

## Screening for breast cancer

This position statement aims to ensure a state-wide consistent approach to breast cancer screening, to increase program participation with BreastScreen, to improve the participant experience, and support health equity in access to and outcomes from breast cancer screening with regard to Aboriginal and/or Torres Strait Islander women.

This statement outlines the following considerations:

- The context of breast cancer screening for Aboriginal and Torres Strait Islander women and people
- Opportunities to enhance Australia's breast cancer screening program
- Risks associated with the breast cancer screening program; and
- Recommendations towards health equity in breast cancer screening of Aboriginal and/or Torres Strait Islander women.

### Context

The mortality rate from breast cancer for Aboriginal and/or Torres Strait Islander women is higher than non-Aboriginal women, with Aboriginal women 1.2 times more likely to die from the disease.<sup>1</sup> Preventable causes related to delayed diagnosis and treatment are substantial contributors, with only two in five Aboriginal and Torres Strait Islander women participating in the BreastScreen Australia program.<sup>1</sup> This may explain why the incidence of breast cancer is lower in Aboriginal women compared with non-Indigenous women.<sup>1</sup>

Aboriginal and Torres Strait Islander women are also more likely to be diagnosed with breast cancer at a younger age, and significantly more likely to reside in socioeconomically disadvantaged or geographically remote areas than other Australian women.<sup>2</sup> *The BreastScreen Australia monitoring report 2023* discussed decreased opportunities to screen for Aboriginal and Torres Strait Islander women being the likely cause behind the lower participation rates, as well as a level of under-reporting of Indigenous status.<sup>1</sup>

A 2018 AIHW report found that breast cancers detected through BreastScreen Australia had a 54-63% lower risk of causing death than breast cancers diagnosed in women who had never screened through BreastScreen Australia<sup>3</sup> so increasing uptake of breast screening in Aboriginal and Torres Strait Islander women would reduce illness and death from breast cancer. To do so, requires investigation into the barriers faced by Aboriginal and Torres Strait Islander women, and co-designed strategies to overcome these.

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<sup>1</sup> Australian Institute of Health and Welfare (2023) BreastScreen Australia monitoring report 2023, catalogue number CAN 155, AIHW, Australian Government. Available from: <https://www.aihw.gov.au/reports/cancer-screening/breastscreen-australia-monitoring-report-2023/summary>

<sup>2</sup> Order D, Webster F, Zorbas H, Sinclair S. Breast Screening and Breast Cancer Survival in Aboriginal and Torres Strait Islander Women of Australia. *Asian Pac J Cancer Prev.* 2012;13(1):147-55. Doi:10.7314/apjcp.2012.13.1.147. Available from: <https://pubmed.ncbi.nlm.nih.gov/22502658/>

<sup>3</sup> Australian Institute of Health and Welfare 2018. Analysis of breast cancer outcomes and screening behaviour for BreastScreen Australia. Cancer series no. 113. Cat. no. CAN 118. Canberra: AIHW. Available from: <https://www.aihw.gov.au/reports/cancer-screening/breastcancer-outcomes-screening-behaviour-programs/summary>

## Broader policy guidance

The Human Rights Act (Qld) 2019 Section 37 outlines that every person has a right to access health services without discrimination.<sup>4</sup> Regionality and Indigenous status should not play a role in access to breast cancer screening services, but as demonstrated above, still continues today.

The first socio-economic target of the National Agreement on Closing the Gap aims to close the gap in life expectancy within a generation, by 2031.<sup>5</sup> The literature demonstrates how breast cancer contributes to this gap in life expectancy between Aboriginal and Torres Strait Islander women and non-Indigenous women. Formal partnerships with Aboriginal community-controlled health organisations (ACCHOs) and building the community-controlled health sector in the area of breast cancer screening address the first two priority reforms from this National Agreement and contribute to putting this target back on track.

Any local Health and Hospital Service (HHS) or Queensland Health related action plans should be linked to Health Equity Strategy efforts required under the *Making Tracks Together- Queensland's Aboriginal and Torres Strait Islander Health Equity Framework*.<sup>6</sup> At a State-wide level, a co-designed implementation plan for a health equity strategy with QAIHC, could support health equity and improve Aboriginal and Torres Strait Islander outcomes in regards to breast cancer awareness, screening and treatment as well as reducing institutionalised or systemic racism within the Queensland health system that may foster disparities in access to health services.

## Barriers to screening

A Queensland report conducted over nine months during 1998-1999 looked at the user experience of 101 Aboriginal and Torres Strait Islander women, majority aged over 40 years, at BreastScreen Australia services.<sup>7</sup> Participants were recruited from urban (Brisbane, Sunshine Coast), rural (Cherbourg and Cunnamulla), and remote settings (Mt Isa, Cairns, Weipa, Kowanyama, Aurukun and Cloncurry). It demonstrated women were generally satisfied, with pleasant staff and a clear explanation of the screening process. This was emulated in the feedback received from several QAIHC members services consulted in 2024. However, there were issues around location of mobile services as some services deemed them to be poorly accessible for those who did not have access to public or private transport. Issues around location seem to have largely improved over the years with more mobile vans, and assistance with transport to centralised clinics, but infrequent visits by mobile vans to some regions still need to be addressed.

Another identified barrier was the use of a fixed appointment system with a preference for a 'drop-in' service. Women in rural communities, felt particularly 'safe' and at ease when the screening services took place in an ACCHO with the use of Aboriginal and Torres Strait Islander health workers.<sup>7</sup>

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<sup>4</sup> Queensland Government. Human Rights Act 2019.

<sup>5</sup> Coalition of Aboriginal and Torres Strait Islander Peak Organisations and Australian Government. National Agreement on Closing the Gap. July 2020.

<sup>6</sup> Queensland Health. Making Tracks Together - Queensland's Aboriginal and Torres Strait Islander Health Equity Framework. Available from: <https://www.health.qld.gov.au/public-health/groups/atsihealth/making-tracks-together-queenslands-atsi-health-equity-framework>

<sup>7</sup> McMichael C, Kirk M, Manderson L, Hoban E, Potts H. Indigenous women's perceptions of breast cancer diagnosis and treatment in Queensland. Aust N Z J Public Health. 2000 Oct;24(5):515-9. Doi: 10.1111/j.1467-842x.2000.tb00502.x. Available from: <https://pubmed.ncbi.nlm.nih.gov/11109689/>

QAIHC member services have not reported a large uptake in their patients seeking breast cancer screening outside of BreastScreen Australia. One service reported that some patients were seeking breast cancer screening outside of BreastScreen Australia when the mobile vans did not visit their region annually in order to aid timely diagnosis.

The main barriers to breast cancer screening appear to be due to ease of access, beliefs around health, and the quality of care.

Ease of logistical access is a particular problem in remote areas due to inaccessible roads, increased transport and accommodation costs, separation from families due to need to travel, and lack of choice of service.<sup>8,9</sup> One service reported the mobile BreastScreen Australia bus only visits its region every two years so patients sometimes need to travel more than 60 kilometres to the location of screening buses that visit annually. Other services have reported improvements in accessing BreastScreen mobile vans, with the local ACCHOs assisting with transport if required. They also reported positive communication with BreastScreen Australia in organising community breast screening days.

Varying beliefs around health can influence uptake of screening such as previous unpleasant experiences with breast cancer screening services or hearing about other's unpleasant past experiences.<sup>10</sup> Competing health and life priorities, and lack of knowledge about screening and 'shame' or fear related to breast examination or screening continues today.<sup>7,11,12</sup> Services report that regardless of the health promotion resources, the 'shame' or fear factor continues to play a role in the reduced uptake of screening in Aboriginal and Torres Strait Islander women, but this may vary across culturally diverse Aboriginal peoples and Torres Strait Islander peoples.

Services also believe that increased education to clinical staff about breast cancer screening would help promote breast screening services and provide better advice to patients.

A lack of cultural awareness or safety at breast cancer screening services, as well as historical apprehension about health services due to after-effects of colonisation and intergenerational trauma are other barriers to consider.<sup>9,10</sup>

Finally, health programs using a holistic approach to screening are particularly important to Aboriginal and Torres Strait Islander women because healthcare should not focus exclusively on one disease.<sup>7</sup> This is consistent with the comprehensive model of care adopted by ACCHOs and considered best practice primary health care.

<sup>8</sup> Byers L, Michell K, McCullough K. Awareness, acceptability and access to screening mammography for remote Aboriginal women. *Health Promot J Austr.* 2018 Dec;29(3):366-367. Doi: 10.1002/hpja.40. Available from: <https://ro.ecu.edu.au/ecuworkspost2013/5513/>

<sup>9</sup> Campbell J, Kurnoth P. Well women making a difference – evaluation report and program guide. Northern Territory Dept of Health and Community Services. 2000 Apr. Available from: <https://digitallibrary.health.nt.gov.au/prodjspui/handle/10137/8496>

<sup>10</sup> Hedges S, Davidson M, Forrester S, Casey A, Pridmore V, Cooper A et al. A Breast Screening Shawl to Help Aboriginal Women Feel More Comfortable and Culturally Safe. *J Glob Onc.* 2018 Sept 28;4(20). Doi: 10.1200/jgo.18.11200. Available from: <https://ascopubs.org/doi/abs/10.1200/jgo.18.11200>

<sup>11</sup> Christie V, Green D, Amin J, Pyke C, Littlejohn K, Skinner J et al. What Is the Evidence Globally for Culturally Safe Strategies to Improve Breast Cancer Outcomes for Indigenous Women in High Income Countries? A Systematic Review. *Int J Environ Res Public Health.* 2021 Jun; 18(11):6073. Doi: 10.3390/ijerph18116073. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8200222/>

<sup>12</sup> Pilkington L, Haigh M, Durey A, Katzenellenbogen J, Thompson S. Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. *BMC Public Health.* 2017 Sept 11;17(1):697. Doi: 10.1186/x12889-017-4701-1. Available from: <https://pubmed.ncbi.nlm.nih.gov/28893225/>

## Opportunities

These barriers can be addressed by ongoing collaboration and formal partnerships with ACCHOs and their peak body, to improve cultural and logistical accessibility of breast cancer screening services.

### Collaboration with ACCHOs at local level

To make breast screening services more effective, facilitating this collaboration and partnership with ACCHOs can take many forms.

1. Sharing information (e.g. visit and location schedules that can be tailored to suit services)
2. Mutual acceptance of interdependence (one cannot achieve the same outcome alone as could be achieved together)
3. Sharing of resources to support mutually agreed actions
4. Agreements with clear roles and responsibilities of each partner to ensure trust and respect.

These relationships with ACCHOs require investment in human resources and in relationship building to develop tailored breast cancer screening services and appropriate and more effective health promotion activity. Such investments in breast screening service catchment areas have the potential to substantially increase the participation rates of Aboriginal and Torres Strait Islander women.

Following a cancer diagnosis, Aboriginal and Torres Strait Islander people visited their primary health service nearly six times a year. The frequency of visits was higher in remote areas, and in those socioeconomically disadvantaged patients.<sup>13</sup> This highlights the importance of forming formal partnerships and linking in early with their primary health care providers, particularly ACCHOs.

There is a growing body of evidence surrounding different strategies to increase breast cancer screening among Aboriginal and Torres Strait Islander women with the highest success where there is collaboration with ACCHOs.<sup>11,14,15</sup> The strategies that focus on resourcing community-led initiatives to raise awareness, involve Aboriginal and Torres Strait Islander health workers and link with primary health care services appear to facilitate an increase in uptake.<sup>11</sup>

A systematic review and thematic analysis of 15 studies indicated that culture makes a positive difference to improving outcomes for Aboriginal and Torres Strait Islander women with breast cancer and requires strong community leadership and governance at all stages. The concepts that prevailed in their review were “community participation and governance at all stages”, and “incorporation of culture in research design”.<sup>11</sup> This can be achieved by involving Aboriginal and Torres Strait Islander community representatives (through ACCHOs) at early stages of external program design (e.g. breast cancer screening service program delivery)

<sup>13</sup> Valery P, Bernardes C, de Witt A, Martin J, Walpole E, Garvey G et al. Patterns of primary health care service use of Indigenous Australians diagnosed with cancer. *Support Care Cancer*. 2020 Jan;28(1):317-327. Doi: 10.1007/s00520-019-04821-1. Epub 2019 May 2. Available from: <https://pubmed.ncbi.nlm.nih.gov/31049670/>

<sup>14</sup> Christie V, Rice M, Dracakis J, Green D, Amin J, Littlejohn K et al. Improving breast cancer outcomes for Aboriginal women: a mixed-methods study protocol. *BMJ Open*. 2022;12(1):e048003. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8788241/>

<sup>15</sup> Reath J, Carey M. Breast and cervical cancer in indigenous women-overcoming barriers to early detection. *Aust Fam Physician*. 2008 Mar;37(3):178-82. Available from: <https://pubmed.ncbi.nlm.nih.gov/18345371/>

to ensure the Aboriginal and Torres Strait Islander community has ownership over the program, and it is tailored to meet the needs of their culture and region.

Ongoing quantitative and qualitative monitoring of uptake of breast screening services in Aboriginal and Torres Strait Islander women is important. Appropriate patient experience measures need to be supported. Evaluation reports shared with the ACCHO sector can foster continuous quality improvement.

## Collaboration with ACCHOs at state level

At a state level, collaboration between peak bodies to enable action plans and evaluation frameworks to underpin these investments should be supported with QAIHC.

QAIHC understands that at a state-wide level, there is limited engagements between ACCHOs and the BreastScreen program in Queensland (BSQ). The local engagement is dependent on Hospital and Health Services (HHS) boundaries so can be variable. Each BSQ service currently needs to seek individual funding arrangements to organise morning teas events, professional development sessions and projects (e.g. the shawl project). QAIHC believes a consistent state-wide approach to engagement with local ACCHOs through formal partnerships and program co-design with QAIHC will equitably benefit all Queenslanders.

A consistent approach could assist in sharing and enhancing the development of culturally appropriate and effective health promotion strategies between services and build on success stories e.g. shawl project, morning teas, professional development days and community screening days. Ideally these cancer screening days could be linked with other wellness initiatives including promotion of immunisations, skin checks and social and emotional wellbeing support. This would require thorough collaboration and planning with the local ACCHO through linked agreements that support partnerships and collaboration.

Such engagement will require an action and evaluation plan. Outcome measures should include breast cancer screening participation rates and other performance measures (including qualitative analysis and patient experience measures) that can be disaggregated by service location in order to attribute outcome measures to the quality of collaboration and engagement efforts with ACCHSs.

HHSs may link these action plans to Health Equity Strategy efforts required under the *Making Tracks Together- Queensland's Aboriginal and Torres Strait Islander Health Equity Framework*.<sup>6</sup>

**QAIHC recommends BreastScreen Queensland (BSQ) considers a formal partnership between QAIHC and BreastScreen Queensland with specific resourcing to assist with coordinating BSQ collaborations with ACCHOs to enhance access and uptake to breast screening services and contribute to Closing the Gap in life expectancy by 2031.**

## Culturally appropriate follow up

QAIHC understands that if a GP is not identified at the timing of screening, then abnormal screening results are followed up by the BreastScreen Queensland clinical staff with the patient directly which may or may not be culturally appropriate. If the screening result does not indicate any sign of cancer but the patient still requires further diagnostic work-up, the patient is contacted via mail to recommend discussing this process their health care provider. There are a number of issues with this, including some patients not having a fixed address, so linking in directly with ACCHOs to ensure adequate follow up of patients is essential to providing and connecting ongoing care across the patient journey.

BreastScreen Australia could also work with local ACCHOs to organise follow up phone calls, visits or support from an Aboriginal and Torres Strait Islander Health Worker for patients to check in post-screening and discuss their experience, barriers and future management options. Such linkages may be formalised through agreements with ACCHOs that can be facilitated through QAIHC.

## Continuity of care

The *Breast Screen Australia monitoring report 2023* discussed the significantly lower participation rates in 2020 and 2021 from the initial suspension of BreastScreen services in the COVID-19 pandemic, and then a reduction in services coinciding with ongoing COVID-19 restrictions. After these restrictions were lifted, the report noted ongoing hesitance to seek essential services like healthcare.<sup>1</sup> The broader impact of health system functioning may impact adversely and disproportionately on the Aboriginal and Torres Strait Islander community than on other Australians. This requires ongoing vigilance and monitoring to address.

## Addressing primordial risk factors

Ultimately, the social determinants of health (e.g. education, employment, poverty and housing) are key barriers to cancer screening. Whilst action plans for breast cancer screening services cannot directly address these determinants, it is through partnership with comprehensive primary health care services that health equity gains can occur. ACCHOs can identify the patients who underutilise health services and need additional supports to access health care as well as a range of other social supports.<sup>16,17,18</sup>

Health systems and programs that utilise, and resource a robust, viable and comprehensive primary health care system offer best practice opportunities for breast cancer screening. All of the suggestions outlined previously (including formal partnership with the Aboriginal and Torres Strait Islander community, addressing cultural barriers to health inequity, transport support, health prevention and promotion activities) will break down access barriers and reduce the negative impacts of social determinants of health.

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<sup>16</sup> Cancer Council Australia. Social and cultural determinants of Indigenous health consultation. 2017 May 5. Available from: <https://www.cancer.org.au/assets/pdf/submission-to-the-department-of-health-on-the-social-and-cultural-determinants-of-indigenous-health>

<sup>17</sup> Cancer Australia, Cancer Council. Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Available from: <https://www.cancer.org.au/assets/pdf/optimal-care-pathway-for-aboriginal-and-torres-strait-islander-people-with-cancer>

<sup>18</sup> Haigh M, Burns J, Potter C, Elwell M, Hollws M, Mundy J et al. Review of cancer among Aboriginal and Torres Strait Islander people. Australian Indigenous HealthBulletin. 2018 Sept 12;18(3). Available from: <https://healthbulletin.org.au/articles/review-of-cancer-2018/>

## Case study

A positive case study is the collaborative work between BreastScreen Queensland, Sunshine Coast Hospital and Health Service and North Coast Aboriginal Corporation for Community Health (NCACCH). Commencing a partnership in 2007, the three services have been holding regular BreastScreen clinics across numerous locations within the Sunshine Coast and Gympie region.

With six dedicated clinics held yearly, each service coordinates and commits staff to their nominated clinic location/s as well as assisting with transport, morning teas and providing a confidential and comfortable space. There are also mobile vans that visit remote areas, and a yearly professional development day for Aboriginal and/or Torres Strait Islander health workers including a tour of the Nambour clinic and meeting the breast screening staff.

In addition, quarterly yarning circles between relevant Aboriginal and/or Torres Strait Islander agencies were commenced in 2019 to discuss various projects and collaborations to increase uptake of Aboriginal and/or Torres Strait Islander women. For consideration is the shawl project, where customised screening shawls designed by local talented Aboriginal and Torres Strait Islander women and artists are provided to the women, which has been successfully rolled out in other parts of Queensland.<sup>10</sup>

## Risks

While the potential risk of overdiagnosis and unnecessary investigation is there, the bigger issue in Aboriginal and Torres Strait Islander women is reduced uptake of screening and delayed diagnosis leading to an increased mortality rate.

## Recommendations

1. QAIHC recommends BreastScreen Queensland (BSQ) considers a formal agreement between QAIHC and BSQ with specific resourcing to assist with coordinating BSQ collaborations with ACCHOs to streamline and standardise enhanced access and uptake to breast cancer screening services.
2. QAIHC recommends formal local engagement between BreastScreen Australia local services and local ACCHOs to tailor health services to the community's needs and ensure culturally appropriate follow up is maintained.
3. QAIHC recommends health services involved with breast screening services, including BreastScreen Queensland, should link any action plans to the Health Equity Strategy efforts required under the *Making Tracks Together- Queensland's Aboriginal and Torres Strait Islander Health Equity Framework*.<sup>6</sup>
4. QAIHC recommends evaluation reports of breast cancer screening services in Aboriginal and Torres Strait Islander women should be shared with the ACCHO sector to foster continuous quality improvement.
5. QAIHC recommends ongoing quantitative and qualitative monitoring of uptake of breast screening services in Aboriginal and Torres Strait Islander women including appropriate patient experience measures.