



# Context

It is estimated that 43% of the Canadian population will be diagnosed with cancer in their lifetime, and amongst women, breast cancer is the most commonly diagnosed form of cancer (accounting for one in four of new cases), followed by lung cancer, colorectal cancer and uterine cancer.(1) Although some cancerous mutations are genetically inherited, most health differences between population groups stem from variations in socioeconomic status and

# **Rapid Synthesis**

# Strategies to Improve Health Outcomes and Care Experiences for Black Women With Cancer

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access to healthcare rather than biology. Research shows that neighbourhoods with lower socio-economic status and higher numbers of Black people and other racialized groups have lower cancer screening uptake and adherence to recommendations even in the presence of screening programs.(1) It is important to understand how racialized populations access cancer-care services and to design strategies that can address the barriers that racialized populations may face. This rapid synthesis explores strategies that can be used to improve healthcare experiences and health outcomes for Black women with breast cancer and other common cancers.

# Question

What strategies have been used to successfully improve health outcomes and care experiences for Black women who have breast cancer and other common cancers?

# High-level summary of key findings

#### Research evidence

- We identified 26 evidence documents relevant to the question, of which we deemed 24 to be highly relevant and two to be of medium relevance.
- Most of the strategies and interventions we identified from the evidence were designed to educate Black women about the importance of screening for breast cancer and other common cancers.
- These screening-specific strategies were delivered in a variety of ways, including through educational community-based outreach programs, visual tools, mass media campaigns, a virtual health assistant-delivered intervention, and spiritual-based health messaging.
- Besides educational strategies, we also identified a case management intervention, two home-based self-screening
  interventions and screening prediction tools that resulted in improved access to cancer screening for Black
  women.
- In terms of strategies that focused on improving cancer diagnosis, treatment and survivorship for Black women, we identified a comprehensive multidisciplinary care program, an intervention that incorporated narratives from cancer survivors and predictive models that were used to forecast trends in future incidences of cancer.
- Considerations for developing and implementing strategies to improve cancer screening for Black women were also identified from the evidence and included concerns communicating with healthcare providers, language

barriers, religious beliefs, structural challenges associated with healthcare systems, access to health insurance, familial secrecy and past trauma and stress related to accessing healthcare.

#### Jurisdictional scan

- Our jurisdictional scan of experiences from Australia, New Zealand, the United Kingdom (U.K.), the United States (U.S.) and all Canadian provinces and territories identified strategies and programs that primarily focused on enhancing education for Black women about screening services for breast, cervical and colorectal cancers.
- These included the Face Your Health cervical cancer screening program and the NYC CONNECT patient navigation cancer screening program in the U.S., the Every Breast Counts program, Love & Nudes breast cancer campaign, and the Olive Branch of Hope program in Ontario, as well as the Annie Parker Foundation in Nova Scotia
- We also identified three programs in the U.K. that provide cancer-care support for cancer survivors through peer-to-peer support groups, events, podcasts, a YouTube series and other initiatives

#### Key informant interviews

- We interviewed 24 key informants who had experience providing, coordinating or supporting care for Black women with cancer in Ontario (e.g., family physicians, surgeons, researchers, community health centre representatives) and identified a number of strategies at the system, provider and community level that could address existing barriers and enhance the delivery of cancer care to Black women.
- Barriers identified by key informants were gaps in education and awareness of Black women around screening, limitations of the current breast cancer screening guidelines in Ontario, care access issues related to socioeconomic status and other sociodemographic factors, mistrust due to negative experiences of systemic racism within the healthcare system and providers, and lack of funding for targeted research and resources at the community level.
- System-level strategies recommended by key informants included: updating the process for Ontario's breast cancer screening eligibility to women, transgender and nonbinary people from age 40 for the general population and earlier for those who may be at higher risk; increasing opportunities for race-based research through targeted grants and other financial means; improving collaboration and information sharing between providers, researchers, decision-makers and organisations at all levels; and ensuring that Black people are represented in healthcare leadership roles and decision-making.
- Provider-level strategies recommended by key informants were mandatory cultural awareness training and
  education for healthcare providers to address any inherent racial biases, and a focused effort to increase the
  number of Black health and social services providers available to serve Black communities.
- Community-level strategies recommended by key informants included: increasing community-partnered and culturally tailored supports, education and awareness-raising events and campaigns for Black communities; increasing and allocating dedicated funding for community-level programs that facilitate education and care access to Black communities; increasing representation of Black people and other racialized groups from diverse backgrounds in cancer awareness media campaigns (particularly for breast cancer); and enabling easy access to wraparound social supports for those who need them.

# Framework to organize what we looked for

- Most common forms of cancer among Black women
  - o Breast
  - o Lung
  - o Colon
  - o Uterine

- o Cervical
- o Endometrial
- Components of the cancer-care continuum
  - o Screening
  - o Diagnosis
  - o Treatment
  - o Survivorship
  - o End-of-life care
- Features of how delivery arrangements are leveraged across the cancer-care continuum
  - o How strategies are designed to meet the needs of Black women, including availability of care, timely access to care, and culturally appropriate care
  - o By whom are the strategies delivered
  - o Where the strategies are delivered
  - o With what supports are the strategies delivered, including quality monitoring and improvement systems.
- Features of implementation strategies
  - o Consumer-targeted strategies (e.g., education of patients and caregivers)
  - o Provider-targeted strategies
- Impact of strategies
  - o Patient experiences
  - o Patient health- and population-health outcomes
  - o Costs
  - o Provider experiences
- Findings related to one or more equity-deserving groups from PROGRESS-Plus framework
  - o Place of residence
  - o Race/ethnicity/culture/language
  - o Occupation
  - o Gender/sex
  - o Religion
  - o Education
  - o Socio-economic status
  - Social capital
  - o (plus) Personal characteristics associated with discrimination and/or exclusion (e.g., age, disability), features of relationships (e.g., young caregivers) and time dependant relationships (e.g., recently discharged from hospital, released from prison)

# What we found

We identified 26 evidence documents relevant to the question, of which we deemed 24 to be highly relevant and two to be of medium relevance. The highly relevant evidence documents include:

- one evidence synthesis
- one protocol
- 22 primary studies

We outline in narrative form below our key findings related to the question from highly relevant evidence documents, jurisdictional scans and insights shared from key informants.

# **Key findings from highly relevant evidence sources**

## Screening

Educational strategies and interventions

We identified strategies and interventions specifically designed to inform and educate Black women about the importance of screening for breast cancer and other common cancers. All interventions that involved providing educational information on breast cancer screening were implemented in jurisdictions within the U.S. A visual tool described in one primary study that was developed to disseminate breast cancer information to African-American women living in rural and urban counties in South Carolina, U.S., was found to enhance the general awareness of participants about risk factors for breast cancer.(2) Another primary study that described a community-based educational outreach program for at-risk African-American women used survivor videos, patient/neighbourhood outreach programs and direct-mail campaigns to increase breast cancer awareness, affect timely care and diagnosis, and encourage mammogram registration. As a result of this intervention, some participants benefited from early breast cancer screening and diagnosis.(3)

# Box 1: Approach and supporting materials

We identified evidence addressing the question by searching HealthEvidence, Health Systems Evidence and PubMed to identify evidence syntheses, protocols for evidence syntheses and primary studies. All searches were conducted on 13 March 2023. The search strategies used are included in Appendix 1. We identified jurisdictional experiences by hand searching government and stakeholder websites for information relevant to the question from four countries (Australia, New Zealand, the U.K., the U.S.) as well as all Canadian provinces and territories.

In contrast to our rapid-evidence profiles, which provides an overview and insights from relevant documents, this rapid synthesis provides an in-depth understanding of the evidence.

We appraised the methodological quality of evidence syntheses that were deemed to be highly relevant using AMSTAR. Note that quality appraisal scores for evidence syntheses such as rapid syntheses/reviews are often lower because of the methodological shortcuts that need to be taken to accommodate compressed timeframes. AMSTAR rates overall quality on a scale of 0 to 11, where 11/11 represents an evidence synthesis of the highest quality. It is important to note that the AMSTAR tool was developed to assess evidence syntheses focused on clinical interventions, so not all criteria apply to evidence syntheses pertaining to delivery, financial or governance arrangements within health systems or to broader social systems.

This rapid synthesis was prepared in a 60-business-day timeline.

A separate appendix document includes:

- 1) methodological details (Appendix 1)
- 2) a summary table of evidence organized by the cancer-care continuum (Appendix 2)
- 3) a summary table and a more detailed table of experiences from other countries and Canadian provinces and territories (Appendix 3)
- 4) a summary table of barriers and strategies identified by key informants (Appendix 4)
- 5) questions and analysis framework for key informant interviews (Appendix 5)
- 6) findings from each evidence document, organized by document type, and sorted by relevance to the question (Appendix 6)
- 7) documents excluded at the final stages of reviewing (Appendix 7)

To address disparities in providing education to Black women about breast cancer, one primary study conducted in the U.S. highlighted the importance of using mass media, text messaging, smartphone apps and 'Black radio' as dissemination tools for health messages on breast cancer screening.(4) The study also emphasized that church-based interventions increased acceptability of receiving cancer education, and highlighted the importance of pastoral input and personal testimonies from members of the church community as useful tools to increase breast cancer awareness in Black communities. Recommendations for structuring health messaging in church and other spiritual-based interventions were provided in another U.S.-based primary study that examined important spiritual elements to include in breast cancer health communication.(5) The study suggested that the information should be structured by starting with the health message and trying to personalize the message through a spiritual lens, focusing on positive aspects to promote breast cancer screening.

We also identified interventions that promoted education for Black women on cervical cancer and colorectal cancer. The Community-based, HEalth literacy-focused intervention for Cervical Cancer group (CHECC-uP) was piloted in one primary study based in Baltimore, Maryland, U.S. to promote Pap testing among Black women living with HIV (human immunodeficiency virus).(6) The study found that the intervention, consisting of 30- to 60-minute individualized health literacy-focused education sessions, monthly phone counselling, and navigation assistance for completing a Pap test, was effective at improving health literacy and other psychosocial outcomes only at three months post-intervention; the trend was attenuated at six months. One primary study with a focus on colorectal cancer screening incorporated Black women from North Florida into the development process for a virtual health assistant (VHA)-delivered intervention that was designed to promote the use of fecal immunochemical testing (FIT) screening amongst Black women.(7) The study found that by using a user-centred design and adapting the content iteratively, improvements were seen overall in user perceptions and willingness of Black women to engage with the intervention.

Lastly, we identified two primary studies that described cancer screening interventions tailored for Black communities in Ontario, Canada. A <u>quality-improvement program implemented at TAIBU Community Health Centre (CHC)</u> in Toronto, Ontario that consisted of cancer screening education programs, a patient callback program (operated in the fall to coincide with influenza vaccinations), provider audits, and a mammography promotion day was found to be successful in increasing patient and healthcare providers participation in cancer screening from 2011 to 2018 for rates of breast, colorectal and cervical cancer screening.(8) Similarly, the "Ko-Pamoja" breast and cervical cancer screening program for Black women in Ontario was successful at increasing participants' awareness of cancer susceptibility and screening guidelines through the use of pre- and post-session questionnaires.(9)

Strategies and interventions to enhance access to cancer screening

Several of the interventions we identified from the evidence focused specifically on enhancing Black women's access to cancer screening. One primary study that described a <u>case management intervention designed to reduce barriers to breast cancer screening</u> and follow-up diagnosis appointments found that providing Black women living in Boston, Massachusetts with access to case managers who could refer them to social services based on their identified barriers, as well as support for navigating screening and making follow-up appointments led to an uptake in breast cancer screening.(10) However, changes in longitudinal patterns were limited by housing concerns and the lack of a regular provider. Another primary study we identified found that utilizing a 'choice' model of HPV self-sampling intervention that was distributed to African-American women in the Mississippi Delta displayed greater effectiveness, with a reduction in cervical cancer risk of 14.8% (as opposed to the 'standard of care,' which was 6.4%), and a cost-effectiveness that totalled \$62,720 every five years per year of life saved.(11)

We also identified a study that described a home-based endometrial cancer screening intervention that involved the use of a home-based tampon testing kit by women in Jacksonville, Florida.(12) The study noted that while many participants were accepting of a home sampling cancer screening method, concerns arose from the possible complexities and risks involved with this self-sampling intervention, particularly given that it was noted that many Black women reported lower comfort with tampons. These findings highlight the importance of developing cancer screening interventions that not only enhance access but also appeal to users' preferences to increase uptake.

#### Prediction tools used in cancer screening

Two of the primary studies we identified described prediction tools for breast cancer. In one study, an agent-based model (ABM) was used to simulate screening mammography, diagnostic resolution and the stage of cancer at diagnosis for 50- to 74-year-old African-American women in Chicago, Illinois.(13) Simulation results suggested that network navigation may have led up to a 13% increase in screening completion rate, a 7.8% increase in the rate of diagnostic resolution, and a 4.9% increase in early-stage diagnosis. The other study examined whether individualized breast cancer risk estimates as part of routine primary health care in medically underserved communities in Chicago were associated with an increase in the rate of mammography.(14) The study authors found that providing individualized breast cancer risk estimates was associated with increased use of mammography among women from racialized groups.

# Diagnosis, treatment and survivorship

The evidence we identified also provided key insights on breast cancer diagnosis, treatment and survivorship among Black women. In terms of diagnosis, multilevel methods and geospatial mapping were used in a primary study to determine whether the race and income versions of the neighbourhood Index of Concentration at the Extremes (ICE) metrics could identify trends in triple negative breast cancer (TNBC) disparities in New Castle County, Delaware, where there are elevated rates of TNBC.(15) The study found that women with TNBC were young, twice as likely to be Black and to present with late-stage cancer, and more likely to have Medicaid or no insurance. Women living in the most disadvantaged neighbourhoods were more likely to have higher rates of comorbidities that increased the odds of developing TNBC, highlighting the relationship between TNBC and socio-economic status.

Breast cancer treatment was the focus of a primary study on a comprehensive multidisciplinary care (cMDC) program conducted in southeast Michigan, U.S., that assessed the referral and use of genetic testing after a cMDC program for breast cancer treatment was implemented.(16) Racial disparities in the results of the study that included 431 newly diagnosed patients with invasive breast cancer (43.4% African American and 56.4% Caucasian) were also assessed. The study found that after the cMDC program was implemented, there was a significant increase in genetic referrals and in the attendance of participants at genetic testing appointments, but the overall rate of genetic referrals did not increase disproportionately based on race. Additionally, African Americans in this study were less likely to attend genetic testing appointments and more appropriate referrals were made for participants with private insurance.

In terms of survivorship, we found evidence that <u>narratives of African-American breast cancer survivors were used in an intervention</u> to determine what impact viewing survivor stories had on newly diagnosed non-metastatic breast cancer patients' quality of life.(17) Participants in the intervention group were asked to watch an interactive video program using 207 clips of stories (one to three minutes long) in addition to standard medical care. The results of the study indicated that the intervention had no significant impact on quality of life (QoL), depressive symptoms, or concerns of the participants about recurrence, but longer exposure to the intervention was associated with decline

in the three QoL subscales of emotional well-being, fatigue and role limitations due to physical health, as well as an increase in engagement of participants.

Lastly, <u>race/ethnicity-specific survival machine learning (ML) models</u> for Black and Hispanic women with breast cancer were compared in a primary study to a general ML model with all race data to assess their performance in forecasting future events.(18) The study found that the survival ML model, which allowed health professionals to identify high-risk cancer patients by learning patterns from high-dimensional data and complex feature interactions, outperformed the general model when predicting race/ethnicity-specific outcomes.

#### Considerations for developing and implementing strategies and interventions

Several studies, including the medium-quality evidence synthesis we found, provided a wide range of considerations for developing and implementing strategies and interventions that target Black women with breast cancer. The evidence synthesis described several barriers for women from Black, Asian and minority ethnic (BAME) backgrounds attending breast cancer screening, including decreased appreciation of preventive medicine, the stigma associated with cancer, the fears of marital consequences and lack of family support due to treatment, discomfort being examined by a male professional, and logistical factors (e.g., cost of attendance, time convenience, and distance).(19) Forming interprofessional relationships between BAME women and health professionals was identified as a facilitator to encourage screening. Additional barriers were identified in a primary study that considered the perceptions of Haitian patients on a breast cancer screening program in Québec that sends out mammogram referral letters.(20) The study highlighted that low levels of literacy, stress related to mammograms, and the importance of religious beliefs in Haitian culture are valuable factors to consider when creating screening referral letters for this specific population. Participants of the study suggested translating the words "breast," "mammogram" and "cancer" into Creole, a shorter referral letter using simpler, more appealing and accessible language, and communicating mammography and breast cancer screening programs on television and radio to improve the response of the Haitian patients to screening referral letters.

One primary study that assessed factors associated with adherence to the US National Comprehensive Cancer Networks' breast cancer screening guidelines by African-American church goers found that older age, having a personal diagnosis of cancer, and having health insurance and ideal patient-provider communication was associated with increased odds of screening adherence. (21) Another primary study that developed a culturally sensitive narrative intervention to promote genetic counselling for African-American women with hereditary breast cancer found that barriers associated with genetic counselling included a nearly universal misconception among participants that they would be told that they have breast cancer, structural challenges associated with healthcare systems (e.g., costs, complexity, discrimination), familial secrecy, and lack of trust and poor communication with providers. (22)

Trade-offs of screening strategies in Black women in the U.S. were compared in one study to those of white women using a race-specific simulation model, which found that the most efficient screening for Black women was biennial screening from ages 45-74, while the most equitable screening was from ages 40-74.(23) The study results suggest that Black women should consider initiating biennial screening for breast cancer at age 40 rather than age 50. Another unique study that explored ways to increase recruitment of Black women into a genetic breast cancer research study in Memphis, Tennessee, U.S., found that two major factors that contributed to successful recruitment were the development of partnerships with breast cancer advocates in the Memphis community and the incorporation of culturally sensitive educational workshops.(24)

Two primary studies identified considerations for developing cervical cancer screening interventions for African-American women, including barriers such as past trauma, apprehension regarding the administration and accuracy of self-test interventions, and prioritizing the well-being of children over themselves.(25) One of the studies also

found that a lack of a regular health provider, poor self-rated health, concerns communicating with providers and having less than a high school education had an impact on the recency of Pap smear screening. Insurance status was also identified as the key factor in timely follow up of abnormal results. (26)

Finally, the <u>study protocol</u> that we found aims to develop a community-based care coordination intervention for Black, non-Hispanic women in Boston who are at risk for delays in breast cancer care. (27) The intervention includes patient navigation services, shared patient registry and a web-based social determinants of health platform to identify and address barriers of care.

# Key findings from jurisdictional scans

Our jurisdictional scan of experiences from Australia, New Zealand, the U.K., and the U.S., and all Canadian provinces and territories yielded limited results. The majority of programs we found that had an impact on Black women with cancer focused on enhancing education for Black women about screening services for breast, cervical and colorectal cancers. The <u>US CDC has a cervical cancer screening program</u> called Face Your Health that was developed with input from African-American community health workers (CHWs) and program administrators. The program provides educational resources that are grounded in behaviour-change theories (e.g., learning sessions, materials, visual aids) and are offered at different reading skill levels. CHWs provide learning sessions that can be adapted based on the number of participants, setting and level of interaction. <a href="NYC CONNECT">NYC CONNECT</a>, a patient navigation program in New York, also helps to increase screening of breast cervical, and colorectal cancers by using trained patient navigators to help people overcome health-system barriers to cancer-care access.

Within Canada, a resource hub in Ontario called <u>Every Breast Counts</u> provides evidence-based cancer information for breast cancer primarily, but also for cervical and uterine cancers. Black-centred resources can be located on the project's webpage, and the resource hub offers many community events, such as <u>Breast Health for Black Women</u>, <u>Breast and Cervical Cancer Screening for Black Women</u>, and <u>Best Health for Black Women</u> in partnership with <u>the Canadian Cancer Society</u>. These events have generated positive feedback from participants who have expressed the need for more events.

In January 2023, the Love & Nudes lingeric company announced a breast cancer campaign that was centred around including a bra insert in multiple skin tones that had been made to mimic how a cancerous lump may look on a person of colour. The Toronto-based company collaborated with a surgical oncologist in Toronto to design the insert for their breast cancer campaign. We also found that the Annie Parker Foundation in Nova Scotia provides information on a website about breast cancer, healthy lifestyles and places to look for breast cancer screening, and Olive Branch of Hope in Toronto supports Black women living with breast cancer through support groups (e.g., informative and uplifting meetings), educational seminars (e.g., health and nutrition topics every three months), faith-based supports, and conversations with community ambassadors. The program's webpage includes resource articles on a variety of subject areas, and the program also hosts a number of events for the community, including Sowing the Seeds: Fundraising Gala and Lymphedema: After Breast Cancer Treatment.

Finally, we found three programs in the U.K. that provide cancer-care support for cancer survivors, namely <u>Black Women Rising cancer support program</u>, <u>Cancer Black Care</u>, and <u>NHS England YouTube series</u>. Both Black Women Rising cancer support program and Cancer Black Care facilitate peer-to-peer support groups, events, podcasts and other initiatives to support, educate and bring opportunities for Black women. NHS England's YouTube series consists of <u>a set of three videos</u> to help providers and commissioners understand how <u>perceived bias</u>, <u>poor communication</u> and <u>dignity issues</u> can worsen patient experience for Black and minority ethnic cancer patients.

# **Key findings from key informant interviews**

We organized the findings from the 24 key informants interviewed by strategies that may address barriers at the system, provider and community level. The strategies and barriers identified by key informants are described below. See Appendix 4 for additional insights from key informants, including illustrative quotes.

#### System-level strategies

Engage in guideline development and update the process for breast cancer screening eligibility to include women, transgender and nonbinary people from age 40 for the general population and earlier for those who may be at higher risk

The Ontario Breast Screening Program (OBSP) currently specifies that women, transgender and nonbinary people ages 50 to 74 are eligible for breast screening through the OBSP. It also specifies that people outside of the OBSP screening population who meet High Risk OBSP requirements can be screened through the OBSP if they have a referral from their primary-care provider and meet other eligibility criteria. Key informants, however, highlighted that they have heard from Black women that many primary-care providers hold fast to the current screening eligibility age of 50 and refuse to issue referrals for breast cancer screening to people younger than age 50 even though there is evidence that certain populations, specifically Black women, are genetically predisposed to more aggressive forms of cancer at a younger age (as early as their 20s) and often at later disease stages due to delayed screening. (28)

The <u>United States Preventative Task Force</u> recommended recently that the eligible age for biennial screening mammography be lowered from age 50 to 40, and the <u>American Cancer Society</u> has recommended that women start getting mammograms at age 40 since 2003. Most key informants fully supported updating the breast cancer screening eligibility to include women from age 40 and younger for high-risk groups, in alignment with increasing expert recommendations.

Some key informants also called for targeted protocols, guidelines, or education and training for primary-care providers to reinforce the changes to the recommendations around screening and treatment for groups who may be at increased risk of cancer or have poor health outcomes after a cancer diagnosis (due to family history or sociodemographic factors), including Black women.

Increase opportunities for race-based research through targeted grants and other financial means

Most key informants identified that the lack of race- or ethnicity-based data in Canada presents a significant barrier to having evidence that can justify the need for policy changes that can address the needs of Black women with cancer. Several key informants mentioned that they have had to resort to using race-based data from the United States to inform care provision for Black women with cancer, even though they know that its application is limited by differences in socio-demographic and cultural factors between Black Canadians and Black Americans. It was recommended that more opportunities be provided to researchers to collect race-based data through grants and other financial means.

Race-based data can be used to develop predictive tools to identify high-risk cancer patients, as identified previously by the evidence, and to better understand the needs of Black women with cancer in Canada. For example, a narrative interview study being conducted by Dr. Andrea Covelli was mentioned by a few key informants as an example of valuable research that can be conducted to learn more about the needs of Black women with cancer and how to address them. Through qualitative interviews with patients, Dr. Covelli's study aims to broaden our understanding in the Canadian context of how Black women experience breast cancer, to improve their care.

Improve collaboration and information sharing between providers, researchers, decision-makers and organisations at all levels

There was a strong interest expressed by key informants in collaboration and knowledge sharing amongst healthcare providers, researchers, advocates and others working towards and interested in improving healthcare for Black women with cancer. A few key informants elaborated on the siloed nature of the health system that makes care coordination and case management of cancer patients challenging. Key informants also discussed the complexity of navigating the health system and how this makes it difficult for many people to access the care they need, especially those with lower literacy levels or less exposure to the health system (e.g., immigrants and newcomers). To address these barriers, key informants recommended that more efforts be made to improve information sharing amongst healthcare providers using a patient-centred approach. In alignment with the literature, they also recommended increasing the number of health system navigators at the community-level to support patients in completing health forms, understanding and coordinating their care, and connecting with additional resources.

Ensure that Black people are represented in healthcare leadership roles and decision-making

Many key informants pointed to the lack of representation at all leadership and decision-making levels in healthcare. One key informant indicated that, "We have to have representation across the healthcare system at all levels; not just at front-line staff, but also at senior leadership at the hospitals and the Ministry of Health. When there are decision-makers around the table, you have to have a variety of perspectives." Key informants highlighted that having Black women with cancer and/or their representatives at the table when policy changes are proposed that will impact them is crucial for understanding and being informed about the implications of policy decisions before they are made.

#### Provider-level strategies

Mandatory cultural awareness training and education for healthcare providers to address any inherent biases

Key informants noted that they are aware of and on occasion have experienced anti-Black racism and sexism from healthcare providers when accessing care. Consequently, key informants indicated that in their experience, many Black people avoid interacting with the health system. One key informant, a physician, described how she often meets Black patients labelled by colleagues as 'poor historians' – a term used by physicians to describe a person who finds it difficult to explain their health history in a linear way – and finds that they are not 'poor historians' but rather come from a different culture or background and communicate in a way that Western providers are not trained to recognize. To address barriers like these, key informants recommended that anti-Black racism and cultural-awareness training be mandated in training and continuing education programs for all healthcare professionals as well as within healthcare organizations.

Focused effort to increase the number of Black health and social services providers available to serve Black communities

Several key informants emphasized that building trust in healthcare providers is crucial to improving access to care for Black women. They highlighted that there is an inherent trust and at times a sense of relief amongst Black people when they see and are cared for by healthcare providers who look like them. One key informant who is a Black physician described being sought out for a second opinion by a Black woman who had received a cancer diagnosis because she felt like her particular situation would be better understood by a Black physician. A few key informants recommended building Black provider capacity by supporting programs that aim to increase enrollment of Black students in medical school, such as the <u>University of Toronto's Black Student Application Program</u> and <u>Queen's University's Accelerated Route to Medical School</u>. They also recommended that healthcare organizations enhance efforts to hire more Black healthcare staff to increase representation within the health system. While

discussing the importance of these strategies, one key informant cautioned that Black physicians cannot exclusively be relied on to provide care to Black communities and re-emphasized the importance of cultural competency training for all providers, as previously mentioned.

## Community-level strategies

Increase the availability, use and sharing of culturally tailored supports, community-partnered education and awareness-raising events and campaigns for Black communities

In alignment with findings from the evidence and our jurisdictional scan, education around cancer screening was highlighted by most key informants as a key strategy to improve cancer screening uptake among Black women with cancer. Most key informants working at the community level emphasized the important role that community health centres (CHCs) play in bridging gaps in the delivery of care and building trust within communities. Key informants who work at CHCs pointed out that the key to implementing successful programs is meeting people where they are by partnering with the communities they serve to design and improve their programs so that they can effectively meet the needs of communities. Several key informants described highly successful 'field trips' to mammogram units at hospitals and 'screening days' where free breakfast and transportation were provided, as well as goodie bags and grocery gift cards to incentivize community members to attend. Consistent with the evidence, outreach at community locations such as churches, mosques, hair salons, schools and malls was also mentioned by many key informants as an important strategy for meeting people where they are and building trust through allied community partners. One key informant also highlighted a culturally tailored video called Feel Up Yuh Breast by Dr. Michael Abrahams who used rhyming, humour, and clear language to deliver a message in Patois to Jamaican women about the importance of breast self-examination. This was viewed as an excellent example of what culturally tailored communication can look like.

Several strategies found in the evidence and jurisdictional scan were also mentioned by key informants as examples of successful initiatives, including Best Health for Black Women educational webinars about breast and gynecological health and wellness, the bra inserts by Love & Nudes company designed to provide education on what a cancerous lump may look like on a person of colour, the online resource hub Every Breast Counts, and CHC-partnered Breast & Cervical Cancer Screening for Black Women events that offer accessible screening. The value of The Olive Branch of Hope was also frequently highlighted as an effective grassroots organization providing support to Black women with breast cancer through its community-based support groups and education seminars. One key informant mentioned Uncovered: A Breast Recognition Project launched in 2020 by breast cancer patient Michele Audoin to amplify the voices and experiences of Black women with breast cancer to counter misinformation and increase awareness and education for both patients and providers. The project features video and written accounts of Black, Indigenous, and People of Colour (BIPOC) women sharing their stories, with powerful imagery of women showing and discussing their mastectomies. At the centre of all these initiatives is person-centred care that considers the emotional aspects of cancer screening and connects Black people to additional supports.

Several other key informants discussed the effectiveness of small group conversations in community settings with peers and healthcare professionals where Black women can ask questions in a comfortable and non-judgmental environment. In alignment with evidence-scan findings, a few key informants noted that discomfort discussing screening or being examined by a male provider is a barrier for some women. They recommended education for women on how to have these discussions and advocate for themselves.

Many key informants felt as though cancer care in its entirety is centred around white perspectives and experiences, from screening initiatives to fundraising events to palliative care. Key informants identified the survivorship realm

as particularly exclusionary of Black people, lacking culturally tailored resources such as diverse wig colours and textures or information about breast reconstruction (e.g., scarring and keloids) and how to access it. They emphasized the need to make more culturally tailored resources available for Black women to ensure that their needs are being addressed.

Lastly, most key informants expressed the desire to collaborate with each other and share ideas and experiences of strategies that are in progress or have worked to support Black women with cancer. They emphasized the need to synthesize and share developments in the types of supports described above so that all stakeholders involved are made aware of the work that has been done and can support each other more efficiently with ongoing work in the future.

Increase and allocate dedicated funding for community-level programs that facilitate education and care access to Black communities

Many key informants highlighted funding as key to implementing, sustaining and expanding effective programs to educate and increase access to care services for Black communities. While there were reports of successfully implemented community programs, a few key informants pointed out that the work of implementing these programs is not sustainable due to a lack of consistent funding. A CHC representative, in particular, emphasized how much their CHC is in need of an increase in resources and how investment in CHC programs and similar health promotion initiatives that focus on racialized communities would benefit the government financially in the longer term by reducing the volume of people utilizing the primary-care system. Equitable allocation of funding from the provincial government and Canadian funding organizations to initiatives that support Black women with cancer and to Black communities in general was strongly recommended.

Increase representation of Black people and other racialized groups from diverse backgrounds in cancer awareness media campaigns

Key informants also highlighted a lack of representation of Black women in cancer media as a significant barrier, particularly in breast cancer screening, awareness-raising and fundraising campaigns, and online media. They pointed out that many Black women believe breast cancer is "a white woman's disease" because they have not seen themselves represented in cancer awareness campaigns. Key informants called for increasing representation in cancer media, both online and in-print, of Black women and people from diverse backgrounds and identities, including nonbinary, transgender, queer and disabled Black people. One key informant recommended specifically that inclusive language is needed in cancer awareness and screening media for individuals who have undergone chest masculinization, including nonbinary and transgender people, as it is highly likely that they will have breast tissue remaining that could become cancerous. Complementary provider education and training was also recommended. Lastly, a breast reconstructive surgeon we interviewed highlighted the need for inclusivity of Black people in breast reconstruction before and after images so that prospective patients can see what reconstruction looks like on Black skin and address concerns about scarring.

Enable easy access to wraparound social supports for those who need them

All key informants identified that Black women face barriers in accessing healthcare because of socioeconomic issues. One barrier brought up on several occasions was a lack of paid sick days or benefits to provide compensation when time must be taken off from work to attend cancer-care appointments. Another barrier highlighted was challenges of immigrants and newcomers to Canada with navigating the unfamiliar Canadian health system, compounded by the need for self-advocacy at times to access care. One key informant pointed out that depending on their country of origin, some newcomers expect that they would have to pay for healthcare and are unaware of how to obtain a provincial health card and access care services that are provided free of charge. There is also the issue of a lack of available family physicians in the province, which key informants pointed out is a

significant concern for racialized communities. To address these barriers, some CHCs have funding to provide care to uninsured individuals and have also partnered with hospitals to reserve a handful of time slots for women in their communities access some services without a physician referral. Health, social services and peer navigators may also be available to help community members manage their cancer care and access social services and additional resources. Most key informants emphasised the need for more accessible wraparound social supports like these to address the social determinants of health for Black people.

In alignment with findings from the synthesis of evidence, several key informants also discussed how Black women's role in their family and community sometimes takes priority over their own physical health and that this can cause them to delay or avoid getting cancer screening or accessing care services. Key informants called for social supports and resources for Black women that will emphasize to them the need to prioritize their health. One suggested strategy was to develop a respite centre where women can retreat to for the short-term for post-treatment recovery and care. Supports would be put in place to ensure that women's familial responsibilities are taken care of while they are recovering. Through strategies like these, Black women would be able to have the supports they need to improve their care access and experiences.

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