1.1.1.

HealthConsult

Department of Health and Aged Care

# BreastScreen Australia Quality and Safety Review

## BreastScreen Australia Review Workstream 2 Quality and Safety - Priority Populations Final Report

23 April 2024

# Acknowledgements

This paper was developed for the Department of Health and Aged Care Screening Policy and BreastScreen Section project team.

The following organisations have been consulted as part of this project and informed the development of this paper:

- Cultural and Linguistically Diverse (CALD) Advisory Group
- ACON
- Women with Disabilities WA
- Batchelor Population and Primary Health Service, NT
- Aboriginal Health Council of Western Australia (AHCWA) Member Services / Aboriginal Community Controlled Services
- Royal Perth Bentley Group, East Metropolitan Health Service.

# Contents

# Abbreviations

| | |
|---|---|
| AAA | Abdominal aortic aneurysm |
| ABS | Australian Bureau of Statistics |
| AHCWA | Aboriginal Health Council of Western Australia |
| AMS | Aboriginal Medical Service |
| BSA | BreastScreen Australia |
| CALD | Culturally and Linguistically Diverse |
| CQI | Continuous Quality Improvement |
| IT | Information Technology |
| LGBT | Lesbian, gay, bisexual and transgender |
| LGBTI | Lesbian, gay, bisexual, transgender, intersex |
| LGBTIQA+ | Lesbian, gay, bisexual, transgender, intersex, questioning, asexual |
| NACCHO | National Aboriginal Community Controlled Health Organisation |
| NHS | National Health Service |
| NSQHS | National Safety and Quality Health Service |
| NSW | New South Wales |
| NT | Northern Territory |
| PI | Population index |
| VACCHO | Victorian Aboriginal Community Controlled Health Organisation |

# Executive Summary

On 6 November 2023, the Department of Health and Aged Care (the Department) engaged HealthConsult to undertake the **quality and safety review to inform the BreastScreen Australia (BSA) National Policy and Funding Review (BSA Review)**. Specifically, HealthConsult has been engaged to assess the efficiency and effectiveness of the current accreditation system and identify alternative options to ensure the ongoing safety and quality of the BSA program.

This report summarises one aspect of the quality and safety review, specifically focused on breast cancer screening quality and safety initiatives that are facilitators or barriers to consumer experience belonging to five priority populations, including:

**1.** First Nations women
**2.** CALD women
**3.** LGBTIQA+ people
**4.** Women with disabilities
**5.** Women with mental health issues.

A literature review was first conducted to identify quality and safety initiatives, and then stakeholders representing each priority population were interviewed about their views on the literature and gaps in the evidence base. A stocktake of publically available information on all BSA websites was also undertaken.

## Barriers

Barriers to providing safe and quality breast cancer screening were identified at three levels: individual, service, and system. The barriers were similar across all five population groups. Within these three levels, the barriers can be summarised into main areas:

1. **Individual level barriers:**
    - **Acceptability** barriers include cultural and spiritual beliefs, such as fatalism or modesty, along with concerns about privacy, fear of discomfort and apprehension about potential diagnoses. Additionally, Fears of unconscious bias and discomfort with the screening facility's environment, such as elements like pink branding.
    - **Approachability** barriers include lack of social support, fear, mistrust of healthcare providers, negative past experiences, difficulty understanding screening concepts and lack of available information. Other barriers include finding suitable facilities, noting suitability of a facility differs by the type of priority population (e.g. wheel chair access, screening chair)), disempowerment and mental health concerns or cognitive deficits.

- **Accessibility** barriers include logistical challenges such as transportation problems, especially in remote areas and venue accessibility issues for those with mobility or sensory issues. Additionally, inaccessible communication methods, the need for childcare, and the scarcity of interpreters.
- **Appropriateness** barriers such as disability and comorbidities impacting the procedures, and lack of acknowledgement of needs related to priority groups. Other barriers include a lack of understanding of mental illness, stigma, unconscious bias and judgement from staff.
- **Affordability** includes financial barriers such as costs for transport, childcare, lost wages, and downstream expenses such as consultation fees, medications, and procedures.

2. **Service level barriers**

- **Acceptability** barriers arise from a cultural understanding gap among service providers, leading to discrimination and mistrust among diverse participant populations. Perceptions of hostility and unconscious biases exacerbate these issues, eroding trust among priority groups. Additionally, the lack of diversity in education materials may further alienate communities.
- **Approachability** hurdles hinder participant access and satisfaction, with staff burnout and time constraints potentially diminishing empathy and responsiveness often made worse by limited access to staff sensitivity training Inflexibility in accommodating reasonable scheduling preferences adds to accessibility barriers. This is further compounded by a lack of workforce diversity that may limit the ability to meet the diverse needs and sensitivities necessary for effectively engaging with diverse populations, thereby exacerbating care disparities.
- **Availability** issues encompass resource-related challenges, including limited access to interpreters and specialised healthcare professionals. Logistical difficulties in coordinating services, inadequate social support, and infrastructural shortcomings.
- **Appropriateness** concerns involve deficiencies in participant-centred and culturally sensitive care delivery, stemming from a lack of communication tools and training among healthcare providers. Limited availability of trauma-informed care and understanding of specific needs, like those of participants with severe mental illness, compound challenges.

3. **System level barriers**

- **Acceptability** challenges include recognising participant diversity and cultural diversity are often undervalued, leading to unsafe environments and mistrust, especially among priority populations. The lack of uniform screening and assessment methods across the country may deter engagement, exacerbating disparities.

- **Approachability** barriers encompass challenges such as geographic accessibility to screening facilities and limited ability to provide contingency plans due to the lack of resources. Limited representation of priority populations in decision-making roles is a barrier to informed equitable care for diverse participation populations.
- **Availability** challenges in resource and infrastructure coordination impede availability, with poor collaboration leading to inefficient data-sharing and logistical hurdles. Limited cultural self-assessment capacity further hampers tailored services.
- **Appropriateness** gaps exist in understanding diverse community needs, hindering effective screening delivery. The lack of a system to record reasonable adjustments to care for priority populations perpetuates disparities.
- **Affordability** challenges include the availability of essential services like transport and accommodation pose significant participant barriers to access.

# Initiatives implemented in Australia

A wide range of initiatives are currently implemented to address barriers to breast cancer screening for priority populations in Australia. However, there are variations across the priority populations and limited information on the effectiveness of these initiatives.

Initiatives for priority populations as displayed on at least one jurisdiction's website are related to education and awareness, accessibility, adaptive equipment/procedure, supportive/ holistic services, cultural sensitivity/ safety, community engagement, appointment scheduling, staff sensitivity and training, continuity of care, consent and privacy, and feedback option (Table 4).

To improve breast screening for priority populations, a multifaceted approach is needed. This includes addressing gaps and areas of improvement identified through a literature review and stakeholder input as initiatives that are:

1. currently implemented by jurisdictions but considered by stakeholders as areas of improvement or requiring adoption by more providers (Figure 1).
4. necessary but not widely available or visible across all priority populations (Figure 2).

While some jurisdictions may have already implemented such initiatives, not every jurisdiction appears to have taken steps to address the barriers for every priority population. Women with mental health are a priority population that requires particular attention, owing to the scarcity of initiatives and standards or policies to address screening challenges in this population. Lambeth et al 2023 found only 30.3% of mental health service users participated in breast screening, compared with 52.7% of other NSW women.

While not the focus of this report, a stakeholder raised homeless women as requiring attention, as was intersectionality across groups when people identify as members of more than one priority population and this results in multiple and complex barriers to screening.

## Figure 1: Initiatives currently implemented by jurisdictions

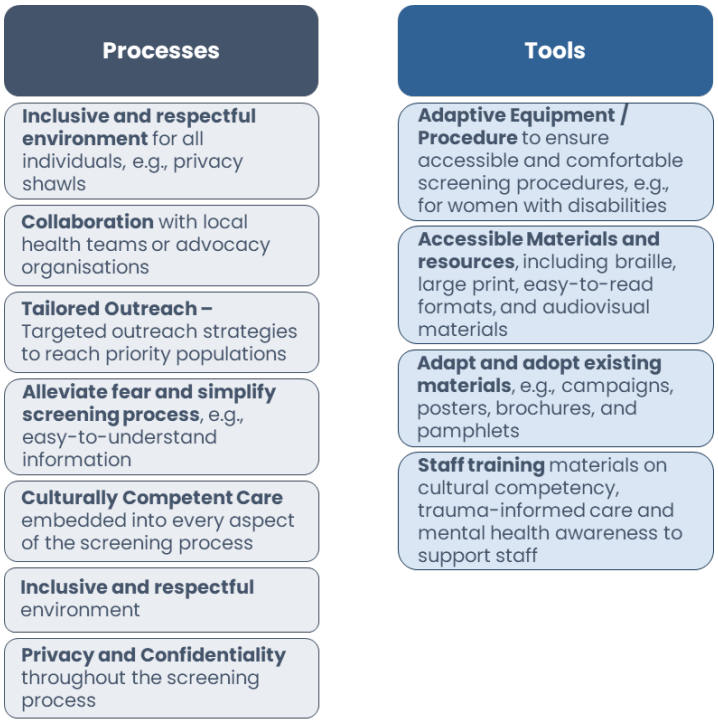
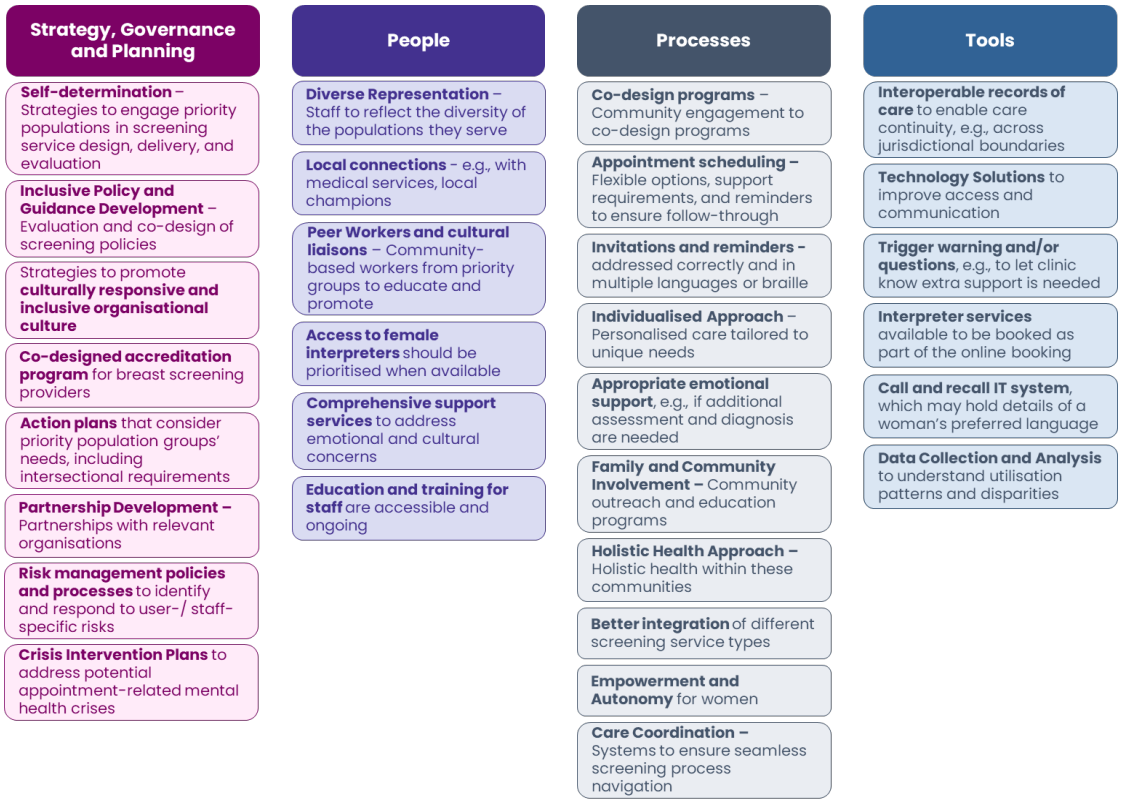



Figure 2 highlights necessary but not widely available or visible initiatives related to processes and tools.

## Figure 2: Necessary but not widely available initiatives



# Suggestions to improve the system

Drawing on the information analysed to prepare this report a comprehensive and targeted approach to address the key findings should be considered. Note: while actions to encourage the participation in breast screening was outside the scope of this review, stakeholders identified the rescreening of participants as a key quality and safety issue.

Suggestions to improve the system include:

**S1. Develop a national priority population strategy, action plan and governance framework.**

- **Actions:** Develop a National Priority Population Strategy to target specific challenges. Review national governance committees membership, roles and responsibilities to ensure diverse perspectives in decision-making. Identify partnerships with relevant organisations to leverage resources and expertise. Develop quality and safety action plans at national, state and territory levels addressing people, process, and technology gaps, and review of existing policies with implementation of inclusive policy development where needed.
- **Purpose:** To promote an organisational culture that is culturally responsive and inclusive

**S2. Implement targeted initiatives in line with the agreed national priority population action plan.**

- **Actions:**
  - Implement targeted initiatives.
  - Mandate regular, comprehensive cultural competence and sensitivity training for all screening staff involved in breast cancer screening programs. This training should be specific to the needs of First Nations women, CALD women, LGBTIQA+ people, women with disabilities, and women with mental health issues. Where possible it should cover trauma-informed care considerations.
  - Ensure screening facilities are appropriately equipped to accommodate individuals with disabilities and provide trauma-informed care. This includes investing in adaptive equipment and providing participant-centred, culturally sensitive care practices.
  - Review the impact of out of pocket costs for a priority population participant attending screening and assessment service and recommend solutions to ensure equitable access. This may need to consider transportation costs, childcare, and downstream medical expenses.
- **Purpose:** To address acceptability, approachability, accessibility, availability, appropriateness and affordability barriers

**S3. Address the major gaps in initiatives to address participants with intersectional co-morbidities**

- **Action:** Take stock of ongoing initiatives across regions to identify gaps. Secondly, partner with advocacy groups and women with firsthand experiences. Finally, use a co-design process involving diverse stakeholders to develop new programs. This approach ensures tailored and effective solutions, empowering women and promoting their well-being.
- **Purpose:** To provide effective quality and safety initiatives for all priority populations

### S4. Conduct regular reviews and make adjustments

- **Action:** Implement a system for continuous monitoring and evaluation of breast cancer screening programs, including the effectiveness of initiatives aimed at priority populations. Seek and incorporate feedback from these communities to inform adjustments and improvements.
- **Purpose:** To ensure that screening programs remain responsive to the needs of priority populations and that implemented initiatives effectively address identified gaps and barriers.

### S5. Expand the reach of effective and efficient quality and safety initiatives being implemented by sharing across different priority populations and jurisdictions.

- **Actions:** Gather information on all ongoing initiatives, not just those on websites. Evaluate initiatives to see what works best, this may require further engagement with priority population groups to validate or modify designs. Ensure consistency across jurisdictions for these initiatives and create an adopt and adapt approach to enable resources to be shared and localised. Widely distribute available staff educational materials. Provide community education materials that reflect the diversity of the community, including materials tailored for different cultural backgrounds, languages, and literacy levels that can be adapted in consultation with the local priority population communities
- **Purpose:** To improve the availability, effectiveness, and cost of quality and safety initiatives across jurisdictions by providing a starting point that can be used or adapted in consultation with the communities.

### S6. Strengthen collaboration and communication within the healthcare system

- **Action:** Improve data-sharing and coordination among healthcare providers, government agencies, and community organisations who are involved in the participant's breast screening, assessment and treatment pathways (e.g. Aboriginal Health Workers). Develop a centralised system for tracking participant screenings and follow-ups, ensuring continuity of care. Secondly, promote the use of My Health record facilitating continuity of care in these communities.
- **Purpose:** To address availability issues by enhancing the efficiency and effectiveness of the screening process, and to tailor services to meet the diverse needs of all participants.

# 2. Background

On **6 November 2023**, the Department of Health and Aged Care (the Department) engaged HealthConsult to:

*assist with the Quality and Safety Review. HealthConsult will use the outcomes from previous reviews and undertake a process to compare the efficiency and effectiveness of the current accreditation system with alternative options for ensuring the safety and quality of the BreastScreen Australia program.*

The required services were to:

- review quality and safety mechanisms currently used in cancer screening programs and the latest standard-setting techniques nationally and internationally to ensure quality improvement and the safety of screening participants
- consider options for ensuring quality and safety at the service level (accreditation) as well as jurisdictional and national level (program) and identify similarities and differences
- provide recommendations on possible improvements to the BSA Program's quality and safety mechanisms, including accreditation, to ensure they are responsive to future changes in evidence of best practice screening, and
- provide a summary of the evidence available and/or not available for breast cancer screening among priority populations being First Nations women, culturally and linguistically diverse (CALD) people, LGBTIQA+ people, women with disabilities and women with mental health issues.

## 2.1. Introduction

This report addresses the objective of summarising the evidence available and the gaps in the evidence for breast cancer screening among five priority populations:

1. First Nations women
2. CALD women
3. LGBTIQA+ people
4. Women with disabilities
5. Women with mental health issues.

The report focuses on quality and safety initiatives in breast cancer screening that are facilitators or challenges to consumer experiences for these populations when screened rather than participation rates.

## 2.2. Methodology

A literature review of peer-reviewed and grey literature was conducted to identify current quality and safety initiatives in breast cancer screening for each of the five priority populations, as outlined in Appendix A.

Stakeholders for each population were interviewed regarding their agreement or disagreement with the literature findings, additional facilitators and barriers to breast screening quality and safety and their input into gap areas in the literature (Appendixes B to F).

## 2.3. Report structure

The structure of this document is as follows:

- **Chapter 2:** presents the key findings for the barriers and initiatives implemented across the five priority populations.
- **Chapter 3:** presents gaps or areas for improvement.
- **Chapter 4:** presents conclusions and recommendations.
- **Appendices:** present:
  - the literature review methodology
  - the detailed findings for each priority population from the literature review and stakeholder consultations.

# 3. Barriers

This chapter summarises the barriers to participants' experiences of quality and safety in breast cancer screening identified in the literature review and validated and expanded by stakeholders (Appendix A to F).

## 3.1. Individual level

The **individual-level challenges** can be summarised in **five main areas**:

1. **Acceptability** is crucial for encouraging individuals to participate in screening programs. However, various factors can create discomfort and reluctance among participants. For instance, the environment of screening facilities, including elements like pink branding, may not align with participants' preferences or cultural sensitivities. Moreover, cultural and spiritual beliefs, such as fatalism or modesty, can contribute to feelings of shame or reluctance to undergo screening. Additionally, concerns about privacy assurance, fear of discomfort or pain during screening, and apprehension about potential diagnosis and its consequences can deter individuals from participating in screening initiatives. Furthermore, fears of unconscious bias and judgement from healthcare staff may exacerbate feelings of unease and reluctance to engage with screening services.
2. **Approachability** issues also significantly affect screening access, particularly concerning individuals' perceptions and experiences with healthcare providers and systems. Factors such as lack of social support, fear and mistrust of healthcare providers, and negative expectations based on past experiences can contribute to hesitancy and avoidance of screening. Moreover, difficulties understanding the concept of screening or available information and finding a facility where individuals feel comfortable attending can further hinder engagement. Additionally, disempowerment, mental health issues, or cognitive deficits may impact individuals' motivation and ability to participate in screening programs.
3. **Appropriateness** considerations are vital for ensuring that screening programs effectively meet the needs of diverse populations. Factors such as disability and comorbidities affecting suitability for screening procedures, inability to assume the correct position for screenings, and lack of acknowledgement of the needs related to priority populations (such as LGBTIQA+ groups, individuals with disabilities, and cultural preferences) can pose significant challenges. Furthermore, a potential lack of understanding of mental illness, stigma, unconscious bias, and judgement from screening staff may further exacerbate barriers to appropriateness.
4. **Accessibility** is another critical aspect of screening access, particularly concerning the logistical and practical challenges individuals may face in accessing screening services.

Transportation issues, especially in remote areas, and accessibility of venues for individuals with mobility challenges or sensory sensitivities can create significant barriers. Additionally, inaccessible communication methods for making appointments, the need to secure childcare, and the lack of available interpreters further compound accessibility challenges, limiting individuals' ability to engage with screening initiatives.

5. **Affordability** concerns also significantly impact individuals' experience and access to screening services. Costs associated with transport, childcare, lost wages, and subsequent downstream consultation fees, medicines, investigations and procedures can pose financial barriers. Moreover, out-of-pocket screening costs outside publicly funded programs may exacerbate affordability challenges.

Table 1 summarises the **key individual-level challenges** in providing quality and safe breast cancer screening to priority populations. These challenges were identified in the literature, then validated and expanded by stakeholders during the consultations. Note: the list includes challenges that may be relevant to all women and other priority populations.

## Table 1: Summary of key opportunities for improvement for the provision of quality and safe breast screening - individual level

| Challenge | First Nations | CALD | LGBTIQA+ | Disabilities | Mental health |
|---|---|---|---|---|---|
| **Acceptability** | | | | | |
| Discomfort with screening facilities' environment (e.g. pink branding) | | | ✓ | | |
| Cultural/spiritual beliefs (e.g., fatalism, shame, modesty, preference for same-gender healthcare providers) | ✓ | ✓ | | | |
| Fear of discomfort, pain, or emotional trauma during screening | ✓ | ✓ | ✓ | ✓ | ✓ |
| Embarrassment or shame associated with screening (e.g. interpreters in the intimate situation of screening) | | ✓ | | ✓ | ✓ |
| Lack of privacy assurance | | ✓ | ✓ | ✓ | |
| Increased fear of diagnosis and its consequences, or fear of "bad news" (although likely to be relevant to all women) | | ✓ | | | ✓ |
| Dysphoria relating to screening, procedures, information or correspondence and avoidance of medical care | | | ✓ | | |
| Fear of unconscious bias and judgement from healthcare staff | ✓ | ✓ | ✓ | ✓ | ✓ |
| **Approachability** | | | | | |
| Lack of social support or, family/community priorities, or busyness | ✓ | ✓ | ✓ | ✓ | ✓ |
| Fear and mistrust of healthcare providers and systems | ✓ | | | | |
| Negative expectations based on past experiences or perceptions of disrespect or negative experiences of other | ✓ | ✓ | ✓ | ✓ | |
| Difficulty understanding the concept of screening or available information | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lack of knowledge about screening | ✓ | ✓ | ✓ | ✓ | ✓ |
| Unable to find a facility they are comfortable to attend | | ✓ | ✓ | | |
| Disempowerment | ✓ | | | ✓ | |

| Challenge | First Nations | CALD | LGBTIQA+ | Disabilities | Mental health |
|---|---|---|---|---|---|
| Mental health issues or cognitive deficits impacting motivation and ability to engage | | | | ✓ | ✓ |
| **Appropriateness** | | | | | |
| Disability and comorbidities affecting suitability for screening procedures | ✓ | ✓ | | ✓ | |
| Inability to assume the correct position for screenings | | | | ✓ | |
| Lack of acknowledgement of needs related to the priority population (LGBTIQA+ needs across their diverse groups, disability-related needs and cultural preferences) | | ✓ | ✓ | ✓ | |
| Lack of understanding of mental illness, stigma, unconscious bias, and judgement from screening staff | ✓ | ✓ | ✓ | ✓ | ✓ |
| **Accessibility** | | | | | |
| Transportation issues, especially in remote areas | ✓ | | | ✓ | ✓ |
| Accessibility of venue, e.g. for wheelchairs, guide dogs, support persons, or if there is sensory over-stimulating | | | | ✓ | ✓ |
| Inaccessible communication methods (internet/phone) for making appointments | ✓ | ✓ | | ✓ | |
| Need to secure childcare | | ✓ | | | |
| Lack of interpreters or not being aware they are free | ✓ | ✓ | | ✓ | |
| **Affordability** | | | | | |
| Costs associated with consultation fees, medicines, transport, childcare, lost wages, subsequent downstream investigations and procedures, although screening itself is free, especially for those from lower socio-economic status | ✓ | ✓ | ✓ | ✓ | |
| Out-of-pocket costs of screening outside of the BreastScreen program especially those from lower socio-economic status (likely to be relevant to all women from lower socio-economic status) | ✓ | | | | |

## 3.2. Service level

The **service-level challenges** can be summarised in **four main areas**:

1. In terms of **acceptability**, a notable deficit exists in cultural understanding among service providers, resulting in misunderstandings and instances of discrimination faced by diverse participant populations. Moreover, potential hostility and unconscious biases within healthcare settings exacerbate these issues, contributing to a lack of trust and comfort among priority population groups. Additionally, the failure to incorporate diversity into education materials further alienates certain communities, hindering their engagement with services and information vital to their screening experience.
2. Regarding **approachability**, services grapple with significant obstacles that impede participant access and satisfaction. Staff burnout, coupled with time constraints, can diminish the empathy and responsiveness of healthcare professionals, undermining the quality of care provided. Moreover, the reluctance or inability of staff to accommodate participant's scheduling needs and preferences poses additional barriers to accessibility. Furthermore, a lack of workforce diversity may limit the ability to meet the diverse needs and sensitivities necessary to effectively engage with diverse participant populations, exacerbating care disparities.
3. **Availability** issues encompass a range of resource-related challenges that undermine service accessibility. Limited access to interpreters and specialised healthcare professionals, particularly for priority populations communities such as First Nations or LGBTIQA+ individuals, compounds existing barriers to care. Additionally, logistical challenges in coordinating screening services, inadequate social support structures, and infrastructural shortcomings further restrict participants' ability to access timely and appropriate screening services, particularly in remote or underserved areas.
4. **Appropriateness** concerns encompass deficiencies in delivering participant-centred care and providing culturally sensitive services. The lack of appropriate communication tools and training among healthcare providers impedes effective engagement with diverse participant populations, contributing to disparities in care outcomes. Furthermore, the absence of trauma-informed care and the failure to understand the specific needs of certain participant groups, such as those with severe mental illness, further compound the challenges faced by these communities in accessing appropriate and equitable screening services.

Table 2 summarises the **key service-level challenges** in providing quality and safe breast cancer screening to priority populations. These challenges were identified in the literature, then validated and expanded by stakeholders during the consultations.

## Table 2: Summary of key opportunities for improvement in the provision of quality and safe breast screening - service level

| Challenge | First Nations | CALD | LGBTIQA+ | Disabilities | Mental health |
|---|---|---|---|---|---|
| **Acceptability** | | | | | |
| Limited understanding and awareness of diverse cultures and disabilities, leading to misunderstandings, assumptions, and discrimination | ✓ | ✓ | ✓ | ✓ | ✓ |
| Hostility of healthcare professionals, stigma, unconscious bias | | | ✓ | | ✓ |
| Lack of diversity in educational materials to reflect the diversity of clientele | | ✓ | ✓ | | |
| **Approachability** | | | | | |
| Lack of time and staff burn-out leading to reduced empathy | | | | | ✓ |
| No means of knowing participant needs in advance | | | | | ✓ |
| Staff unwilling to be flexible with booking systems and other actions that would facilitate participation and continued participation, including longer appointment times | ✓ | | | ✓ | |
| Lack of diversity in the workforce to reflect the diversity of clientele | ✓ | ✓ | ✓ | | |
| Participants are not informed or aware of the availability of interpreters and that they are free, and do not request one | | ✓ | | | |
| **Availability** | | | | | |
| Scarce resources, including limited access to interpreters and gender-specific healthcare professionals and access to First Nations, CALD or LGBTIQA+ staff | ✓ | ✓ | ✓ | ✓ | |
| Attracting and retaining staff, especially for First Nations or CALD staff, or not making effective use of bicultural staff | ✓ | ✓ | | | |
| Insufficient social supports | | ✓ | | ✓ | |
| Lack of coordination with local health teams | ✓ | | | | ✓ |

| Challenge | First Nations | CALD | LGBTIQA+ | Disabilities | Mental health |
|---|---|---|---|---|---|
| Screening services not situated in suitable or safe venues for the population (e.g. remote locations and communities) | ✓ | | ✓ | | |
| Inaccessible equipment or lack of physical access | | | | ✓ | |
| Lack of Transportation | ✓ | | | ✓ | ✓ |
| Lack of internet access | ✓ | | | ✓ | |
| Communication of results in communities without postal services | ✓ | | | | |
| **Appropriateness** | | | | | |
| Lack of communicative tools, especially in other languages, appropriate language and appropriate wording, and female-centred screening information materials and services not suitable for some groups | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lack of skills, experience, and training among providers, including communication training | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lack of consultation and/or notification | | | | ✓ | ✓ |
| Lack of trauma-informed care, risking re-traumatising clients | | ✓ | | | ✓ |
| Lack of understanding of the need for family involvement in obtaining consent | | ✓ | | | |
| Interpreters lack the training to understand the context of breast screening and are unprepared | | ✓ | | | |
| Use of unfamiliar biomedical jargon | ✓ | ✓ | | ✓ | ✓ |
| Staff only receive intermittent or once-off training in cultural sensitivity and cultural safety | ✓ | ✓ | | | |
| Lack of information and knowledge of the needs of the priority population, e.g. Lack of understanding of severe mental illness, reasonable adjustments, accessible information | | | | ✓ | ✓ |
| Limited participant-centric care, the Service finds complex participants difficult | | | | ✓ | ✓ |

## 3.3. System level

The **system level challenges** can be summarised in **five main areas**:

1. **Acceptability** involves recognising and respecting the diversity of participants. Unfortunately, cultural diversity is often undervalued, resulting in unsafe and unresponsive environments. This can lead to discomfort and mistrust among participants, particularly those from priority populations. Moreover, there is a perceived inflexibility in screening services, where eligibility criteria may not adequately consider the varied needs of different populations. Additionally, stringent standards addressing the needs of priority populations can inadvertently discourage their engagement, further exacerbating disparities in screening access, satisfaction and outcomes.
2. **Approachability** in healthcare refers to how easily participants can access and engage with services. However, notable system-wide barriers to approachability hinder participation experience and satisfaction. In addition to geographic accessibility to screening facilities issues, there is often a lack of flexibility and contingency planning to accommodate unforeseen events due to resource constraints. Moreover, the limited representation of priority populations in decision-making roles making it challenging to provide informed equitable care for diverse participation populations.
3. **Availability** encompasses the resources and infrastructure necessary to deliver healthcare services effectively. Yet, numerous challenges impede availability. Poor collaboration and communication between different parts of the healthcare system lead to inefficient data-sharing, transport, and accommodation coordination. Additionally, equipment maintenance and logistical challenges in transporting participants, staff, and equipment further hinder timely and appropriate screening delivery. Moreover, a lack of capacity for cultural self-assessment and limited reliable data on cultural safety can make it difficult to tailor services to the diverse needs of participants.
4. **Appropriateness** in screening involves aligning services with participants' specific needs and preferences. However, there are notable gaps in this regard. Many healthcare providers lack a deep understanding of the varied needs of different communities, hindering their ability to facilitate effective screening and care. Additionally, there is often no systematic approach to recording reasonable adjustments for priority populations, further perpetuating screening access, satisfaction and outcomes disparities.
5. **Affordability** plays a crucial role in access. Lack of funding for essential services such as transport and accommodation can pose significant participant barriers.

Table 3 summarises the **key system-level challenges** in providing quality and safe breast cancer screening to priority populations. These challenges were identified in the literature, then validated and expanded by stakeholders.

### Table 3: Summary of key opportunities for improvement for the provision of quality and safe breast screening - system level

| Challenge | First Nations | CALD | LGBTIQA+ | Disabilities | Mental health |
|---|---|---|---|---|---|
| **Acceptability** | | | | | |
| Not valuing diversity | ✓ | ✓ | ✓ | ✓ | |
| Lack of culturally safe, secure, and responsive environments | ✓ | ✓ | ✓ | ✓ | ✓ |
| Perceived inflexibility of screening service regarding participant eligibility criteria | | | ✓ | | |
| Standards to address a priority population's needs can be overly rigorous, discouraging uptake | | | ✓ | | |
| **Approachability** | | | | | |
| Lack of flexibility and contingency planning to accommodate unforeseen events | ✓ | | | | |
| Lack of people from the priority population among decision-makers in the health sector | | ✓ | ✓ | ✓ | ✓ |
| Staff training in cultural sensitivity and cultural safety is not available or not compulsory, or not commenced early enough in staff members' training/careers | ✓ | ✓ | | | |
| **Availability** | | | | | |
| Poor collaboration and communication between different parts of the health system, e.g. data-sharing, transport and accommodation coordination | ✓ | ✓ | | ✓ | ✓ |
| Equipment issues and maintenance | ✓ | | | | |
| Logistical challenges transporting participants, staff and equipment | ✓ | | | | |
| Lack of capacity for cultural self-assessment and data on cultural safety of services | | ✓ | | | |
| Lack of reliable data in the priority population, to inform best practice | | | ✓ | ✓ | ✓ |
| Wait time location of services and equipment not appropriate | | | | ✓ | |

| Challenge | First Nations | CALD | LGBTIQA+ | Disabilities | Mental health |
|---|---|---|---|---|---|
| Access to peer workers and support workers | | | | ✓ | ✓ |
| **Appropriateness** | | | | | |
| Lack of understanding of the different needs and institutionalised cultural knowledge of various communities to facilitate screening | ✓ | ✓ | ✓ | ✓ | ✓ |
| Lack of a system to record reasonable adjustments to care for priority population | | ✓ | | ✓ | ✓ |
| **Affordability** | | | | | |
| Lack of funding to provide participants with transport and accommodation | ✓ | | | | |

# 4. Initiatives implemented in Australia

This Chapter summarises the safety initiatives implemented in Australia to address these barriers across the five priority populations. Note: This review does not focus on improving participation rates but rather on the screening experience of the priority populations. However, there is significant overlap, especially in getting women from priority populations to attend future screening or further follow-up assessments.

Appendix A to Appendix F present details of the quality and safety initiatives identified by stakeholders of each priority group. Further, a stocktake of state and territory initiatives was undertaken by reviewing the information provided on all BSA websites in December 2023. This information was supplemented by BreastScreen NT, who do not maintain an extensive website presence given the highly rural and remote community they service. These communities likely do not access the internet, regular phone service or a mailbox to send results to (refer to 3.2 Case Study).

## 4.1. Summary of publically available information

Table 4 describes available initiatives for priority populations as displayed on at least one jurisdiction's website following a stocktake of publically available information on all BSA websites. It is acknowledged that some initiatives may not have been publically stated or could not be easily found on the reviewed websites. There was no information found about women with Mental Health issues on the websites.

**Table 4: BreastScreen initiatives (source: all BSA websites accessed December 2023 and supplemented by BreastScreen NT)**

| Initiative | First Nations | CALD | LGBTIQA+ | Disabilities |
|---|---|---|---|---|
| **Education and Awareness** | | | | |
| The website provides priority population-specific information | ✓ | ✓ | ✓ | ✓ |
| The website/brochure includes whether breast cancer screening is recommended | | | ✓ | ✓ |
| The website/brochure includes the criteria to be met successfully for a woman to undergo a screening mammogram | | | ✓ | ✓ |
| The website/brochure includes advice for women to talk to their doctor about breast screening to decide if it is suitable for them | | | ✓ | ✓ |
| The website has an audio "listen" function (in English) | ✓ | ✓ | | ✓ |

| Initiative | First Nations | CALD | LGBTIQA+ | Disabilities |
|---|---|---|---|---|
| The website includes other accessibility options, including easy-to-read information about breast screening | | | | ✓ |
| The website can be translated or is available in other languages | | ✓ | | |
| Runs special events specific for the priority population | ✓ | ✓ | ✓ | |
| Community Service Announcement (radio) recorded in multiple languages for distribution to radio networks | | ✓ | | |
| Access to priority population-specific health promotion material (in multiple languages), including videos | ✓ | ✓ | ✓ | ✓ |
| Note on the priority population page screening is free | ✓ | ✓ | ✓ | ✓ |
| Links to priority population-specific websites for more resources | ✓ | | ✓ | |
| Links to other government websites for more resources | ✓ | ✓ | ✓ | ✓ |
| Contact number for more information | | | ✓ | |
| Education tools for community events | | ✓ | ✓ | |
| **Accessibility** | | | | |
| Mobile vans | ✓ | ✓ | ✓ | ✓ |
| Access to free interpreters | | ✓ | | ✓ |
| Women who are deaf or have a hearing or speech impairment can contact BreastScreen through the National Relay Service. An interpreter can assist at the appointment. | | | | ✓ |
| Wheelchair (most types) accessible service/ mobile van (including advice on parking/ local transport options) | | | | ✓ |
| Access to a counsellor to discuss the risks and benefits of screening | | | ✓ | |
| Contact number for more information | | | | ✓ |
| **Adaptive Equipment/Procedure** | | | | |
| Changing the breast screening procedure for women who have difficulties with movement. Some clinics offer appointments where an extra radiographer is available to assist | | | | ✓ |
| **Supportive / Holistic Services** | | | | |
| Allowing a support person, guide or dog to come with the participant into the breast screening room | | | ✓ | ✓ |
| Work with or encourage access to local Health Workers so they can make breast screening appointments for participants | ✓ | | | |
| **Cultural Sensitivity/Safety** | | | | |
| All-women screening staff (as per priority population website) | ✓ | ✓ | | |

| Initiative | First Nations | CALD | LGBTIQA+ | Disabilities |
|---|---|---|---|---|
| Acknowledge the priority population's cultural and individual needs/ cultural safety (e.g., provide free privacy shawls/ sarongs) | ✓ | ✓ | | |
| Commitment to LGBTIQA+ inclusive/ welcoming/ safe services (incl. Rainbow tick accreditation) on the website | | | ✓ | |
| A policy guiding priority population policy breast screening highlighted on the website | | | ✓ | |
| **Community Engagement** | | | | |
| Promote the use of the priority population Advisory group or Community Led design | ✓ | | | |
| **Appointment Scheduling** | | | | |
| Offering priority population-only screening days | ✓ | | ✓ | |
| Longer appointments | | | | ✓ |
| Group bookings | ✓ | ✓ | | ✓ |
| Familiarisation visits | ✓ | ✓ | | ✓ |
| Work with local disability services to arrange group bookings and familiarisation visits | | | | ✓ |
| **Staff Sensitivity and Training** | | | | |
| Staff (e.g., receptionists, radiographers) trained to provide culturally safe and appropriate services (e.g. via VACCHO Cultural Safety Training Program) | ✓ | | | |
| Adequately trained and equipped staff (e.g. specially trained female medical imaging technologists) to provide care for women with a disability | | | | ✓ |
| Online training module for staff is highlighted on the website | | | ✓ | |
| **Continuity of Care** | | | | |
| With the woman's (or carer's) consent, the woman's nominated doctor is informed if breast screening cannot be provided as a result of her disability. | | | | ✓ |
| Provides educational material "Cancer screening for people with disabilities: A guide for general practice" | | | | ✓ |
| **Consent and Privacy** | | | | |
| If it is not possible to obtain clear verbal consent from a client with an intellectual disability, consent can be provided by the authorised support person or substitute decision-maker. Even if an authorised support person or substitute decision-maker has provided consent, a radiographer may stop the screening procedure if the client's non- | | | | ✓ |

| Initiative | First Nations | CALD | LGBTIQA+ | Disabilities |
|---|---|---|---|---|
| verbal behaviour indicates they do not want the procedure to continue. This can apply before or during the screening procedure. | | | | |
| Clarify data collection and disclosure on the website | | | ✓ | |
| Feedback option | | | | |
| Contact to provide feedback on the page | | ✓ | ✓ | |

## 4.2. Case study

This case study showcases how these initiatives work together in practice but also the challenges that exist.

In the Northern Territory, breast screening services are provided to three distinct, very remote types of communities: Desert Mob, Top End Mob and Island Mob. These communities have over 20 dialects with seven main languages. There is likely no access to the internet, regular phone service or a mailbox to send results to. They are often affected by extreme weather events and natural disasters, e.g. extreme heat and annual floods.

Most services are provided on "Millie", the pink bus, on land or a barge for island communities. Millie cannot go on dirty roads and is old with normal suspension, meaning no equipment protection from vibrations due to the remote bitumen roads. There are power requirements that not all communities can provide, and it would cost over $10,000 to install per community.

Access to women in these communities is coordinated by the local Aboriginal Medical Service (AMS), which provides details of the population to be screened and, together with BreastScreening NT, highlights women requiring the most urgent follow-up. AMS organises and funds transport for women from the outlying communities to attend.

The BreastScreen NT Health Promotion team is presently staffed by an Indigenous woman and a born and bred Territorian who understand the need "for a yarn and a cup of tea" as part of the service, even if this extends the appointment time. Staff respect the customs of the local community and understand the impact that "sorry business" and local disputes will have on women coming to be screened. They engage with local health services and ensure they park the bus in a position most conducive to women's business and not near men's business.

Where possible, they work with local communities to hold promotional activities such as:

- Women's Health Weeks is run by the Aboriginal Community Controlled Health Organisation, with broad community involvement. AMS and the local police are passionate about the community's health and well-being. This provides access to the service and allows the women to familiarise themselves with the bus to be comfortable in the future. There is also the sharing of gifts appropriate for the local culture, often funded by local businesses.

- Using local Territorians who have been diagnosed with breast cancer as Breast Screen Ambassadors to ease the way for these women.

Results are returned to the AMS, which will recall the women to share the results and add the relevant recall reminders to the required future screening services. Due to limited funding and resources, there is a long list of items that cannot be addressed to improve this service:

- A purpose-built off-road semi-trailer/ truck that will be able to handle the NT conditions and which includes air suspension
- Access to online booking services
- A Dedicated Breast Screening website
- Promotional videos in the seven main languages
- Funding for more Women's Health Weeks and other promotional activities
- A dedicated driver for the bus
- Access to power in more remote communities

Figure 3 to Figure 10 show “Millie”, the breast screening bus used in NT.

Figure 3: Hermannsburg Community set-up with the BreastscreenNT bus "Millie"


Figure 4: Millie parked at the front of the Harts Range Health Clinic

Figure 5: Millie at Ti Tree Health Clinic


Figure 6: Millie at Yulara Health Clinic


Figure 7: Millie on the barge coming into Maningrida

Figure 8: Little camp dog having out with Millie

Figure 9: Waiting room/reception desk inside Millie

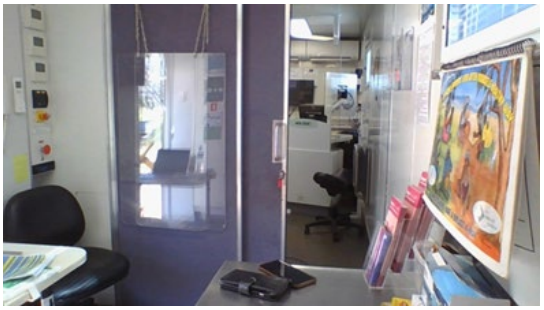


Figure 10: Radiographer desk looking at the mammography machine and waiting/reception room, Millie

# 5. Gaps and areas of improvement

This chapter outlines the initiatives identified in the literature and suggested by stakeholders to address challenges for breast screening of priority populations. This will require a multifaceted approach involving strategies, people, processes, and tools. While some jurisdictions may implement these initiatives, not every jurisdiction has initiatives to address the barriers for every priority population. It is acknowledged that some initiatives may not have been publically stated on the reviewed jurisdictions' websites. Appendix A to Appendix F present details of the quality and safety initiatives identified by the literature and stakeholders.

## 5.1. Strategy, Governance and Planning

The following initiatives were highlighted in the literature and by stakeholders as necessary but **not widely available or visible** across all priority populations:

- **Self-determination** includes sharing power (decision-making and governance). Develop strategies to engage priority populations in designing, delivering, and evaluating breast screening services. This could involve establishing community advisory boards or holding regular forums to gather feedback. New Zealand is implementing a co-governance partnership model for national screening programs involving redesigning the model, reviewing clinical governance, clarifying roles, and resetting relationships.
- **Inclusive Policy and Guidance Development**: Evaluate and co-design updates as required, amend breast screening policies to be more inclusive, and address the needs of priority populations. Ensure policies are culturally sensitive and tackle specific barriers faced by each group. Offer tailored solutions for these communities' challenges without assuming adherence to guidelines by the consumer. New Zealand is co-designing and publishing a comprehensive set of program policies that reflect the Tiriti obligations and a comprehensive commitment to Pasifika health equity. It also co-designs and implements a learning system that underpins a new governance structure. NHS England, Public Health England and Cancer Care Ontario have introduced policies and guidelines aimed at improving breast cancer for priority populations.
- **Develop strategies**:
  - That promotes an organisational culture that is culturally responsive and inclusive.
  - Consumer engagement strategy that addresses the needs of all consumers, including priority populations.

- **Co-design accreditation program** for breast screening providers, including review and redesign to focus on what is most important, based on priority indicators. New Zealand is currently co-designing a kaupapa Māori accreditation program.
- **Develop action plans** that consider the needs of all priority population groups, including their intersectional requirements. This approach ensures that cancer prevention, screening, treatment, and supportive care are accessible to all eligible individuals in an equitable, culturally safe, holistic, and evidence-based manner. By addressing the unique needs and challenges faced by different priority populations and recognising the intersections of various factors such as race, gender identity, disability, and mental health status, these action plans aim to provide comprehensive and inclusive support to everyone who requires cancer-related services. A Breast Screening Action Plan is being developed by Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority) to respond to the recommendations from the Quality Improvement Review of Breast Screening Aotearoa, with a focus on improving access to screening and experiences for Māori and Pacific women.
- **Partnership Development**: Forge partnerships with relevant organisations, including Indigenous health services, CALD groups, LGBTIQA+ organisations, disability support groups, and mental health associations, to enhance access and support for priority populations. Ontario Indigenous Cancer Care has implemented initiatives to build and promote relationships with indigenous partners based on trust and mutual respect, including building, growing, strengthening and sustaining relationships; supporting Indigenous health priorities throughout the health system transition; and promoting respect for and understanding Indigenous knowledge and traditional practice.
- **Risk and issues management policies and processes** should be developed or updated to identify and respond to risks and issues specific to users or staff.
- **Crisis Intervention Plans** considering the potential for mental health crises, screening facilities should have plans in place to address emergencies during or after screening appointments. This may involve collaboration with mental health crisis teams or protocols for immediate support.

## 5.2. People

The following initiatives were highlighted in the literature and by stakeholders as necessary but **not widely available or visible** across all priority populations:

- **Diverse Representation:** Ensure that staff involved in breast screening programs reflect the diversity of the populations they serve. This includes recruiting and retaining individuals from priority populations. Expanding the role of bicultural workers can provide valuable support for staff and clients with specific cultural and trauma care needs. New Zealand aims for equitable representation of Māori health and Pasifika health expertise. This is supported by a

dedicated workforce recruitment and retention strategy for Māori, Pacific peoples and people with lived experience of disability.

- **Local connections:** The provider is local or has local connections (e.g., medical services, local champions), is familiar with local needs and customs, and understands cultural sensitives.
- **Peer Workers and cultural liaisons**: Employ peer workers and cultural liaisons from within priority populations to facilitate trust, communication, and education about breast screening within their communities. Access to peer workers with lived experience can offer invaluable empathy and support to participants, whether volunteer or paid.
- **Access to female interpreters** should be prioritised when available. Services should proactively offer interpreter services to overcome barriers like lack of online booking and awareness of free services, preventing women from arriving without interpreters. While screening appointments are short, assessments can take 3 to 6 hours. Triage of language services based on medical importance may decrease interpreter no-show rates for assessments.
- Offer **comprehensive support services**, including counselling and psychosocial support tailored to address emotional and cultural concerns. Offering personal assistance for those requiring assistance during screening and facilitating effective communication between providers and participants, including discussions about mental health concerns, are essential.
- **Ensure education and training for staff are accessible and ongoing**.
  - Peer Educators: Train individuals from priority populations to serve as peer educators, sharing information about the importance of breast screening and addressing misconceptions or fears.
  - Providing cultural competency training to all staff members. Ensuring screening providers receive cultural competence training to understand and respect the cultural nuances of providing healthcare to these communities. Cultural safety and awareness training should be mandatory at universities for all disciplines
  - Ensure that staff members are knowledgeable about the specific health needs, for example, LGBTIQA+ individuals and the potential impact of hormone therapy, disabilities and mental health issues, and how to provide trauma-informed care
  - Address cultural values, including the potential for unconscious bias, racism and discrimination. For example, providing training to avoid stigma, unconscious bias and judgement from staff can result in a barrier to participants undertaking screening when they arrive at the clinic.

- Interpreters have access to training about the Breast screening program (including consent forms) to ensure they understand the context of the service

## 5.3. Processes

Currently, jurisdictions **have implemented the following initiatives**; however, stakeholders reported that more work is required to refine or expand this approach. These include:

- **An inclusive and respectful environment** for all individuals is provided, regardless of their sexual orientation, gender identity, or expression. This includes using inclusive language, displaying LGBTIQA+friendly signage, and having staff trained to provide culturally competent care. Improve the experience, e.g., displaying pictures/posters/artwork or deco that reflect the cultures and ethnic backgrounds of the assessment sites can help establish trust and reduce anxiety, access to locally made gifts (e.g., privacy shawls).'
- **Collaboration:** Provide services within communities in collaboration with local health teams or advocacy organisations. Coordinate logistics for women from remote areas, including transport and accommodation. Engage local services for contingency planning and flexibility in screening schedules. Noting different communities may have distinct beliefs, practices, and languages. Improve staff's understanding of community priorities, e.g., Sorry Business, community security, housing, food, and natural disasters.
- **Tailored Outreach:** Develop targeted outreach strategies to reach priority populations, including culturally appropriate messaging, materials in multiple languages, and awareness campaigns during relevant cultural events or celebrations. For example:
  - Encourage local health teams to organise community events and workshops to educate and engage communities.
  - Address myths, misconceptions, and cultural taboos related to breast health and screening through targeted educational campaigns
  - Involve community ambassadors and individuals who have undergone breast screening in outreach efforts to share their experiences and encourage participation.
  - Using community-specific channels, such as local radio stations, community events, and social gatherings, to disseminate information and increase the Indigenous youth audience.
- **Alleviating fear and simplifying the screening process**: Provide clear and easy-to-understand information about the screening process, including what to expect during the appointment and how to prepare. Offer information sessions and virtual or in-person tours of the screening facilities to familiarise women with the environment and alleviate anxiety.
- **Culturally Competent Care**: Embed cultural competency into every aspect of the screening process, from scheduling appointments to delivering results. This includes respecting

cultural practices, providing interpretation services, and supporting traditional healing methods. Evaluate services for cultural safety and cultural respect. Cultural respect is achieved when the health system is a safe environment where cultural differences are respected. Aspects of cultural safety include good communication, respectful treatment, empowerment in decision-making and the inclusion of family members.

- **Inclusivity and Respect**: Create an inclusive and respectful environment for all individuals regardless of sexual orientation, gender identity, or expression. Use inclusive language and display friendly signage. Use affirming and inclusive language when discussing health matters. This includes using terms that respect individuals' gender identities and expressions. For example, referring to body parts with gender-neutral terms when discussing breast health.
- **Privacy and Confidentiality**: Ensure privacy and confidentiality throughout the screening process. Reassure individuals about information confidentiality.

The following initiatives were highlighted by stakeholders as necessary but **not widely available or visible** across all priority populations, including:

- **Co-design programs**: Direct community engagement to co-design targeted programs where relevant. Noting different communities may have distinct beliefs, practices, and languages. The co-design approach is being used in Canada and New Zealand
- **Appointment scheduling:**
  - Flexible Scheduling: Implement flexible scheduling options to accommodate the needs of priority populations, such as evening or weekend appointments, mobile screening clinics in remote areas, and other screening options. For example, quiet session times with low lighting, fewer people and fewer sound stimuli.
  - Identify support requirements: Discuss with individuals, their families, carers or others providing support any reasonable adjustments or communication needs people may require.
  - Provide reminders to ensure follow-through. For example, mental health challenges may affect a person's ability to maintain consistent routines
- **Invitation and reminder letters:**
  - are addressed correctly to respect the person's identity and do not use "dead names" (this also relates to Data Collection to correctly identify participants' gender identities).
  - are available in a preferred language or braille, including letters and leaflets, where a woman has indicated that her preferred language is not English, and this is recorded on the Breast Screening Programme.

- **Individualised Approach:** Provide personalised care tailored to unique needs. Capture necessary information for future visits with consent. Recognise ethno-specific variations and health disparities. Consider family and community context for migrant and refugee populations. Offer trauma-informed care for women with mental illness and other complex needs.
- **Appropriate emotional support** is provided, especially if additional assessment and diagnosis are needed.
- **Family and Community Involvement:** Conduct community outreach and education programs. Recognise the influence of family and community dynamics on healthcare decisions.
- **Holistic Health Approach**: Recognise holistic health within these communities. Integrate breast cancer screening into broader health initiatives. New Zealand is broadening the focus of the screening programs to include wellbeing and hauora health gain for individuals, whānau and the community.
- **Better integration of different cancer screening service types** so that cancer screening is a better experience and women can access all cancer screening programs as being implemented in New Zealand.
- **Empowerment and Autonomy**: Empowering women to take control of their health while respecting their autonomy is essential. For example, in some cases, involving mental health professionals in discussions about healthcare decisions may be beneficial. This involves providing clear information about the benefits and potential risks of breast screening and respecting their autonomy in the decision-making process.
- **Care Coordination:** Establish care coordination systems to ensure seamless navigation through the screening process, particularly for individuals with complex needs or barriers. For example, healthcare professionals (Screening and Mental Health Professionals) need to discuss the importance of breast screenings, addressing any concerns or fears the individual may have related to both mental health and the screening procedure.

## 5.4. Tools

Currently, jurisdictions **have implemented the following initiatives**; however, stakeholders reported that more work is required to refine or expand these approaches. These include:

- **Adaptive Equipment / Procedure**: To ensure that breast screening procedures are accessible and comfortable for women with disabilities, as well as individuals with sensory sensitivities such as those on the autism spectrum, screening facilities can implement adaptive measures such as providing adjustable examination tables and mammography machines to accommodate diverse physical abilities. Sensory considerations, including

lighting, temperature, and odours, should be addressed to create a comfortable environment that minimises anxiety and sensory overload.

- **Accessible Materials**: Develop accessible materials and resources, including braille, large print, easy-to-read formats, and audiovisual materials, to cater to diverse needs. For example:
  - Measure the impact of existing resources and adapt program correspondence, materials, and media for more inclusive language and images using diverse "poster children" in promotional materials.
  - Involve community members in designing and reviewing educational materials to ensure cultural relevance and sensitivity.
  - Create video resources featuring interviews with women who have undergone screening, including those from diverse backgrounds and experiences.
  - Continuing to develop culturally sensitive educational materials and campaigns (with an emphasis on health literacy, lived experience and in a language of their choice)
  - Information packs for outreach and education programs
  - Materials to communicate effectively with individuals who have hearing or speech impairments and provide tools like social stories for individuals with autism.
  - Consideration should be given to how mammographers will support non-English speakers through the screening process when they attend. Providers can consider using pictures in a storyboard to explain the process or, where facilities are available, accessing a video explanation of the process as implemented by NHS England.
- **Adapt and adopt existing materials**, e.g. campaigns, posters, brochures, and pamphlets. Provide materials that can be localised for local needs. For example, have someone who has gone through the breast screening journey tell their story and have ambassadors from the community make videos about their journey.
- **Staff training materials** on cultural competency, trauma-informed care and mental health awareness are available to support screening office and mammography staff in this process to avoid stigma, unconscious bias, and judgment.

The following initiatives were highlighted by stakeholders as necessary but **not widely available** across all priority populations, including:

- **Interoperable records of care** enable continuity of care within the public and private sectors and across jurisdictional boundaries. For example, results are routinely available on My Health Record.

- **Technology Solutions**: Utilise technology to improve access and communication, such as online appointment scheduling, telehealth consultations, and mobile applications for educational resources. For example, for online booking systems:
  - a trigger warning may be appropriate, and/or a question such as "Would you like us to be aware of something that would influence your behaviour?" or to be able to let the clinic know they need extra support.
  - Interpreter services should be available to be booked as part of the online booking system for a range of common languages (i.e., not require a phone call)
  - NHS England has implemented the call and recall Information technology (IT) system, which may hold details of a woman's preferred language, where this has been populated. It may also indicate if an interpreter is required, which would be useful if a woman needs to attend an assessment clinic. This field is updated by the population index (PI), like other demographic information, and can be manually added or amended by the breast screening service.
- **Data Collection and Analysis**: Collect and analyse data to understand utilisation patterns and disparities among priority populations. Use this information to tailor interventions and allocate resources effectively. By supporting targeted research initiatives focused on improving technologies and methodologies tailored to groups such as LGBTIQA+ individuals, people with disabilities, and those with mental health issues, the goal is to gather evidence on program performance and compile information to enhance the overall screening experience. This includes increasing the involvement of individuals with lived experience in research endeavours and respecting community autonomy in data collection and usage. Strengthening stakeholder engagement, particularly with Indigenous communities, and promoting cultural safety within screening environments are central to ensuring equitable access and participation. Moreover, addressing the lack of information regarding breast cancer screening for individuals with mental illnesses underscores the need for expanded research efforts to improve understanding and support for these populations.

# 6. Suggestions to improve the system

This report reviewed the priority populations' challenges in receiving a quality and safe breast cancer screening experience and the current initiatives to address them. International practices, literature and stakeholder suggestions relevant to the challenges were also canvassed, which may or may not be currently implemented in breast cancer screening services.

Overall, the key findings identified included:

- The **key barriers** identified were similar across population groups; however, initiatives to address these barriers differed by population group. The main barriers included acceptability, approachability, availability, accessibility, appropriateness and affordability. This requires a multifaceted approach to address, with the most important being to promote an organisational culture that is culturally responsive and inclusive.
- A **wide range of initiatives** is implemented in Australia to address these barriers. However, there were variations across priority populations and jurisdictions. Additionally, there was limited information on the effectiveness of these initiatives.
- Initiatives to address challenges for breast screening of priority populations identified in the literature and by stakeholders covered strategy, governance and planning, people, processes and tools. This list included:
  - Initiatives currently implemented that stakeholders reported that more work is required to refine or expand this approach, and
  - Initiatives highlighted by stakeholders as necessary but not widely available or visible across all priority populations.
- **Women with mental health issues** are a priority population that requires particular attention, owing to the scarcity of initiatives and standards or policies to address screening challenges in this population.
- While not the focus of this report, a stakeholder raised **homeless women** as requiring attention, as was **intersectionality across groups** when people identify as members of more than one priority population and this results in multiple and complex barriers to screening.

To improve breast screening for priority populations, a multifaceted approach is needed. Table 5 summarises six suggestions for potential initiatives.

**Table 5: Suggestions for consideration**

| Suggestions to improve the system | Actions/Intervention |
|---|---|
| **1.** Develop a national priority population strategy, action plan and governance framework<br><br>Purpose: To promote an organisational culture that is culturally responsive and inclusive | • Develop a national priority population strategy<br>• Review national governance committee memberships, roles and responsibilities to ensure that diverse perspectives and expertise are brought to the table, leading to well-rounded and informed decision-making processes.<br>• Develop partnerships with relevant organisations<br>• Develop quality and safety action plans (national and state and territory-based) to address people, process and technology gaps<br>• Review existing policies and implement inclusive policy development where required |
| **2.** Implement targeted initiatives in line with the agreed action plan.<br><br>Purpose: To address acceptability, approachability, accessibility, availability, appropriateness and affordability | • Implement targeted initiatives<br>• Mandate regular, comprehensive cultural competence and sensitivity training for all screening staff involved in breast cancer screening programs. This training should be specific to the needs of First Nations women, CALD women, LGBTIQA+ people, women with disabilities, and women with mental health issues. Where possible it should cover trauma-informed care considerations.<br>• Ensure screening facilities are appropriately equipped to accommodate individuals with disabilities and provide trauma-informed care. This includes investing in adaptive equipment and providing participant-centred, culturally sensitive care practices<br>• Review the impact of out of pocket costs for a priority population participant attending screening and assessment services and recommend solutions to ensure the equitable access. Some participants are able to access additional resources to cover the costs associated with screeningThis may need to consider, such as transportation costs, childcare, and downstream medical expenses |
| **3.** Address the major gaps in initiatives to address participants with intersectional co-morbidities | • Undertake a stock take of initiatives being implemented by jurisdictions |

| Suggestions to improve the system | Actions/Intervention |
|---|---|
| Purpose: To provide effective quality and safety initiatives for all priority populations | • Develop partnerships with advocacy organisations and women with lived experience<br>• Implement a co-design process to develop new programs |
| **4.** Conduct regular reviews and adjustments<br>Purpose: To ensure that screening programs remain responsive to the needs of priority populations and that implemented initiatives effectively address identified gaps and barriers | • Implement monitoring, reporting and evaluation of priority populations initiatives and experiences, including applying data sovereignty principles, data quality and co-design and implementing data collection, analytics, monitoring, reporting frameworks and new research<br>• Build a quality and safety learning system across all jurisdictions apply training and quality improvement methods, and develop and implement specific quality improvement programs<br>• Identification and reporting of adverse events |
| **5.** Expand the reach of effective and efficient quality and safety initiatives being implemented by sharing across different priority populations and jurisdictions<br>Purpose: To improve the availability, effectiveness, and cost of quality and safety initiatives across jurisdictions by providing a starting point that can be used or adapted in consultation with the communities | • Undertake a stock take of initiatives being implemented by jurisdictions that may not be listed on their websites<br>• Implement an evaluation framework to review the effectiveness of quality and safety initiatives<br>• Implement a strategy to establish consistency across jurisdictions regarding the quality and safety initiatives initiated for priority populations<br>• Widely distribute educational materials available that reflect the diversity of the community, including materials tailored for different cultural backgrounds, languages, and literacy levels<br>• Create an adopt and adapt approach to enable resources to be shared and localised in consultation with the local priority population communities |
| **6.** Strengthen collaboration and communication within the healthcare system<br>Purpose: To address availability issues by enhancing the efficiency and effectiveness of the screening process, and to tailor services to meet the diverse needs of all participants. | • Improve data-sharing and coordination among healthcare providers, government agencies, and community organisations. Develop a centralised system for tracking participant screenings and follow-ups, ensuring continuity of care<br>• Promote the use of My Health record |

# Appendix A - Literature review methodology

## A.1. Research questions

- What are the quality and safety considerations for cancer screening in priority populations?
- What are the specific issues in breast cancer screening in these priority populations (e.g., cultural safety, safety and considerations for trans and gender-diverse people)?

## A.2. Inclusion criteria

Table 6 presents the inclusion criteria for peer-reviewed and grey literature. The search will prioritise breast cancer populations but will incorporate relevant information from other cancer screening programs.

**Table 6: Inclusion criteria**

| Parameter | Criteria | |
|---|---|---|
| Population | Priority populations<br>• Women with disabilities, including mental illness<br>• First Nations people<br>• LGBTIQA+ people<br>• Culturally and linguistically diverse (CALD) **AND** | Cancer screening programs, not exclusively breast cancer |
| Interest/intervention | **1.** Current quality and safety mechanisms<br>**2.** Current standard-setting techniques<br>**3.** Future quality and safety mechanisms considerations<br>**4.** Improving service delivery and experience (e.g., access for women with disabilities to screening location)<br>**5.** Acceptability, cultural safety, intervention | |
| Publication types | • Peer-reviewed publications<br>• Review and evaluation reports from government bodies, organisations relevant to cancer screening, and quality and accreditation institutions, with reference to engagement with priority populations | |
| Publication date | Last 10 years | |

| Parameter | Criteria |
|---|---|
| Language | English |
| Countries | Australia, New Zealand, UK, Canada, Denmark, European Union |
| Notes | The focus is on participant cultural safety, experience and comfort, not on participation or invitation to screening programs. |

Exclusion criteria will be publications published before 2013 (i.e., more than 10 years ago) and publications not in English.

## A.3. Databases and sources

Peer-reviewed publications were identified through PubMed. The search strategies are presented in section A.4. Table 7 presents the grey literature sources

**Table 7: Grey literature sources**

| Australia | International |
|---|---|
| Cancer Australia | BME Against Cancer UK https://www.bmecancer.com/ |
| Cancer Council Australia – cultural diversity https://www.cancervic.org.au/about/culturally-linguistally-diverse-communities | |
| National Breast Cancer Foundation Australia | NHS England, e.g., Breast Cancer Screening Program – England |
| Australian Institute of Health and Welfare | Race Equality Foundation UK https://raceequalityfoundation.org.uk/health-and-care/cancer-and-black-and-minority-ethnic-communities/ |
| Ethnic Communities Council of Queensland | European Cancer Organisation's Inequalities Network https://www.europeancancer.org/topic-networks/7:inequalities.html |
| Australian Multicultural Health Collaborative | |
| Federation of Ethnic Communities Councils of Australia | Canadian Cancer Society https://cancer.ca/en/research/our-impact/saving-lives/cancer-care-delivery |
| Culturally and Linguistically Diverse Communities Health Advisory Group, Department of Health and Aged Care | Canadian Taskforce on Preventive Health Care |

| Australia | International |
|---|---|
| Women with Disabilities Australia | Cancer Care Ontario (Ontario Breast Screening Program) |
| National LGBTI Health Alliance (Australia) | |
| National Centre for Aboriginal and Torres Strait Islander Wellbeing Research (ANU) | |

Key search terms are presented in Table 8.

**Table 8: Key search terms**

| Topic | Key search terms | |
|---|---|---|
| Cancer screening | Cancer screening program | |
| Quality, safety | Quality assurance<br>Quality improvement<br>Quality monitoring<br>Standards<br>Patient safety | Benchmarking<br>Key performance indicator<br>Guideline adherence/compliance<br>Governance |
| Culturally diverse | CALD<br>Culturally and linguistically diverse<br>First Nations<br>Indigenous<br>Aboriginal and Torres Strait Islander<br>Migrant<br>Ethnic minority, ethnic groups<br>Multi-lingual groups | LGBTIQ, LGBTQI, LGBTIQA+<br>Gender-diverse<br>Sexual minorities, gender minorities<br>Lesbian, gay, bisexual, transgender and queer populations<br>Non-binary<br>Disability, disabilities, disabled<br>Physical disability, developmental disability, intellectual disability<br>Intellectual and developmental disabilities<br>Mental illness |
| Consumer experience, acceptability, sensitivity | Patient/consumer safety<br>Patient/consumer experience<br>Culturally sensitive, culturally safe, culturally appropriate, culturally tailored | Acceptability<br>Personal experience |
| Consumer engagement | Community engagement and consultation<br>Facilitators, enablers, access, accessibility | Engagement<br>Empathy<br>LGBTIQ Competence |

| Topic | Key search terms | |
|---|---|---|
| | Barriers, inhibitors, exclusive practice<br>Culturally responsive, culturally competent, cultural competence, cultural humility | Inclusive practice, reflective practice, affirmative practice<br>Equitable/inequitable practice |
| Countries | Australia<br>New Zealand<br>UK, England, Wales, Scotland, Northern Ireland | Denmark<br>Canada<br>Europe, European Union |

# A.4. Peer-reviewed literature search results

Table 9 presents the PubMed search strategy.

**Table 9: PubMed search strategy - priority populations and considerations in cancer screening**

| # | Search terms | Results |
|---|---|---|
| 1 | ((((((Cultural Diversity[MeSH Terms]) OR (Indigenous Peoples[MeSH Terms])) OR (Health Disparate, Minority and Vulnerable Populations[MeSH Terms])) OR (Ethnic and Racial Minorities[MeSH Terms])) OR (Ethnicity[MeSH Terms])) OR (Minority Groups[MeSH Terms])) OR (Minority Health[MeSH Terms]) | 256,924 |
| 2 | Sexual and Gender Minorities[MeSH Terms] | 17,435 |
| 3 | ((((Developmental Disabilities[MeSH Terms]) OR (Communication Disorders[MeSH Terms])) OR (Disabled Persons[MeSH Terms])) OR (Intellectual Disability[MeSH Terms])) OR (Mental Disorders[MeSH Terms]) | 1,583,706 |
| 4 | ((((((((((culturally[Title/Abstract] AND linguistically diverse[Title/Abstract]) OR (CALD[Title/Abstract])) OR (First Nations[Title/Abstract])) OR (Indigenous[Title/Abstract])) OR (Aboriginal[Title/Abstract] AND Torres Strait Islander[Title/Abstract])) OR (Migrant[Title/Abstract])) OR (Immigrant[Title/Abstract])) OR (Ethnic minorit*[Title/Abstract])) OR (Multilingual group*[Title/Abstract])) OR (Multi-lingual group*[Title/Abstract])) OR (Ethnic group*[Title/Abstract]) | 131,562 |
| 5 | ((((((((((gender diverse[Title/Abstract]) OR (LGBTIQ*[Title/Abstract])) OR (LGBTQI*[Title/Abstract])) OR (lesbian[Title/Abstract])) OR (gay[Title/Abstract])) OR (bisexual[Title/Abstract])) OR (homosexual[Title/Abstract])) OR (transgender[Title/Abstract])) OR (queer[Title/Abstract])) OR (nonbinary[Title/Abstract])) OR (non-binary[Title/Abstract])) OR (sexual minorit*[Title/Abstract]) | 40,871 |

| # | Search terms | Results |
|---|---|---|
| 6 | ((((((((((disabled person*[Title/Abstract]) OR (disabled[Title/Abstract])) OR (disability[Title/Abstract])) OR (disabilities[Title/Abstract])) OR (physical disability[Title/Abstract])) OR (developmental disability[Title/Abstract])) OR (intellectual disability[Title/Abstract])) OR (intellectual[Title/Abstract] AND developmental disability[Title/Abstract])) OR (mental disorder[Title/Abstract])) OR (mental illness[Title/Abstract])) OR (behavior disorder[Title/Abstract])) OR (psychiatric disorder[Title/Abstract])) OR (psychiatric illness[Title/Abstract]) | 334,884 |
| 7 | #1 or #2 or #3 or #4 or #5 or #6 | 2,115,273 |
| 8 | (((Health Services for Persons with Disabilities[MeSH Terms]) OR (Culturally Appropriate Technology[MeSH Terms])) OR (Cultural Competency[MeSH Terms])) OR (Culturally Competent Care[MeSH Terms]) | 8,692 |
| 9 | (((((patient safety[MeSH Terms]) OR (patient comfort[MeSH Terms])) OR (patient participation[MeSH Terms])) OR (Patient Acceptance of Health Care[MeSH Terms])) OR (Health Services Accessibility[MeSH Terms])) OR (Empathy[MeSH Terms]) | 348,594 |
| 10 | ((((((((((patient safety[Title/Abstract]) OR (consumer safety[Title/Abstract])) OR (patient experience[Title/Abstract])) OR (consumer safety[Title/Abstract])) OR (culturally sensitive[Title/Abstract])) OR (culturally safe[Title/Abstract])) OR (cultural safety[Title/Abstract])) OR (culturally appropriate[Title/Abstract])) OR (culturally tailored[Title/Abstract])) OR (patient acceptability[Title/Abstract])) OR (consumer acceptability[Title/Abstract]) | 68,525 |
| 11 | ((((((((((((((((((((community engagement[Title/Abstract]) OR (consumer consultation[Title/Abstract])) OR (facilitator*[Title/Abstract])) OR (enabler*[Title/Abstract])) OR (accessibility[Title/Abstract])) OR (barrier*[Title/Abstract])) OR (inhibitor*[Title/Abstract])) OR (exclusive practice[Title/Abstract])) OR (exclusion practice[Title/Abstract])) OR (culturally responsive[Title/Abstract])) OR (culturally competent[Title/Abstract])) OR (cultural competence[Title/Abstract])) OR (cultural humility[Title/Abstract])) OR (patient engagement[Title/Abstract])) OR (consumer engagement[Title/Abstract])) OR (empathy[Title/Abstract])) OR (LGBTIQ competence[Title/Abstract])) OR (inclusive practice[Title/Abstract])) OR (affirmative practice[Title/Abstract])) OR (reflective practice[Title/Abstract])) OR (equitable practice[Title/Abstract])) OR (inequitable practice[Title/Abstract]) | 2,023,910 |
| 12 | #8 or #9 or #10 or #11 | 2,376,323 |
| 13 | early detection of cancer[MeSH Terms] | 38,726 |
| 14 | cancer screening[Title/Abstract] | 42,361 |
| 15 | (((program[Title/Abstract]) OR (programme[Title/Abstract])) OR (pathway[Title/Abstract])) OR (assessment[Title/Abstract]) | 2,783,578 |

| # | Search terms | Results |
|---|---|---|
| 16 | #14 and #15 | 10,905 |
| 17 | #13 or #16 | 44,703 |
| 18 | ((((((((((((Quality Improvement[MeSH Terms]) OR (Quality Assurance, Health Care[MeSH Terms])) OR (Quality of Health Care[MeSH Terms])) OR (Patient Satisfaction[MeSH Terms])) OR (Patient Comfort[MeSH Terms])) OR (Benchmarking[MeSH Terms])) OR (Program Evaluation[MeSH Terms])) OR (Health Care Quality, Access, and Evaluation[MeSH Terms])) OR (Health Care Evaluation Mechanisms[MeSH Terms])) OR (Patient Safety[MeSH Terms])) OR (Guideline Adherence[MeSH Terms])) OR (Certification[MeSH Terms])) OR (Accreditation[MeSH Terms])) OR (Governing Board[MeSH Terms])) OR (Clinical Governance[MeSH Terms]) | 8,870,310 |
| 19 | (((Accreditation[Title/Abstract]) OR (Accreditation program[Title/Abstract])) OR (Accreditation programme[Title/Abstract])) OR (Accreditation requirement[Title/Abstract]) | 19,297 |
| 20 | ((((((Quality requirement[Title/Abstract]) OR (Quality assurance[Title/Abstract])) OR (Quality improvement[Title/Abstract])) OR (Quality monitoring[Title/Abstract])) OR (Quality criteria[Title/Abstract])) OR (Quality assurance protocol[Title/Abstract])) OR (Quality assurance monitoring plan[Title/Abstract]) | 94,355 |
| 21 | (((Monitoring[Title/Abstract]) OR (Audit[Title/Abstract])) OR (Auditing[Title/Abstract])) OR (Auditing plan[Title/Abstract]) | 695,499 |
| 22 | ((((Standard[Title/Abstract]) OR (Standards[Title/Abstract])) OR (Standards criteria[Title/Abstract])) OR (benchmark[Title/Abstract])) OR (benchmarking[Title/Abstract]) | 1,311,038 |
| 23 | (((Evaluation[Title/Abstract]) OR (Program evaluation[Title/Abstract])) OR (Programme evaluation[Title/Abstract])) OR (Feedback[Title/Abstract]) | 1,657,969 |
| 24 | (Regulatory framework[Title/Abstract]) OR (Assessment framework[Title/Abstract]) | 4,474 |
| 25 | (((Guideline compliance[Title/Abstract]) OR (Policy compliance[Title/Abstract])) OR (Protocol compliance[Title/Abstract])) OR (governance[Title/Abstract]) | 23,166 |
| 26 | (Key performance indicator[Title/Abstract]) OR (KPI[Title/Abstract]) | 981 |
| 27 | (standards development[Title/Abstract]) AND (technique[Title/Abstract]) | 5 |
| 28 | ((((((((Health care quality assessment[Title/Abstract]) OR (Healthcare quality assessment[Title/Abstract])) OR (Health care quality assurance[Title/Abstract])) OR (Healthcare quality assurance[Title/Abstract])) OR (Quality of care[Title/Abstract])) OR (Healthcare evaluation[Title/Abstract])) OR (Health care evaluation[Title/Abstract])) OR (Health care evaluation | 47,256 |

| # | Search terms | Results |
|---|---|---|
| | mechanisms[Title/Abstract])) OR (Healthcare evaluation mechanisms[Title/Abstract]) | |
| 29 | #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 | 10,901,793 |
| 30 | #7 and #12 and #17 and #29 | 1,436 |
| 31 | ((((((((((Australia[MeSH Terms]) OR (New Zealand[MeSH Terms])) OR (Canada[MeSH Terms])) OR (Denmark[MeSH Terms])) OR (United Kingdom[MeSH Terms])) OR (England[MeSH Terms])) OR (Scotland[MeSH Terms])) OR (Northern Ireland[MeSH Terms])) OR (Wales[MeSH Terms])) OR (Europe[MeSH Terms])) OR (European Union[MeSH Terms]) | 1,936,052 |
| 32 | ((((((((((Australia[Title/Abstract]) OR (New Zealand[Title/Abstract])) OR (Canada[Title/Abstract])) OR (Denmark[Title/Abstract])) OR (United Kingdom[Title/Abstract])) OR (England[Title/Abstract])) OR (Scotland[Title/Abstract])) OR (Northern Ireland[Title/Abstract])) OR (Wales[Title/Abstract])) OR (Great Britain[Title/Abstract])) OR (Europe[Title/Abstract])) OR (European Union[Title/Abstract]) | 603,991 |
| 33 | #31 or #32 | 2,192,802 |
| 34 | #30 and #33 | 245 |
| 35 | English[Language] | 31,694,236 |
| 36 | #34 and #35 | 237 |
| 37 | ("2013/01/01"[Date - Publication] : "3000"[Date - Publication]) | 13,878,212 |
| 38 | **#36 and #37** | **194** |

Search date: 4 December 2023

One hundred and ninety-four citations were retrieved. No duplicates were found. One hundred and ninety-four citations were screened by title and abstract and 27 were screened by full text. Nineteen publications were included in this report.

Publications on breast cancer screening were prioritised; studies of other cancer screening programs were included for the LGBTIQA+ population group as none were identified for breast cancer screening.

# Appendix B – First Nations women

## B.1. Context

Cancer is the second largest contributor to the burden of disease with breast cancer being the most common invasive cancer diagnosed for females. Despite a lower breast cancer incidence compared with non-indigenous women, fatalities occur at an elevated rate and breast cancers have an earlier age of onset. For First Nations women, there are also more advanced and distant tumours at diagnosis, fewer hospitalisations for breast cancer, and lower participation in breast screening[1].

## B.2. Barriers to the provision of quality and safe screening

Table 10 summarises a range of barriers identified from studies on participation in mammographic screening (Pilkington et al 2017[2]), barriers identified in preventing the early detection of cancer (Australian Indigenous HealthInfoNet 2020[3]) and factors impacting cancer outcomes[4,5]. These were validated and expanded in consultation with stakeholders.

**Table 10: Barriers to the provision of quality and safe breast screening – First Nations women**

| Individual level | Service level | System level |
|---|---|---|
| Accessibility<br>• Financial, transportation, remoteness, accommodation<br>• Family and community priorities, limiting a person's time to attend screening<br>• Participant disability and other comorbidities | **Acceptability and Appropriateness**<br>• Limited cultural knowledge and understanding<br>• Cultural misunderstandings, poor communication and discrimination (conscious and unconscious)<br>• Staff unwilling to be flexible with booking systems and other | • Valuing diversity<br>• Culturally safe environments; culturally secure and responsive environments<br>• Culturally appropriate service<br>• Wait time, short consultation, location of services<br>• Poor collaboration and communication between different |

[1] Tapia KA, Garvey G, Mc Entee M, Rickard M, Brennan P. Breast Cancer in Australian Indigenous Women: Incidence, Mortality, and Risk Factors. Asian Pac J Cancer Prev. 2017 Apr 1;18(4):873-884. doi: 10.22034/APJCP.2017.18.4.873. PMID: 28545182; PMCID: PMC5494235. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5494235/

[2] Pilkington, L., Haigh, M.M., Durey, A. et al. Perspectives of Aboriginal women on participation in mammographic screening: a step towards improving services. BMC Public Health 17, 697 (2017). https://doi.org/10.1186/s12889-017-4701-1

[3] https://healthinfonet.ecu.edu.au/healthinfonet/getContent.php?linkid=642055&title=Summary+of+cancer+among+Aboriginal+and+Torres+Strait+Islander+people&contentid=39480_1

[4] e-Learning Module 1: Improving Cancer Outcomes for First Nations Australians https://www.youtube.com/watch?v=TT1sHpiWQ6g

[5] https://www.mensies.edu.au/icms_docs/272632_Cancer_and_Aboriginal_and_Torres_Strait_Islander_people.pdf

| Individual level | Service level | System level |
|---|---|---|
| • Lack of internet access or phone service access<br>Appropriateness<br>• Language<br>• Cultural and spiritual beliefs e.g., fear of the results, combined with fatalistic beliefs around cancer and shame (e.g being naked)<br>• Health literacy<br>Approachability and Acceptability<br>• Lack of knowledge<br>• Other priorities in the community, eg Sorry Business<br>• Fear of discomfort<br>• Mistrust of health providers and systems[a]<br>• Distrust of staff who lack cultural literacy and sensitivity<br>• Disempowerment<br>• Experience of others<br>Affordability<br>• Costs associated with consultation fees, medicines, transport and lost wages<br>• For women who miss the BreastScreen mobile bus but require screening, it is $330 to be screened and Medicare does not cover | actions that would facilitate participation and continuing participation of First Nations women<br>**Availability**<br>• Access to First Nations staff<br>• Scarce resources, eg funding<br>• High staff turnover in First Nations-specific roles and organisations;<br>• Attracting and retaining staff<br>• Lack of interpreter<br>• Access to gender health professionals<br>• Communication of results in communities without postal services<br>• Availability of services in remote locations and communities<br>• Lack of coordination with local health teams<br>**Appropriateness**<br>• Lack of communicative tools (especially other languages)<br>• Lack of skills and training among providers | parts of the health system. This includes data-sharing to ensure participant follow-up care and the coordination required to provide transport and accommodation for women from remote communities. It is important to work with people and centres on the ground<br>• Equipment issues and maintenance<br>• Logistical issues of transporting participants, staff and equipment to screening locations for remote and very remote communities<br>• Lack of funding to transport women from remote communities to BreastScreen buses and to provide the necessary accommodation<br>• Lack of flexibility and contingency planning in scheduling BreastScreen bus appointments to accommodate event such as Sorry Business or natural disasters<br>• Lack of understanding that each remote community is different (e.g. level of remoteness) and has different needs in order to facilitate screening |

a Historic factors such as colonisation (including racism), and political and socio-economic disadvantage, which have had flow-on effects across generations and can include a lack of trust in healthcare professionals

It is noted that making a service **accessible** does not necessarily mean the service is **acceptable or appropriate**.

## B.3. Quality and safety initiatives for First Nations women

Table 11 describes the initiatives available across jurisdictions based on information readily available on websites. Note it does not mean that the service is not provided, only that it could not be easily found as being provided on the website.

## Table 11: BreastScreen initiatives by jurisdiction (websites accessed December 2023 and information provided by NT BreastScreen)

| Initiative | ACT [6] | NSW [7] | NT [8] | QLD [9] | SA [10] | TAS [11] | VIC [12] | WA [13] | C'wlth [14] |
|---|---|---|---|---|---|---|---|---|---|
| Education and Awareness | | | | | | | | | |
| The website provides access to information specific to First Nations people | | ✓ | | ✓ | ✓ | | ✓ | ✓ | ✓ |
| The website has an audio "listen" function | ✓ | | | | | | | | |
| Runs special events for Aboriginal women | | | ✓ | | ✓ | | | ✓[15] | |
| Access to a promotional video | | ✓ | ✓ | | ✓[16] | | ✓ | ✓ | |
| Access to written Health promotional material in four Indigenous languages | | | | | | | | | ✓ |
| Access to written Health promotional material (specific for First Nations) | | ✓ | ✓ | | | | ✓[17] | ✓ | |
| Note on the First Nations page screening is free | | ✓ | | | ✓ | | | ✓ | ✓ |
| Links to First Nations-specific websites for more resources | | ✓[18] | | | | | ✓**b** | | |
| Links to other government websites for more resources | ✓ | | ✓ | | ✓ | | | | |
| Holistic Health Approach | | | | | | | | | |
| Work with or encourage access to local Indigenous Health Workers so they can make breast screening appointment for participants | | ✓ | ✓ | ✓ | | | ✓**b** | ✓ | |

[6] https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/breastscreen-act
[7] https://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-for-aboriginal-women/
[8] https://nt.gov.au/wellbeing/cancer-services/breastscreennt
[9] https://www.breastscreen.qld.gov.au/client-support/aboriginal-and-torres-strait-islander-women
[10] https://www.breastscreen.sa.gov.au/community-engagement/aboriginal-people
[11] https://www.health.tas.gov.au/health-topics/cancer-screening/breast-screening
[12] https://www.breastscreen.org.au/community-support/aboriginal-people/
[13] https://www.breastscreen.health.wa.gov.au/Breast-screening/Aboriginal-women
[14] https://www.health.gov.au/our-work/breastscreen-australia-program
[15] https://www.breastscreen.health.wa.gov.au/About-Us/Information-sessions
[16] https://www.cancersa.org.au/aboriginal-cancer-screening-video-resources-for-health-professionals/
[17] https://www.breastscreen.org.au/resources/community/
[18] https://www.ourmobandcancer.gov.au/common-cancer-types/breast

| Initiative | ACT [6] | NSW [7] | NT [8] | QLD [9] | SA [10] | TAS [11] | VIC [12] | WA [13] | C'wlth [14] |
|---|---|---|---|---|---|---|---|---|---|
| Offer group bookings | | | ✓ | ✓ | ✓ | ✓* | ✓b | ✓ | |
| Offering screening days that are only for Aboriginal and Torres Strait Islander women in clinics or mobile vans | | | ✓ | ✓ | | | | ✓ | |
| Cultural Sensitivity/Safety | | | | | | | | | |
| Screening staff are all women (on the First Nations website) | | | ✓ | | ✓ | | | | |
| Acknowledge First Nation women's cultural and individual needs/ cultural safety | | ✓ | ✓ | | ✓ | | ✓ | ✓ | |
| Provide free privacy shawls or sarongs | | | ✓ | | | | ✓b | | |
| Culturally Competent Healthcare Providers | | | | | | | | | |
| Required to provide culturally safe and appropriate services to clients. BreastScreen receptionists, radiographers and health promotion staff were all trained | | | ✓ | | | | ✓b | | |
| Access to Healthcare | | | | | | | | | |
| Mobile vans | | ✓ | ✓a | ✓ | ✓ | ✓a | ✓ | ✓a | |
| Provide screening regular screening for 40 -74 every two years (specific for First Nations) | | ✓ | ✓ | | | | | | |
| Community Engagement | | | | | | | | | |
| Promote the use of Aboriginal Advisory group or Community Led design | | | ✓ | | | | ✓b | ✓ | |

a Not specifically for First Nations people

b As part of the Beautiful Shawl Project Implementation model

* https://www.health.tas.gov.au/health-topics/cancer-screening/breast-screening/make-breast-screening-appointment#group-bookings

Abbreviations: VACCHO, Victorian Aboriginal Community Controlled Health Organisation

# B.4. Quality and safety initiatives being implemented for First Nations women internationally

This review includes Ontario[19] and New Zealand[20] First Nations services, with a focus on additional services to those being published as being available in Australia as outlined in Table 11.

## B.4.1. Breast Screening Aotearoa (New Zealand)

In May 2023, Health New Zealand released a Quality Improvement Review of Breast Screening Aotearoa, which sets out the pathway to improve breast screening services for women across New Zealand.[21] The review team recommended a strengthened focus on improving cancer screening access and experiences for wāhine Māori and Pacific women. It included 26 recommendations focused on:

- Opportunities to work as one system: the Breast Screening Aotearoa program is not achieving equity for Māori and Pasifika. Health system reforms provide the opportunity to develop a cohesive, coordinated, population-based approach to all cancer screening in Aotearoa New Zealand. Creating a one system culture will require a significant reset of relationships between the National Screening Unit and providers and with Māori, Pasifika consumers and communities they serve.
- Te Tiriti o Waitangi with co-governance partnership model over the national screening programs
- Equity:
  - The Breast Screening Aotearoa program is not achieving equity and is not meeting the needs of wāhine Māori and Pasifika women.
  - Other underserved groups such as women living with disabilities and women who live rurally need to be identified, their lived experience understood and equitable approaches embedded within the Breast Screening Aotearoa program.
- Consumer and family engagement:

[19] https://www.cancercareontario.ca/en/cancer-care-ontario/programs/aboriginal-programs/indigenous-cancer-strategy
[20] https://www.nsu.govt.ns/health-professionals/breastscreen-aotearoa
[21] https://www.tewhatuora.govt.ns/whats-happening/news-and-updates/older-news-items/quality-improvement-review-sets-out-new-pathway-for-breast-screening-services-in-aotearoa/

- the National Screening Unit acknowledges it needs to improve its approach to consumer and whānau engagement and intends to develop a consumer and whānau engagement strategy.
- Information for and communication with consumers and whānau needs to be improved.

- Clinical quality and safety include:
  - the design of the Breast Screening Aotearoa co-governance model a review of the clinical governance model; a review of roles and responsibilities; and a reset of relationships
  - co-design and publish a comprehensive set of Breast Screening Aotearoa program policies that reflect the Tiriti obligations and a comprehensive commitment to Pasifika health equity
  - review and redesign the Breast Screening Aotearoa's external auditing program to focus on what is most important, based on priority indicators
  - co-design and implement a learning system that underpins a new governance structure
  - identification and reporting of adverse events
- Monitoring, reporting and evaluation, including applying data sovereignty principles, data quality and co-design and implementing data collection, analytics, monitoring, reporting frameworks and new research
- Workforce, including equitable representation of Māori health and Pasifika health expertise and developing a culturally safe and competent non-Māori workforce
- Continuous quality improvement to build a quality and safety learning system across the program with the support of Te Whatu Ora and Te Aka Whai Ora, applying training and quality improvement methods, and developing and implementing specific quality improvement programs.

A Breast Screening Action Plan will be developed by Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority) to respond to the recommendations, with a focus on improving access to screening and experiences for Māori and Pacific women. The Action Plan focuses on:

- a dedicated workforce recruitment and retention strategy for Māori, Pacific peoples and people with lived experience of disability
- co-designing bespoke services for whānau and Pacific peoples, including targeted programs and a new whānau and consumer panel
- broadening the focus of the screening programs to include well-being and Hauora health gain for individuals, whānau and the community

- better integrating different types of cancer screening services, so that cancer screening is a better experience and women can access all cancer screening programs
- co-design of a kaupapa Māori accreditation program for breast screening providers
- new research to improve access to screening for wāhine Māori, Pacific women, Tangata Whaikaha consumers with lived experience of disability, and other groups at increased risk of breast cancer death who are underserved by the screening program including rural and lower socio-economic communities

### B.4.2. Ontario Indigenous Cancer Care (Canada)

To date, the Ontario Indigenous Cancer Care Unit has focused on developing culturally relevant material for First Nations people to help them learn more about cancer and other chronic diseases and has published many culturally relevant resources to encourage Indigenous people to accept and participate in cancer education, screening, prevention and treatment programs. While they continue that work, they will also aim to improve healthcare providers' understanding of the historical and cultural factors that contribute to Indigenous experiences of cancer, and other chronic diseases and the healthcare system by:

- Building and promoting relationships with indigenous partners based on trust and mutual respect including:
  - Build, grow, strengthen and sustain relationships
  - Support Indigenous health priorities throughout the health system transition
  - Promote respect for and understanding of Indigenous knowledge and traditional practice
- Measurement, Monitoring and Evaluation
  - Compile and develop information to improve the quality of the cancer experience for participants, families and healthcare providers (including identifying, accessing and analysing health data, addressing relevant health priorities using data, supporting communities in using health data for policy and program development and understanding the related implications and explore opportunities to partner with organisations with shared health data goals.
- Prevention
- Screening - increase participation in cancer screening among First Nations people across the province including:
  - improve access and participation in screening
  - improve coordination and integration of screening service
  - support specific initiatives to improve organised screening programs

- Palliative and end of life care
- Education increases the knowledge and awareness among First Nations people about cancer and other chronic diseases and among healthcare providers about cultural safety including:
  - Address gaps in education and programming, including measuring the impact of resources and increasing indigenous youth audience and engagement with cancer education initiatives
  - Support and increase culturally safe education and programming, including sustaining, enhancing and evaluating the Indigenous Relationship and Cultural Awareness Courses and working with partners to gather information on cultural safety activities across the health system
  - Support education and training for providers and Indigenous people, inform and adapt resources, training and tools for providers working with Indigenous people and continue to develop and disseminate culturally appropriate education resources for First Nations people
  - Collaborate with partners to engage in knowledge transfer and exchange, including compiling and sharing information to respond to Indigenous peoples' emerging health education needs and priorities and continue to support knowledge sharing and dissemination with Indigenous partners

## B.5. Additional quality and safety initiatives for consideration

Based on the review of the information above, the range of information included in the references below and input from stakeholders, the following list of potential gaps in information, initiatives or areas where more work is required are listed for review. These considerations have also been mapped to the National Aboriginal Community Controlled Health Organisation (NACCHO) Aboriginal and Torres Strait Islander Cancer Plan Strategic Objectives and Outcomes. They include:

- **Funding and resources**
  - To be able to provide a comparative service across states e.g. mobile van with air suspension, online booking, promotional events, maintenance of the mobile vans and screening equipment, transport of equipment, staff and participants, accommodation for staff and participants, for "privacy shawls", resources in language
  - Access to resources that can be adapted and adopted, e.g videos in seven main dialects, paper materials, website content

- Funding barriers that limit access for women from remote communities who require transport and accommodation to be screened.
- Alternative funding pathways for women who miss the BreastScreen mobile bus but require screening; it is $330 to be screened, and Medicare does not cover it.

- **Collaboration**
  - Provide services within remote communities wherever possible in collaboration with the local health teams who can prepare the community. Where this is not possible, Holistic coordination and a large team approach are required to bring women from remote communities to a BreastScreen bus site. Also, to allow for forward planning and logistical planning, so women from remote communities can be provided with transport and accommodation to undertake screening. This requires advanced notice and ongoing contact to coordinate
  - Engagement with local services prior to sending BreastScreen buses to allow for contingency planning for events such as Sorry business or natural disasters. This may also require the flexibility of screening schedules to accommodate unforeseen events and result in women missing out on screening. This can result in costs for the women if they require screening outside of the BreastScreen service.
- **Cultural sensitivity/safety, responsiveness and security:**
  - Services are evaluated if culturally safe and First Nations peoples find it culturally safe and welcoming[22] (NACCHO 4.2)
    - Cultural respect is achieved when the health system is a safe environment for Indigenous Australians, and where cultural differences are respected[23].
    - Aspects of cultural safety include good communication, respectful treatment, empowerment in decision-making and the inclusion of family members[24].
  - Widespread involvement of First Nations leaders, elders, and community members in the development and implementation of breast cancer screening programs to ensure cultural relevance, noting different communities may have distinct beliefs, practices, and languages.

[22] https://insightplus.mja.com.au/2023/44/australias-breast-cancer-policies-failing-indigenous-women/
[23] https://www.aihw.gov.au/reports/indigenous-australians/cultural-safety-health-care-framework/contents/summary
[24] https://www.aihw.gov.au/reports/indigenous-australians/cultural-safety-health-care-framework/contents/summary

- Women are given appropriate emotional support especially if additional assessment and diagnosis[25,26] (NACCHO 4.5)
- Access to an interpreter, to ensure Aboriginal and Torres Strait Islander peoples receive and can discuss cancer-related information in their language of choice (NACCHO 1.3).

- **Community Engagement:**
  - Engagement with First Nations communities in a meaningful way to build trust and understanding. Established partnerships with local organisations, leaders, and healthcare providers, people with lived experience. Considering community preferences and perspectives when designing and promoting breast cancer screening programs (NACCHO 1.1), (NACCHO 1.3), (NACCHO 1.5), (NACCHO 4.5)
  - A relationship between the local BreastScreen service and Aboriginal and Torres Strait Islander Health Workers and Health Practitioners to educate, recruit, and support women being screened for the first time or rescreened (NACCHO 4.1), (NACCHO 4.3)
  - Policy is rewritten in consultation with Indigenous people and provides solutions to the acknowledged issues[27] (NACCHO 1.1)
  - Co-designing bespoke services including targeted programmes (NACCHO 1.1)
  - Engaging with the community and local health services to identify the best ways to attract women to attend screening and explain the procedure and to identify women who are a priority for screening.
  - Access to locally made gifts (e.g privacy shawls) to improve the experience
- **Access to Healthcare:**
  - Continuing to address barriers to healthcare access to improve participation rates and the experience of the First Nations participants. (NACCHO 1.3), (NACCHO 1.4), (NACCHO 3.3). For example, staff being flexible with scheduling bookings and other actions and activities needed to facilitate First Nations women's participation and continued participation in breast screening. Also, the logistical barriers for women from remote communities, who will require transport and accommodation to attend screening.

[25] A handbook for Aboriginal and TorresStrait Islander Health Workers and Health Practitioners https://www.canceraustralia.gov.au/sites/default/files/publications/breast-cancer-handbook-aboriginal-and-torres-strait-islander-health-workers/pdf/2022_bcat_handbook.pdf

[26] https://insightplus.mja.com.au/2023/44/australias-breast-cancer-policies-failing-indigenous-women/

[27] https://insightplus.mja.com.au/2023/44/australias-breast-cancer-policies-failing-indigenous-women/

- There are tailored protocols for abnormal results catering to setting and community[28] (NACCHO 4.1), (NACCHO 4.2), (NACCHO 4.3), with supporting educational material (NACCHO 4.4)
- Logistical planning to make it more feasible for women from communities to attend screening in terms of location and transport.
- Communication of results for communities that do not have postal services. E.g., by sending letters to health services and AMSs so they can contact participants to discuss results, organise assessments if needed and set recall dates.
- Explore if 715 health checks can be utilised for catch-up screening to avoid the cost associated with a mammogram for asymptomatic participants.

- **Education and Awareness:**
  - Continuing to develop culturally sensitive educational materials and campaigns (with an emphasis on health literacy, lived experience and in a language of their choice) (NACCHO 1.3), (NACCHO 1.5), (NACCHO 2.1)
  - Using community-specific channels, such as local radio stations, community events, and social gatherings, to disseminate information and increase the Indigenous youth audience (NACCHO 2.1)
  - Measuring the impact of existing resources
  - Acknowledging, sharing and respecting Aboriginal and Torres Strait Islander peoples' cancer journeys and celebrating positive experiences to change the cancer narrative and remove the stigma and fear associated with cancer (NACCHO 5.2)
  - Staff understanding of community priorities, eg Sorry Business, community security, housing, food, and natural disasters.
  - Encouraging women from the community to visit screening facilities and meet the staff, even if they do not get screened that day.
  - Provide materials which can be localised for local needs. For example, having someone who has gone through the breast screening journey tell their story and having ambassadors from the community make videos about their journey.
  - Support and encourage local health teams to provide local events to educate and communicate with communities.
- **Holistic Health Approach (NACCHO 4.4) including:**

[28] https://insightplus.mja.com.au/2023/44/australias-breast-cancer-policies-failing-indigenous-women/

- Recognising the importance of holistic health within Indigenous communities, which includes considering physical, mental, emotional, and spiritual wellbeing.
- Integrating breast cancer screening into broader health initiatives and emphasising the connection between overall health and cancer prevention. For example, treating breast screening as "women's business", where they can also have health promotion yarning and have a Pap smear.

- **Culturally Competent Healthcare Providers include:**
  - Ensuring screening providers receive cultural competence training to understand and respect the cultural nuances of providing healthcare to First Nations women (NACCHO 3.3), (NACCHO 4.2)
  - Promoting the recruitment, retention and funding of First Nations healthcare professionals to enhance trust and cultural understanding (NACCHO 1.2), (NACCHO 4.1)
  - Individuals, organisations and systems ensure their cultural values do not negatively impact on Aboriginal peoples, including addressing the potential for unconscious bias, racism and discrimination[29] (NACCHO 4.2)
  - The provider is local and familiar with Indigenous culture and community. The provider is then likely to understand local needs, customs and culture[30]
  - Co-design of First Nations accreditation programme for breast screening providers (NACCHO 1.1)
  - Established and permanently employed dedicated cancer support officer positions and local champions to enhance and deliver culturally safe cancer care to Aboriginal and Torres Strait Islander peoples (NACCHO 4.2)
  - Attracting health staff who live in the community.
  - Working with local healthcare providers e.g. AMS, to understand any cultural sensitives for that area

- **Data Collection and Research:**
  - Improved evidence on current program performance for this priority group
  - Compile and develop information to improve the quality of the BreastScreen experience for participants, families and screening providers
  - Respect community autonomy and obtain informed consent when collecting and using health data

[29] https://www.health.vic.gov.au/health-strategies/aboriginal-and-torres-strait-islander-cultural-safety
[30] https://insightplus.mja.com.au/2023/44/australias-breast-cancer-policies-failing-indigenous-women/

- Improve Indigenous Data Sovereignty so that Aboriginal and Torres Strait Islander health data – including cancer data – are used for shared decision-making, co-design and local leadership (NACCHO 5.1)
- Strengthen stakeholder engagement and adoption by mainstream health systems and data custodians of the five agreed principles for Indigenous Data Sovereignty (NACCHO 5.1)
- Ensure cancer research and evaluation focuses on priorities identified and led by Aboriginal and Torres Strait Islander Communities (NACCHO 5.2)
- Increase the number of Aboriginal and Torres Strait Islander academic scholars and their access to research infrastructure (NACCHO 5.2)
- Listen to and incorporate views and feedback of Aboriginal and Torres Strait Islander peoples affected by cancer and the workforce who manage these issues every day (NACCHO 5.3)
- Support organisations to apply CQI frameworks in evaluating information management system software in order to identify data gaps (NACCHO 5.4)
- Improve data accessibility and sharing to allow for follow-up care. For example, send results to AMS and share results on My Health Record
- Improve data sovereignty by providing a better understanding of what data is collected and how it is shared

- **Strategic and institutional reform:**
  - Individuals, organisations and systems ensuring self-determination for Aboriginal people. This includes sharing power (decision-making and governance) and resources with Aboriginal communities. It's especially relevant for the design, delivery and evaluation of services for Aboriginal people[31] (NACCHO 1.1)
  - Aboriginal and Torres Strait Islander women are consulted in the formation. That policy states the pathway women with symptoms of breast cancer should take (instead of only stating they are not appropriate candidates for screening). That policy must provide appropriate solutions for the barriers that Aboriginal and Torres Strait Islander women face. The policy should not be based on the assumption of adherence to guidelines by the consumer[32] (NACCHO 1.5), (NACCHO 4.4)

[31] https://www.health.vic.gov.au/health-strategies/aboriginal-and-torres-strait-islander-cultural-safety

[32] Christie V, Riley L, Green D, Snook K, Henningham M, Rambaldini B, Amin J, Pyke C, Varlow M, Goss S, Skinner J, O'Shea R, McCowen D, Gwynne K. Does breast cancer policy meet the needs of Aboriginal and Torres Strait Islander women in Australia? a review. Int J Equity Health. 2023 Jul 5;22(1):129. doi: 10.1186/s12939-023-01941-3. PMID: 37408069; PMCID: PMC10324194.

- Collaborate with partners to engage in knowledge transfer and exchange (including compiling and sharing information to respond to First Nations peoples' emerging health education needs and priorities and continue to support knowledge sharing and dissemination with Indigenous partners)

Note: The recent Aboriginal and Torres Strait Islander Cancer plan by NACCHO[33] further highlighted this vision for this Plan must be sufficient to sustain effort across all components of the Australian healthcare system. It must meet the needs of all Aboriginal and Torres Strait Islander peoples, including intersectional groups such as people with a disability or other chronic conditions and people who identify as lesbian, gay, bisexual, transgender, intersex, queer, asexual and other sexually or gender-diverse identities (LGBTIQA+). This ensures equitable, culturally safe, holistic and evidence-based cancer prevention, screening, treatment, and supportive care can be accessed by all Aboriginal and Torres Strait Islander peoples.

## B.6. Other documents reviewed

1. Christie, V.; Green, D.; Amin, J.; Pyke, C.; Littlejohn, K.; Skinner, J.; McCowen, D.; Gwynne, K. 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, 18, 6073. https://doi.org/10.3390/ijerph18116073
2. Byers L, Michell K, McCullough K. Awareness, acceptability and access to screening mammography for remote Aboriginal women. Health Promot J Austr. 2018;29(3):366-7.
3. The National Aboriginal and Torres Strait Islander Health Plan from 2021 to 2031
4. The National Aboriginal and Torres Strait Islander Cancer Framework
5. Cancer Australia's Australian Cancer Plan — one of this plan's strategic objectives is achieving equity in cancer outcomes for Aboriginal and Torres Strait Islander peoples;
6. Victorian Aboriginal Cancer strategy from 2023 to 2028, Victorian Aboriginal Community Controlled Health Organisation (VACCHO); and the marra ngarrgoo, marra goorri, the Victorian Aboriginal Health, Medical and Wellbeing Research Accord (VACCHO).

[33] https://www.naccho.org.au/app/uploads/2023/10/NAC_CancerPlan_Oct2023_231018_FA_online.pdf

# Appendix C – CALD women

## C.1. Context

In the 2021 census, just over 7 million people in Australia were born overseas, representing 27.6% of the population. The proportion of Australian residents born overseas (first generation) or have a parent born overseas (second generation) has moved to above 50% (51.5%). Australia has continued to be a CALD country with the growth of communities from Nepal, India, Pakistan, Iraq and the Philippines. In 2021, 5.8 million people (22.8%) reported using a language other than English at home. This was an increase from 4.9 million people (21.6%) in 2016. In 2021, 872,000 people spoke English not well or not at all. This represented 15.1% of the 5.8 million people who used another language at home. Between 2019 to 2020, the biennial breast screening participation rate for CALD women in NSW aged 50 to 74 was 39.3% compared to 52.6% for non-CALD women.

## C.2. Barriers to the provision of quality and safe screening

The majority of the literature focused on the barriers to healthcare for multicultural populations, with a small number of publications relevant to breast screening. A range of barriers have been summarised in Table 12 the documents reviewed are included at the end of this Appendix. Note that not all barriers are relevant to all CALD groups. These barriers were validated and expanded in consultation with stakeholders.

**Table 12: Barriers to the provision of quality and safe breast screening – CALD women**

| Individual level | Service level | System level |
|---|---|---|
| **Accessibility**<br>• Practical challenges associated with making appointments. Online booking systems that direct consumers to telephone if they need an interpreter is an additional barrier, especially if they do not speak English<br>• Accessing screening services<br>• Managing priorities, such as family commitments<br>**Appropriateness**<br>• Communicative problems (including not being able to use the booking system)<br>• Low health literacy | **Approachability**<br>• Using unfamiliar biomedical jargon<br>• Lack of knowledge of the needs of people<br>• Lack of experience<br>• Staff lacking training in cultural sensitivity and cultural safety, which should be ongoing and not once-off or intermittent<br>• Underutilising of bicultural workers, who can support both consumers and healthcare workers<br>**Acceptability**<br>• Insufficient social supports<br>• Limited multicultural sensitivity knowledge and understanding<br>• Making cultural assumptions | • Valuing diversity<br>• Institutionalised cultural knowledge<br>• Culturally safe environments<br>• Culturally appropriate service<br>• Poor collaboration between different parts of the health system<br>• Lack of a system to record the reasonable adjustments to care for multicultural persons<br>• Multicultural person inclusion among decision-makers in the health sector |

| Individual level | Service level | System level |
|---|---|---|
| • Lack of acknowledgement of clients' individual needs and cultural preferences<br>**Approachability and acceptability**<br>• A lack of knowledge and awareness of screening<br>• Screening is not a feature of the health system within countries of origin and is an entirely new concept<br>• Difficulty in using or understand available information<br>• Lack of social support or the skills needed to navigate healthcare services<br>• Fear of cancer diagnoses and its consequences<br>• Afraid privacy will not be maintained<br>• Fear driven by personal beliefs<br>• Negative expectations<br>• Health literacy domains were related to lower emotional breast screening barriers<br>• Fatalistic cancer attitudes<br>• Perceived disrespect from screening providers<br>• Feelings of embarrassment<br>• Experiencing pain<br>• Discomfort<br>• Past negative experiences<br>• Lack of social support<br>• Number of comorbid condition<br>• Cultural or religious beliefs about modesty, including if a male health worker is conducting screening.<br>• Talking about their bodies and serious illnesses is considered unusual and embarrassing.<br>• Having an interpreter in the intimate situation of screening is awkward and embarrassing, eg having a male interpreter, or having to access interpreters online in smaller or rural services.<br>• Experience of trauma<br>**Affordability**<br>• Costs of taking time off work<br>• Need to secure childcare | • Risk misinterpretation<br>**Availability**<br>• Lack of interpreter (this includes the effectiveness of interpreters when the service is provided over the phone)<br>• Participants not informed/aware interpreters are available and free and so do not ask for one.<br>**Appropriateness**<br>• Lack of communicative tools. Videos are expensive to prepare but may be needed for some groups who do not have reading literacy.<br>• Lack of skills and training among providers<br>• Risk of re-traumatising clients in the absence of trauma-informed approaches to care<br>• Obtaining consent may need family involvement beyond giving family information about the person's procedure because in some cultures, the family needs to agree to the procedure or older people may rely on family members for decision-making.<br>• Adapt service delivery so that it reflects an understanding of the diversity between and within cultures.<br>• Diversity in the service workforce to reflect the diversity of the consumer, so that consumers see people they are familiar with.<br>• Cultural safety of workforce members. To attract and retain diverse staff, they need to be "looked after", eg if they face racism<br>• Health promotion campaigns need to have diversity as well or CALD women, if they don't see someone like them in a campaign, think breast cancer does not affect them, or if it does, they cannot attend to get help.<br>• Interpreters lack training to understand the context of breast screening and so are unprepared. | • Capacity for cultural self-assessment<br>• Inconsistencies in record management systems. There needs to be connection and streamlining between private and public, an easy way to manage and look after participants to ensure continuity of care, so participants do not have to tell their stories again and again. Also to mitigate fears from consumers and staff that something is left out.<br>• Staff training in cultural sensitivity and cultural safety may not be compulsory for all workforce<br>• Units covering cultural sensitivity and cultural safety may not be available and/or mandatory under the university medical/clinical health programs<br>• Lack of data on the cultural safety of services. This also includes the accessibility of feedback/evaluation forms<br>• Lack of a nationwide mandatory set of 'CALD-related participant data' that is easily accessible for staff e.g. country of birth, interpreter required, main language other than English spoken at home, etc. This would ensure all medical professionals in contact with the participant are aware of the participant's needs. |

# C.3. Quality and safety initiatives for CALD women

Table 13 describes the initiatives available across jurisdictions based on information readily available on websites. Note it does not mean that the service is not provided, only that it could not be easily found as being provided on the website.

**Table 13: BreastScreen initiatives by jurisdiction (websites accessed December 2023)**

| Initiative | ACT [34] | NSW [35] | NT [36] | QLD [37] | SA [38] | TAS [39] | VIC [40] | WA [41] | C'wlth [42] |
|---|---|---|---|---|---|---|---|---|---|
| **Education and Awareness** | | | | | | | | | |
| The website has access to information specific to women from multicultural communities | ✓ | ✓ | | ✓ | ✓ | | ✓ | ✓ | |
| The website has an audio "listen" function (in English) | ✓ | | | | | ✓ | | | |
| The website can be translated or is available in multiple languages easily or available in other languages | ✓ | ✓ | | | ✓ | | ✓ | | |
| Screening staff are all women (on the CALD information page) | ✓ | ✓ | | | | | | | |
| Videos in other languages | | | | ✓ | | | | | |
| Access to written health promotional material (in other languages) | ✓ | ✓ | | ✓ | | | ✓ | ✓ | ✓ |
| Note on the page that screening is free | | ✓ | | | ✓ | | | ✓ | |
| The website includes culturally appropriate references | | | | | ✓ | | ✓ | ✓ | |
| Links to other government websites for more resources | ✓ | ✓ | | | | | | | |
| Education tools for community events | | ✓[43] | | | | | | ✓ | |
| Information sessions | | | | | ✓ | | | ✓ | |
| Community Service Announcement (radio) developed for distribution to | | ✓[44] | | | | | | | |

[34] https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/breastscreen-act
[35] https://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-in-other-languages
[36] https://nt.gov.au/wellbeing/cancer-services/breastscreennt
[37] https://www.breastscreen.qld.gov.au/client-support/women-from-multicultural-communities
[38] https://www.breastscreen.sa.gov.au/community-engagement/culturally-and-linguistically-diverse-people
[39] https://www.health.tas.gov.au/health-topics/cancer-screening/breast-screening
[40] https://www.breastscreen.org.au/community-support/culturally-and-linguistically-diverse-people/
[41] https://www.breastscreen.health.wa.gov.au/Breast-screening/Multicultural-women
[42] https://www.health.gov.au/resources/translated?f[0]=h_translations_our_work:7420
[43] https://www.breastscreen.nsw.gov.au/resources/facilitator-manual-breast-health-and-breast-screening/
[44] https://www.breastscreen.nsw.gov.au/resources/multicultural-promo-%E2%80%93-community-service-announcement-(radio)/

| Initiative | ACT [34] | NSW [35] | NT [36] | QLD [37] | SA [38] | TAS [39] | VIC [40] | WA [41] | C'wlth [42] |
|---|---|---|---|---|---|---|---|---|---|
| radio networks and has been recorded in multiple languages | | | | | | | | | |
| **Communication Accessibility** | | | | | | | | | |
| Providing access to free interpreters. | | | | | ✓ | | | | |
| Providing access to free interpreters. Note: "If you need an interpreter, you won't be able to book a breast screening appointment online" or "call the Translating and Interpreting Service to book an appointment and arrange an interpreter" | | ✓ | | ✓ | | ✓ | ✓ | | |
| **Appointment Scheduling** | | | | | | | | | |
| Group bookings | | | | ✓ | ✓ | ✓a | ✓ | ✓ | |
| Familiarisation visits | | | | | | | ✓ | | |
| Feedback | | | | | | | | | |
| Contact to provide feedback on the page | | | | | | | | ✓ | |

a. Not specifically for CALD communities

# C.4. Quality and safety initiatives being implemented for CALD women internationally

NHS England provides "Guidance on Breast screening: reducing inequalities updated 8 June 2022"[45] includes information on:

- Recording ethnicity for women who attend for screening and estimate whether particular ethnic groups have lower attendance for screening.
- The call and recall IT system may hold details of a woman's preferred language, where this has been populated. It may also indicate if an interpreter is required, which would be useful if a woman needs to attend an assessment clinic. This field is updated by the PI in the same way as other demographic information and can also be added or amended manually by the breast screening service.
- Training resources are available to support both the screening office and mammography staff in this process.

[45] https://www.gov.uk/government/publications/breast-screening-identifying-and-reducing-inequalities/breast-screening-reducing-inequalities#reducing-barriers-to-attendance

- Communicating with women, including letters and leaflets available online in 10 languages other than English and in Braille on request, where a woman has indicated that her preferred language is not English and this is recorded on the NHS Breast Screening Programme.
- It is important women can contact the screening service by methods other than the telephone.
- Breast screening services must provide a trained interpreter during assessment appointments. If an interpreter is unavailable, there needs to be flexibility in the service to be able to change the appointment for the client in order to ensure that a trained interpreter is present or request the service of a phone interpreter.
- Consider any engagement with local community groups.
- Consideration should be given as to how mammographers will support non-English speakers through the screening process when they attend. Providers can consider using pictures in a storyboard to explain the process or, where facilities are available, accessing a video explanation of the process.

## C.5. Additional quality and safety initiatives or gaps in the current services for consideration

Based on the review of the information above, other documents reviewed and information from stakeholders, the following list of potential gaps in information, initiatives or areas where more work is required are presented for review. These considerations have also been mapped to the "Migrant and Refugee Women's Health Partnership Competency Standards Framework for Culturally Responsive Clinical Practice"[46] and the "National Safety and Quality Health Service (NSQHS) Standards User Guide for health service organisations providing care for participants from migrant and refugee backgrounds".[47] They include:

- **Cultural Sensitivity and Awareness:**
  - Screening providers should be culturally sensitive and aware of the diverse beliefs, practices, and preferences related to health and wellness within different communities (Competency standards 1 & 2).
  - Educational materials and awareness campaigns should be culturally appropriate and available in multiple languages to reach a broader audience (Competency standard 5).

[46] https://culturaldiversityhealth.org.au/competency-standards-framework/

[47] https://www.safetyandquality.gov.au/sites/default/files/2021-09/user_guide_for_hsos_providing_care_for_patients_from_migrant_and_refugee_backgrounds._august_2021.pdf

- Ensure that healthcare providers and all involved in the client journey are trained on an ongoing basis to provide culturally competent care and support during the screening process (Competency standard 10 & NSQHS 1.20).
- Cultural safety and awareness training should be mandatory at universities for all disciplines

- **Individualised Approach:**
  - Recognise ethno-specific variations and health disparities of people from migrant and refugee backgrounds. This may include the need for trauma-informed care (Competency standard 1).
  - Recognise the family and community context of people from migrant and refugee backgrounds and its impact on consent, treatment and follow-up (Competency standards 1 & 2).
- **Access to Screening Facilities:**
  - Ensure that breast screening facilities are geographically accessible to culturally diverse populations. This may involve setting up screening clinics in community centres or areas with a high concentration of culturally diverse residents.
  - Consider offering flexible hours and transportation options to accommodate diverse women's schedules and logistical challenges.
- **Tailored Educational Materials:**
  - Develop and distribute educational materials that are culturally sensitive and consider diverse literacy levels including pictures of women from diverse communities. Visual aids, videos, and culturally relevant stories can be effective in conveying information (Competency standard 5 & NSQHS 2.8).
  - Address myths, misconceptions, and cultural taboos related to breast health and screening through targeted educational campaigns (Competency standard 5).
- **Family and Community Involvement:**
  - Recognise the influence of family and community dynamics on healthcare decisions. In some cultures, decisions related to healthcare may involve consultation with family members or community leaders (Competency standards 8 & 9).
  - Encourage open communication within families and communities about the importance of breast screening and early detection (Competency standards 1 & 2).
- **Interpreter Services:**
  - Screening facilities should have interpreter services available to assist women who may not be proficient in the dominant language spoken in the region. This ensures that

communication between providers and participants is clear and accurate, facilitating better understanding of the importance of breast screening (Competency standards 3, 4 & 8 & NSQHS 2.8).

- Wherever possible female interpreters should be utilised
- Services need to be more proactive in offering interpreter services overcoming barriers (e.g. online booking of interpreter services not available and not understanding they are free) many women who need this service arrive at BreastScreen for an appointment without an interpreter.
- Interpreters have access to training about the breast screening program (including consent forms) to ensure they understand the context of the service
- Screening is a short appointment of 10 to 20 minutes. Consideration ought to be given to assessment which can take 3 to 6 hours. Given the length of the assessment appointment:
  - Displaying pictures/posters/artwork or deco that reflect the cultures and ethnic background of the assessment sites can help establish trust and reduce anxiety.
  - Supporting and/or educating language services by 'triaging the medical importance' may reduce 'interpreter did not attend' rates for assessment.

- **Support Services:**
  - Provide support services, such as counselling and psychosocial support, to address the emotional and cultural aspects associated with breast screening.
  - Work with community leaders to increase trust in the screening process (stakeholder recommendation)
  - Utilise bicultural workers more broadly especially to provide support to other staff members and clients with specific aspects of cultural sensitivity and trauma care requirements
- **Advocacy and Policy:**
  - Advocate for policies and guidelines that promote inclusivity in breast screening programs and ensure that the needs of culturally diverse women are considered (Competency standard 8 & NSQHS 1.15).
  - Engage with community organisations to raise their awareness of the resources available to their communities as well as identify ways in which BreastScreen could make its resources more accessible (Competency standard 9).
  - Involve women who reflect the diversity of consumers who use the service in the decision-making, co-design and evaluation processes (NSQHS 2.11).

- The need to establish an organisational culture that is culturally responsive and inclusive (Competency standard 8).

- **Workforce**
  - Employ and support a culturally diverse workforce
- **Technology support**
  - Records of care are interoperable to enable continuity of care within the public sector and with the private sector and across jurisdictional boundaries
  - Interpreter services should be available to be booked as part of the online booking system for a range of common languages ( ie not require a phone call)
- **Data Collection, Research and Innovation:**
  - Support research initiatives that focus on improving breast screening technologies and methodologies (Competency standard 11).
  - Improved evidence on current program performance for this priority group especially from the cultural safety perspective to discover whether people feel culturally safe within that environment including the availability of appropriately accessible evaluation forms (Competency standard 5 & NSQHS 1.20).
  - Compile and develop information to improve the quality of the BreastScreen experience for participants, families and screening providers (Competency standard 5 & NSQHS 1.20).
  - Additional research on the effectiveness of tools and gaps in materials
  - Create opportunities to share knowledge as it develops, with peers, within a sector and with other organisations (Competency standard 11).

## C.6. References reviewed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12. Guide for clinicians working with interpreters in healthcare settings January 2019 https://culturaldiversityhealth.org.au/wp-content/uploads/2019/10/Guide-for-clinicians-working-with-interpreters-in-healthcare-settings-Jan2019.pdf
13. Australian Commission on Safety and Quality in Health Care National Safety and Quality Health Service Standards August 2021 NSQHS Standards User guide for health service organisations providing care for patients from migrant and refugee backgrounds

# Appendix D - LGBTIQA+ people

## D.1. Context

LGBTIQA+ individuals are less likely than non-LGBTIQA+ individuals to present for cancer screening[48], although there is a lack of specific cancer screening data.

## D.2. Barriers to the provision of quality and safe screening

Limited information was available on the barriers to breast screening for LGBTIQA+ people. A range of barriers has been summarised in Table 14 from a range of publications, including barriers identified on the BreastScreen Victoria website[49], studies focused on cervical cancer screening (Curmi et al 2016[50], Kerr et al 2022[51] and Berner et al 2021[52]), a study on the health and wellbeing of LGBTIQA+ people In Australia[53] and studies of LGBTIQA+ people and the healthcare professionals who work with them in cancer care[54,55]. These were validated and expanded in consultation with stakeholders.

**Table 14: Barriers to the provision of quality and safe breast screening – LGBTIQA+ people**

| Individual level | Service level | System level |
|---|---|---|
| **Accessibility**<br>• Inability to find a facility they are comfortable to attend<br>• Lower literacy levels undermine the ability to make informed choices, participate in screening, engage with health services, recognise symptoms, | **Approachability**<br>• Lack of representation in promotional materials,<br>• Lack of experience<br>• Hostility of health professionals, including denying care<br>**Acceptability** | • Valuing diversity<br>• LGBTIQA+ safe environments<br>• LGBTIQA+ appropriate service<br>• Wait time location of services<br>• The lack of reliable LGBTIQA+ data in healthcare services, eg level of breast cancer risk in trans-men who have had |

[48] Haviland KS, Swette S, Kelechi T, Mueller M. Barriers and Facilitators to Cancer Screening Among LGBTQ Individuals With Cancer. Oncol Nurs Forum. 2020 Jan 1;47(1):44-55. doi: 10.1188/20.ONF.44-55. PMID: 31845916; PMCID: PMC7573971.

[49] https://www.breastscreen.org.au/community-support/lgbtiq-people/

[50] Curmi C, Peters K, Salamonson Y. Barriers to cervical cancer screening experienced by lesbian women: a qualitative study. J Clin Nurs. 2016;25(23-24):3643-51.

[51] Kerr L, Fisher CM, Jones T. Improving Cervical Screening in Trans and Gender-Diverse People. Cancer Nurs. 2022;45(1):37-42.

[52] Berner AM, Connolly DJ, Pinnell I, Wolton A, MacNaughton A, Challen C, et al. Attitudes of transgender men and non-binary people to cervical screening: a cross-sectional mixed-methods study in the UK. Br J Gen Pract. 2021;71(709):e614-e25.

[53] Hill, A. O., Bourne, A., McNair, R., Carman, M. & Lyons, A. (2020). Private Lives 3: The health and wellbeing of LGBTIQ people in Australia. ARCSHS Monograph Series No. 122. Melbourne, Australia: Australian Research Centre in Sex, Health and Society, La Trobe University

[54] Ussher, J. M., Power, R., Pers, J., Hawkey, A. J., & Allison, K. (2022). LGBTQI inclusive cancer care: A discourse analytic study of health care professional, patient and carer perspectives. Frontiers in Oncology, 12, 832657.

[55] Ussher, J. M., Pers, J., Allison, K., Power, R., Hawkey, A., Dowsett, G. W.,... & Anasodo, A. (2022). Attitudes, knowledge and practice behaviours of oncology health care professionals towards lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) patients and their carers: A mixed-methods study. Patient Education and Counseling, 105(7), 2512-2523.

| Individual level | Service level | System level |
|---|---|---|
| articulate health concerns and comply with testing and treatment pathways.<br>• More likely to live alone and have reduced access to support systems<br>**Appropriateness**<br>• Lack of acknowledgement of their LGBTIQA+-related needs; the LGBTIQA+ community has diverse groups and thus diverse attitudes to breasts (from celebrating to finding them problematic) and breast screening.<br>**Approachability**<br>• Limited knowledge<br>• Absence of the perceived need for participants to be screened<br>• Avoidance of routine medical care<br>• Afraid privacy will not be maintained<br>• Discomfort with the feminine and female branding of screening services.<br>• Discomfort that if documents and Medicare are needed, their "dead name" on the legal documents does not match their identity<br>• Intersectionality of LGBTIQA+ status, ethnicity, mental health and disability status results in multiple complex barriers<br>**Acceptability**<br>• Previous experiences of discrimination in healthcare<br>• fear that they may have to 'come out' in the process.<br>• Fear of discrimination<br>• negative experiences with health care providers due to their sexuality<br>• Distressing and painful<br>• Sexual abuse victims<br>• Fear of stigma, feeling ostracised, embarrassed or perceived that they were being looked upon negatively<br>• Dysphoria relating to screening, procedure, information or correspondence<br>• The screening process is emotionally traumatic<br>• **Affordability**<br>• Lower levels of education reducing earning capacity and acting as a deterrence to downstream investigations and procedures, | • Limited sensitivity knowledge and understanding (harsher, discrimination, ignorance, unprofessionally by being overtly interested in LGBTIQA+ matters)<br>**Availability**<br>• The availability of LGBTIQA+ specialists<br>• The availability of LGBTIQA+ services, eg use of mobile screening vans at venues LGBTIQA+ people attend or feel safe at<br>**Appropriateness**<br>• Lack of communication tools, use of inappropriate language or inappropriate questions regarding gender identity<br>• Lack of skills and training among providers; training does not provide the expertise that hands-on and face-to-face engagement with participants does. Providers also lack confidence in their skills<br>• Uncomfortable dealing with lesbian women and often avoid discussions about their sexuality<br>• Female-centred screening information materials and services are not suitable for some LGBTIQA+ clients, eg trans-men | top surgery compared to cis-gendered men<br>• LGBTIQA+ inclusion among decision-makers in the health sector<br>• Perception of rigidity and inflexibility of the screening organisation and service regarding participant eligibility criteria and the potential participants they engage with<br>• LGBTIQA+ accreditation standards can be overly rigorous and discouraging for services to engage with local advocacy groups which may provide a better outcome |

| Individual level | Service level | System level |
|---|---|---|
| although breast screening itself is free | | |

# D.3. Quality and safety initiatives for LGBTIQA+ people

Table 15 describes the initiatives available across jurisdictions based on information readily available on websites. Note it does not mean that the service is not provided, only that it could not be easily found as being provided on the website. For example, we are aware of LGBTIQA+ community organisations such as ACON providing training with breast screening providers in New South Wales.

**Table 15: BreastScreen initiatives by jurisdiction (websites accessed December 2023)**

| Initiative | ACT [56] | NSW [57] | NT [58] | QLD [59] | SA [60] | TAS [61] | VIC [62] | WA [63] | C'wlth [64] |
|---|---|---|---|---|---|---|---|---|---|
| **Education and awareness** | | | | | | | | | |
| The website has access to information specific LGBTIQA+ | ✓ | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| Website/brochure includes whether screening for breast cancer is recommended | | ✓ | | ✓ | ✓ | | ✓ | | ✓ |
| Provides information on LGBTIQA+ sites about breast implants and breast screening | | ✓ | | ✓ | ✓ | | ✓ | | ✓ |
| The website/brochure includes advice for clients to talk to their doctor about breast screening to decide whether it is right for them | | | | | ✓ | | ✓ | ✓ | ✓ |
| Access to written health promotional material with reference to LGBTIQA+ | | | | ✓ | | | | | |

[56] https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/breastscreen-act
[57] https://www.breastscreen.nsw.gov.au/about-screening-mammograms/information-for-trans-and-gender-diverse-people
[58] https://nt.gov.au/wellbeing/cancer-services/breastscreennt
[59] https://www.breastscreen.qld.gov.au/should-i-screen/who-can-have-a-breast-screen
[60] https://www.breastscreen.sa.gov.au/
[61] https://www.health.tas.gov.au/health-topics/cancer-screening/breast-screening/getting-breast-screen#trans-and-genderdiverse-people
[62] https://www.breastscreen.org.au/community-support/lgbtiq-people/
[63] https://www.breastscreen.health.wa.gov.au/Breast-screening/LGBTQIA-plus
[64] https://www.health.gov.au/our-work/breastscreen-australia-program/providing-breast-screening-to-participants/managing-breast-screening-participants-with-special-needs-or-conditions#women-with-disabilities

| Initiative | ACT [56] | NSW [57] | NT [58] | QLD [59] | SA [60] | TAS [61] | VIC [62] | WA [63] | C'wlth [64] |
|---|---|---|---|---|---|---|---|---|---|
| Access to written health promotional material specifically for LGBTIQA+ | | | | | | | ✓ | | |
| Note on the LGBTIQA+ page that screening is free | | | | | ✓ | | ✓ | | |
| Links to LGBTIQA+ websites for more resources | | ✓[65] | | | | | ✓ | | |
| Links to other government or cancer websites for more resources | ✓ | ✓ | ✓ | | | | | | |
| Contact number for more information in the LGBTIQA+ Section | ✓ | | | | | | ✓ | ✓ | |
| Stakeholder Communications Toolkit | | | | | | | | ✓ | |
| Information sessions | | | | | | | | ✓ | |
| **Appointment scheduling** | | | | | | | | | |
| Dedicated LGBTIQA+ and trans and gender-diverse screening sessions. | | | | | | | ✓[66] | | |
| **Supportive services** | | | | | | | | | |
| Can bring a support person to appointments | | | | | | | ✓ | | |
| **Staff Sensitivity and Training** | | | | | | | | | |
| Contact to provide feedback on page or brochure | | ✓ | | | | | ✓ | | |
| Access to a counsellor to discuss the risks and benefits of screening. | | | | | | ✓ | | | |
| An online training module for BreastScreen staff is highlighted on the website | | | | | | | ✓ | | |
| Commitment to inclusive, welcoming and safe services for LGBTIQA+ on website | | ✓ | | | | ✓ | ✓ | ✓ | |
| A policy guiding trans and gender-diverse breast screening is highlighted on the website | | | | | | | ✓ | | |
| Rainbow Tick accreditation for service's commitment to safe and inclusive practice | | | | | | | ✓ | | |

[65] https://canwe.org.au/staying-healthy/breast-screening/
[66] https://www.breastscreen.org.au/rainbow-sessions/

| Initiative | ACT [56] | NSW [57] | NT [58] | QLD [59] | SA [60] | TAS [61] | VIC [62] | WA [63] | C'wlth [64] |
|---|---|---|---|---|---|---|---|---|---|
| Clarify on the website on data collection and disclosure | | | | | | | ✓a | | |

Clarify on the website that the service facility will not ask clients to disclose information about sexual orientation, gender identity, or intersex status. "If you would like us to record this information on your file please let us know. If recorded, this information will be visible to the contact centre, reception staff, and clinical staff who access your record. We will not record this information unless you provide consent".

## D.4. Quality and safety initiatives being implemented for LGBTIQA+ people internationally

Cancer Care Ontario has developed a new policy[67] with 17 recommendations on breast cancer and cervical screening for transgender people. The policy will be available on our website in October 2019 on the screening page. "Transgender" (or "trans") refers to people who identify with a gender that is different from the sex they were assigned at birth. "Transgender" is used as an umbrella term and can refer to a wide variety of people with different gender expressions and identities.

The policy includes specific screening recommendations for all transgender people, including people who have undergone hormone therapy and/or gender-affirming surgery. It also includes recommendations on the importance of creating safe spaces in healthcare settings. The policy states that – as with all participants – medical clinics, doctors and nurses should make sure the experience of getting screened for cancer is respectful and comfortable for transgender people. In addition to the policy, Cancer Care Ontario uses gender-neutral language in its products and materials, whenever possible. Gender-neutral language recognises that not everyone identifies as a man or a woman. For example, someone who identifies as a man even though their sex assigned at birth was female may feel excluded if cancer screening materials use "women/woman" throughout.

NHS England[68] provides information for trans (transgender) and non-binary people in England. It provides information about the adult NHS screening programs that are available in England and explains who is invited for screening. Trans is used as an umbrella term to embrace the diverse range of identities outside the traditional male/female definitions. These include transgender, gender fluid and non-binary. NHS England's guidance "Guidance on Breast screening: reducing

[67] https://www.cancercareontario.ca/en/guidelines-advice/types-of-cancer/61546

[68] https://www.gov.uk/government/publications/nhs-population-screening-information-for-transgender-people/nhs-population-screening-information-for-trans-people

inequalities Updated 8 June 2022"[69] includes lesbian, gay, bisexual and transgender (LGBT) people and highlights:

- Breast screening services will not be able to identify people as transgender or non-binary.
- Provision of national guidance for transgender and non-binary people on accessing screening.
- Provision of a training guide for breast screening services explaining what actions they should take when people identified as male or indeterminate are found.
- Breast screening services should consider and be sensitive to the experience of LGBTIQA+ people attending for screening. See the Stonewall sexual orientation guide for the NHS that is designed to improve the health care experience for lesbian, gay and bisexual people.

## D.5. Additional quality and safety initiatives for consideration

Based on the review of the information above, other documents reviewed and input from stakeholders, the following list of potential gaps in information, initiatives or areas where more work is required are presented for review. These considerations have also been mapped to the Latrobe University Rainbow Tick Standards 3rd edition 2020;[70] they are included as follows, together with initiatives and gaps reported by stakeholders:

- **Accessibility**
  - Co-design accessible services with advocacy groups. Include appropriate demographic data collection to be able to individualise the service provided, asking about preferred pronouns
  - Include consideration for alternate pathways for the community where the national program may not be acceptable eg for trans-men who cannot undergo breast screening but would benefit from other interventions.
  - Accessibility in safe places, eg. holding special screening days. Partnerships and working with local organisations that are trusted by the community, which increase the target population's engagement and trust with the screening service. These organisations may be supporting groups, for example.

[69] https://www.gov.uk/government/publications/breast-screening-identifying-and-reducing-inequalities/breast-screening-reducing-inequalities#lesbian-gay-bisexual-and-transgender-lgbt-people

[70] https://rainbowhealthaustralia.org.au/media/pages/rainbow-tick/3214906303-1650953507/rainbow-tick-standards-a-framework-for-lgbtiq-cultural-safety.pdf

- Collaboration and engagement with health clinics that serve members of the LGBTIQA+ community (Rainbow tick standard 3).
- Working with appropriate health promotion dates or events such as “Fair Day” or "Pride Month” providing access with mobile vans.
- Cross program collaboration with targeted access to all screening information, cervical, bowel and other health promotion initiatives

- **Communication**
  - Continue to develop culturally safe materials and resources with direct community engagement to co-design materials (Rainbow tick standard 4).
  - Reviewing and adapting program correspondence, materials and media for more inclusive language and images (Rainbow tick standard 4). Use diverse “poster children” in promotional materials.
  - Adapt and adopt existing materials e.g campaigns, posters, brochures, pamphlets,
- **Culturally competent staff**
  - Screening providers receive training on cultural competence related to sexual and gender diversity. This training can help them understand the unique healthcare needs and concerns of LGBTIQA+ individuals, promoting better communication and trust. (Rainbow tick standard 2).
  - Ensure that staff members are knowledgeable about the specific health needs of LGBTIQA+ individuals. This includes understanding the potential impact of hormone therapy on breast health and addressing any concerns or questions individuals may have. (Rainbow tick standard 2)
  - Evaluate and update if required guidelines to include information specific to LGBTIQA+ health needs. (Rainbow tick standard 2).
  - Education and training for staff is accessible and ongoing.
  - Hands-on and face-to-face engagement with LGBTIQA+ participants, as training alone, does not provide the same degree of experience
  - Adapt and adopt existing training programs and materials
- **Inclusivity and Respect:**
  - Screening providers create an inclusive and respectful environment for all individuals, regardless of their sexual orientation, gender identity, or expression. This includes using inclusive language, displaying LGBTIQA+-friendly signage, and having staff who are trained to provide culturally competent care. (Rainbow tick standard 1).
  - Accessing a service that has been accredited as LGBTIQA+-inclusive (e.g. Rainbow Tick).

- Direct community engagement to co-design programs where relevant (Rainbow tick standard 4).

- **Privacy and Confidentiality:**
  - Ensure that privacy and confidentiality are maintained throughout the screening process. LGBTIQA+ individuals may have concerns about disclosure, and screening providers should reassure them that their information will be kept confidential. (Rainbow tick standard 5)

- **Affirming Language:**
  - Use affirming and inclusive language when discussing health matters. This includes using terms that are respectful of individuals' gender identities and expressions. For example, referring to body parts with gender-neutral terms when discussing breast health. (Rainbow tick standard 4).
  - Invitation and reminder letters and addressed correctly to respect the person's identity and do not use "dead names" (this also relates to Data Collection, to correctly identify participants' gender identities).

- **Understanding Diverse Needs:**
  - Recognise that LGBTIQA+ individuals may have unique healthcare needs and experiences. Transgender and non-binary individuals, for instance, may have specific concerns related to chest health, and healthcare providers should be prepared to address these concerns in a supportive manner. (Rainbow tick standard 4).

- **Advocacy and Policy:**
  - Advocate for policies and guidelines that promote inclusivity in breast screening programs and ensure that the needs of LGBTIQA+ individuals are considered. (Rainbow tick standard 4).
  - Involve LGBTIQA+ individuals in the decision-making, co-design and evaluation processes. (Rainbow tick standard 3).
  - Engage with LGBTIQA+ organisations to raise their awareness of the resources available to their communities as well as identify ways in which BreastScreen could make its resources more accessible. (Rainbow tick standard 3).
  - The need to establish an organisational culture that is LGBTIQA+-inclusive and affirmative. (Rainbow tick standard 1).
  - Risk management policies and processes should be developed or updated to identify and respond to risks specific to LGBTIQA+ service users or staff. (Rainbow tick standard 6).

- **Data Collection, Research and Innovation:**

- Support research initiatives that focus on improving breast screening technologies and methodologies for LGBTIQA+ individuals.
- Improved evidence on current program performance for this priority group. (Rainbow tick standard 1).
- Compile and develop information to improve the quality of the BreastScreen experience for participants, families and screening providers. (Rainbow tick standard 1).
- Increase the number of people with lived experience and their access to research infrastructure.
- Create opportunities to share knowledge as it develops, with peers, within a sector and with other organisations. (Rainbow tick standard 2).
- Collect data on gender identity in a non-judgemental way, in order to research participant experiences and improve services. Australian Bureau of Statistics (ABS) Standard 2020 is an appropriate guide for how to collect this data.

## D.6. Other documents reviewed

1. Cervical cancer screening in Canada Strategies to improve screening for LGBTQ2S+ people https://www.partnershipagainstcancer.ca/topics/cervical-cancer-screening-in-canada-2021-2022/population-outreach/lgbtq2s/

# Appendix E - Women with disabilities

## E.1. Context

International and Australian data indicate that screening participation is lower across all three cancer screening programs for people with disabilities[71]. BreastScreen Australia (BSA) services endeavour to ensure that services are acceptable to and accessible and appropriate for women with disabilities. This includes women with:

- an intellectual disability
- a low level of literacy
- a sight or hearing disability
- a physical disability that limits their mobility.

## E.2. Barriers to the provision of quality and safe screening

A range of barriers have been summarised in Table 16, identified from a range of publications including studies focused on Australians with physical disabilities and breast screening (Peters et al 2014[72]), with physical disabilities and cancer screening in England and Wales (Dikaios et al 2019[73]) and New Zealand (Pearson et al 2020[74]), and international studies of people with all disabilities accessing healthcare services (Matin et al 2021[75] and Greaux et al 2023[76]). These barriers were validated and expanded in consultation with stakeholders.

[71] https://screeningresources.cancervic.org.au/communities/people-with-disabilities/profile-statistics-disability

[72] Peters K, Cotton A. Barriers to breast cancer screening in Australia: experiences of women with physical disabilities. J Clin Nurs. 2015 Feb;24(3-4):563-72. doi: 10.1111/jocn.12696. Epub 2014 Sep 19. PMID: 25236777.

[73] Sakellariou D, Anstey S, Gase S, Girt E, Kelly D, Moore B, Polack S, Pratt R, Tyrer G, Warren N, Wilkinson W, Courtenay M. Barriers to accessing cancer services for adults with physical disabilities in England and Wales: an interview-based study. BMJ Open. 2019 Jun 27;9(6):e027555. doi: 10.1136/bmjopen-2018-027555. PMID: 31248925; PMCID: PMC6597631.

[74] Janet Pearson, Deborah Payne, Karen Yoshida & Nicholas Garrett (2020): Access to and engagement with cervical and breast screening services for women with disabilities in Aotearoa New Sealand, Disability and Rehabilitation, DOI: 10.1080/09638288.2020.1817158

[75] Matin BK, Williamson HJ, Karyani AK, Resaei S, Soofi M, Soltani S. Barriers in access to healthcare for women with disabilities: a systematic review in qualitative studies. BMC Womens Health. 2021 Jan 30;21(1):44. doi: 10.1186/s12905-021-01189-5. PMID: 33516225; PMCID: PMC7847569.

[76] Gréaux M, Moro MF, Kamenov K, Russell AM, Barrett D, Ciesa A. Health equity for persons with disabilities: a global scoping review on barriers and interventions in healthcare services. Int J Equity Health. 2023 Nov 13;22(1):236. doi: 10.1186/s12939-023-02035-w. PMID: 37957602; PMCID: PMC10644565.

## Table 16: Barriers to the provision of quality and safe breast screening – women with disabilities

| Individual level | Service level | System level |
|---|---|---|
| **Accessibility**<br>• Inability to get into the correct position for screening<br>• Too busy<br>• Access to accessible location<br>• No transport<br>• Wheelchair accessibility, including marking a venue or van with the "A" logo<br>• Allowed to have guide dogs<br>• Allowed to have support person in the room<br>• Concerns about privacy for people in traumatic relationships who do not want their location known<br>• Lack of website accessibility for those with visual impairment<br>• Smell trigger for people with allergies<br>**Appropriateness**<br>• Communicative problems (including the inability to use the booking system)<br>• Low health literacy<br>• Lack of acknowledgement of their disability-related needs<br>**Approachability**<br>• Difficulty in using available information<br>• Limited knowledge<br>**Acceptability**<br>• Feeling of not being in control<br>• Being ignored and not listened to<br>• Being helpless, alone and afraid<br>• Experiencing pain, torture and humiliation<br>• Distrust<br>• Past negative experiences<br>• Stress and anxiety<br>• Embarrassment<br>• A lack of family or carers to support attendance<br>**Affordability**<br>• High transportation costs<br>• Not knowing that screening and interpreters are free | **Approachability**<br>• Lack of the needed information<br>• Lack of transparency<br>• Using unfamiliar biomedical jargon<br>• Lack of knowledge of the needs of people<br>• Lack of awareness among screening staff about reasonable adjustments, accessible information and other resources to support people<br>• Lack of experience<br>**Acceptability**<br>• Insufficient social supports<br>• Limited disability sensitivity knowledge and understanding (judging, ignoring, negative attitude, stigma, erroneous assumptions, discriminatory attitudes, impolite, disrespect for persons with disabilities wishes of care)<br>• Lack of interpreter<br>**Availability**<br>• Inaccessible equipment<br>• Transportation<br>• Lack of internet access<br>• Physical access<br>• Lack of consultation and/or notification<br>• Inadequate appointment time leads to the client feeling rushed<br>**Appropriateness**<br>• Lack of communicative tools<br>• Lack of skills and training among providers | • Valuing diversity<br>• Disability safe environments<br>• Disability appropriate service<br>• Wait time location of services with appropriate equipment<br>• Poor collaboration between different parts of the health system<br>• The lack of reliable disability data in healthcare services<br>• Lack of a system to record the reasonable adjustments to care for persons with disabilities<br>• Disability inclusion among decision-makers in the health sector |

# E.3. Quality and safety initiatives for women with disabilities

Table 17 describes the initiatives available across jurisdictions based on information readily available on websites. Note it does not mean that the service is not provided, only that it could not be easily found as being provided on the website.

**Table 17: BreastScreen initiatives by jurisdiction (websites accessed December 2023)**

| Initiative | ACT [77] | NSW [78] | NT [79] | QLD [80] | SA [81] | TAS [82] | VIC [83] | WA [84] | C'wlth [85] |
|---|---|---|---|---|---|---|---|---|---|
| **Education and awareness** | | | | | | | | | |
| The website has access to information specific to women with disabilities | | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | ✓ |
| The website has an audio "listen" function | ✓ | | | | | ✓ | | | |
| The website includes other accessibility options | | | | | | ✓ | | | |
| Providing easy-to-read information about breast screening | | | | ✓ | ✓ | | ✓ | | |
| Website/brochure includes the criteria to be met successfully for a woman to undergo a screening mammogram | | ✓ | | | ✓ | | | ✓ | |
| The website/brochure includes advice for women to talk to their doctor about breast screening to decide whether it is right for them | ✓ | ✓ | | | ✓ | | ✓ | ✓ | |
| Access to written health promotional material specific for women with disabilities | | ✓ | | | ✓ | | ✓ | ✓ | |
| Note on the disabilities page that screening is free | | ✓ | | | | ✓ | | ✓ | |

[77] https://www.canberrahealthservices.act.gov.au/services-and-clinics/services/breastscreen-act
[78] https://www.breastscreen.nsw.gov.au/media/561726/brs-0029-0419_bsnsw-brochure-disability-08-2018-01_lowres.pdf
[79] https://nt.gov.au/wellbeing/cancer-services/breastscreennt
[80] https://www.breastscreen.qld.gov.au/client-support/women-with-disability
[81] https://www.breastscreen.sa.gov.au/community-engagement/people-with-a-disability
[82] https://www.health.tas.gov.au/health-topics/cancer-screening/breast-screening
[83] https://www.breastscreen.org.au/community-support/disability/
[84] https://www.breastscreen.health.wa.gov.au/Breast-screening/Women-with-a-disability
[85] https://www.health.gov.au/our-work/breastscreen-australia-program/providing-breast-screening-to-participants/managing-breast-screening-participants-with-special-needs-or-conditions#women-with-disabilities

| Initiative | ACT [77] | NSW [78] | NT [79] | QLD [80] | SA [81] | TAS [82] | VIC [83] | WA [84] | C'wlth [85] |
|---|---|---|---|---|---|---|---|---|---|
| Links to other government websites for more resources | ✓ | | ✓ | | | | | | |
| **Accessibility of facilities** | | | | | | | | | |
| Providing access for most types of wheelchairs at most service locations | | ✓ | | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Providing access for most types of wheelchairs at most mobile vans | | ✓ | | ✓ | ✓a | | ✓ | ✓ | |
| Contact number to determine the most appropriate breast screening location, as some may be more accessible to a particular participant than others | | ✓ | | ✓ | | | ✓ | ✓ | |
| Contact to discuss their personal health requirements and/or individual circumstances prior to making a booking. Women with a disability may be referred to a medical officer or nurse counsellor to identify and discuss any potential barriers to having a breast screen. | ✓ | ✓ | | | ✓ | ✓ | | | ✓ |
| **Adaptive equipment/procedure** | | | | | | | | | |
| Changing the breast screening procedure for women who have difficulties with movement | | ✓ | | ✓ | ✓ | | | | |
| Some clinics offer appointments where an extra radiographer is available to assist | | | | | | | ✓ | | |
| **Supportive services** | | | | | | | | | |
| Allowing a support person to come with the participant into the breast screening room | | ✓ | | ✓ | ✓ | ✓ | ✓ | | |
| Allowing a guide or assistance dog to come with the participant into the breast screening room | | ✓ | | ✓ | ✓ | | | | |
| **Communication accessibility** | | | | | | | | | |
| Providing access to Australian Sign Language interpreters | | | | ✓ | ✓ | ✓ | ✓ | ✓ | |
| Women who are deaf, or have a hearing or speech impairment, can | | ✓ | | | | | ✓ | | |

| Initiative | ACT [77] | NSW [78] | NT [79] | QLD [80] | SA [81] | TAS [82] | VIC [83] | WA [84] | C'wlth [85] |
|---|---|---|---|---|---|---|---|---|---|
| contact BreastScreen through the National Relay Service. An interpreter can also assist at appointments | | | | | | | | | |
| **Appointment scheduling** | | | | | | | | | |
| Longer appointments | | | | | ✓ | ✓ | ✓ | ✓ | |
| Group bookings | | | | | ✓ | | ✓ | | |
| Familiarisation visits | | | | | ✓ | | ✓ | | |
| Work with local disability services to arrange group bookings and familiarisation visits | | | | | | | ✓ | | |
| **Staff Sensitivity and training** | | | | | | | | | |
| All staff of the service are adequately trained and equipped to provide care for women with a disability | | | | | ✓ | | | | |
| Note on the disabilities page that specially trained female medical imaging technologists are available | | ✓ | | | ✓ | | | ✓ | |
| **Continuity of care** | | | | | | | | | |
| With the woman's (or carer's) consent, the woman's nominated doctor is informed if breast screening cannot be provided as a result of her disability | | | | | ✓ | | | | |
| Provides educational material "Cancer screening for people with disabilities: A guide for general practice" | | | | | | | ✓ | | |
| **Consent** | | | | | | | | | |
| If it is not possible to obtain clear verbal consent from a client with an intellectual disability, consent can be provided by the authorised support person or substitute decision-maker. Even if an authorised support person or substitute decision-maker has provided consent, a radiographer may stop the screening procedure if the client's non-verbal behaviour indicates they do not want the procedure to continue. This can apply before or during the screening procedure. | | | | | ✓ | | | ✓ | |

| Initiative | ACT [77] | NSW [78] | NT [79] | QLD [80] | SA [81] | TAS [82] | VIC [83] | WA [84] | C'wlth [85] |
|---|---|---|---|---|---|---|---|---|---|
| **Transportation** | | | | | | | | | |
| Contact BreastScreen before their appointment to organise access to the service. Advice can be provided about parking and local transport options if required | | ✓ | | | | | | | |

a.There are size and weight restrictions for some wheelchairs attending the mobile screening units.

## E.4. Quality and safety initiatives being implemented for women with disabilities internationally

This review included Ontario[86] and New Zealand,[87,88] which did not provide any information specific to women with disabilities. NHS England was also included and provides the guidance "Guidance on Breast screening: reducing inequalities Updated 8 June 2022",[89] which includes women with a physical disability and women with a learning disability. Public Health England provides a range of information in their publication "Population screening: supporting people with a learning disability: Guidance for health professionals to support people with a learning disability to access screening".[90] This publication includes guidance and resources for local screening providers, commissioners and other partners to help reduce barriers to screening for people with a learning disability, autism or both. It includes sections on:

- informed choice
- barriers to screening
- improving access to screening and understanding of screening
- working with primary care.

The NHS publication draws on information previously developed for program-specific publications for the abdominal aortic aneurysm (AAA), antenatal and newborn, bowel cancer, breast and cervical screening programs. These were developed in collaboration with screening and learning disability health professionals, service users and other partners.

The NHS publication provides a range of suggested interventions, including:

[86] https://www.cancercareontario.ca/en/cancer-care-ontario/programs/screening-programs/ontario-breast-obsp
[87] https://www.nsu.govt.ns/health-professionals/breastscreen-aotearoa
[88] https://www.timetoscreen.ns/breast-screening
[89] https://www.gov.uk/government/publications/breast-screening-identifying-and-reducing-inequalities/breast-screening-reducing-inequalities#women-with-a-physical-disability
[90] https://www.gov.uk/government/publications/population-screening-supporting-people-with-learning-disabilities

- Improving access to screening including a suite of easy guides to help explain screening tests to people with a learning disability and autistic people, who cannot read or do not like written words to the Beyond Words cancer screening picture stories, and 3 short video clips of service users with a learning disability talking about screening.
- Before screening appointments
  - Information and communication including:
    - discuss with individuals, their families, carers or others providing support such as learning disability teams or advocates, any reasonable adjustments or communication needs people may require
    - consider how individuals may like information to be presented and tailor it accordingly – for example, by using easy guides, pictures, simple words, symbols, signing or a film to explain screening
    - interpreter services
    - avoid jargon, use simpler language
    - attend local advocacy groups to demonstrate screening equipment and processes
    - encourage GPs to raise awareness of screening with people with a learning disability, autism or both, for example during annual health checks
    - promote screening at events for people with a learning disability, autism or both
    - liaise with GPs and families in cases where consent is difficult to gain
  - Appointment issues
    - finding out if there is a learning disability liaison nurse, or other health professional involved in the person's care, who can offer support before and during the screening appointment
    - thinking about the logistics for the appointment, such as checking how individuals are going to get there
    - appropriately sharing information and ensuring a coordinated support package is in place so the relevant health professionals can work together – effective handovers can improve accessibility and understanding
    - familiarisation visit
    - allowing extra time for appointments and enabling a family member, carer or chaperone to attend with the individual if needed to reduce anxiety
    - assessing the individual's mental capacity and any safeguarding issues that need to be considered

- considering sensory issues such as lighting, heat, and smell that may trigger anxiety or sensory overload, particularly for autistic people

- During screening appointments, there are lots of specific things health professionals can do to make screening appointments better for people with a learning disability and autistic people. They should:
  - use simple language and avoid long words and long sentences
  - consider ways to help the individual feel more relaxed and comfortable, for example allowing them to play music or wear ear muffs/ear defenders during the screening test
  - speak slowly and clearly, and stop to check understanding at regular points
  - show the individual the relevant screening easy guide, animation or other film and check understanding with them
  - always talk directly to the person with a learning disability, not their carer or supporting professional
  - find out what words the individual uses for parts of the body being looked at to avoid misunderstandings
  - follow the individual's lead and go at their pace
  - be aware that people with a learning disability are more likely to have hearing loss, so do check they can hear you.

## E.5. Additional quality and safety initiatives for consideration

Based on the review of the information above, other documents reviewed and input from stakeholders, the following list of potential gaps in information, initiatives or areas where more work is required are listed for review.

- **Accessibility of Facilities:**
  - Ensure that screening facilities are physically accessible to individuals with different types of disabilities. This includes wheelchair accessibility, ramps, elevators, and accessible restrooms. Having the "A" logo available
  - Ensure a support person can be in the room.
  - Allowing guide dogs to be in the room
- **Adaptive Equipment / Procedure:**

- Provide adaptive equipment, such as adjustable examination tables and mammography machines, to accommodate the needs of women with disabilities.
- Consider sensory issues such as lighting, heat, and smell that may trigger anxiety or sensory overload, particularly for autistic people, or allergies.

- **Individualised Approach:**
  - Recognise that each person is unique, and an individualised approach responsive to their unique needs and requirements is essential. Some women may have a strong support system that can assist in scheduling and attending screenings, while others may need additional support or accommodations to address specific disabilities.
  - Booking services enable the capture of information necessary for the service to be able to individual service. With consent, this information should be retained to optimise future visits.
- **Communication Accessibility:**
  - Address communication barriers by providing information in accessible formats (e.g., large print, picture books, braille, audio and video) and ensuring that staff are trained to communicate effectively with individuals who may have hearing or speech impairments. This includes a "social story" in easy English about what to expect and with minimal text for people with autism.
- **Staff Sensitivity and Training:**
  - Train staff to be sensitive to the needs of women with disabilities. This includes understanding various disabilities, providing assistance as needed, and maintaining an inclusive and respectful environment.
  - Having "open days" where people can tour facilities, meet the nurses and radiographers and see what the screening program does
- **Appointment Scheduling:**
  - Implement flexible scheduling options to accommodate individuals with disabilities. This may include longer appointment times or specific time slots dedicated to individuals who may require additional assistance or accommodations. For example, quiet session times.
  - Discuss with individuals, their families, carers or others providing support any reasonable adjustments or communication needs people may require.
- **Transportation:**
  - Address transportation challenges that women with disabilities may face in reaching screening facilities. This may involve collaborating with transportation services or providing information on accessible transportation options.

- **Support Services:**
  - Offer support services such as personal assistants for individuals who may require assistance during the screening process.
- **Awareness and Education:**
  - Conduct outreach and educational programs specifically targeting women with disabilities to raise awareness about the importance of breast screening, available accommodations, and the benefits of early detection. This could be done with the support of local advocacy groups.
  - Alleviate fear and make the screening process easy.
  - Video resources, such as interviews with women who have just completed screening and with a diverse range of women.
  - Communicate clearly that screening and access to interpreters are free, as the perceived price is a barrier.
- **Continuity of Care:**
  - Appropriately sharing information and ensuring a coordinated support package is in place so the relevant health professionals can work together – effective handovers can improve accessibility and understanding.
  - Primary care or disability services to appropriately alert the screening service to a client's disability prior to their visit to ensure adequate assistance and support is available to assist them.
- **Advocacy and Policy:**
  - Advocate for policies and guidelines that promote inclusivity in breast screening programs and ensure that the needs of women with disabilities are considered
  - Involve women with disabilities and carers in the decision-making, co-design and evaluation processes
  - Engage with the many national disability organisations to raise their awareness of the resources available to their communities as well as identify ways in which BreastScreen could make its resources more accessible
- **Data Collection, Research and Innovation:**
  - Support research initiatives that focus on improving breast screening technologies and methodologies for individuals with disabilities.
  - Improved evidence on current program performance for this priority group
  - Compile and develop information to improve the quality of the BreastScreen experience for participants, families and screening providers

- Increase the number of women with lived experience and their access to research infrastructure.

## E.6. Other documents reviewed


1. Byrnes K, Hamilton S, McGeechan GJ, O'Malley C, Mankelow J, Giles EL. Attitudes and perceptions of people with a learning disability, family carers, and paid care workers towards cancer screening programmes in the United Kingdom: A qualitative systematic review and meta-aggregation. Psychooncology. 2020;29(3):475-84.
2. Gesink D, Nattel L. A qualitative cancer screening study with childhood sexual abuse survivors: experiences, perspectives and compassionate care. BMJ Open. 2015;5(8):e007628.
3. Reidy M, Denieffe S, Foran S. Cancer screening in women with intellectual disabilities: an Irish perspective. J Intellect Disabil. 2014;18(1):51-60.
4. Seaton MB, Muraca L, Devaney J, Angus JE. "I Want to Help, but What Do You Do in a Situation Like That?" Health Care Providers' Qualitative Perspectives on Working with Disabled Women in Breast Cancer Screening. J Med Imaging Radiat Sci. 2018;49(4):383-9.

# Appendix F – Women with mental health issues

## F.1. Context

Studies of other cancer types have found that people living with mental illness have reduced participation in cancer screening. However, there are gaps and inconsistencies in the evidence regarding breast cancer screening. In North American or European health systems, women with mental health conditions are 20–40% less likely to participate in breast cancer screening. A population study of breast cancer screening participation in women using mental health services in NSW, Australia (Lambeth et al 2023[91]) found only 30.3% of mental health service users participated in breast screening, compared with 52.7% of other NSW women.

## F.2. Barriers to the provision of quality and safe screening

A range of barriers have been summarised in Table 18 from a range of publications identified from the NSW study mentioned above and studies looking at influences on uptake of cancer screening in mental health service users (Clifton et al[92]) and studies focused on other types of screening (Mkuu et al 2022[93]). These were validated and expanded in consultation with stakeholders.

**Table 18: Barriers to the provision of quality and safe breast screening – women with mental health issues**

| Individual level | Service level | System level |
|---|---|---|
| **Accessibility**<br>• Too busy<br>• Access to location<br>• Lack of transport<br>• Difficulty remembering appointments<br>• Difficulty leaving the house due to mental health problems<br>• Difficulty taking time off | **Approachability**<br>• Lack of the needed Information<br>• Lack of transparency<br>• Using unfamiliar biomedical jargon<br>• Communication skills training not available to all<br>• Lack of knowledge of the needs of people | • Culturally safe environments and appropriate services<br>• Poor collaboration between different parts of the health system<br>• The lack of reliable data to inform best practice, including from people with mental |

[91] Lambeth, C., Burgess, P., Curtis, J. et al. Breast cancer screening participation in women using mental health services in NSW, Australia: a population study. Soc Psychiatry Psychiatr Epidemiol (2023). https://doi.org/10.1007/s00127-023-02509-w

[92] Clifton, A., Burgess, C., Clement, S. et al. Influences on uptake of cancer screening in mental health service users: a qualitative study. BMC Health Serv Res 16, 257 (2016). https://doi.org/10.1186/s12913-016-1505-4

[93] Mkuu, R.S., Staras, S.A., Ssurek, S.M. et al. Clinicians' perceptions of barriers to cervical cancer screening for women living with behavioural health conditions: a focus group study. BMC Cancer 22, 252 (2022). https://doi.org/10.1186/s12885-022-09350-5

| Individual level | Service level | System level |
|---|---|---|
| • Inflexible appointment times<br>**Approachability**<br>• Difficulty in using available information<br>• Limited knowledge<br>**Acceptability**<br>• Fear of bad news<br>• Diagnostic overshadowing<br>• Traumatising<br>• Additional burden<br>• Past negative experiences<br>• Mental health symptoms reduce motivation for self-care<br>• Stress and anxiety<br>• Embarrassment<br>• Stigma, unconscious bias and judgement from screening staff<br>• Cognitive deficits<br>• Past experiences of sexual trauma<br>• Screening environment aggravates mental health symptoms (eg overstimulation by sounds); staff can be rushed; staff can be rough<br>• Lack of understanding of mental illness in screening professionals | • Lack of awareness among screening staff about reasonable adjustments, accessible information and other resources to support people<br>• Lack of experience<br>• Staff burn-out leads to reduced empathy<br>**Acceptability**<br>• Provider attitudes regarding mental illness, including stigma, unconscious bias and judgement (this can stop people from attending in the future and may impact attendance to healthcare services)<br>• Limited Trauma-informed care<br>• Limited participant-centric care<br>**Availability**<br>• Transportation<br>• Lack of consultation and/or notification<br>**Appropriateness**<br>• Lack of communicative tools<br>• Lack of skills and training among providers<br>• Lack of knowledge of severe mental illness and how some mental illnesses present<br>• Service finds complex participants difficult<br>• Lack of time<br>• No means of knowing participant needs in advance | illnesses that have not been diagnosed<br>• People with lived experience and carers' inclusion among decision-makers in the health sector<br>**Mental Health Providers**<br>• Lack of knowledge of program and/or procedures; promotion of screening not prioritised; lack of physical health expertise<br>• Access to peer workers and support workers |

# F.3. Quality and safety initiatives for women with mental health issues

There was no information readily available on websites across jurisdictions based on information. Note it does not mean that the service is not provided, only that it could not be easily found as being provided on websites accessed in December 2023.

Western Australia Health is about to bring in a paid peer workforce. Peer workers have lived experience while support workers do not necessarily have this. Peer workers also have a huge role in change management and culture change in a service.

## F.4. Quality and safety initiatives being implemented for women with mental health issues internationally

This review includes Ontario[94] and New Zealand[95], and NHS England,[96] which did not provide any information specific to women with mental health issues.

## F.5. Additional quality and safety initiatives for consideration

Based on the review of the information above, other documents reviewed and input from stakeholders, the following list of potential gaps in information, initiatives or areas where more work is required are listed for your review.

- **Awareness and Education:**
  - Women with mental health issues may face challenges in maintaining regular healthcare routines, including attending breast screenings. Screening facilities should be aware of the potential impact of mental health issues on a woman's ability to prioritise preventive care.
  - Training to avoid stigma, unconscious bias and judgement from staff can result in a barrier to participants undertaking screening when they arrive at the clinic.
  - A need for trauma-informed focus and how trauma may have resulted in a mental illness. A greater understanding by staff of why people have mental illnesses
- **Communication and Support:**
  - Effective communication between screening providers and participants is crucial. It's important for healthcare professionals (Screening and Mental Health Professionals) to discuss the importance of breast screenings, addressing any concerns or fears the individual may have related to both mental health and the screening procedure.
  - Access to peer workers with lived experience who can provide empathy and support to the participant (volunteer or paid).
- **Individualised Approach:**
  - Recognise that each person is unique, and an individualised approach to screening is essential. Some women with mental health issues may have a strong support system

[94] https://www.cancercareontario.ca/en/cancer-care-ontario/programs/screening-programs/ontario-breast-obsp
[95] https://www.nsu.govt.ns/health-professionals/breastscreen-aotearoa
[96] https://www.nhs.uk/conditions/breast-screening-mammogram/

that can assist in scheduling and attending screenings, while others may need additional support or accommodations. This may include the need for trauma-informed care.

  - Women with mental illness are a complex cohort of women (including diagnosed and undiagnosed). They may also be from other priority populations such as First Nations, CALD and LGBTIQA+ requiring personalised quality and safety service individualised to their requirements.

- **Integrated Care:**
  - Collaboration between healthcare providers specialising in mental health and those providing breast screening services is important. Mental health professionals can offer support and guidance, addressing any specific concerns or challenges related to mental health.
- **Accessible and Friendly Environments:**
  - Creating screening environments that are welcoming and accommodating can help individuals with mental health issues feel more comfortable seeking medical care. This includes ensuring that the screening facilities are designed to be non-threatening and that staff are trained to provide sensitive and compassionate care.
  - Campaigns to address sectors of the populations with known mental illness issues such as homeless women e.g. Mobile breast screening vans.
  - Comprehensive training for staff, there is a high rate of burn-out that can lead to staff becoming dispassionate about care
- **Flexible Scheduling:**
  - Offering flexible scheduling options for screenings may help women with mental health issues better manage their healthcare appointments. This could include extended hours, weekend appointments, the ability to select a quiet session time (with low lighting, fewer people and less sound stimuli), after-hours appointment times or other accommodations to meet individual needs.
  - Mental health challenges may affect a person's ability to maintain consistent routines, including healthcare appointments. Screening providers should work with individuals to establish a regular screening schedule and provide reminders to ensure follow-through.
- **Empowerment and Autonomy:**
  - Empowering women to take control of their health, while respecting their autonomy, is essential. In some cases, involving mental health professionals in discussions about healthcare decisions may be beneficial. This involves providing clear information about

the benefits and potential risks of breast screening and respecting their autonomy in the decision-making process.

- For online booking systems, a trigger warning may be appropriate and/or a question such as "Would you like us to be aware of something that would influence your behaviour?" or to be able to let the clinic know they need extra support.

- **Community Outreach and Education:**
  - Conducting community outreach and education programs can help raise awareness about the importance of breast screenings, particularly within communities that may face additional challenges, including those related to mental health.
- **Crisis Intervention Plans:**
  - Considering the potential for mental health crises, screening facilities should have plans in place to address emergencies during or after screening appointments. This may involve collaboration with mental health crisis teams or having protocols for providing immediate support.
- **Continuity of Care:**
  - Appropriately sharing information and ensuring a coordinated support package is in place so the relevant health professionals can work together – effective handovers can improve accessibility and understanding.
  - Primary care or mental health services to appropriately alert the screening service to their visit to ensure adequate assistance and support is available to assist them.
- **Advocacy and Policy:**
  - Advocate for policies and guidelines that promote inclusivity in breast screening programs and ensure that the needs of women with mental health issues are considered.
  - Involve women with lived experience of mental health issues in the decision-making, co-design and evaluation processes.
  - Engage with the many national mental health organisations to raise their awareness of the resources available to their communities as well as identify ways in which BreastScreen could make its resources more accessible
- **Data Collection, Research and Innovation:**
  - There is a lack of information about women with mental illnesses and breast cancer screening, including for women who identify as LGBTIQA+ and who have high rates of mental illness. Best practice needs data to inform it.

- Support research initiatives that focus on improving breast screening technologies and methodologies for individuals with mental health issues.
- Improved evidence on current program performance.
- Compile and develop information to improve the quality of the BreastScreen experience for participants, families and screening providers. This includes data from people who have a mental illness but have been diagnosed as having a mental illness.
- Increase the number of women with lived experience and their access to research infrastructure.

## F.6. Other documents reviewed


1. Garcia-Alcaras, C., Binda, A., Gordon, J.R. et al. Intervention recommendations to improve uptake of breast, cervical, and colorectal cancer screening among individuals living with serious mental illness. Cancer Causes Control (2023). https://doi.org/10.1007/s10552-023-01791-y
2. Woodhead, C., Cunningham, R., Ashworth, M. et al. Cervical and breast cancer screening uptake among women with serious mental illness: a data linkage study. BMC Cancer 16, 819 (2016). https://doi.org/10.1186/s12885-016-2842-8
3. Mitchell AJ, Pereira IES, Yadegarfar M, Pepereke S, Mugadsa V, Stubbs B. Breast cancer screening in women with mental illness: comparative meta-analysis of mammography uptake. British Journal of Psychiatry. 2014;205(6):428-435. doi:10.1192/bjp.bp.114.147629
4. Thomas M, James M, Vittinghoff E, Creasman JM, Schillinger D, Mangurian C. Mammography Among Women With Severe Mental Illness: Exploring Disparities Through a Large Retrospective Cohort Study. Psychiatr Serv. 2018;69(1):48–54. pmid:28945184
5. Hwong A, Wang K, Bent S, Mangurian C. Breast cancer screening in women with schizophrenia: a systematic review and meta-analysis. Psychiatr Serv. 2020;71(3):263-268. doi:10.1176/appi.ps.201900318