

HE-24 Breast Cancer Survey & Focus Group Data



Canadian
Cancer
Society

- People with lived experience of breast cancer (patients, survivors, thrivers, caregivers, family members or friends) were invited to participate in a survey and subsequent focus group on research priorities for breast cancer research. There were 6 groups of participants:
 1. [Adolescents and Young Adults \(AYA\)](#)
 2. [Black](#)
 3. [Indigenous*](#)
 4. [Male Breast Cancer](#)
 5. [Metastatic](#)
 6. [Rural and Remote](#)
- Conducted a qualitative analysis of survey and focus group results, and categorized findings by 5 major themes (prevention, screening and detection, treatment, survivorship, other).
- This document lists the common priorities seen across all groups, and the major priorities for each group



Frequent Themes

- Gaps in the data landscape
 - lack of information/data (specific to groups of people) about breast cancer across the cancer care continuum, i.e. not only at treatment stage
 - lack of research on causation factors, side effects, treatments, etc.
 - lack of patient-reported data (outcomes, experiences, etc.)
 - leads to a lack of awareness
- Improvements in onboarding (process after diagnosis) - increased access/communications, resources should be tailored to the patient
 - information (specific to the person whether they are black, male, living in a remote area, etc.)
 - tailored resources
 - culturally-specific people/groups (social worker, psychologist, support group)
 - psychosocial support (what does diagnosis mean for you/your family)
 - treatments/next steps
- Improvements in screening and treatment pathways
 - broaden screening guidelines, develop and use new screening modalities (e.g. genetic testing, ultrasound, PET scans)
 - better access to treatments (i.e., remove barriers to surgical options) and clinical trials



Frequent Themes

- Lack of trust between healthcare worker (HCW) and patient across the cancer care continuum - patients expressed wanting to be treated with respect/as a person
 - delayed diagnosis due to dismissal of concerns, racial bias/stereotypes
 - failure to have sufficient and/or relevant information/data
 - lack of transparency; failure to communicate information (about treatments, clinical trials) → can lead to compromised patient-informed consent
 - lack of continued support/communication post-treatment - mental health supports, quality of life concerns, supplemental services, support groups
- HCW education/training – person-centric approach to healthcare
 - HCWs lack knowledge/support AND are a barrier to knowledge/support/treatment
 - self-advocacy is an unnecessary burden
 - e.g., address stigma/misinformation within cultural groups, directing to relevant support groups, demonstrate empathy/communication/lack of bias in practice, recognize/communicate symptoms specific to POC (person of colour)

- Each topic (prevention, screening and detection, treatment, survivorship) was discussed extensively (i.e., changes in policy/practice are required **across the cancer care continuum**, from risk reduction to post-treatment)
 - Examples:
 - awareness and communication on modifiable risk factors (alcohol, exercise, nutrition), environmental factors, etc. (e.g., education in schools, social media campaigns)
 - alternate methods for detection, update screening criteria to allow earlier screening for breast cancer, awareness and implementation of self exams
 - more research on treatment, more treatment options (e.g., take-home treatments), supportive/supplemental care (e.g., nurse navigator, counsellor, etc.)
 - fertility support
 - continued medical team access
 - mental health supports
 - self-advocacy resources and supports

Priorities: Black

- Emphasis on **healthcare worker (HCW) education/training** (lack of trust between patients + HCWs)
 - Examples:
 - dismissal of Black people's symptoms (racism, stereotypes, bias)
 - lack of diversity in medical training (e.g., recognizing/communicating symptoms specific to Black people/skin, ethno-specific data)
 - lack of respect for patient's wishes; lack of patient-informed consent
 - patients reporting experiences in which their HCW failed to demonstrate empathy, sensitivity, respect, communication
- Increased need for self-advocacy – unnecessary burden
 - many patients don't know how to or don't have the resources to learn how to self-advocate
 - self-advocacy efforts are dismissed by HCWs
- Need for changes in standardized care in hospitals – HCWs should provide information/diagnoses/treatments tailored to Black people (culturally responsive approach)
- Need for supplemental services to ensure support across the cancer care continuum (e.g., Black support groups)

Prevention/Risk Reduction

- Culturally-sensitive research and education on modifiable risk factors (diet, exercise and awareness of risk factors in schools; access to healthy food in remote communities)
- Consider indirect prevention strategies (e.g., access to a primary care provider and the effect of breast feeding)

Screening and Detection

- Research on mobile breast screening clinics and uptake, accessibility for remote communities and young people
- Alternate methods of detection (e.g., development of blood tests for breast cancer screening)
- The impact of earlier screening and more frequent screening for those with family history
- More research on self exams or physician done annual breast exams

Treatment

- Research on system changes so that treatment can be closer to home and travel is reduced; reduce wait times, consider treatments that reduce travel (e.g., oral)
- Supports during treatment (e.g., financial)
- More communication on side effects of treatment and availability of nurse navigators

Survivorship

- Continued follow ups with the medical team (after discharge, on survivorship and quality of life)
- Reducing the risk of recurrence and optimizing recovery
- Support groups (including counselling) for Indigenous people, in rural areas, and in other languages than English and French on outcomes

Other

- Impact of cancer on community, workforce, caregivers (family and spouses)

Priorities: Male Breast Cancer

- Emphasis on **psychosocial support** for males with breast cancer
 - Feelings of isolation and anxiety because the system is tailored towards women (e.g., going to a women's health center for a mammogram)
 - Lack of information and resources, treatment options, mental health support for males with breast cancer
 - Reliance on supplemental services as treatment/quality of life options (e.g. music therapy for pain relief, creative outlets like writing to deal with side effects/grief, sports as a preventative measure for recurrence/side effects)
 - Need for advocacy efforts towards male breast cancer awareness (remove pink-washing, reduce the stigma)



Priorities: Metastatic

- Emphasis on lack of **research/information** about metastatic breast cancer
 - Examples
 - causation / risk factors / environmental exposures
 - mechanisms of metastatic breast cancer – progression, mortality, demographics, standardized staging
 - pregnancy and (metastatic) breast cancer (e.g., hormonal triggers)
 - lobular breast cancer (detection and treatment)
 - triple-negative breast cancer (treatment)
 - treatment options with curative intent
 - statistics / data / awareness
 - number and accessibility of clinical trials for genomic testing
 - Adolescents & young adults (AYA) and palliative care
 - Patient care/experience can be hindered by healthcare workers' (HCWs) lack of knowledge/understanding about:
 - resources (onboarding process after diagnosis, tailored supports)
 - treatment options (patients are not informed about clinical trials, palliative care)
 - diagnosis (concerns are dismissed, alternate methods of diagnosis for hard-to-image cancers)
 - Need for changes in standardized care (e.g., resource sharing, cross-care communication between hospitals, patient portals for patient-reported outcomes) & HCW re-education to improve patient-informed consent

Priorities: Rural and Remote

- Emphasis on lack of **accessibility** (to information, resources, primary care, treatments, financial support, etc.)
 - Examples:
 - access to primary care
 - mobile units for screening/detection
 - improved treatment pathways (e.g., reduced wait times, oral therapies, treatments closer to home, linked surgery and chemo/radiation centers)
 - continued medical team access during and post treatment
 - More/better knowledge and accessibility could lead to
 - increased compliance, risk-reducing/health seeking behaviors
 - earlier detection
 - better cancer outcomes
 - fewer side effects
 - better quality of life
 - Policy/practice changes around these issues could lead to an improved cancer care continuum for patients living in rural and remote areas