding of the barriers we all face.

**We need a strategy for how to collect the data AND how it will be used:** Many of the barriers to data collection experienced by different groups within the health care system are shared. For example, lack of clarity for how the data will be used impacts patients who may not want to give their personal information; front-line providers and administrators who may not buy-in and support initiatives without information on how it will be used to improve outcomes for patients; and planners and policy makers who may feel these types of initiatives are too costly and resource intensive.

**Health equity is not one person's job:** Everyone (patients, caregivers, providers, administrators, planners, policy makers) has a role to play in advocating or supporting these types of initiatives and a successful approach will ensure all perspectives are included in the discussion.
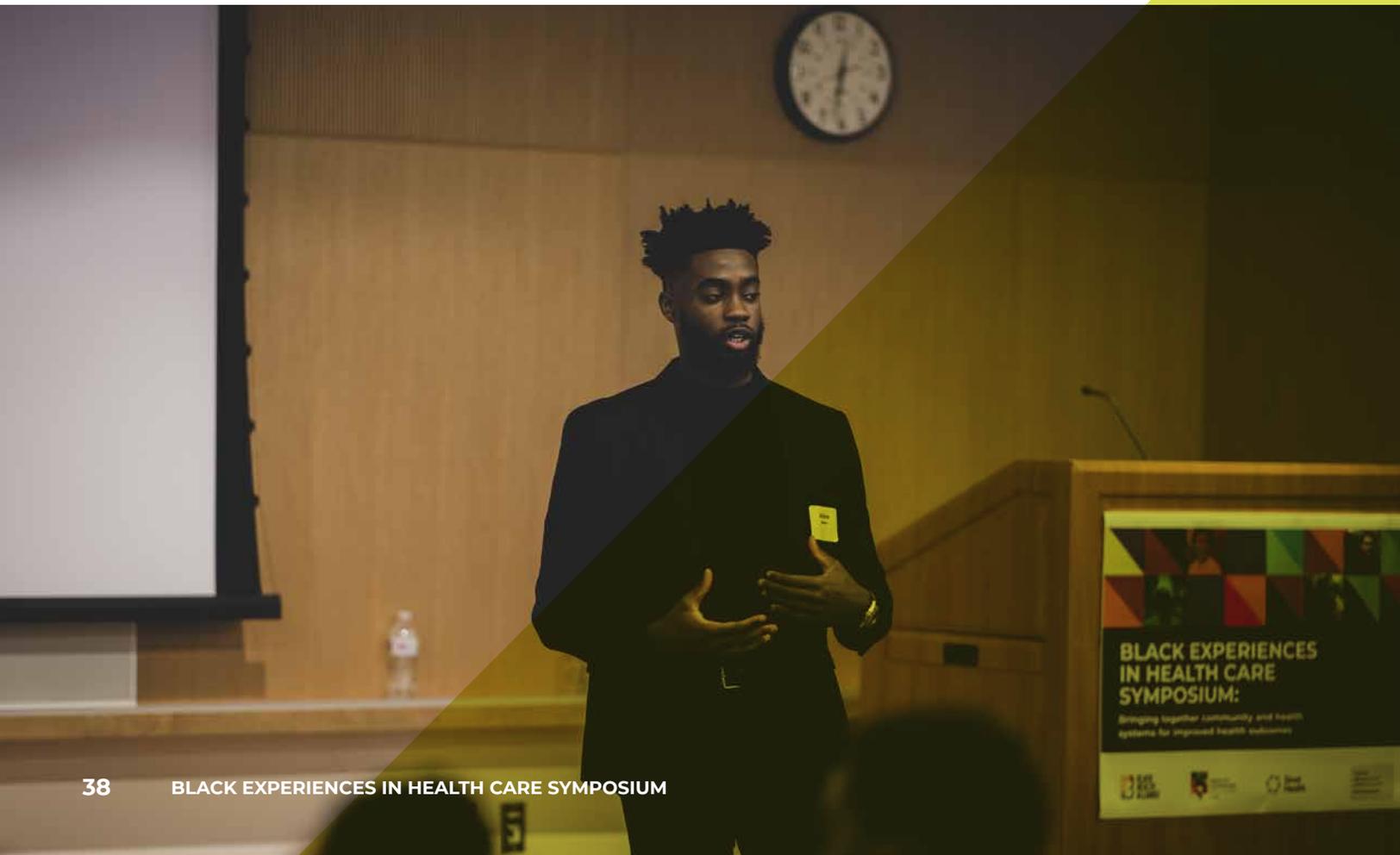
# PARTICIPANT GENERATED RECOMMENDATIONS

The coalitions created several recommendations, grounded in unique perspectives, assigned to reflect the priorities of different stakeholders in Ontario health care. Participants worked through how these perspectives inform responses to the perceived value of race-based data collection, their role in supporting the collection of race-based data collection, and some of the barriers they face along the way.



Please refer to Appendix D
  1) Values
  2) Roles
  3) Barriers

**1** Create a Black Health Strategy that outlines a clear plan for how data will be used to improve outcomes
  · Show how smaller one-off data collection initiatives have been used to create change and make a difference in care
  · Make the success criteria for the data collection improved outcomes for patients and learning outcomes for staff, rather than 'number of people trained'
  · Ensure that discussions on data collection are done in the broader context of societal discourse regarding racism and other similar systemic barriers

**2** Make advancing equity part of organizational culture and incorporate in the daily operations - ensure staff understand this as part of everyone's job

**3** Increase and amplify inter-sectoral partnerships and work with allies outside of health care

**4** Create alliances with all marginalized and racialized populations with a common agenda (shared outcomes, strategies, etc.) and share infrastructure to support the work

**5** Mandate the collection of this data and ensure enforcement across the province (by Ministry of Health, Ministry of Long-Term Care, Ontario Health, Ontario Health Teams, etc.) and tie funding accountability across sectors to equity outcomes

**6** Publicly report on data collected to increase accountability

**7** Require Ontario Health Teams to consider race as a determinant of health and explain how they will identify and address disparities identified among racialized communities

**8** Ensure that provincial digital solutions for Ontario Health Teams have equity data collection built in

**9** Centralize support for data collection and guidelines for standardization to ensure data quality
  · Create an advisory committee or board that is representative of different perspectives and sectors to give expertise on implementation
  · Ensure that data collection tool or framework collects adequate sociodemographic information so that intersectionality can be properly measured
  · Don't stop at collection – think about possibilities with data linkages to increase the impact

**10** Support education to communities with a robust knowledge translation and communication strategy

# BREAKOUT SESSION 3: Developing principles for collecting and acting on data for Black communities

## Facilitators and Speakers:

**Paul Bailey**, President, Black Health Alliance

**Dr. Winston Husbands**, Senior Scientist, Ontario HIV Treatment Network

**Sara Wolfe**, Director, Indigenous Innovation Initiative, Grand Challenges

**LLana James**, Researcher

This session focused on what needs to be true for collecting and acting on data for Black communities. Three individuals presented their diverse perspectives on what principles must be considered before, during, and after data is being collected. **Sara Wolfe** (Grand Challenges Canada) spoke of her experience founding an Indigenous-led midwifery practice, the importance of Indigenous-led research and data collection, and the need for communities to be involved in all aspects. **Winston Husbands** (Ontario HIV Treatment Network) spoke about the tension between lack of data collection and lack of Black involvement in data collection. Finally, **LLana James** focused on data justice, which challenges the status quo and does not assume that data collection is inherently neutral. The session echoed the importance of responsibilities and accountability in data collection to prevent further harm to Black communities and the value of Black people doing interpretation, analysis, and synthesis of the data.

# WHAT DID WE LEARN?

## Sara Wolfe

Those who the data is about must be involved in all areas of data collection, processing, and storage.

- Once collected, data needs to be contextualized in lived experiences of individuals and communities.
- Black communities have been one of the biggest allies to Indigenous communities, we need to continue to support each other.

> **"No, you can't take data and understand it properly without us. We need to be involved in all aspects."**
> – Sara Wolfe, Director, Indigenous Innovation Initiative, Grand Challenges

## Dr. Winston Husbands

- An abundance of data is being collected but Black communities are not involved and the data is not shared with the communities it is about.
- Lessons learned through research advocacy for Black involvement must be shared throughout the data collection process, instead of just offered as conclusions once the process is over.
- A lot of scattered data sits locked and underutilized inside universities. We need a strategy for managing data collection, appropriate use, and implementing structure(s) to bring it together.

> **"Issue is not if there should be data, we are past this point. Lots of data is being collected already, but the Black community is not involved. It's happening behind our backs or above our heads."**
> – Winston Husbands, Senior Scientist, Ontario HIV Treatment Network

## LLana James

- Data justice challenges the status quo and does not assume that data collection is only beneficial. There is a need to better understand how data collection may be harmful in order to make sure that it isn't.
- Technology is constantly shifting which affects the context of how data is collected, stored, and shared. We also need to move beyond health care and consider other types of data that affect our communities.
- It's time to move beyond data principles, as principles often have no reinforcement.

> **"Data justice challenges the status quo, it does not assume that data collection is inherently neutral, good or beneficial and facilitates redress."**
> – LLana James, Researcher

# RECOMMENDATIONS

**1** 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.

**2** Increased accountability for universities and other research institutions around transparency and intended data use when engaging with Black communities. The restrictions around what communities are debriefed with prior to engagement do not always illustrate the full extent to which data on Black communities will be used.

**3** Identify, support, and resource those already conducting research within/for Black communities on the intersectionalities of data analytics and social justice, also referred to as Data Justice.

**4** Identify ways to encourage foster and support multi-generational ways of knowing to inform data collection, analysis, and interpretation.
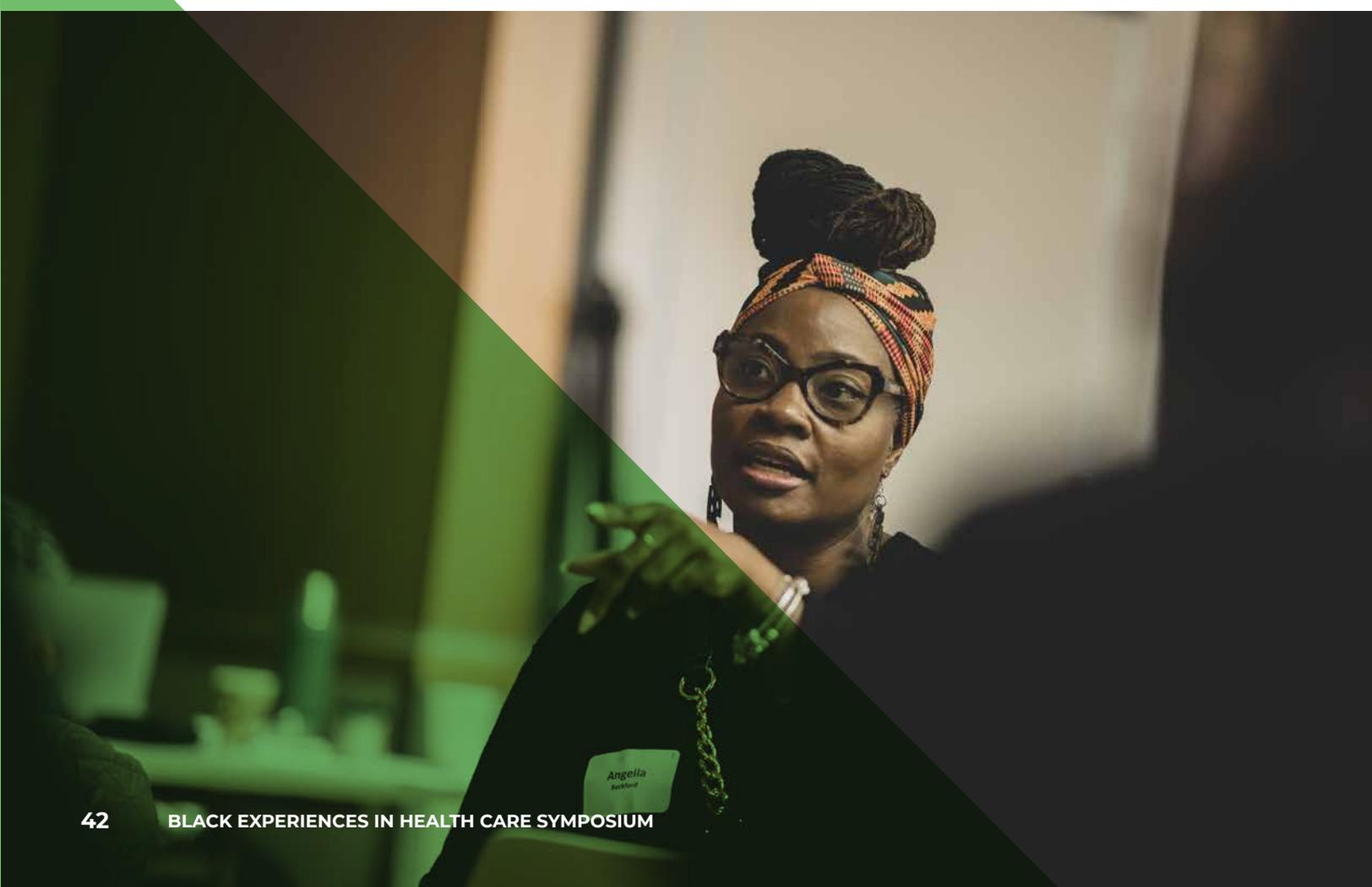
# BREAKOUT SESSION RECAP

The afternoon started with an interactive session that invited participants to share impressions, ideas, takeaways, and memorable moments from the breakout sessions. The session was designed to give all attendees an overview of the themes discussed across all three sessions and provide an opportunity for people to reflect on their own, in pairs, as small groups, and as a collective community.

## PARTICIPANT GENERATED THEMES & NEXT STEPS

Themes that emerged include:

### THE BLACK LEADERSHIP PIPELINE

▶ Account for the impact of racism on the development and lack of opportunities for young Black professionals.
▶ Black leadership is needed at all levels and across all sectors.

▶ Recognize nuances of navigating institutions as a Black professionals, researchers, educators, students, and patients.
▶ Centre the importance of Black Liberation, Racial Justice & Equity.
▶ Eliminate tokenism.
▶ Amplify the value of unpacking both universal experiences of discrimination and unique individual experiences.

### ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

▶ Get diverse communities working together.
▶ Ensure intersectionalities within communities are present at decision making tables.
▶ Address hiring processes to ensure there are Black communities reflected.
▶ Have organizational leaders put Black people in decision making positions.
▶ Provide special training and mentorship for Black students in and outside of universities on how to navigate health system for leadership positions.

# REDEFINING ALLYSHIP

- Allies need to be involved in raising the issues first and also moving the work forward.
- Education is needed to encourage allyship with the ultimate goal of progressing community needs further.

## ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

- Engage people from other cultures and professions that intersect with health care.
- Have uncomfortable conversations.
- Acknowledge and address White Fragility when dealing with race and racism in health care (including for Black and other racialized staff in their work environments).
- Dismantle White Supremacy.
- Start with decolonization first.
- Implement the Implicit Bias Assessment in organizations.

# REFRAMING RESEARCH: COMMUNITIES ARE THE EXPERTS

- When consulting Black communities, we must understand where that expertise about our communities lies within those communities.
- Redefine "Black Engagement" and cancel engagement approaches that further perpetuate discrimination or harm.
- Decolonize data collection.
- Build trust with Black communities.
- Recognize and elevate local and grassroots efforts.
- Address the "Culture of research" and restructure top-down frameworks.
- Community must be regarded, respected, and approached as experts in all engagements.

## ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

- Create inclusive, safe environments that promote Black engagement and allow race-based data to be collected.
- Use culturally informed knowledge when creating space or inviting communities.
- Build solidarity through BIPOC (Black, Indigenous and People of Colour) communities working as collectives.
- Build data infrastructure outside of health care institutions that is owned by Black communities.
- Educate clients on the importance of providing correct demographic data during intake.
- Frame research within the structural context in which Black people experience health systems in order to provide a nuanced interpretation of the data.
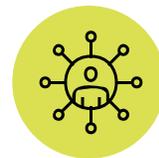
# BUILDING COALITIONS WITH CROSS-SECTOR PARTNERS & DIVERSE COMMUNITIES

- Coalitions are important because they acknowledge one person does not have to do all the work.
- They build more collective knowledge to draw from.
- Build solidarity for Black and Indigenous (intersectionalities for people who identify as both) communities working as collectives.
- Build coalitions and redefine allyship to make the case stronger.
- Elevate the importance of building trust and eliminating lateral violence.

## ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

- Open an honest dialogue with ourselves.
- Identify long term and short term change(s).
- Connect leaders of individual organizations on initiatives, programs, and data collection.
- Locate agency and responsibility in every role.

# RESHAPING GOVERNMENT INVOLVEMENT IN BLACK HEALTH LOCALLY PROVINCIALLY & FEDERALLY

▶ Advance health equity data collection by having it built into accountability agreements by Ontario Health and Ontario Health Teams and having Black people identified as a priority population.

▶ Mandate the collection and application of socio-demographic/race-based data in health care and compare data with similar data sets collected across other social services.

▶ Involve provincial and government bodies specifically around accountability.

▶ Historically government has created policies and procedures that have negatively impacted the health of Black communities (Eg. Carding). It is important that any government involvement is defined by Black communities.

## ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

▶ Accountability must be tied to funding metrics.

▶ Put pressure on funders like CIHR for diverse grants to support the range of issues racialized communities face (eg. Breast cancer in Black women).

▶ Propose a Provincial Black Health Strategy.

# DATA JUSTICE

▶ The importance of the quality of race-based data collected and the appropriate data infrastructure, including ownership, ethics, access, and more will be foundational to realizing change.

▶ Leverage Data Justice as a tool for Black Liberation.

▶ Standardize Ethics + Principles around race-based data collection.

▶ Create a hierarchy of accountability in data use.

▶ Ensure communities own this work to prevent potential misuse.

▶ Reinforce that it matters who owns the data.

▶ Develop required infrastructure of support.

▶ Stay alert that data collection is not inherently neutral or benevolent.

## ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

▶ Use Health Equity Impact Assessment Tool.

▶ Develop partnerships between race based groups and government.

▶ Create policies/legislation that can actually be enforced around data ownership for communities that have provided their data.

▶ Support those working and researching to develop accountability measures for contemporary data concerns (eg. A.I, Tech and health).

▶ Ensure required cultural competency and sensitivity is enforced in interpretation of data.

▶ Rebuild trust first when it comes to data collection because of historical and generational mistrust.

# QUALITY OF RACE-BASED DATA

▶ Harmonize data ecosystem to reduce duplication and enhance existing datasets.

▶ Develop fuller data sets that can lead to better analysis for change.

▶ Note that the impact good quality data has on funding and quality of care is immense.

## ACTION-ORIENTED NEXT STEPS/ IMPORTANT CONSIDERATIONS

- Adopt a minimum raced-based standard to collect information.
- Develop a mandate with actionable next steps.
- Learn strategies and train teams on race-based data management.
- Challenge frameworks of data collection in organizations and advocate for change.
- As an organization, begin collecting data in compliance with existing standards.
- Establish standards and guidelines for conducting data collection and analysis.
- Develop a Research and Data Ethics Board made up of a collaborative team of multi-sectoral Black professionals and community members to govern data.

## OTHER PARTICIPANT GENERATED THEMES

- **Context cannot be overlooked:** A history of violence, surveillance, and the contemporary risks of data collection still play a huge role in outcomes.
- **Partnerships can expedite results:** Building coalitions and redefining allyship will make the case stronger.
- **Vocalizing Black Liberation:** Recognize and elevate a lineage of resilience.
- **Anti-Black racism extends beyond health care:** The impacts of Anti-Black racism on our well being is far-reaching.
- **Levels of accountability:** Unpack where "I" impact the work (as an ally).
- **Creating space for Black Stories in health and beyond:** Create space in public health discourse for Black communities to share their successes, achievements, solutions, innovations, and continuous resilience.

# WHAT WE HEARD:
## Participant Experience

The following information is a summary of the evaluation forms completed by attendees at the Symposium.

## SUMMARY:

▸ **62** participants completed an evaluation, for a response rate of **74%**. Overall, participants provided positive feedback on their experience

▸ After today's session, participants want to learn more about:

**1. How they and their organizations and communities can get involved**

**2. The current state of race-based data collection**

**3. Data ownership and data justice**

**4. Coalition/ alliance building**

▸ Areas for Improvement:
  • Having longer and more interactive sessions
  • More consideration of who is in the room
  • More discussion of the current state of data collection
  • Comments on logistical improvements

## KEY POINTS:



**95%** strongly agreed or agreed that they made a new connection with an individual or organization
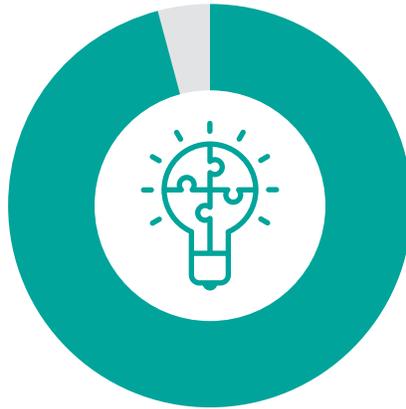
**96%** strongly agreed or agreed that they learned something new about race-based or socio-demographic data and how it relates to health care

**83%** strongly agreed or agreed that they have a clearer understanding of the work that needs to be done to improve health outcomes and reduce health disparities for the Black community

**"Thank you! It was a great day to bring together leaders across the health system to learn and move forward by implementing change & action."**

\- BEHCS 2020 Attendee

**"This was a really important discussion to have but one that cannot just occur just once a year, if there are opportunities to continue this conversation please let attendees know!"**
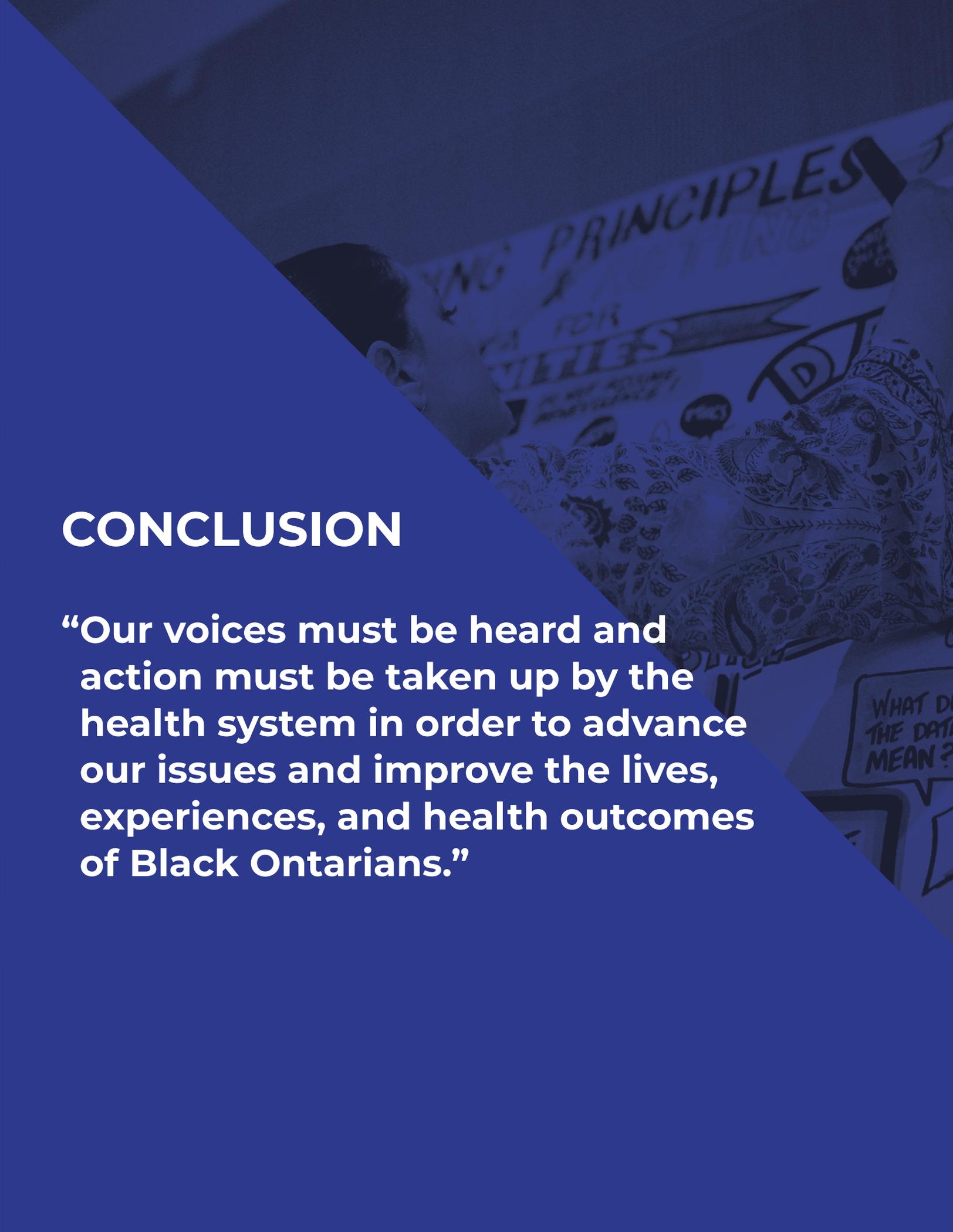
\- BEHCS 2020 Attendee

**"Meeting professionals who represent the Black diaspora built hope and solidarity to continue the work."**

\- BEHCS 2020 Attendee

**"The curation of the keynote speakers and breakout sessions was exceptional. I especially enjoyed that they designed for individual reflection, group discussion, and larger/broader engagement."**

\- BEHCS 2020 Attendee

## CONCLUSION

"Our voices must be heard and action must be taken up by the health system in order to advance our issues and improve the lives, experiences, and health outcomes of Black Ontarians."

# NEXT STEPS

This report provides an overview of the core themes, challenges and recommendations that emerged from the Symposium. The report also highlights the importance of participants' personal lived experience as Black people working in and/or engaging with the health care system, and signals the dire need for a more equitable health system going forward.

The event was a call to action for the individuals, communities, organizations, and institutions who have an interest and role in improving the health of Black communities. This report summarizes those calls to action and provides direction for further exploration, convenings, discussions, and next steps.

In 2017, the first Black Experiences in Health Care Symposium saw many important themes and priorities raised and documented in the first event summary report. Three years later, little change has occurred and many of the same issues are being raised by the community again. Our voices must be heard and action must be taken up by the health system in order to advance our issues and improve the lives, experiences, and health outcomes of Black Ontarians.

During the 2020 Symposium, a number of potential partnerships and actions were proposed in order to bring together health systems and communities for collaboration on next steps:

**1**

## 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)

## 2

# 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.

## 3

# 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.

# CLOSING CALL TO ACTION

The 2020 Black Experiences in Health Care Symposium is the second iteration of a conversation that has been happening long before this formal setting or vehicle for organizing was established. This convening falls within a long lineage of organizing, advocating, and pushing forward Black Liberation work that has existed and continues to exist in Toronto and Canada more broadly. It provides a platform for Black communities to share their priorities and a space for health systems to understand and locate their successes and shortcomings.

The event surfaced the importance of collecting and utilizing race-based data, holding health systems accountable for the health outcomes of communities they're mandated to serve, and the value of Black leaders at decision making tables. Going forward, this work plans to include a multi-sectoral approach to many of the issues raised throughout the Symposium. It is more evident now than ever before that real change needs to include everyone but for it to be sustainable, it must centre those who will be most impacted by the change.

Through creating shared understanding, building capacity, leveraging the voices of communities, and supporting those already doing the work of change, many people have created many incremental shifts that build towards a larger vision of equity. The work of creating a future with a more integrated health system that accounts for the needs and priorities of those who have been historically the most marginalized or oppressed is not easy. More importantly, the struggles and challenges that Black people, families, and communities face every day to access health services and their experiences are also far from "easy." Change is needed and, regardless of where you sit in the system, from providers to planners, the commitment to ensuring the system works for everybody is a priority. Black Health Alliance and Health Commons Solutions Lab look forward to working closely and partnering with all health partners committed to advancing the health equity agenda and improving the health of Black Ontarians.

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# 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.

## PLANNING COMMITTEE

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## ORGANIZATIONS

Black Physicians' Association of Ontario
Mississauga Halton LHIN
Sinai Health
TAIBU Community Health Centre
Toronto Central LHIN
Wellesley Institute

## VENDORS

Photography- Jalani Morgan
Videography- Andre Williamson
Catering- Twist Catering
Graphic Recording- Think Link Graphics

# APPENDIX

## APPENDIX A:
## List of attendee/participant organizations:

- A Nursing Service with Every Resource
- Academic Model Providing Access to Healthcare (AMPATH)
- Access Alliance
- Adaptive Strategy Partners
- Addictions Services for York Region
- Addictions Services for York Region
- Alliance for Healthier Communities
- Amblecare Health
- Better Outcomes Registry & Network (BORN) Ontario
- Black Creek Community Health Centre
- Black Health Alliance
- Black Physicians Association of Ontario
- Black Women in Motion
- Bramalea Community Health Centre
- Canadian Cancer Society
- Carea Community Health Centre
- Centre for Addiction and Mental Health
- Change Foundation
- Corner Counsellor
- CSVB Insights Inc.
- Dalla Lana School of Public Health
- Diabetes Canada
- Family Transition Place
- Global Alliance of Sickle Cell Disease Organizations
- Grand Challenges Canada
- Holland Bloorview Kids Rehabilitation Hospital
- Markham Stouffville Hospital
- MATERNAL - NEONATAL HEALTH
- Max International LLc
- Mississauga Halton LHIN
- Moyo Health and Community Services
- North York General Hospital
- Nyanda Consulting
- Ontario Health
- Ontario Indigenous Cultural Safety Program
- Papaswallet
- Parkdale Queen West Community Health Centre
- Peel Public Health

- Planned Parenthood Toronto
- Provincial Health Services Authority
- Public Health Ontario
- Queensborough Health Informatics Solutions Inc.
- Racialized Health Alliance
- Reflet Salveo
- Regent Park Community Health Centre
- Roots Community Services
- Scarborough Health Network
- Sinai Health
- The Hospital for Sick Children
- Toronto Central LHIN
- Toronto Public Health
- Unity Health
- University Health Network
- University of Toronto
- VHA Home HealthCare
- Wellesley Institute
- Wellfort
- Weston King Neighbourhood Centre
- WombCare Inc
- Women's College Hospital
- Women's Health in Women's Hands Community Health Centre
- Womxn of Colour Collective
- WoodGreen Community Services

# APPENDIX B:
# Symposium Agenda

| AGENDA | |
|---|---|
| **Time** | |
| 8:30 - 9:00 a.m. | **REGISTRATION & BREAKFAST**<br>Main Floor Auditorium |
| 9:00 - 9:15 a.m. | **Opening Remarks & Land Acknowledgement**<br>**Speaker(s):**<br>*Sophia Ikura*, Executive Director, Health Commons Solutions Lab<br>*Paul Bailey*, President, Black Health Alliance |
| 9:15 - 9:30 a.m. | **My Life, My Story**<br>**Speaker:** *Karen Dickson*, Patient Partner |
| 9:30 - 9:45 a.m. | **Setting the Context for Change in Health Care Delivery**<br>**Speaker:** *Dr. Gary Newton*, CEO, Sinai Health |
| 9:45 - 10:15 a.m. | **Keynote Address**<br>**Bringing Together Community & Health Systems to Improve Health Equity Outcomes**<br>**Speaker:** *Camille Orridge*, Senior Fellow, Wellesley Institute |
| 10:15 - 11:00 a.m. | **Panel Session**<br>**Data for Health: Race-based Data & Opportunities For Action**<br>**Moderator:** *Dr. Onye Nnorom*, President, Black Physicians Association of Ontario<br>**Panelists:**<br>*Notisha Massaquoi*, Principal, Nyanda Consulting<br>*Camille Orridge*, Senior Fellow, Wellesley Institute<br>*Caroline Bennett AbuAyyash*, Assistant Professor, Dalla Lana School of Public Health, University of Toronto |
| 11:00 - 11:15 a.m. | **BREAK** |

| Time | Session |
|---|---|
| 11:15 - 12:15 p.m. | **Breakout 1: Reshaping patient-centred approaches to include Black experiences in  health care**<br>**Facilitator(s):**<br>*Corey Bernard*, Manager, Patient Partnership, Community Outreach & Health Equity Mississauga Halton Local Health Integration Network<br>*Ryan Hinds*, Community Engagement, Toronto Central LHIN<br>*Cian Knights*, Experience & Engagement Specialist, Unity Health<br>*Aman Sium*, Director, Client & Family Integrated Care, Holland Bloorview<br>*Vanessa Downer*, Patient Partner<br><br>**Breakout 2: Surfacing the value in race-based data collection & mobilizing coalitions for advocacy**<br>**Facilitator(s):**<br>*Gideon Quaison*, Data Analyst, Health Commons Solutions Lab<br>*Sonia Gaudry*, Senior Project Lead, Health Commons Solutions Lab<br>*Cynthia Damba*, Manager, Health Analytics, Toronto Central LHIN<br><br>**Breakout 3: Developing principles for collecting and acting on data for Black communities**<br>**Facilitator(s):**<br>*Paul Bailey*, President, Black Health Alliance<br>*Winston Husbands*, Senior Scientist, Ontario HIV Treatment Network<br>*Sara Wolfe*, Director, Indigenous Innovation Initiative, Grand Challenges |
| 12:15 – 1:15 p.m. | **LUNCH**<br>*Marian Walsh* Auditorium, 10th Floor |
| 1:15 - 2:15 p.m. | **Breakout-Session Recap**<br>**Facilitator(s):**<br>*Sophia Ikura*, Executive Director, Health Commons Solutions Lab<br>*Gideon Quaison*, Data Analyst, Health Commons Solutions Lab |
| 2:15 - 2:45 p.m. | **Keynote Address**<br>**If Not Now, When: Leadership, Allyship, Action**<br>**Speaker:** *Angela Robertson*, Executive Director, Parkdale Queen West Community Health Centre |

| Time | Session |
|---|---|
| 2:45 - 3:00 p.m. | **Closing Remarks**<br>**Speaker(s):**<br>*Gideon Quaison*, Data Analyst, Health Commons Solutions Lab<br>*Lydia-Joi Marshall*, Vice President, Black Health Alliance |
| 3:00 -4:00 p.m. | **NETWORKING & SOCIAL**<br>*Marian Walsh* Auditorium, 10th Floor |

# APPENDIX C:
# Breakout Session 2 Tools

**GROUP #_____**

## BUILDING OUR SHARED UNDERSTANDING

Discuss the different perspectives within your coalition.
Document the discussion by adding to this sheet!

| COALITION MEMBER | YOUR ROLE? | YOUR BARRIER(S)? |
|---|---|---|
| Patient | • Share personal information<br>• | |
| Front-line Staff | • Collect data from clients<br>• | |
| Hospital Administrator | • Ensure data is collected, reported and used by my organization<br>• | |
| Program Planner | • Use data to plan and evaluate our services<br>• | |
| Advisor to Minister | • Ensure stakeholders are happy with our strategy<br>• | |

## OTHER THINGS WE TALKED ABOUT...

**GROUP #_____**

## BRAINSTORMING OUR COLLECTIVE ASK

Considering the diverse perspective in your coalition, generate a list of potential recommendations you would make to your health system partner(s) related to race-based data. There are no bad ideas!

# APPENDIX D:
# Breakout Session 2 Table of perspectives:

## SUMMARY OF SESSION PARTICIPANTS' FEEDBACK

| PERSPECTIVE | VALUE OF RACE-BASED DATA | MY ROLE | BARRIERS / EXPERIENCE |
|---|---|---|---|
| PATIENT | · Contributes towards improved and customized quality care for myself and those of my race<br>· Value depends on if my data contributes to systemic and long-lasting positive changes | · Share my personal information<br>· Advocate for improvements in health care experience (e.g. member of patient advocacy groups)<br>· Be involved in analysis of data and future planning if I am engaged in co-design | · Lack of trust and fear of being over-surveilled<br>· Not provided information about how the data will be used<br>· Providers do not see me as an expert in my own care<br>· My time to do advocacy work is limited<br>· My time with my provider is limited and I want to spend it on things that are more important to me<br>· The process is not engaging<br>· I don't see myself in the racial categories I am asked to select from<br>· Want to ensure my data is not used without context or to further stigmatize my community<br>· Data collection does not acknowledge the intersectionality of my identities |
| FRONT-LINE STAFF | · Allows me to see disparities in service provision, tailor the care I provide, and identify areas of improvement<br>· Empowers me to make positive changes to my practice<br>· Helps me know more about my patients | · Collect data from clients<br>· Increase trust by communicating the purpose, intended use and privacy/security measures for the data we collect<br>· Listen to and answer questions from clients/patients<br>· Adjust my approach to client/patient care based on the needs identified by the individual<br>· Be a champion for collecting data in my organization | · Lack of resources to do the collection including my time<br>· Asking these questions may make them uncomfortable and impact my ability to give them the best quality care experience<br>· Management is not always supportive of these initiatives<br>· I'm not sure the data will be used in meaningful ways<br>· I don't have what I need to connect my patients to appropriate services/supports based on needs they may identify as a result of asking these questions<br>· I was not included in the creation of the data collection process and I am not bought in |

| PERSPECTIVE | VALUE OF RACE-BASED DATA | MY ROLE | BARRIERS / EXPERIENCE |
|---|---|---|---|
| HOSPITAL ADMIN | · Highlights inequities in care and outcomes for Black patients<br>· Validates anecdotes and patient stories<br>· Helps me advocate for funding, resources and targeted programming<br>· Ensures we are meeting the needs of the community<br>· Measure improvements, successes and challenges at an organizational level | · Ensure data is collected, reported and used by my organization<br>· Fund advocacy and outreach initiatives<br>· Resource allocation<br>· Increase profile and visibility of equity work within our organization<br>· Ensure organizational accountability<br>· Training and informing both staff and patients<br>· Suggest and advocate for system improvements based on the experience of our patients and organizations<br>· Be a champion for this within our organization (to both staff and senior leadership) and in the broader health system | · Lack of tools to collect data between systems<br>· Budget – collecting this information puts stain on staffs' time<br>· Individual and collective objection from staff<br>· If this is an isolated effort, it will not have a long-lasting impact on our organization<br>· Organizational changes may dilute the effort; resistance to change my impact our ability to make improvements based on this data<br>· Need support from IT to ensure data privacy, security and management<br>· Don't have a clear path to make this data actionable |
| PROGRAM PLANNER | · Identify disparities between clients/patients in who is able to access and benefit from our programs<br>· Monitor the impact of our service on the Black community and suggest areas of improvement<br>· Advocate for more resources, funding and supports | · Use data to plan and evaluate our services<br>· Inform the data collection and reporting process based on review of existing data<br>· Expose disparities in program access or outcomes<br>· Be a champion for this within our program and across our organization<br>· Play a connector role between organizations by ensuring they also collect similar information so we can compare | · Need buy-in and commitment from management to collect and make use of the data<br>· Funding in resource-constrained environment<br>· Once we collect the data, we have a responsibility to make changes; organization may be resistant to change<br>· Lack of decision-making authority within the organization<br>· Lack of technology or resources for collection and timely analysis of data<br>· Data quality and ensuring the data we collect captures how populations see themselves |
| ADVISOR TO MINISTER | · Support evidence-based decision making at the policy level<br>· Ensure the appropriate and equitable distribution of resources for Black communities<br>· Step forward in targeting a root cause of health system challenges (systemic racism)<br>· If we collect and report this data, we can be seen as a leader for other jurisdictions | · Ensure stakeholders are happy with our strategy<br>· Identify perspectives and necessary partners<br>· Be aware of political risks for encouraging or being silent on data collection<br>· Measure, understand, collect data<br>· Ensure standardization of collection and use in planning<br>· Advocate for funding<br>· Pushing for legislation to mandate collection and use of race-based data | · Lack of acceptance that systemic racism is present<br>· Competing demands – why this issue instead of another issue<br>· Balancing multiple views, including barriers (real or perceived) by health care stakeholders<br>· Once we have the data, we have a responsibility to act |

# APPENDIX E:
# Think Link Sketches

## 1. BREAK OUT SESSION 1 RESHAPING PATIENT-CENTRED APPROACHES TO INCLUDE BLACK EXPERIENCES IN HEALTH CARE
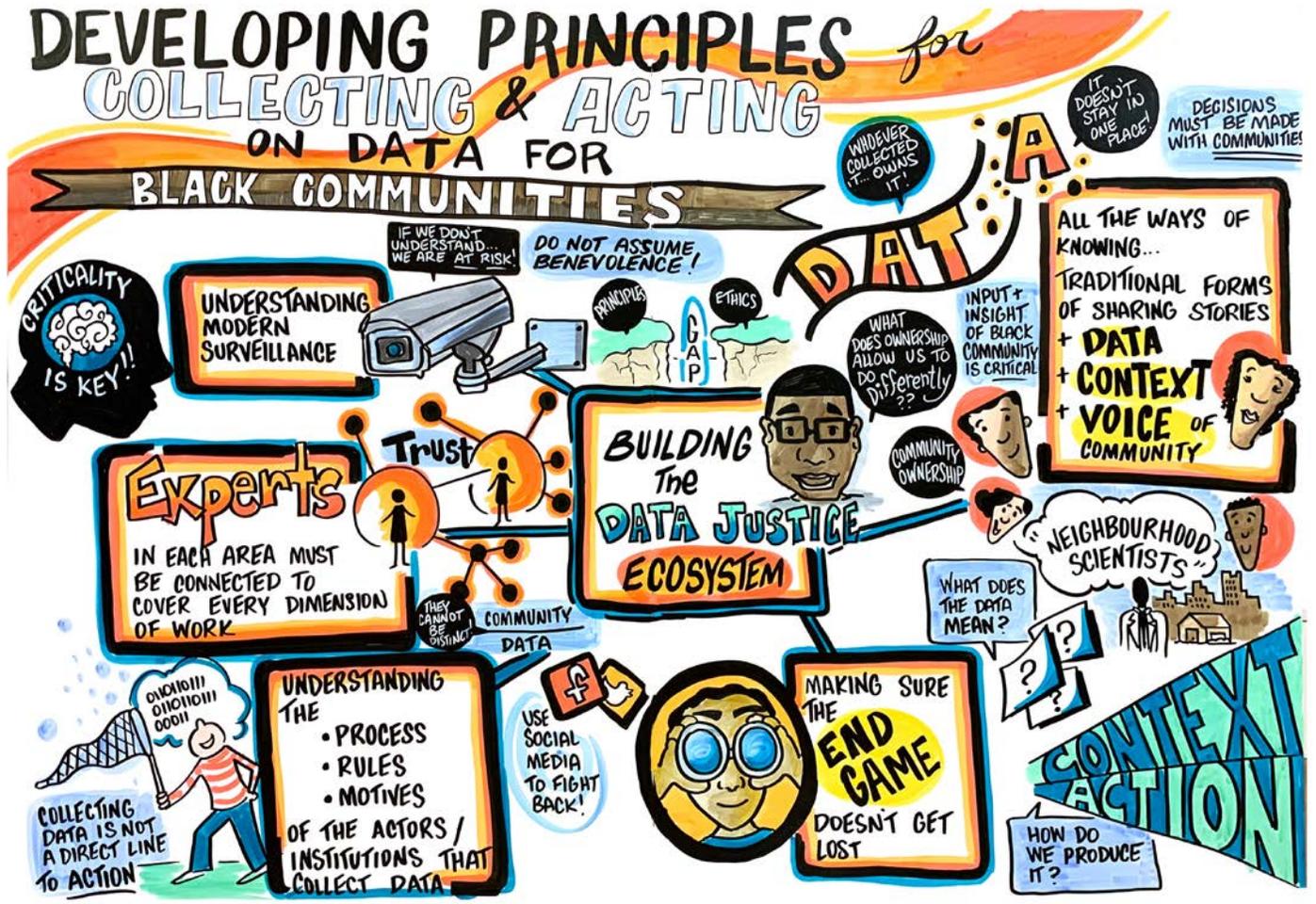


BLACK EXPERIENCES IN HEALTH CARE SYMPOSIUM

## 2. BREAK OUT SESSION 2: SURFACING THE VALUE IN RACE-BASED DATA COLLECTION & MOBILIZING COALITIONS FOR ADVOCACY

BLACK EXPERIENCES IN HEALTH CARE SYMPOSIUM

# APPENDIX F:
# Break Out Recap Tool

## 1. What stands out?

Take a moment to reflect on what has been shared and said today.

In the box below, highlight an important theme from today that has stood out to you and why.

## 1. What stands out?

Take a moment to reflect on what has been shared and said today.

In the box below, highlight an important theme from today that has stood out to you and why.