

QUALITY IMPROVEMENT REVIEW OF CLINICAL QUALITY AND SAFETY FOR BREASTSCREEN AOTEAROA NEW ZEALAND

Whāia te mātauranga
hei oranga mō koutou

Seek after learning
for the sake of your
wellbeing

CONTENTS

RĀRANGI RARAUNGA – LIST OF FIGURES	4
RĀRANGI RIPANGA – LIST OF TABLES	5
HE MIHI – ACKNOWLEDGEMENTS	6
1. WĀHANGA TUATAHI – EXECUTIVE SUMMARY	7
Introduction and purpose	7
Background and context	7
Scope	10
Methods	11
Limitations	11
Key findings	12
Recommendations	17
2. WĀHANGA TUARUA – BACKGROUND AND OVERVIEW	21
Screening programmes	21
BreastScreen Aotearoa New Zealand	22
Summary of epidemiological aspects of breast cancer screening in Aotearoa New Zealand	25
3. WĀHANGA TUATORU – TE TIRITI O WAITANGI AND EQUITY	33
Te Tiriti o Waitangi	34
Ōritetanga – Equity	38
Māori models of screening	46
Pasifika models of screening	47
Strategic documents	47
COVID-19 screening response	49
Transparency of information	49
Workforce	51
RECOMMENDATIONS	53
4. WĀHANGA TUAWHĀ – VOICE OF CONSUMERS AND WHĀNAU	56
Improving equity for consumers and whānau	58
Improving consumer information	65
Building and maintaining strong relationships with consumer advocacy	67
RECOMMENDATIONS	67
5. WĀHANGA TUARIMA – CLINICAL QUALITY AND SAFETY	68
Governance	69
Clinical leadership	71
Performance and accountability	73
Monitoring, reporting, audit, evaluation and research	75
Continuous quality improvement	79
RECOMMENDATIONS	81

6. WĀHANGA TUAONO – IDENTIFICATION AND REPORTING	83
Definition of impacted people	83
Policies in place to communicate to impacted consumers	84
Robustness of 2DHB review process	87
RECOMMENDATIONS	88
7. WĀHANGA TUAWHITU – IMPROVEMENT OPPORTUNITIES	90
Opportunities to work as one system	90
Changes to systems, policies and process:	92
RECOMMENDATIONS	92
KUPUTAKA – GLOSSARY	96
TE TĀPIRITANGA TUATAHI – APPENDIX 1 TERMS OF REFERENCE	100
TE TĀPIRITANGA TUARUA – APPENDIX 2 LIST OF INTERVIEWEES	105
TE TĀPIRITANGA TUATORU – APPENDIX 3 LIST OF DOCUMENTS REVIEWED	106
TE TĀPIRITANGA TUAWHĀ – APPENDIX 4 PEER REVIEWERS	110
TE TĀPIRITANGA TUARIMA – APPENDIX 5 MEMBERSHIP OF MĀORI MONITORING AND EQUITY GROUP (MMEG)	111
TE TĀPIRITANGA TUAONO – APPENDIX 6 ROLES AND RESPONSIBILITIES OF CURRENT NSU GOVERNANCE GROUPS	113
TE TĀPIRITANGA TUAWHITU – APPENDIX 7 BREASTSCREEN AOTEAROA MONITORING REPORTS	114
TE TĀPIRITANGA TUAWARU – APPENDIX 8 RECOMMENDATIONS FROM MĀORI GP INTERVIEWS	117
REFERENCES	118

RĀRANGI RARAUNGA

LIST OF FIGURES

Figure 1. Trends in incidence of breast cancer in Māori, Pasifika, and non-Māori non-Pasifika, all ages; Māori and Pasifika 3 year moving average rates age standardised to WHO world population, 2007–2019	25
Figure 2. Trends in breast cancer mortality rates by ethnic group for all ages; Māori and Pasifika 3 year moving average rates age standardised to WHO world population, 1996–2017	26
Figure 3. Equity gaps: percentage increase in incidence and mortality, and percentage decreases in coverage, timely rescreens, and 5-year survival, in wāhine Māori and Pasifika compared to non-Māori and non-Pasifika.	29
Figure 4. Breast cancer incidence and mortality rates, ages 45–69, by ethnic group, age standardised to the WHO world population, 2007–2017.	39
Figure 5. Rescreening: percentage of women enrolled in BSA getting the next screen within 27 months by first or subsequent screen, age group, and ethnicity, BSA data, 2018–2020	41
Figure 6. Stage distribution of screen detected invasive breast cancers in women aged 45–69 years, 2010–2016	42
Figure 7. Stage distribution of clinically detected invasive breast cancers in women aged 45–69 years, 2010–2016	43
Figure 8. Decrease in BSA coverage by ethnic group, year and quarter in the COVID-19 period, 2020–2022	44
Figure 9. Current advisory group and UDG structure for the BSA programme, July 2022	69

RĀRANGI RIPANGA

LIST OF TABLES

Table 1. BreastScreen Aotearoa quality improvement review recommendations	17
Table 2. Equity gaps between Māori, Pasifika, and non-Māori non-Pasifika for breast screening indicators	28
Table 3. BreastScreen Aotearoa monitoring reports: summary of monitoring and evaluation national indicator reports commissioned or produced by the National Screening Unit	114
Table 4. Provider clinician performance monitoring in the BreastScreen Aotearoa programme	116

HE MIHI ACKNOWLEDGMENTS

E te hunga kua ngaro i te mate ūtaetae. Moe mai rā ki ngā tini whetū, ki ngā parirau o Hine-nui-te-pō.

E maumahara ana mātou ki a koutou.

To all those who have lost their lives to breast cancer. Rest in peace in the protective embrace of Hine-nui-te-pō. We remember you.

E ngā muka tāngata me ngā kōrero kua rangitāmirotia nei e tā tātou arotake. Tēnei mātou e mihi atu nei mō ā koutou mahi, ō koutou mōhiotanga me ō koutou whakaaro.

To the many people and voices that have been woven together in this review. We thank you for your contributions, your thoughts, and insights.

E koutou, e ngā wāhine katoa o Aotearoa New Zealand. E mihi atu nei ki ō koutou kaha ō koutou mahinga mō te whakatairanga o te mātauranga, te hauora, te pāpori, te ahurea me te ōhanga o ngā whānau me ngā hāpori o te motu. E mihi kau ana mātou ki a koutou.

To all women of Aotearoa New Zealand. We acknowledge your strengths and your roles in elevating the educational, health, social, cultural and economic wellbeing of whānau and communities of the nation. We unreservedly acknowledge you.

We are grateful to the many people who made time to share their knowledge and experience of BreastScreen Aotearoa New Zealand. Our independent quality improvement review of the breast screening programme reflects the generous contribution of academic and subject matter experts, clinicians, non-government and community organisations, consumers, breast screening service providers, and tangata whenua. We thank all review participants for their insights and advice which were generously and candidly shared. We have done our best to reflect your views and your voices are woven throughout the report.

We recognise the women of Aotearoa New Zealand who have survived breast cancer and the friends and whānau who walked the journey with them. We also recognise women currently living with breast cancer and those who are supporting and caring for them.

We acknowledge the efforts of all people involved in co-ordinating and delivering breast screening services and recognise the lifesaving benefits of breast screening for the women of Aotearoa New Zealand, their whānau and communities.

Our recommendations are offered in the spirit of improving programme quality, achieving equitable participation and outcomes from screening, and promoting mana wāhine Māori and the mana of all women in Aotearoa New Zealand.

**Ngā mihi nui
The Review Panel**

1. WĀHANGA TUATAHI EXECUTIVE SUMMARY

E ngā mana, e ngā reo, e ngā kārangatanga. Tēnā koutou kātoa

Me aro koe ki te hā
o Hineahuone. Mai
te tīmatanga, ko
Papatūānuku, te whaea
whenua, ko Hineahuone
te ira tangata tuatahi, he
wāhine. Tīhei Mauriora!

Pay heed to the dignity
of women. From the
beginning of time was
Papatūānuku, the Earth
Mother, then Hineahuone
the first human created,
a woman.

This whakataukī reminds us to respect the mana and iho of wāhine and to honour their central role in the lives and wellbeing of whānau, hapū, iwi and communities of Aotearoa New Zealand. It draws on ancient narratives that continue to resonate and find relevance in our contemporary lives.

Introduction and purpose

This is a report of an independent quality improvement review of the national breast screening programme, BreastScreen Aotearoa (BSA). The review was commissioned by the Chief Executive of Te Whatu Ora – Health New Zealand in May 2022.

The purpose of the quality improvement review was to assess whether the arrangements for clinical safety and quality for the BSA programme are fit for achieving the objectives of the programme. This includes determining whether the arrangements have been put into operation equitably and effectively and providing recommendations for change or improvement.

Background and context

Impetus for the review

The impetus for the review was the identification that a large number of consumers in the Wellington region had been waiting longer than the 60 working day target from enrolment to offer of an appointment for their first screening mammogram. For some consumers this delay may have led to breast cancer becoming more advanced by the time of diagnosis. This specific incident is subject to a separate investigation (2DHB review) that will follow established adverse event review processes. Investigators will report directly to the Chief Executive of Te Whatu Ora. [1]

Context

BSA has been in place in Aotearoa New Zealand for twenty-four years since its official launch in 1998. BSA is one of three national cancer screening programmes in Aotearoa New Zealand, the other two are bowel and cervical screening. Many of the challenges identified in this report reflect the way in which screening programmes have been established and the substantial resources required to initiate and maintain high quality screening programmes. Each cancer screening programme has been established as a self-contained programme. Despite cross-functional oversight groups further work is needed to improve coordination and integration across the programmes. For example, there is not a population screening register for all screening programmes.

The benefits from an integrated population register approach across screening programmes has been discussed for some time and there is general agreement about the approach to be taken after the first population register was implemented in the bowel screening programme. However, COVID-19 and resource requirements have delayed the implementation of the national breast and cervical population registers. At present each screening programme has its own separate, unlinked information system.

The imperative to focus on te Tiriti o Waitangi (te Tiriti) and equity, along with responding to the themes of the health system reforms, provide an opportunity to develop a cohesive, coordinated, population-based approach, led in partnership with Māori and co-designed with Māori, Pasifika and consumers, for all cancer screening in Aotearoa New Zealand. For example, opportunities for an integrated approach when people engaged through one screening programme are provided access, along with their whānau, to the other two programmes, and access to other haoura enhancing initiatives such as cardiovascular disease and diabetes checks.

The review panel is mindful that the wider health system is grappling with the challenge of giving effect to te Tiriti and achieving ōritetanga (equity), particularly for Māori and Pasifika, and implementing the Code of expectations for health entities' engagement with consumers and whānau.[2 p14] Similar issues were identified across the health sector by the Waitangi Tribunal in its report on stage one of its Health Services and Outcomes Inquiry (Wai 2575).[3]

There are strong findings and recommendations in this report, but they should not be taken out of this context. The shortcomings identified in the BSA programme reflect health system wide issues that are longstanding. The health system reforms provide the opportunity for Te Whatu Ora in partnership with Te Aka Whai Ora to drive much needed reform across the entire health system.

The BSA programme was last formally reviewed in 2011.[4, 5] This review identified a number of issues and made recommendations for improvement. Many of the issues identified in this review are similar to those identified in 2011. It is essential that these issues are addressed, and continuous quality improvement and systematic evaluation are embedded in the programme. Quality improvement should "create a cycle of critical review of services".[6 p14] Assurance of the programme's quality and safety cannot depend on ad hoc reviews in response to incidents.

The impact of COVID-19 on the BSA programme has been significant. Over the last decade, the coverage of the BSA programme for wāhine Māori has been persistently around 10 percentage points below that of women of non-Māori non-Pasifika ethnicities.[7] This still applies in the most recent data, with all coverage rates being reduced by COVID restrictions, with Pasifika women experiencing the greatest decrease in coverage during the pandemic (2020–2022).[8] Disruptions to services related to COVID-19 over the past two years has resulted in some 50,000 (9%) fewer women being screened compared to service levels in late 2019/early 2020 (or around 11% of eligible women, when accounting for population growth)[7]¹; these data are not reported by ethnicity.

Modelling commissioned by the National Screening Unit (NSU) has predicted: screening rates will get back to pre-COVID-19 levels by December 2022; the COVID-19 backlog² (estimated to be 28,500 screenings missed in 2020–21 (again, these data are not reported by ethnicity), will be cleared by end June 2023; and equitable coverage² will be achieved over a period of three years starting from 1 July 2023.[7] However, the modelling report notes that addressing the COVID-19 backlog may temporarily limit the ability to progress other objectives such as achieving equitable coverage; and it may create a long tail effect as the additional women screened in 2022–23 will return every second year until they reach the maximum age of eligibility.[7] The panel acknowledges the critical workforce issues that have impacted health care services during COVID-19 and continue post the pandemic, particularly workforce availability and wellbeing, and the challenges these continue to present for the BSA programme.

The modelling report predicts the likely effect of COVID-19 on demand and capacity to enable workforce and resource planning.[7] The primary goal of breast screening, however, is to reduce breast cancer deaths. The likely effect on breast cancer mortality due to delays in re-screening has not yet been modelled but will be important to ensure efficacy of the programme is maximised at times when demand exceeds capacity.

The COVID-19 pandemic has exacerbated issues that existed for BSA before COVID-19 and created new challenges. The programme's Quality Framework, published in 2015, states that achieving equity "is the absolute focus for the future".[6] Achieving equity between Māori and non – Māori/non-Pasifika and Pasifika and non – Māori/non-Pasifika-continues to be the greatest challenge for the programme. Improving participation among wāhine Māori and Pasifika is likely to result in proportionately higher health gains given the higher morbidity and mortality risk for these two groups than for other ethnic groups.[7]

The review panel has heard many different views and experiences. What stood out is the need for Māori and Pasifika leadership, and the voice of consumers and whānau to be heard and their voice integrated into all levels of the programme. Addressing equity is best achieved through involving consumers, whānau and communities; their full and effective participation and trust in the programme depends on partnership, shared decision making, co-design, and open, transparent communication.[9]

1 The authors estimate the backlog could be 61,500 after accounting for population growth that is indicated in population projections and applying the 2019 uptake rates by ethnicity.

2 Equitable coverage is defined in the modelling report as "uptake for each ethnicity in each region is at least 72% for all women in the 45–69 age range".

Scope

The terms of reference for the review are set out in Appendix One.

The scope of the review included the 2017–2022 period and focused on the systems, processes, and procedures in place for ensuring the clinical safety and quality of the BSA programme.

The review team was asked to address the following key questions:

Insights and analysis

1. What systems, policies, and processes (including monitoring, audit and clinical governance, clinical expertise and input) are in place to manage equity, consumer/whānau voice, clinical quality and safety across the BSA programme, and are they being operationalised effectively?
2. Are systems, policies and processes meeting the needs of Māori and Pasifika people who are enrolled in the programme?
3. Is there clarity about roles and responsibilities in relation to these systems, policies, and processes across the BSA programme?

Relationships and clinical decision-making

4. What arrangements are in place to manage relationships between the NSU and BSA Lead Provider Managers and Clinical Directors?
5. Are there any recommendations for improving these relationships and how the teams work together?

Delays in identification and reporting

6. Do BSA providers have appropriate policies in place to appropriately communicate to impacted people if there are delays, or capacity constraints? Are these consistent with good practice?
7. Has the 2DHB review been sufficiently robust to give confidence in the process and outcomes, and to give assurance that all reasonable steps have been taken to identify all impacted people?

Improvement opportunities

8. What opportunities to work better as one system will HNZ and Māori Health Authority³ structures bring? How can these be maximised?
9. Whether any changes to systems, policies and process are required to ensure appropriate BSA programme monitoring and quality, including equity and consumer/whānau voice, now and into the future, taking into account the development of the future IT system?

Out of scope

The following were excluded from the review:

- Re-examine the evidence that supports the current BSA eligibility criteria
- Other screening programmes managed by the National Screening Unit
- The audit or review of individual cases

³ Now known as Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority)

Methods

A mixed method approach was utilised for this review.

As part of primary data collection, stakeholder interviews were conducted (45 individual stakeholders and seven groups) between July-October 2022. A list of interviewees is set out in [Appendix Two](#). Interviewees represented a wide range of groups including wāhine representatives, the NSU, lead providers, screening support services, general practitioners (GPs), non-government organisations, and academic and subject matter experts.

Interviews were conducted via Zoom or Microsoft Teams with at least one panel member and one member of the secretariat. The interviews were semi-structured; participants were provided with a set of guide questions in advance. Interviews were recorded by the members of the secretariat taking notes. After each interview, the notes were collated, rewritten using thematic analysis and emailed to the interviewees for review.

A written response was received from one person who was unable to attend an interview within the review's timeframe.

All data was stored on a confidential MS Teams page and was accessible to all panel and secretariat members.

Secondary data collection and analysis included review of published and grey literature. Grey literature included publicly available programme reports, documents provided by the NSU, BSA monitoring reports, and extracts of data obtained for the epidemiology review.[8] A list of the documents reviewed by the team is set out in [Appendix Three](#).

An examination of epidemiological aspects of breast cancer screening relevant to Aotearoa New Zealand was undertaken by Professor Mark Elwood, Professor of Cancer Epidemiology at the Faculty of Medical and Health Sciences at the University of Auckland.[8] Professor Elwood's findings are referred to throughout this report. A summary of Professor Elwood's findings is set out in [Wāhanga tuatoru \(Section 3\): te Tiriti o Waitangi and equity](#).

Prior to finalising the report, the panel sought input from peer reviewers. The ten peer reviewers are set out in [Appendix 4](#). The panel would like to acknowledge the peer reviewers' valuable feedback which has been incorporated in the report.

Limitations

The review was limited by the following factors:

Time.

This review was completed over 14 weeks, which limited the primary and secondary data available to inform the review.

Number and diversity of people and groups interviewed.

45 people and seven groups were interviewed for this review. The team received rich insights from the women and groups that were interviewed. However, the overall number of interviewees was small, and the group could have been more diverse to represent the whole screening population. For example, interviews did not include Asian women, the voices of disabled, LGBTQIA+ or women who did not engage in the system. The panel notes that these are areas that require further exploration.

Pasifika input.

The panel received input from Pasifika women for this review through personal interviews and one written submission from a Pasifika GP. The panel acknowledges the diversity of Pasifika communities and would have valued more time and opportunity to connect with, and understand the perspectives of, a wider range of Pasifika consumers and clinicians.

Data completeness and quality.

Limitations to BSA programme data include a limited data set (for example, data from private providers are not included in the BSA data set), insufficient data linkages, poor quality of data, and gaps in data (for example ethnicity and disability data). These limitations affect the reporting of important programme performance indicators, notably the total number of wāhine Māori and all women eligible for the programme; the number of eligible wāhine Māori and all women who are not enrolled (unscreened), and interval cancer rates. Opportunities to address the data limitations are discussed in [Wāhanga Tuawhitu \(Section 7\): Improvement Opportunities](#).

Key findings

Opportunities to work as one system

- The BSA programme is not meeting all of its obligations under te Tiriti o Waitangi, and is not achieving equity for Māori and Pasifika. The health reforms provide an opportunity to create a health system that is te Tiriti-compliant, equitable, accessible, cohesive and whānau-centred. Achieving pae ora requires a step change in how health entities address population health and work collectively to create a one-system culture and ethos.[10]
- Cancer screening programmes in Aotearoa New Zealand have been established as self-contained programmes. More work is needed to improve coordination and integration across the programmes. The 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 requires all entities to work collectively and in partnership with each other. This will require a significant reset of relationships between the NSU and providers, and with Māori, Pasifika, consumers, and communities they serve.

Te Tiriti o Waitangi

- The NSU has committed to implement a Tiriti co-governance partnership model over the national screening programmes. Work has commenced and has been approached with integrity. However currently the BSA programme is not meeting all its obligations under te Tiriti o Waitangi. The programme function and service delivery are not informed by Māori leadership, mātauranga Māori or grounded in te ao Māori:
 - The BSA's governance system does not give effect to te Tiriti and the principles of the Pae Ora (Healthy Futures) Act 2022. It does not sufficiently value and recognise the centrality and importance of whānau in te ao Māori and provide opportunities for Māori to exercise decision-making authority. The governance system does not reflect the principles of shared decision-making, partnership and co-design. Māori partnership arrangements are not embedded in the NSU or at any level of the BSA programme and there is no wāhine Māori involvement within the programme's governance.
 - Published policies and plans appear to have minimal content expressing comprehensive commitment to te Tiriti and Māori health equity.
 - Māori voices, those of wāhine, whānau, and Māori experts from along the screening pathway are not involved with decision making. Racism and bias exist across the programme. Kaupapa models including holistic and whānau ora approaches have not been resourced, prioritised and scaled across the programme.

Equity

- The BSA programme is not achieving ōritetanga (equity) and is not meeting the needs of wāhine Māori and Pasifika women.
- Ōritetanga is a te Tiriti principle and a fundamental component of a high-quality service. The objective of the BSA programme is to reduce deaths/mortality from breast cancer by the early detection and early treatment of asymptomatic cancers. Studies report the programme is achieving its objective of reducing mortality, however it is not being achieved equitably.
- BSA leaders have acknowledged the screening programme has “not done equity well”. There are significant and persistent equity gaps in incidence, survival and mortality from breast cancer, and in access to screening, between Māori, Pasifika, and non-Māori non-Pasifika women. The NSU’s Strategic Plan 2010 to 2015 states “achieving equity and coverage for Māori and Pasifika populations remains the biggest challenge for the NSU”, and this is still the case.
- For the screening programme to be successful, high levels of programme enrolment and participation are required. Given that breast cancer is such an important cause of cancer death and reduced life expectancy for wāhine Māori and Pasifika, increasing access to cancer screening has the potential to substantially improve breast cancer survival for wāhine Māori and for Pasifika women and reduce survival inequity between Māori, Pasifika and non-Māori, non-Pasifika women.
- There are multiple barriers to women participating along the screening pathway, including the lack of a national breast screening register with a list of all eligible women and the systematic invitation and recall to screen. An ICT system that enables a national breast screening register with systematic invitation and recall is an imperative if the programme is going to achieve the $\geq 70\%$ screening target for wāhine Māori and Pasifika and for implementing this review’s recommendations. A new BSA programme ICT platform scheduled for implementation in 2024 aims to provide such a system. The ICT replacement project will benefit from close monitoring and support from Te Whatu Ora’s Data and Digital Directorate to ensure the project delivers a fit-for-purpose, modern screening ICT system.
- Studies of access to breast screening for Māori and Pasifika women are few. The importance of listening to and understanding the lived experience of wāhine Māori and Pasifika is essential to understanding how to address barriers to access and maximise wāhine Māori and Pasifika participation in the programme.
- COVID-19 has had a significant impact on Māori and Pasifika. Pasifika women had the largest decrease in participation in the programme 2020–2022 and wāhine Māori continue to have the lowest participation in the programme. Development of a Māori specific, and a Pasifika specific, COVID-19 and cancer screening response and recovery plan is required.
- To address the significant gaps in equity and meet the needs of Pasifika women several issues need to be addressed including the lack of Pasifika representation within the NSU and BSA programme; the need for strategic commitment to Pasifika health equity; the need for services that are tailored for, and meet the needs of, Pasifika women; and the need for a range of Pasifika voices – those of consumers, family, community, and Pasifika experts – leading decision making.
- There is poor understanding of equity in relation to other underserved populations, including a distinct gap in data about women living with disabilities (including tangata whaikaha Māori) and women who live rurally. Underserved groups within the BSA programme need to be identified, their lived experience understood, and equitable approaches for them embedded within the programme. This work is a priority set by the Government for 2022–2024.

Consumers and whānau

- There is limited understanding of, and attention given to, consumer engagement within the programme, which is a critical aspect of quality improvement. The NSU acknowledges it needs to improve its approach to consumer and whānau engagement and intends to develop a consumer and whānau engagement strategy.
- There is an urgent need to establish consumer participation within the BSA programme, at all levels including being part of governance and decision-making.
- Information for consumers and whānau, and communication with them, needs to be improved.

Clinical quality and safety

- Engagement and partnership with Māori clinician leaders is critical to the success of a revised NSU and BSA governance structure. Māori clinical leadership has not been a priority for the programme.
- The principles of co-design and distributive leadership are important to ensure the highly dispersed expertise in the programme is included in governance. The programme's governance does not involve co-design, shared decision-making and distributive leadership, and the clinical governance structure provides little opportunity for clinicians to be involved.

Monitoring, reporting and evaluation

- Effective equity monitoring requires high quality ethnicity data that is made accessible to whānau, hapū, iwi Māori and Pasifika organisations. The BSA needs to improve its equity analysis monitoring frameworks and ensure that quality ethnicity data is analysed using equal explanatory power and analysis principles.
- There are issues with ethnicity data quality in health databases which means there is undercounting of Māori and Pasifika. Using prioritised ethnicity undercounts the number of Pasifika affected, and there are now growing numbers of people identifying as both Māori and Pasifika. Embedding consistent use of the Ethnicity Data Protocols for the health and disability sector [11], and use of existing tools such as the primary care data audit toolkit, could improve data quality.
- The programme standards need to be formally revised. There are too many standards, and they need to be simplified. The NSU intends to commence formal revision of the standards in 2023; this needs to be a co-design process from the start.
- The amount of monitoring and reporting on the BSA programme is large, and the number of performance indicators is very large. There is a lack of prioritisation of key indicators, regular and rapid reporting, and clarity about actions to be taken if problems occur. The BSA programme does not, but should, have a monitoring framework that includes clearly defined indicators that are prioritised, describes the frequency of reporting and where indicators will be reported, and escalation protocols if an indicator is out of line.
- Consumers have not been directly involved in the development of the BSA programme indicators since 2013, and the NSU does not systematically measure patient-reported experience (PREs/PREMs) and patient reported outcomes (PROs/PROMs).[12] Consumers and whānau have not been included in the process of determining which outcome measures are reported, what is most important to them, and how information is presented. The NSU ICT project will include technology to communicate directly with consumers; designing measures to capture and report PRO and PRE data to inform quality improvement has not been identified as a priority in the implementation of this project.

- Reporting of indicators is not regular or timely and is not transparent. Most monitoring reports produced by NSU are overdue. The last mortality evaluation report was published in 2015 for data from 1999–2011; and the last interval cancer report was published in 2018 for data from 2008–2009, although the standard specified by the NSU is that interval cancers will be reported annually. The NSU does not report breast cancer mortality by time series (including ethnicity and age) as a routine part of BSA programme reporting, in contrast to the National Cervical Screening Programme (NCSP) programme.[13] Similar annual time series mortality reporting should be part of routine reporting of the BSA programme. Transparency of reporting is essential for quality, safety, accountability, and informed decision making. Monitoring reports and detailed analysis supporting significant decisions made by the NSU, including prioritisation decisions, have not been shared with providers, consumers and the public in a timely manner.

Workforce

- Currently, there is no clear structure for ensuring there is an equitable representation of Māori health and Pasifika health expertise within the NSU and within the BSA programme. There are no specific roles that are designated as 'equity' lead or advisor roles. Development of the Māori and Pasifika health workforce and clinical leadership for the BSA programme must be given high priority.
- Developing a culturally safe and competent non-Māori workforce in breast screening is also important. Currently, there is no systematic, comprehensive training for the BSA's non-Māori workforce in the understandings of te reo me ona tikanga (Māori language and protocols) and te ao Māori (Māori ways of life). Training in anti-racism, cultural safety, and health literacy is also required.

Continuous quality improvement

- Encouraging continuous improvement is a key element of a screening programme's quality assurance system that helps ensure the programme is operating high-quality services. Currently the BSA programme is not using information systematically to support learning and continuous quality improvement. There is an opportunity to build a quality and safety learning system across the BSA programme 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 programmes.

Ensuring these recommendations are implemented

- There have been several reviews of the BSA programme and recommendations made to improve the programme. Interviewees were critical that these recommendations have not been implemented. It is important that the issues identified in this review are addressed. Interviewees have generously shared their expertise and given their time to this review with the trust that they will be listened to and improvements are made to the BSA programme. The review panel has recommended the appointment of a Pae Whakaterere to oversee and ensure the panel's recommendations are implemented in a timely way.
- The successful implementation of these recommendations will depend on adequate resourcing. A business case will need to be developed along with an implementation plan to ensure adequate resourcing and sustained improvement.
- There should be an evaluation of the implementation of the recommendations of this review prior to the completion of the term of the Pae Whakaterere.

Recommendations

The following recommendations should be seen in the light of work the NSU has commenced, and is planning, to improve cancer screening and the BSA programme.

This includes work to align the screening programmes across a common National Screening Solution Platform and to replace the BSA ICT system; implementing a te Tiriti co-governance partnership model over the national screening programmes; employing a Māori public health physician to align all the activities of the NSU with te Tiriti o Waitangi and the Pae Ora Legislation; working with Māori health data experts to explore how to apply Māori data sovereignty principles to its data collection, analytics, monitoring and reporting frameworks; and implementing cultural safety and multi-level anti-racism workforce programmes and training for all staff in the BSA programme.

The panel acknowledges the NSU's commitment to change and work that is underway. This work will provide a foundation for further improvements identified in this review.

Recommendations are summarised in the table below with responsible roles and an indicative timeframe identified (Table 1. BreastScreen Aotearoa quality improvement review recommendations). A more detailed description of the recommendations can be found at [Wāhanga Tuawhitu \(Section 7\): Improvement Opportunities](#).

Table 1. BreastScreen Aotearoa quality improvement review recommendations

RECOMMENDATION	RESPONSIBLE	TIMEFRAME FOR ACTION	
SYSTEM LEVEL			
1	Develop a comprehensive, coordinated population-based approach to all cancer screening services in Aotearoa New Zealand. This should include a review of the form and function of the NSU.	<ul style="list-style-type: none"> ▪ Ministry of Health ▪ National Director, National Public Health Service, Te Whatu Ora ▪ Chief Executive, Te Aka Whai Ora 	12 months
2	Develop a monitoring and performance framework over the NSU screening programmes' Tiriti responsive cowgovernance	<ul style="list-style-type: none"> ▪ Te Aka Whai Ora ▪ Ministry of Health 	6 months
3	Monitor and support the BSA ICT replacement project to ensure the project delivers a fit-for-purpose, modern screening ICT system	<ul style="list-style-type: none"> ▪ National Director, Data and Digital, Te Whatu Ora 	6 months

RECOMMENDATION		RESPONSIBLE	TIMEFRAME FOR ACTION
PUBLIC HEALTH DIRECTORATE – NSU LEVEL			
<i>Te Tiriti o Waitangi</i>			
4	Appoint a Pae Whakaterere comprising two to three suitably qualified people to oversee, guide and monitor the implementation of the BSA quality improvement review recommendations and co-governance model, for a period of up to two years	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora ▪ Public Health Lead, Te Aka Whai Ora 	3 months
5	Establish an expert working group to support the Pae Whakaterere	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora ▪ Public Health Lead, Te Aka Whai Ora 	3 months
6	Resource a wānanga for Māori stakeholders and partners to explore how best to establish a kaupapa Māori community of practice	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora 	3 months
<i>Equity</i>			
7	Resource a Pasifika-led co-design process to develop a strategy and action plan to identify and address Pasifika priorities for breast cancer screening	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora 	3 months
8	Develop a national programme of work to rapidly increase participation in the BSA programme for wāhine Māori and Pasifika to at least 70%.	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora 	6 months
9	Co-design Māori and Pasifika plans that include developing and implementing approaches to achieve equity, along with a monitoring and reporting framework	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora 	12 months
10	Develop a Māori specific, and a Pasifika specific, COVID-19 and cancer screening response and recovery plan	<ul style="list-style-type: none"> ▪ National Director, National Public Health Service, Te Whatu Ora 	6 months

RECOMMENDATION		RESPONSIBLE	TIMEFRAME FOR ACTION
<i>Monitoring, research and evaluation</i>			
11	Apply Māori data sovereignty principles to the NSU and BSA programme's data collection, analytics, monitoring and reporting frameworks	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	6 months
12	Ensure that quality ethnicity data are collected and used so that the BSA programme is making decisions based on the most accurate data possible	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	12 months
13	Develop a monitoring and reporting framework for the BSA programme with Māori, Pasifika, consumers and service providers	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	6 months
14	Monitor and continuously update the evidence-base for development of the programme and make this transparent with regular, timely publication	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	6 months
15	Develop and implement a plan to fund research into improving screening, including pathways for wāhine Māori, Pasifika women, underserved groups and research in other priority areas	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	12 months
<i>Workforce</i>			
16	Develop and implement cultural safety and multi-level anti-racism workforce programmes and training for all staff in the BSA programme including lead providers	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	12 months
17	Co-design and implement a dedicated recruitment and retention strategy which includes training opportunities, and pathways to recruit and develop Māori staff, Pasifika staff and staff with lived experience of disability.	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora Lead providers People and Culture Lead, Te Whatu Ora 	12 months
18	Co-design a kaupapa Māori accreditation programme for breast screening providers	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora Lead providers Te Aka Whai Ora 	12 months

RECOMMENDATION		RESPONSIBLE	TIMEFRAME FOR ACTION
Consumers			
19	Set up a consumer and whānau panel to oversee the redesign of the BSA governance structure and provide advice on issues identified in this review	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	3 months
20	Partner with the Health Quality & Safety Commission to develop a consumer and whānau engagement framework based on the HQSC Code of expectations for health entities' engagement with consumers and whānau, with an action plan for the next six months to implement the framework	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora Health Quality & Safety Commission 	6 months
Clinical quality and safety			
21	Include in the design of the BSA co-governance model a review of the clinical governance model; a review of roles and responsibilities; and a reset of relationships	<ul style="list-style-type: none"> Chief Medical Officer, Te Whatu Ora Clinical Lead, Te Aka Whai Ora 	6 months
22	Co-design and publish a comprehensive set of BSA programme policies that reflects te Tiriti obligations and a comprehensive commitment to Pasifika health equity.	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	12 months
23	Review and redesign the BSA's external auditing programme to focus on what is most important, based on priority indicators	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	12 months
24	Co-design and implement a learning system that underpins a new governance structure	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora National Director of Innovation and Improvement, Te Whatu Ora 	12 months
Identification and reporting adverse events			
25	Develop a clear pathway to implement the NSU's Open Communication, Adverse Event Management and Complaint Management policies that includes an escalation pathway	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora 	12 months
26	Provide updated training for all NSU and lead provider staff on the recognition and management of adverse events, and open communication	<ul style="list-style-type: none"> National Director, National Public Health Service, Te Whatu Ora Lead providers 	12 months

2. WĀHANGA TUARUA BACKGROUND AND OVERVIEW

Nāku te rourou nāu te
rourou ka ora ai te iwi

With your basket and
my basket the people
will live

This section provides background to screening programmes, a description of the structure of breast cancer screening services in Aotearoa New Zealand, and an overview of the status of breast cancer in Aotearoa New Zealand today.

Screening programmes

Screening programmes test large numbers of people and will only make a substantial difference to population health if a sufficient proportion of the eligible population uses them. Two common terms used to describe and measure the use of screening services are coverage, which is the proportion of the eligible population that has been screened within a defined time period; and uptake (participation): the proportion of the invited population that has been screened.[14]

A screening test is never 100% accurate; it does not provide certainty but only a probability that a person is at risk (or risk-free) from the condition of interest. An effective screening programme can save lives; but screening can also lead to harm. Harm from screening is unintended and inevitable for a number of reasons including: screening tests are not 100% sensitive or specific, there will always be false positives and negatives, and earlier detection may lead to over-diagnosis and over-treatment.[14]⁴ Most people who are screened do not have the condition, therefore more people can be exposed to the harm of screening than may be able to benefit from screening.

Because screening programmes can cause harm, it is essential that the benefits of screening are maximised, and harm is minimised. Failure to operate a screening programme according to specific requirements can have significant repercussions such as: the expected benefits are not achieved, and the programme is no longer cost-effective; the reputation is damaged, and the population no longer believes in the benefits of the programmes and fails to attend; and serious incidents occur that harm the population rather than benefit it.[16]

⁴ Overdiagnosis occurs because conditions can be detected that would never cause that individual harm in their lifetime; and overtreatment can occur, for example because benign conditions found as part of screening are treated unnecessarily, such as surgical removal of small benign breast lumps, or because over-diagnosed cancer is treated, or a low-risk cancer receives more treatment than is necessary for cure.

For a screening programme to be effective, it needs to fulfil specific requirements including: the eligible population is defined according to the evidence; all screening providers use quality standards based on the evidence; the test (mammogram) is offered systematically based on a register of the eligible population using a call and recall system; and screening is supported by an information system linked to a population register.[14] A screening programme operated in this way is called an organised screening programme or a population screening programme.[14]

The most important way to maximise the benefits of screening programmes is to make sure the programme is operating high-quality services through a quality assurance system: the process of checking that each provider meets national standards, ensuring that the screening programme is safe, equitable and effective, and encouraging continuous improvement.[14]

BreastScreen Aotearoa New Zealand

BreastScreen Aotearoa New Zealand (BSA) is Aotearoa New Zealand's publicly funded, national breast screening programme offering asymptomatic women aged 45 to 69 years a free mammogram (X-ray of the breasts) every two years.

BSA was established in December 1998, initially to provide screening for women aged 50 to 64 years. In July 2004 the age range was extended to include women aged 45 to 69 years. BSA aims to reduce the mortality (deaths) from breast cancer through mammographic screening and early detection and early treatment of asymptomatic cancers. The risk of being diagnosed and dying of breast cancer increases with age. Survival after a breast cancer diagnosis (and subsequent treatment) is directly related to the stage at which the cancer is diagnosed.[15] Early detection of breast cancer means treatment can be commenced sooner, reducing the likelihood of death.[16]

Individuals with especially high risk for breast cancer, and women who present with symptoms or signs of breast cancer follow a different pathway outside of the BSA programme.

Breast screening pathway

The breast screening pathway has multiple components including:

- engagement with whānau, hapū, iwi, communities and service providers
- screening and health promotion
- identification and enrolment of eligible women
- invitation and recall of women eligible for screening every two years
- support to access services, including transport
- mammography
- recall to assessment for those with identified abnormalities on mammography
- multidisciplinary assessment for screened women (i.e., additional imaging including and other modalities where necessary, clinical examination, ultrasound, biopsy, and pathology services)
- communication of screening results to women and their primary health care provider
- support and counselling for women who are being assessed
- referral to treatment for women with breast cancer
- an information system which supports the programme
- quality assurance, audit, monitoring and evaluation

National Screening Unit

Aotearoa New Zealand's three national cancer screening programmes are centrally coordinated and monitored through the NSU of Te Whatu Ora. Previously the NSU was a business unit in the Ministry of Health. The NSU does not deliver the screening programmes directly, rather it is responsible for the development, monitoring and oversight of all national population-based screening programmes. The NSU contracts and funds providers to deliver screening services.

Lead providers

The BSA programme is delivered through eight lead providers (LPs) located in regions around the country. Mammograms are performed by lead providers in clinics and mobile units, with further diagnostic tests and treatments provided at hospitals and at outpatient facilities.

Screening support services

Eleven screening support service providers help recruit and retain women in the programme, offering individual-level support to help priority group women (wāhine Māori, Pasifika women, under screened women, and unscreened women) access breast (and cervical) screening. The NSU recently commissioned the evaluation of screening support services.[17] The services provided include individualised support to screening appointments (e.g., transport or support to attend appointments) and promotion of the benefits of screening to the community.

A range of providers are contracted by the NSU to provide screening support services, including iwi, Pasifika, health districts, primary health organisations and a commissioning agency.

Recruitment and enrolment of wāhine

The BSA programme does not have a national register of eligible women; and does not invite women for initial screening, unlike the bowel screening programme. Currently, all eligible women are required to give their permission to be enrolled in the BSA programme. Women must find out about the programme and apply to participate; then they can be offered an appointment ('opt-in' enrolment system). Each lead provider is responsible for inviting eligible women for their initial screening episode and recalling them to be rescreened every two years[18]⁵.

Eligible women can self-enrol through the BSA 0800 number, via the NSU website,⁶ on GP referral, through screening support service providers, or through privately funded services. Privately funded breast screening does not form part of the BSA programme.

In recent years BSA lead providers have worked with primary care providers to undertake data matching to identify eligible women who are not enrolled in BSA. Once enrolled, women are sent an invitation to have a screening appointment every two years.

Screening register

In 2011, a review of the BSA programme recommended a national population register be established for the programme, stating "A national register is the cornerstone of population screening that is essential in monitoring quality, performance standards and the outcomes of cancer screening programs". A national population register for the BSA programme has not yet been established. There is a BSA Critical Infrastructure (ICT) Replacement project underway that aims to implement such a register.[19]

Pseudo-population views have been constructed matching to the primary care enrolment register in both breast and cervical programmes to identify unscreened populations, to offer screening. The use of these tools has been variable across the country and could be further leveraged (as a population register would be) to focus on priority populations. However, it is important to note that even if this approach was consistently rolled out, other methods would need to be developed to identify and engage Māori and Pasifika for important Māori and Pasifika specific health promotion and invitation to screening initiatives, because of significant undercounting and under-representation of Māori and Pasifika in health and disability sector data.[20-22] This issue is discussed further in [Wāhanga Tuatoru \(Section 3\): Te Tiriti o Waitangi and Equity](#).

⁵ Women can be re-screened between 21 and 27 months, as lead providers do not have capacity to screen all women at exactly 24 months.

⁶ <https://www.timetoscreen.breast-screening/sign-up/>

Summary of epidemiological aspects of breast cancer screening in Aotearoa New Zealand

Breast cancer screening in Aotearoa New Zealand

Breast cancer is the most common cancer diagnosed in women in Aotearoa New Zealand and the second most common cause of cancer deaths for women. Approximately 3,500 women are diagnosed, and 635 die from breast cancer each year.[23]

Equity

There are significant inequities in breast cancer screening and outcomes for wāhine Māori and Pasifika women. More detailed analysis is set out in [Wāhanga Tuatoru \(Section 3\): Te Tiriti o Waitangi and Equity](#) of this report and in the epidemiology report of Professor Mark Elwood prepared for this review.[8] In summary:

- Wāhine Māori at all ages have the highest incidence of breast cancer (127.4 per 100,000) and a 39% higher incidence of breast cancer than non-Māori non-Pasifika, in the period 2007–2017.⁷ In the screening age group (45–69 years) wāhine Māori have a 45% higher incidence than non-Māori non-Pasifika. Pasifika women have the second highest incidence at all ages (112.4 per 100,000) compared to non-Māori non-Pasifika (91.5 per 100,000) for the same period 2007–2017.[8, 24, 25] Trends in breast cancer incidence over the period 2007–2019 are shown in Figure 1. Trends in incidence of breast cancer in Māori, Pasifika, and non-Māori non-Pasifika, all ages; Māori and Pasifika 3 year moving average rates age standardised to WHO world population, 2007–2019.

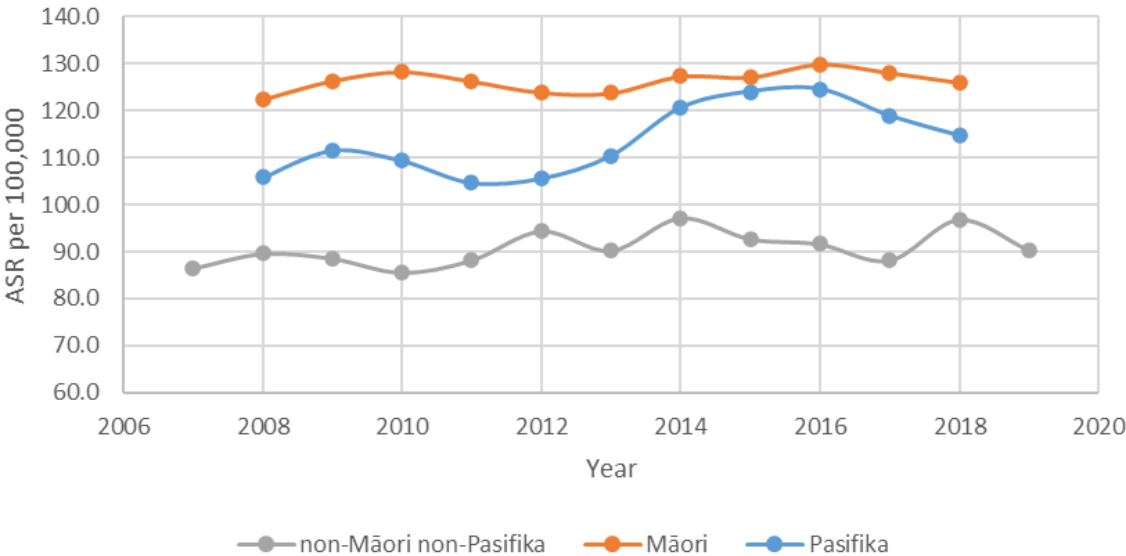


Figure 1. Trends in incidence of breast cancer in Māori, Pasifika, and non-Māori non-Pasifika, all ages; Māori and Pasifika 3 year moving average rates age standardised to WHO world population, 2007–2019

7 Based on New Zealand Cancer Registry and mortality data for 2007–2017.

- Wāhine Māori and Pasifika women had a 65% higher mortality from breast cancer than non-Māori non-Pasifika women, at all ages during the same period (2007–2017). The excess mortality in the screening age group was similar (68%).^[8] While overall mortality has decreased for all groups over the period 1996–2017, the mortality equity gap for wāhine Māori and Pasifika compared with non-Māori non-Pasifika has persisted (Figure 2. Trends in breast cancer mortality rates by ethnic group for all ages; Māori and Pasifika 3 year moving average rates age standardised to WHO world population, 1996–2017, Table 2).^[8]

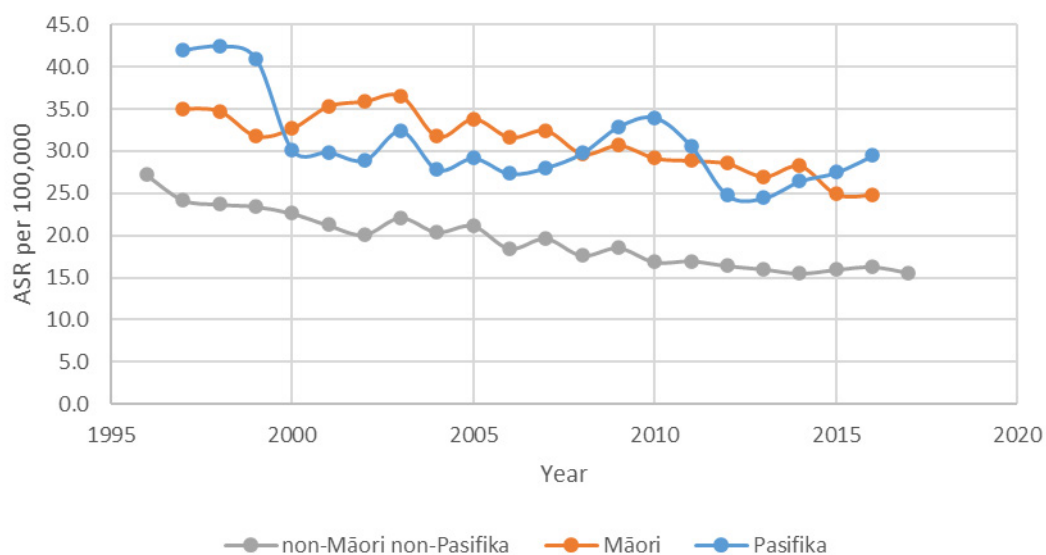


Figure 2. Trends in breast cancer mortality rates by ethnic group for all ages; Māori and Pasifika 3 year moving average rates age standardised to WHO world population, 1996–2017

- Wāhine Māori are more likely to be diagnosed with higher-risk breast cancers and are less likely to survive breast cancer. Breast cancer specific survival for wāhine Māori is the second lowest at five years (89%) and ten years (84%), compared to Pasifika (87% 5yrs; 81% 10yrs), NZ European (91% 5yrs; 87% 10yrs), and Asian women (95% 5yrs; 91% 10yrs)(Table 2, Figure 3).^[8]
- Pasifika women are more likely to be diagnosed with late stage breast cancer and have the lowest 10 year breast cancer survival rates (81%) compared to Māori (84%), Asian (91%) and other women (87%) as a result of late diagnosis, deprivation and differences in access to and quality of care after diagnosis (Table 2).^[8, 26]
- Research indicates these inequitable outcomes for wāhine Māori are mainly due to a delay along diagnosis and treatment pathways. Wāhine Māori experience lower rates of initial screens, are less likely to receive timely subsequent screens, and if treatment is required are more likely to wait longer for first surgery.^[27]
- Participation in the BSA programme is estimated by the coverage: the number of women screened as a fraction of the census population. Wāhine Māori have the lowest breast screening coverage rates of all women in Aotearoa New Zealand;⁸ this inequity has persisted since the national programme began. As at September 2022, the two-year coverage rate for wāhine Māori aged 45-69 years was 59.1% against the target of $\geq 70\%$ of women aged 50–69 years participate in screening in the most recent 24-month period^[18, Standard 1: Access and Participation; element 1.1.1] while the two-year coverage rate for all women was 65.3%.⁹

8 Coverage is defined as the proportion of women eligible for screening who have been screened in the previous two-year period. The number of women eligible is derived from Statistics NZ Census base populations at the midpoint of the two-year screening period: [https://www.nsu.govt.nz/health-professionals/breastscreen-Aotearoa New Zealand/breast-screening-dhb-quarterly-reports#:~:text=Coverage%20is%20defined%20as%20the,the%20previous%20two%2Dyear%20period.](https://www.nsu.govt.nz/health-professionals/breastscreen-Aotearoa-New-Zealand/breast-screening-dhb-quarterly-reports#:~:text=Coverage%20is%20defined%20as%20the,the%20previous%20two%2Dyear%20period.)

9 BreastScreen Aotearoa Coverage Report (shinyapps.io)

- While breast screening coverage in the BSA programme exceeded 70% in Pasifika women and in non-Māori non-Pasifika women in the two-year period ending at the end of 2020, Pasifika women experienced the greatest fall (11.8%) in coverage during COVID-19 (in the two-year period ending at the end of 2021).[8] As at September 2022, the two-year coverage rate for Pasifika women was 63%¹⁰.

Table 2: Equity gaps between Māori, Pasifika, and non-Māori non-Pasifika for breast screening indicators Selected data from epidemiology report [8]

INDICATOR	GROUP	MĀORI (M)	PASIFIKA (P)	NON-MĀORI NON-PASIFIKA (NMNP)	EQUITY GAP M VS NMNP ^g	EQUITY GAP P VS NMNP ^g
Incidence per 100,000 women 2007 to 2019 ^a	age 45–69	383.0	331.7	263.5	45%	26%
	age 45–49	294.2	261.3	228.7	29%	14%
	age 50–69	419.3	359.9	277.1	51%	30%
Mortality 2007 to 2017 ^b	age 45–69	59.8	61.3	35.6	68%	72%
	age 45–49	42.1	45.7	25.4	66%	80%
	age 50–69	80.2	79.6	47.3	70%	68%
Screening coverage ^c	Aug-22	59.2	63.3	66.7	11%	5%
	Aug-21	58.6	61.2	65.4	10%	6%
	Aug-20	59.8	66.9	67.1	11%	0%
	Aug-19	62.8	72.1	72.8	14%	1%
	Aug-18	62.9	73.1	73.0	14%	0%
Timely rescreening after first screen ^d	age 45–49	70.9	69.8	78.8	10%	11%
	age 50–67	56.1	55.9	66.5	16%	16%
Timely rescreening after subsequent screen ^e	age 45–49	81.3	80.6	84.8	4%	5%
	age 50–67	81.7	81.0	85.8	5%	6%
5-year survival non screen detected ^f	age 45–69	84.2	80.2	91.1	8%	12%
5-year survival screen detected ^f	age 45–69	97.1	94.1	97.5	0%	3%

- a Age standardised rate per 100,000 population, WHO world standard. Data sourced from New Zealand Cancer Registry, 2007–19
- b age standardised rate per 100,000 population, WHO world standard. Data sourced from New Zealand Mortality Collection, 2007–17
- c women screened in BSA divided by census population of relevant area. Data sourced from <https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/>
- d The percentage or proportion of eligible women screened by the programme, calculated as the number of women screened, divided by the number of those who are eligible by age and domicile according to the Census. The Māori coverage rate is calculated as the number of self-identified Māori women screened, divided by the number of Māori women, as identified by the Census. [18] Data sourced from BSA, 2018–2020[28]

10 BreastScreen Aotearoa Coverage Report (shinyapps.io)

- e The number of women rescreened within 27 months of their previous screen as a percentage of the number of women eligible for a rescreen. Target Initial: $\geq 75\%$ of women who are eligible for rescreen are re-screened within 27 months. Target Subsequent: $\geq 85\%$ of women who are eligible for rescreen are re-screened within 27 months. Data sourced from BSA, 2018–2020 [28]
- f Breast-cancer specific survival at 5 years from diagnosis, Kaplan-Meier methods Stage 1–3 only; diagnosed 2005–2013; Auckland and Waikato only. Data sourced from Lawrenson et al., 2019 [29]
- g Percentage excess: $= (\text{rate in M or P group} - \text{rate in comparison group}) / \text{rate in comparison group} * 100$ or Percentage deficit: $= - (\text{rate in M or P group} - \text{rate in comparison group}) / \text{rate in comparison group} * 100$

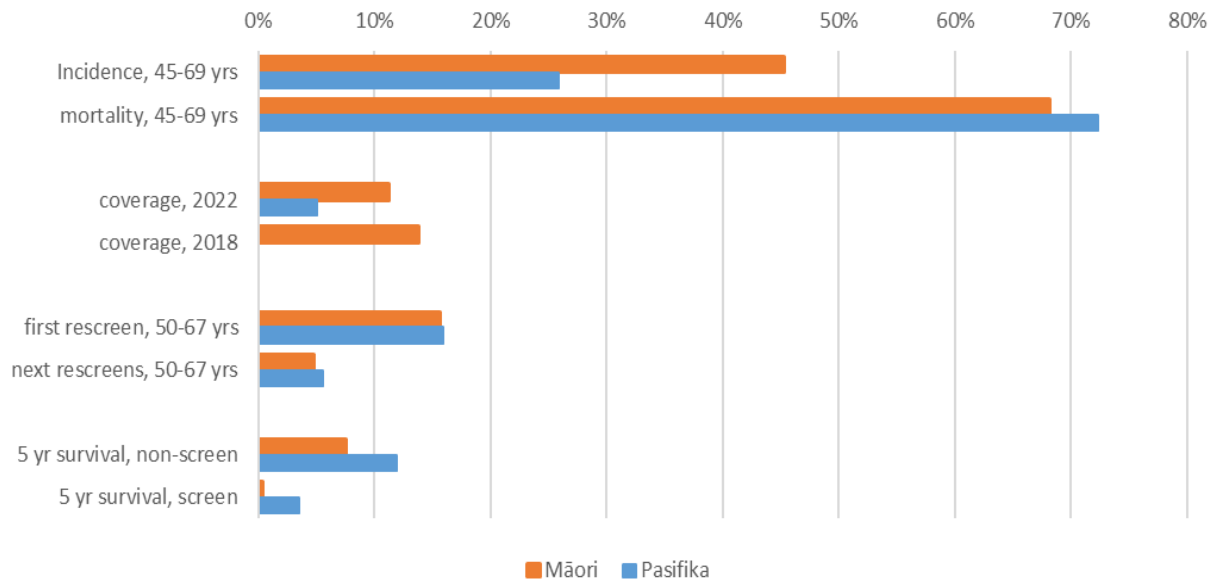


Figure 3. Equity gaps: percentage increase in incidence and mortality, and percentage decreases in coverage, timely rescreens, and 5-year survival, in wāhine Māori and Pasifika compared to non-Māori and non-Pasifika. Selected data from Table 2: Equity gaps between Māori, Pasifika, and non-Māori non-Pasifika for breast screening indicators Selected data from epidemiology report [8] [8]

Impact of screening

There is evidence to support the success of breast cancer screening for wāhine Māori: those who have breast cancer detected via screening have outcomes comparable to that of NZ Europeans.[30] For Pasifika women, participating in the screening programme has a significant beneficial impact on their risk of dying from breast cancer.[8] If more wāhine Māori had their breast cancer detected early, the disparity in breast cancer mortality can be reduced.[31] Increasing breast cancer screening rates has the potential to improve survival for wāhine Māori and for Pasifika women and reduce breast cancer survival inequity between Māori and NZ European women.[30]

Strengths of the BSA programme

The overall design of the Aotearoa New Zealand's BSA programme, and its overall participation rates, compare well with public sector programmes in many other developed countries. Most programmes start at age 50, but several generally smaller and more recently established programmes start at 45 or 40. The upper age range of 69 is also used by most programmes, with a few extending screenings to age 74.

Two-yearly screening is used by almost all programmes worldwide, with the exception of the United Kingdom programme using three yearly, and several programmes use a mixture of two-yearly and annual screening.

Coverage must underestimate actual participation, as no account is taken of ineligible women, including higher risk women, or women being screened in the private sector. Reported coverage exceeds 70% in several European programmes, but how coverage is defined varies. Coverage is lower in some major countries such as Australia and Canada. However, while the overall participation rates in Aotearoa New Zealand compare well with other countries programmes, there is a significant equity gap in participation between wāhine Māori and (to a lesser extent) Pasifika women, and non-Māori non-Pasifika women.

Impact of the BSA programme

Breast cancer mortality in Aotearoa New Zealand, as in many other developed countries, has fallen by almost half from around 1988 to the latest data available, 2017. This fall began before the screening programme started and is usually attributed to improvements in treatment. The rate of decline increased after implementation of the programme. The most detailed studies on the BSA programme report that the death rate has been reduced by 17% in the first few years of the programme, and women who participate have a 34% reduction in their risk of breast cancer death. The effects on trends in mortality, and the estimates of individual benefit, are generally consistent with those in other developed countries.[8]

Therefore, the BSA programme is consistent with current scientific evidence and programmes operating in other developed countries and has contributed substantially to reducing breast cancer deaths. However, as noted above, the benefit of the BSA programme is not evenly distributed, with New Zealand European women benefiting more than wāhine Māori and Pasifika women. Given that breast cancer is such an important cause of cancer death and reduced life expectancy for wāhine Māori, this breast cancer screening inequity is likely to have a substantial impact on inequities in overall cancer deaths and in life expectancy between Māori and non-Māori.[7 p3, 32]

The BSA programme is extensively monitored, with performance criteria set for many aspects of the programme. The extent of monitoring is considerably greater than the monitoring for most health services, including treatment for breast cancer patients and screening for women assessed as having higher risks.

Opportunities for improvement

The target of at least 70% coverage appears to be interpreted as 70% being a satisfactory level, despite meaning that up to 30% of women do not have the advantages of breast cancer screening. True participation rates are unknown as this requires estimating the numbers of women using breast cancer screening outside BSA, having clinical reasons making screening inappropriate for them, or making an informed decision not to participate. Studies of access to breast screening for Māori and Pasifika are few. The importance of listening to the lived experience of wāhine Māori and Pasifika is essential to understanding how to address barriers to access and maximise wāhine Māori and Pasifika participation in the programme.

BSA is currently an opt on programme meaning women must enrol to be invited. BSA providers work closely with Primary Health Care to identify and invite eligible women to screening, but no systematic approach to encourage this is in place; and there is no national approach for identifying and inviting the large number of women who are seen in hospital services. Many programmes in other countries identify and invite women, and active promotion and support to participants has been shown to be important. Invitations were used in the Aotearoa New Zealand breast screening pilot programmes.

Initiatives to improve the invitation to screening pathways for breast screening and bowel screening have been successful at increasing Māori participation rates. This is most evident in Te Kaha where rates rose from below 40 to over 98 percent.[33] In the bowel screening pilot, mechanisms to improve the invitation pathway resulted in a significant reduction in the equity gap for Māori and Pasifika.[34] Improvements to the invitation system should be developed and tested and successful ones rolled out.

Aotearoa New Zealand operates two other cancer screening programmes, for cervical cancer and for bowel cancer. These programmes have separate communication processes and advertising. The bowel cancer programme actively gives invitations, to men and women in the age range 50 to 74 for Māori and Pasifika, and 60–74 years for others. Therefore, women in these age groups will be actively invited for bowel cancer screening, and may be invited for cervical cancer screening through their GP. Coordination of these different recruitment processes for cancer screening have many advantages and should be tested. In addition, coordination of cancer screening with other diagnostic and preventive services, for example for cardiovascular disease and diabetes, may be beneficial. Development of screening models of care that bring together multiple opportunities for hauora gain for whānau Māori and for Pasifika need to be developed, tested and rolled out.

BSA has extensive records of women participating in the programme. But there appears to be little effective linkage with clinical records for all women diagnosed with breast cancer. The New Zealand Cancer Registry and the four more detailed New Zealand clinical breast cancer registries (now part of the Breast Cancer Foundation National Register – Te Rehita Mate Utaetai¹¹), record if a woman's cancer was screen detected or clinically detected but do not record whether she was participating in the BSA screening programme, and therefore do not record whether she has had an interval cancer. Such information may be available to clinicians when assessing a newly diagnosed breast cancer patient but is not consistently recorded. Improved linkage between data sets would be valuable.

The BSA programme is designed for 'average risk' women. 'Average risk' has not been defined. Many women are at higher risk, and in both the private and public sectors such women may receive more intensive screening, for example annual screening or screening from an earlier age. There is no reliable data on the numbers of women who receive such further screening, and there appears to be no linkage of information on such women with the BSA information.

The amount of reporting on the BSA programme is large, and the number of performance indicators is very large. However, while some indicators are reported on rapidly and frequently, such as participation data from screening providers, other indicators are only reported on occasionally with long delays, such as interval cancers. Prioritisation of key indicators, emphasis on regular and rapid reporting, and on the actions to be taken if problems are suggested, all need attention.

Future challenges

Over the past decade, the coverage of the BSA programme has been substantially lower for wāhine Māori than for Pasifika or non-Māori non-Pasifika. This still applies in the most recent data, with all coverage rates being reduced by COVID-19 restrictions, particularly for Pasifika women. There has been little work done on mechanisms to increase wāhine Māori participation in the BSA programme, and only a few localised programmes to improve participation, but some of these have had major success.

To allow better evaluation of the programme, linkages need to be made between BSA data, clinical records on all breast cancer patients, and information on screening outside BSA.

The constantly increasing international scientific knowledge relevant to breast cancer screening needs to be kept under review, especially as it may impact on major aspects of the programme which need further consideration. These aspects include the lower age range (whether screening commences earlier than age 45) and the upper age range (whether screening continues beyond age 69); higher risk women (how they should be identified, by which factors, and whether these women should have more intensive screening and screening using different methods), and lower risk women (can they be identified and benefit from less intensive screening); and breast density (whether and how it should be accounted for). All of these aspects need to be assessed for their impact on equity. Reviews of international scientific knowledge need to be made transparent (eg timely publication of what is being reviewed and results of reviews).

More detailed epidemiological analysis is set out in the epidemiological report prepared by Professor Mark Elwood for this review.[8]

11 <https://www.breastcancerfoundation.org.nz/what-we-do/research-and-medical/breast-cancer-register>

3. WĀHANGA TUATORU TE TIRITI O WAITANGI AND EQUITY

He tina ki runga,
he tāmōre ki raro

In order to flourish above,
one must be firmly
rooted below

This section addresses the following questions from the Terms of Reference for this review:

- Is the BSA programme meeting its obligations under te Tiriti o Waitangi?
- Is the BSA programme achieving ōritetanga (equity) for Māori and underserved populations
- Is the BSA programme meeting the needs of Māori and Pasifika people?

The framework used for answering these questions is based on:

- The priority areas for action set out in Whakamaua: Māori Health Action Plan 2020–2025 (Whakamaua) [35]
- The Interim Government Policy Statement on Health 2022–2024[10]
- The code of expectations for health entities' engagement with consumers and whānau [2]

Findings

- The NSU has committed to implement a Tiriti co-governance partnership model over the national screening programmes. Work has commenced and has been approached with integrity.
- However, currently:
 - The BSA programme is not meeting its obligations under te Tiriti o Waitangi. To give effect to te Tiriti the programme needs to develop authentic tāngata whenua and tāngata Tiriti partnerships, share power and resources, enable Māori leadership, eliminate inequities, support the development and growth of kaupapa Māori and whānau-centred services, and tackle racism in all its forms.
 - The BSA programme is not meeting the needs of, or achieving ōritetanga (equity) for, Māori and Pasifika, and there is poor understanding of equity in relation to other underserved populations. Māori and Pasifika have a higher incidence and mortality from breast cancer than non-Māori non-Pasifika, lower survival, and lower participation in screening.

Te Tiriti o Waitangi

'A health system that honours te Tiriti will uphold the rights of Māori (including tāngata whaikaha Māori) and give effect to the principles of the Pae Ora (Healthy Futures) Act 2022 (Pae Ora Act). This means re-orienting the system to one that is more enabling of Māori leadership, sharing power and resources, tackling racism in all its forms, and developing authentic tāngata whenua and tāngata Tiriti partnerships to realise Māori aspirations, including in the prioritisation, design, development and delivery of health services for Māori'[10]

Te Tiriti o Waitangi guarantees Māori the right to design health systems that best meet Māori aspirations and maximise Māori health gain. Te Tiriti o Waitangi provides an imperative for the Crown to protect and promote the health and wellbeing of Māori, including responding to Māori health aspirations and meeting Māori health needs.[27, 36]

The Interim Government Policy Statement on Health 2022–2024 is a public statement of what the Government expects the health system to deliver and achieve over the next two years, and how success will be measured, monitored and reported[10]. Te Tiriti o Waitangi is at the core of the Interim Government Policy Statement. The Statement's six priority areas and objectives include: achieving equity in health outcomes; strengthening Māori leadership and decision making at all levels, increasing access to kaupapa Māori and whānau-centred services; and developing the health workforce of the future.

Governance arrangements

Ngā pātuitanga i waenga i te Māori me te Karauna – Māori-Crown partnerships

Governance arrangements within and over the NSU fail to meet te Tiriti o Waitangi obligations. Further, Māori partnership arrangements are not embedded in the NSU or at any level of the BSA programme.

There is one Māori advisory group funded by the NSU – the Māori Monitoring and Equity Group (MMEG). MMEG provides advice to the NSU on all the national screening programmes and is the only mechanism for enabling Māori participation in BSA programme design, quality assurance and monitoring. MMEG's role is purely advisory and the group has no ability to make decisions or direct resources to drive the improvements needed across the BSA programme.

The range of expertise in MMEG membership has declined over the last decade, and many ex-members of MMEG the panel spoke with reported resigning because either they were not listened to or were otherwise frustrated with the NSU. Current MMEG membership is provided in [Appendix 5](#).

Interviewees for this review noted that MMEG's role was limited by a lack of resources, its lack of Māori clinical screening and monitoring expertise, only meeting three-four times a year, and limited resources to act as an active group outside its formal meetings.

'There's a responsibility on MMEG to raise key issues with NSU at every chance we get. But we don't get opportunities to do this with only meeting four times per year.'

'Governance needs to reflect a partnership arrangement – values, principles, tikanga'

NSU and MMEG Tiriti Governance Partnership

In March 2022, the NSU with the Māori Monitoring and Equity Group announced the start of a process to review and inform the NSU's governance to develop and implement a Tiriti governance partnership model over the national screening programmes.¹² A project team for the governance review has been established and is co-led by the NSU and MMEG. Phase one of two phases has been completed with options for aligning governance of the NSU with the principles of te Tiriti o Waitangi discussed with the NSU, MMEG, and a small number of key leaders within Māori screening. Phase 2 of the project will need a broader wānanga-like approach.

The NSU has agreed to increase power sharing with the intent to shift to larger scale change.

'We're having these conversations with NSU about values, tikanga to underpin our partnership approach. We're looking at a co-governance framework with NSU in partnership that will start to devolve power, resources. We're laying the foundation at the moment. We need to start at the top and it will come down through all levels.'

The project aims are to develop a model of NSU-Māori governance over the national screening programmes that aligns with the principles of te Tiriti; and to establish a framework to monitor the performance of the NSU and the national screening programmes.'

'Where we want to and need to get to is tino rangatiratanga, and have control over the things we want to control. This is a little while away. Keep that as our goal, but got to work with structure and opportunities we currently have.'

'The vision is co-governance over all screening programmes from the beginning design to execution.'

Māori co-governance with the NSU would enable testing of approaches for enhanced power sharing between Māori and the government and for working towards tino rangatiratanga. Co-governance would also enable development of the leadership, organisational structure, and culture that is required to drive improvement, maximise hauora gain for whānau Māori, and eliminate inequities in screening services.

¹² See: <https://kapomaori.com/news/bulletin-board/maori-monitoring-and-equity-group-to-lead-te-tiriti-governance-partnership-with-the-national-screening-unit/>

The improvements required are discussed throughout this report and include: ensuring that a range of Māori voices – those of wāhine, whānau, and Māori experts from along the screening pathway – are leading decision making; data collection and monitoring are excellent and uphold the principles of indigenous data sovereignty; racism and bias are eliminated; and there is intentional support for Māori rights development as described in the United Nations Declaration on the Rights of Indigenous Peoples.¹³

There was optimism amongst some interview participants that the co-governance approach in development between MMEG and the NSU could provide a path forward that honours te Tiriti and forges movement towards Māori-Crown partnerships. However, it is important to note that many of the interviewees for this review, including Māori stakeholders, were unaware of the governance re-design work. They wanted to be informed and involved. Some were concerned that the work seemed to be happening in an “NSU bubble” and that MMEG is not sufficiently independent from the NSU to be able to drive the co-governance work. There was also concern that other Māori screening experts were not linked in and that the work could end up being a “cultural wash” exercise without the real power, leadership, service design and resourcing required to make change.

‘Māori screening leaders and experts/kaupapa partners need to get together to develop a preferred governance structure for NSU.’

Consideration needs to be given to the relationship that any new co-governance structure has with Te Aka Whai Ora (the Māori Health Authority). Similarly, the role of Hei Āhuru Mōwai¹⁴ needs to be considered. Hei Āhuru Mōwai does not have a formal relationship with the NSU but does have a relationship with Te Aho o Te Kahu (the Cancer Control Agency). The relationship between Hei Āhuru Mōwai and Te Aho o Te Kahu provides an example of a model towards co-governance.

More work is required to define the proposed Māori and NSU partnership arrangements and how they will work. Nonetheless, it is clear, from those that the panel spoke with, that the work initiated by MMEG, and entered into by the NSU leadership, has been done with integrity and holds potential to revolutionise screening in Aotearoa New Zealand.

13 The United Nations Declaration on the Rights of Indigenous Peoples was adopted on 13 September 2007 as a non-binding, aspirational declaration of the General Assembly of the United Nations. The New Zealand government announced its support for the Declaration in April 2010 at the United Nations. <https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html>. The Declaration includes: the right of Māori to equity and development (develop and determine health programmes; administer programmes through their own institutions; financial and technical assistance from the State); and the State shall take necessary steps to achieving progressively the full realisation of the right to equity and development (support Māori self-determination; continuous equity improvement; public equity monitoring; holistic and Māori models of care).

14 Hei Āhuru Mōwai, Māori Cancer Leadership Aotearoa New Zealand, is 'a network of Māori cancer specialists who are committed to rangatiratanga in cancer control, eliminating cancer inequities between Māori and non-Māori and ensuring better outcomes for whānau': <https://www.heiahurumowai.org.nz/>

Working to eliminate racism in all its forms

'Racism is the elephant in the room. For example, mobile vans are sent where the population is largest, not where most Māori can access it.'

It is well established that experience of racism is a key determinant of health that negatively affects health and wellbeing and is an important driver of health inequities in Aotearoa New Zealand.[3, 37, 38] Additionally, racism in all forms is a breach of international human rights obligations, including the United Nations Declaration on the Rights of Indigenous Peoples, and, within a New Zealand context, is a breach of te Tiriti o Waitangi.¹⁵ The need to address racism in the health sector has been prioritised in key government documents and work programmes.[10]

Racism is a major driver in the production and maintenance of inequities across all screening programmes in Aotearoa New Zealand. In the NSU screening support services review [17], racism was identified across all levels of the screening system. Examples of systemic racism found in the review include:

- preferring non-Māori organisations for contracts
- differing (more arduous) reporting requirements or delivery expectations for kaupapa Māori versus universal organisations
- racist clinical decision making (for example, offering fewer treatments to Māori)
- negative attitudes from leadership in large organisations
- decisions that reflect notions of 'good' and 'bad' neighbourhoods
- 'watering down' of kaupapa Māori approaches by non-Māori organisations
- devaluing kaupapa Māori approaches
- being asked to validate achievements (via kaupapa Māori approaches) in the absence of similar challenges to non-Māori providers

'A feeling still exists within NSU that if we do something "special" for wāhine Māori then we need to do something for all women – trying to be equal rather than equitable.'

'NSU should develop an anti-racism programme for existing staff.'

'There are concerns around staff who have deliberately obstructed equity. Those of us who work in DHBs battle against it every day.'

Research shows that anti-racism interventions must work across all levels of an organisation (be multi-level) and not solely rely on 'one-off' training – and that anti-racism approaches need to be embedded throughout an organisations structure, from leadership through to strategy and policy as well as in workforce development.[39]

BSA needs a specific focus on addressing racism to make progress towards eliminating inequities in Māori and Pasifika health. This will require a strong commitment from leadership to eliminate health inequities and embed visible and long-term anti-racism approaches, actions and measures throughout the screening programme. The Health Quality & Safety Commission (HQSC) provides learning and education resources on understanding bias in health and te Tiriti o Waitangi, colonisation and racism.¹⁶

¹⁵ There are three levels of racism; Institutional racism (structural), personally mediated racism and internalised racism (see Jones, 2000).

¹⁶ Available at: [Learning and education modules on understanding bias in health care | Health Quality & Safety Commission \(hqsc.govt.nz\)](https://www.hqsc.govt.nz/).

Ōritetanga – Equity

Kia tū te ōritetanga o te hauora – Achieving equity in health outcomes

Equity¹⁷ is a fundamental component of a high-quality service and BSA has a goal of providing equitable screening and achieving equitable outcomes for Māori, Pasifika, and other populations in Aotearoa New Zealand. BSA leaders have acknowledged the screening programme has “not done equity well” and that there is considerable work to be done in this area. Twelve years ago, the NSU in its Strategic Plan, stated that “achieving equity and coverage for Māori and Pasifika populations remains the biggest challenge for the NSU”, and this very much remains the case.[40] The work required to achieve and sustain equity and coverage for Māori and Pasifika and other underserved communities needs to be Māori and Pasifika led, properly resourced, supported and closely monitored and informed by intersectionality approaches.[41, 42]

Māori health equity

The BSA programme is not meeting the needs of wāhine Māori.

Mortality

The goal of breast screening is to reduce mortality or deaths from breast cancer. Breast cancer is second only to lung cancer as a cause of death from cancer for Māori and is a major cause of overall avoidable deaths for Māori. Breast cancer is also a top driver of inequities in avoidable deaths and inequities in life expectancy between Māori and non-Māori New Zealanders.[32]

During the period 2007–2017, wāhine Māori and Pasifika women had a 65% higher mortality from breast cancer than non-Māori non-Pasifika women, at all ages. For the screening age group (45–69), the excess mortality was similar (68%) (Figure 4. Breast cancer incidence and mortality rates, ages 45–69, by ethnic group, age standardised to the WHO world population, 2007–2017. [8]).

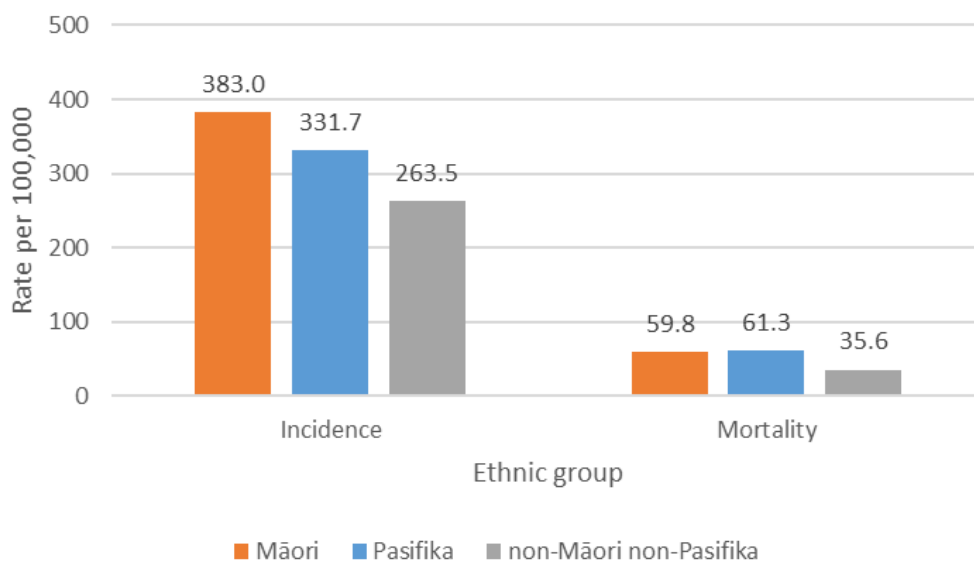


Figure 4. Breast cancer incidence and mortality rates, ages 45–69, by ethnic group, age standardised to the WHO world population, 2007–2017. [8]

17 The Ministry of Health has developed the following definition of equity: “People have differences in health that are not only avoidable but unfair. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.” See: <https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity>

Incidence – wāhine Māori have a high incidence of breast cancer

Wāhine Māori at all ages have the highest incidence of breast cancer (127.4 per 100,000 in 2007–2017), and a 39% higher incidence of breast cancer than non-Māori non-Pasifika¹⁸. In the screening age group (45–69 years) the incidence for wāhine Māori was 383 per 100,000 and a 45% higher incidence than non-Māori non-Pasifika (Figure 4. Breast cancer incidence and mortality rates, ages 45–69, by ethnic group, age standardised to the WHO world population, 2007–2017. [8]).

Survival

Analysis from the four clinical cancer registries shows breast cancer specific survival for wāhine Māori is the second lowest at five years (89%) and ten years (84%), compared to Pasifika (87% 5yrs; 81% 10yrs), NZ European (91% 5yrs; 87% 10yrs), and Asian women (95% 5yrs; 91% 10yrs).[8, 25]

Survival for wāhine with screen detected breast cancer – wāhine Māori diagnosed via screening have similar clinical outcomes to non-Māori women

Wāhine Māori who have breast cancer detected via screening have survival outcomes comparable to that of NZ European women.[30] This demonstrates the considerable benefit of access to regular screening mammograms for wāhine Māori. Increasing breast cancer screening rates has the potential to substantially improve survival for wāhine Māori and reduce breast cancer survival inequity between Māori and NZ European women, as well as impact on cancer and life expectancy inequities.[8, 30-32]

Breast Screening Coverage – wāhine Māori continue to have the lowest coverage rates of all women in Aotearoa New Zealand

Wāhine Māori have the lowest breast screening coverage rates of all women in Aotearoa New Zealand.¹⁹ Between 2003 and 2020, less than 50% of wāhine Māori with breast cancer had their cancer detected by screening mammogram.[17]

Coverage of the BSA programme over the last decade has been substantially lower for wāhine Māori than for Pasifika or non-Māori non-Pasifika women. This still applies in the most recent data, with all coverage rates being reduced by COVID-19 restrictions. There has been little work done to increase participation in the BSA programme for wāhine Māori; and there have been only a few localised programmes to improve participation, but some of these have had major success.

The panel heard examples of models that work well for wāhine Māori, designed by local communities and supported by strong partnerships. For example, Te Whānau-ā-Apanui Community Health Service (TWAACH) in the Eastern Bay of Plenty (Te Kaha) is providing services to the population living in the Te Whānau-ā-Apanui rohe (tribal region). The approach used by TWAACH included redesigning the invitation to screening pathway. The service improved participation in BSA breast screening for eligible wāhine Māori, from less than 45% in 2003 to over 98% in 2005 and ongoing.[33]

In Northland, a lead provider has collaborated with community screening support services and other providers serving a rural community, to enable providers to make appointments for wāhine, and providers' staff are working as the receptionists for the mobile service to welcome wāhine when they arrive for their mammogram appointment. The service has seen an increase from 45% to 55% of wāhine Māori screened and a 5% reduction in lost appointments (not attended) in a year.

However, successful models such as these have not been adapted and scaled nationally.

Interviews with wāhine Māori as part of the review clearly outlined a view that there is much work yet to do to embed equitable approaches for Māori within BSA. It is critical that this work is done, and with urgency.

¹⁸ Based on cancer registry and mortality data for 2007–2017.

¹⁹ Coverage is defined as the proportion of women eligible for screening who have been screened in the previous two-year period. The number of women eligible is derived from Statistics NZ Census base populations at the midpoint of the two-year screening period: <https://www.nsu.govt.nz/health-professionals/breastscreen-Aotearoa-New-Zealand/breast-screening-dhb-quarterly-reports#:~:text=Coverage%20is%20defined%20as%20the,the%20previous%20two%20year%20period.>

Timely rescreening

Inequity persists for wāhine Māori with respect to timely rescreening. BSA aims to have $\geq 75\%$ of women access rescreening between 20 and 27 months of their initial screen and $\geq 85\%$ rescreened within 20 and 27 months of any subsequent screen. During the two years to June 2020, timely rescreening rates for wāhine Māori were lower than for non-Māori non-Pasifika women after both initial and subsequent screens (Figure 5. Rescreening: percentage of women enrolled in BSA getting the next screen within 27 months by first or subsequent screen, age group, and ethnicity, BSA data, 2018–2020 [28]).

Wāhine who access regular screening mammograms have a lower risk of dying from breast cancer than those who access fewer regular screens.[16] If there is too long an interval between screens, new cancers have a longer time to develop beyond the early stages and screening is less effective at preventing illness and death.

The risk of breast cancer increases with increasing age, therefore screening older women will result in the detection of more cancers than screening younger women.

The additional number of wāhine Māori aged 45–67 who needed to be rescreened within 27 months to achieve the targets was 2,106 for the period 2018–2020. To achieve equitable rates with non-Māori non-Pasifika women, the additional number required was 2,509 wāhine Māori.[28]

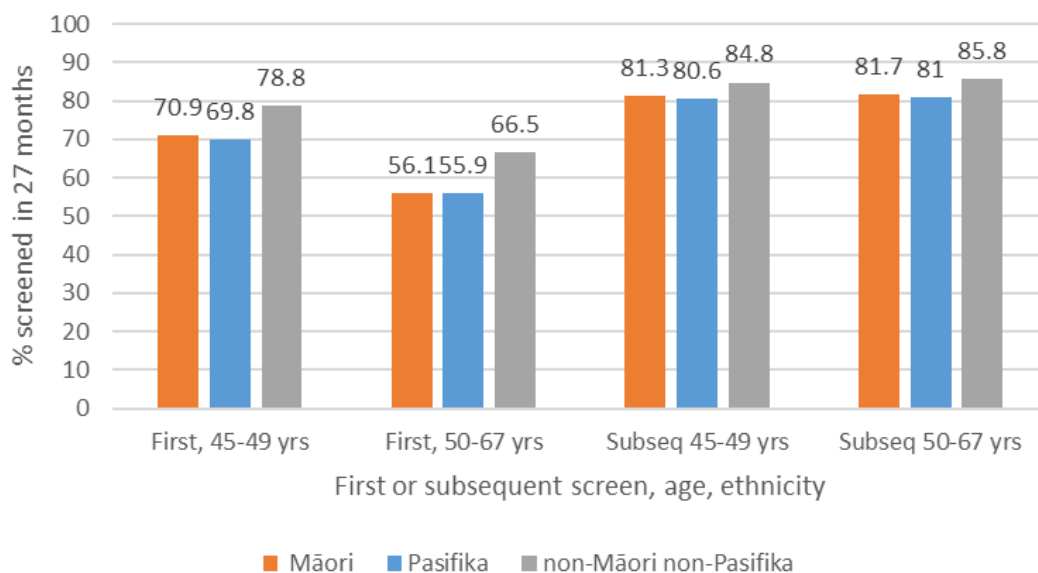


Figure 5. Rescreening: percentage of women enrolled in BSA getting the next screen within 27 months by first or subsequent screen, age group, and ethnicity, BSA data, 2018–2020 [28]

The impact of COVID-19 on timeliness of rescreening (2020–2022 data) has not yet been reported. During this period the BSA provided guidance to lead providers to prioritise screening. The guidance provided by the NSU to lead providers in December 2020 (BSA breast screening prioritisation for lead providers post COVID-19, December 2020) stated:

- “Māori and Pacific women should be invited first for all the following screening categories
- never screened women or women who are more than 5 years since a previous screen
 - overdue women more than 27 months since a previous screen
 - regularly screened women”

This potentially could lead to longer waiting times for rescreening (beyond 27 months) and it will be important to closely monitor this data including any variation between lead providers. It is also important to monitor the impact of prioritising initial screens versus subsequent screens when there is limited capacity to provide screens for women. This is because the risk of breast cancer developing is greater in older women, therefore the risk of missing a cancer diagnosis is greater if subsequent screens are delayed versus initial screens.

Decrease in screening coverage during the COVID-19 pandemic

At the end of March 2020 (at the start of the first lockdown), the two-year breast screening rate for Māori was 67%.^[43] By September 2021, the breast screening rate for wāhine Māori had dropped to 58%.^[44] Given, that overall, wāhine Māori have the lowest coverage of all ethnic groups, any further decrease in coverage is likely to put screening-derived survival gains at risk resulting in more avoidable breast cancer deaths for wāhine Māori.^[25]

Pasifika health equity

The BSA programme is not meeting the needs of Pasifika women.

Pasifika women have a higher incidence of breast cancer, are most likely to be diagnosed with higher risk breast cancer, have a lower survival after being diagnosed with breast cancer, and are more likely to die from breast cancer than non – Māori non-Pasifika women.

Pasifika women at all ages have a 23% higher incidence of breast cancer than non-Māori non-Pasifika. In the screening age group (45–69 years) Pasifika women have a 26% higher incidence than non-Māori non-Pasifika.^[8]

Data from the four clinical breast cancer registries in Aotearoa New Zealand 2010–2016 show Pasifika women are most likely to be diagnosed with higher-risk breast cancer (14% of screen detected cancers are stage 3 and 4 in Pasifika compared to 6% in European/Other; and 39% of clinically detected breast cancers are stage 3 or 4 in Pasifika compared with 22.7% in European/Other) (Figure 6. Stage distribution of screen detected invasive breast cancers in women aged 45–69 years, 2010–2016, Figure 7. Stage distribution of clinically detected invasive breast cancers in women aged 45–69 years, 2010–2016).^{[6, 7]²⁰}

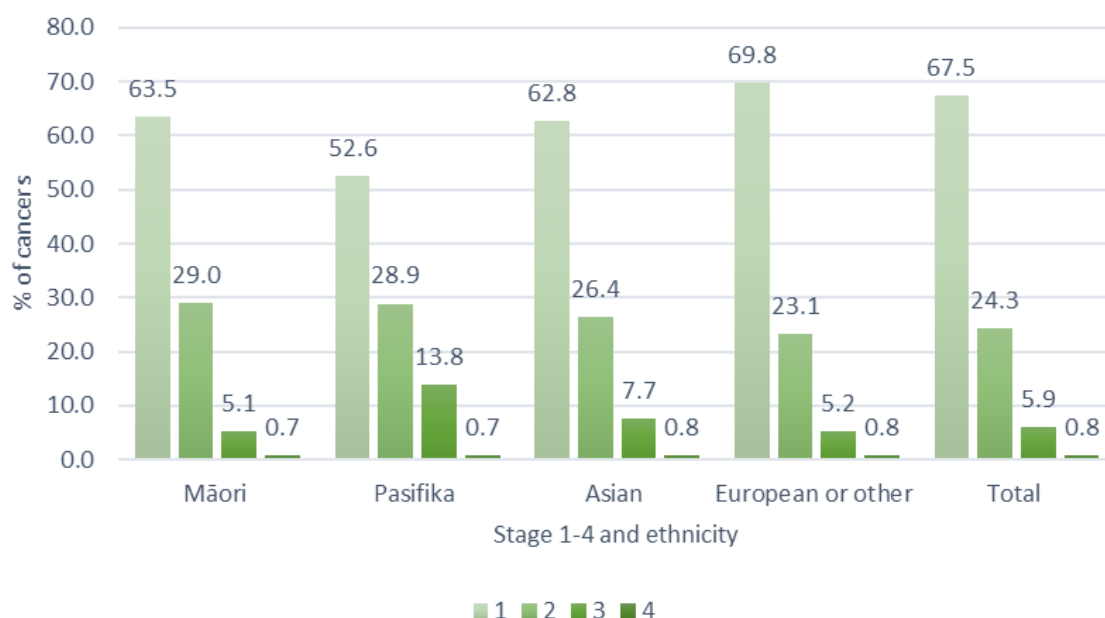


Figure 6. Stage distribution of screen detected invasive breast cancers in women aged 45–69 years, 2010–2016

²⁰ Stage of cancer is the extent of cancer at the time of diagnosis.

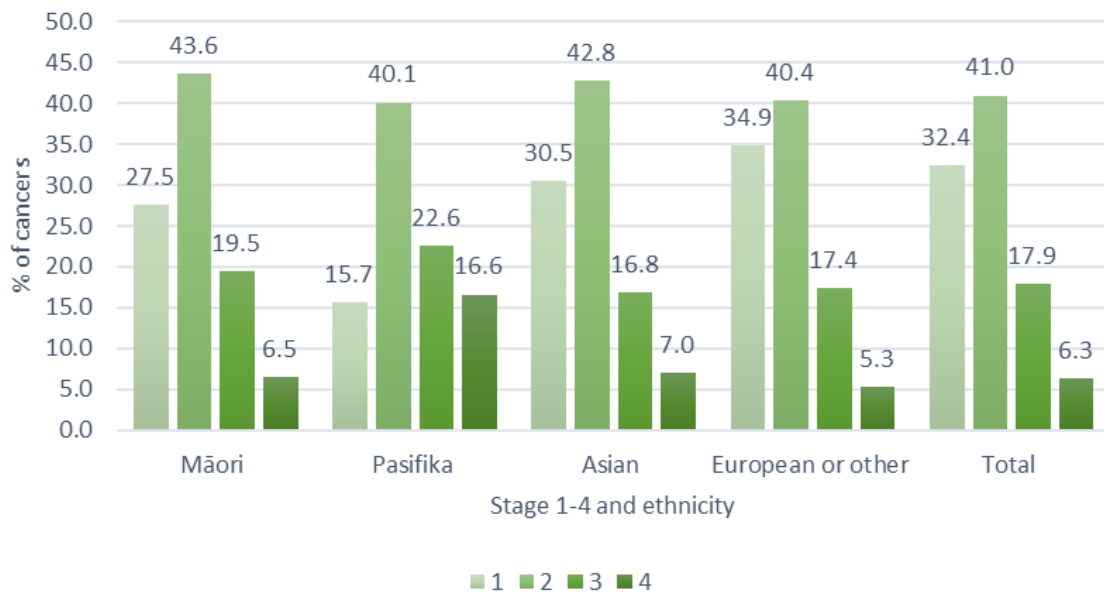


Figure 7. Stage distribution of clinically detected invasive breast cancers in women aged 45–69 years, 2010–2016

During the period 2007–2017, Pasifika women (all ages) had a 65% higher mortality from breast cancer than non-Māori non-Pasifika women. The mortality rate in the screening age group (45–69) was 68% higher in Pasifika than the rate in non-Māori non-Pasifika women.[8]

Pasifika women had the lowest five-year (87%) and ten-year (81%) breast cancer specific survival compared to Māori (89% 5yrs; 84% 10yrs), NZ European (91% 5yrs; 87% 10yrs), and Asian women (95% 5yrs; 91% 10yrs).[8]

For Pasifika women, participation in the breast screening programme has a significant beneficial impact on their risk of dying from breast cancer

The BSA Mortality Evaluation found that participating in the screening programme had a significant beneficial impact on Pasifika women’s risk of dying from breast cancer. This demonstrates the benefit of access to regular screening mammograms for Pasifika women. Increasing breast cancer screening rates has the potential to improve survival for Pasifika women and reduce breast cancer survival inequity between Pasifika and NZ European women.[8, 16, 30, 31]

For Pasifika women coverage rates across Aotearoa New Zealand are not equitable

From Dec 2015 to Dec 2019, the coverage target ($\geq 70\%$ of women aged 50–69 years participate in screening in the most recent 24-month period) was met in Pasifika, with rates somewhat lower for Pasifika women aged 45–49. Close to three-quarters of Pasifika women in the screening age group reside in three lead provider regions (Waitematā-Northland, Auckland, and Counties Manukau). While coverage is higher for Pasifika women than for Māori, and higher than or similar to the coverage for all women in each of these lead providers as well as for the overall national coverage rate, this masks the fact that Pasifika coverage in other lead providers is lower than the target and lower than non-Māori non-Pasifika coverage, despite the smaller numbers of women to be screened. Equitable coverage for Pasifika women will be achieved when participation is high in all regions.[28]

Timely rescreening

Inequity also persists for Pasifika women in relation to timely rescreening. Although coverage was higher overall for Pasifika women during the two years to June 2020, timely rescreening rates were lower than for non-Māori non-Pasifika women after both initial and subsequent screens for both age groups (45–49; 50–67).[28]²¹

The additional numbers of women aged 45–67 who needed to be rescreened within 27 months to achieve the targets were 1,096 for Pasifika. To achieve equitable rates with non-Māori non-Pasifika women, the additional numbers required were 1,271 Pasifika women.[28]

Pasifika women had the greatest decrease in screening coverage during the COVID-19 pandemic

While breast screening coverage in the BSA programme exceeded 70% in Pasifika women and in non-Māori non-Pasifika women in the two-year period ending at the end of 2020, it then fell sharply reaching minimum levels in the two-year period ending at the end of 2021 (Figure 8. Decrease in BSA coverage by ethnic group, year and quarter in the COVID-19 period, 2020–2022)(8). The fall was greater in Pasifika (max 11.8%) and in non-Māori non-Pasifika (8%) women than in Māori women (5%).[8]

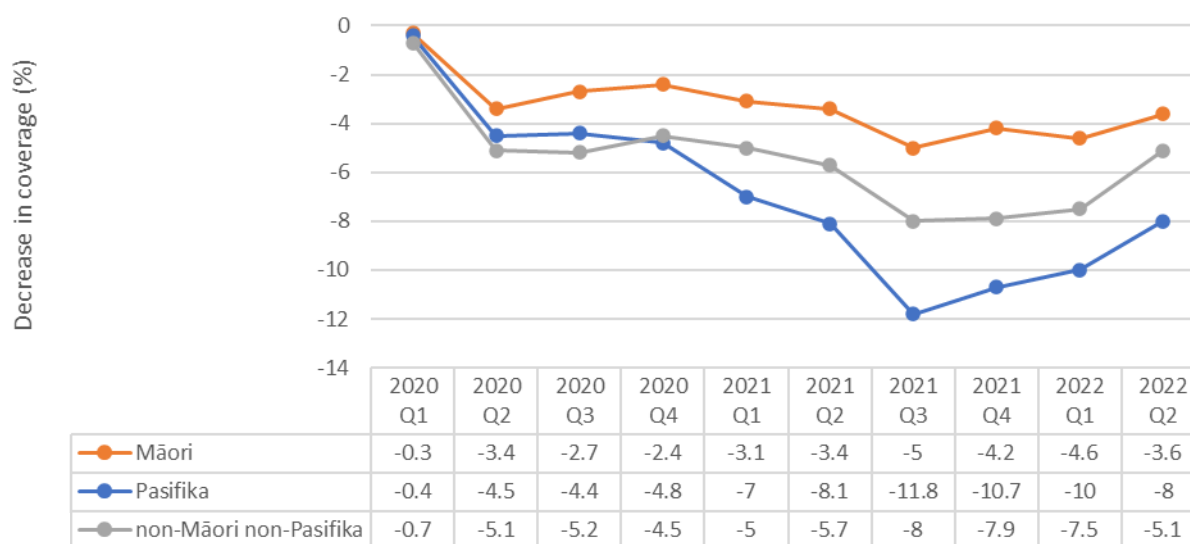


Figure 8. Decrease in BSA coverage by ethnic group, year and quarter in the COVID-19 period, 2020–2022²²

Ōritetanga (equity) for women with lived experience of disability and other communities and groups

One of the Government's priorities and objectives for 2022–2024 is a specific focus on people who have been historically underserved – including Māori, Pasifika, disabled peoples including tāngata whaikaha, LGBTQIA+ communities, Asian peoples, refugee and migrant communities, rural communities, and people with lived experience of mental health and addiction – to close the gaps in equity of access and outcomes: “It is not enough to deliver good outcomes for some groups, but to leave others behind. Communities who have been under – served by the health system are at the heart of how we strengthen services, access and outcomes.”[10 p14/p16]

In terms of how well the BSA programme is achieving equity, there has been little attention given to factors other than ethnicity, age group, and provider (and therefore, region). Most data when reported by ethnic group are reported for Māori, Pasifika, and ‘Other’, meaning non-Māori non-Pasifika. Some data are available for Asian, and therefore non-Māori non-Pasifika non-Asian groups.[25]

21 The target for rescreening is screening within 20 to 27 months of the previous negative screen, and is 75% after the first screen, and 85% after a second or further screen.

22 From <https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/> accessed Aug 20, 2022

It is likely that socio-economic deprivation, income levels, urban/rural residence, and co-morbidity, which have been shown to be associated with breast cancer incidence, mortality, stage distribution, and survival, are important influences on how women interact with the breast screening programme and vice versa. Other factors which should be considered include time of immigration, usual language, disabilities, and sexual identification, but no information is available on such factors in relation to breast cancer screening in Aotearoa New Zealand.[8]

There is a distinct data gap about women living with disabilities (including tangata whaikaha Māori) with no data reported on disability status. The 2013 Disability Survey reported 45% of the Māori wāhine population aged 45–64 years identified as disabled.²³

Meeting the needs of women with lived experience of disability is a neglected area that needs to be addressed. Likewise, there is a lack of data about equity in relation to rural women. Interviewees highlighted concerns about rural women's access to services, particularly because they are the group most dependent on mobile screening services. Interviewees want to have more information on rural and urban populations and disadvantaged groups within these populations.

'We need a data set to show us where the highest risk population reside. We currently don't get that level of detail; i.e. we know Tairāwhiti has low coverage, but not what particular area. Is it urban or rural areas'

23 Disability survey 2013 <https://www.stats.govt.nz/information-releases/disability-survey-2013>

Māori models of screening

Ngā kaiārahi Māori me te whakawhanaketanga o te rāngai hauora – Māori leadership and Māori health sector development

The New Zealand Cancer Action Plan 2019–2029 states that the entire cancer care sector needs to focus on and support kaupapa Māori and mātauranga Māori initiatives.[36] Kaupapa Māori approaches to cancer care align with the aspirations of He Korowai Oranga,²⁴ ensuring that whānau have control over their cancer journey. Kaupapa Māori is a 'by Māori for Māori' approach to health services and project development and implementation centred around tino rangatiratanga and self-determination.[45, 46]

Kaupapa Māori approaches may improve all facets of hauora for Māori who are living with cancer and their whānau. This can include prevention initiatives, wairua and mauri support, education, psychosocial support, treatment, rehabilitation and palliative care. Currently, the BSA programme function and service delivery is not Māori led, nor informed purposefully by mātauranga Māori or grounded in te ao Māori. Among Māori interviewed for this review, there was strong support for a holistic model and whānau ora approach to screening services.

'Stop treating us as body parts, treat us like a whole person'

'We should be drawing on other examples of holistic models underway in other programmes. The NSU needs to be flexible enough to respond to such requests, possibly including other tests at the point of care. Plus enquire about other whānau members who would be eligible for the screening programme – a whānau ora approach'

In order to determine what works best for local communities, the NSU and BSA providers need to work in partnership with local iwi, hapū, Māori health providers, and screening support services providers. This involves taking the time for whakawhanaungatanga and manaakitanga – developing and fostering relationships and being prepared to share power.

'What does success look like? It feels as if it's Māori owned and Māori led. Needs to start in Māori providers so it is seen as a Māori programme, not a NSU programme; seen as Māori doing rather than being done to by NSU. Has to be led from ground up, we saw this in COVID times, it was only community groups who can/could do this stuff, not central organisations.'

Some interviewees expressed caution about working in co-design and stressed that this needs to come from a position of true partnership and a willingness to share power.

²⁴ He Korowai Oranga, the Māori Health Strategy, sets the framework to guide the government and the health and disability sector to achieve the best health outcomes for Māori. For more details, see He Korowai Oranga on the Ministry of Health website: www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga

*'We talk about co-design etc but I feel like we're in a weak position.
There's a lot of work still to be done'*

*'Māori need to be involved in (lead) any proposed re-design
of system and processes'*

The panel heard examples of excellent models of care that work well for wāhine Māori, designed by local communities and supported by strong partnerships; these have been previously noted.[33]

'[We] need to better articulate how Māori providers operate to enable better holistic Māori models of care within the programmes. In fact, all providers should be enabled to provide holistic care. At the very least all providers should be able to offer culturally safe care.'

However, successful models have not been scaled across the programme and still encounter many roadblocks within the system. There are no 'learning loops' – communities, providers and the NSU joined up, learning about and sharing best practice, adapting and scaling across Aotearoa New Zealand. There needs to be greater sharing of models that work well for wāhine Māori and these models need to be appropriately resourced and prioritised. Space and resourcing need to allow sharing with other communities to learn, adapt and develop successful models for their own communities. This requires trust, flexibility and a partnership approach based on tino rangatiratanga.

'In certain areas with high populations of priority women, the mobiles have stopped attending (Ōpōtiki and Kawerau) because of poor attendance but in reality, a better system was needed. Need to replicate what works in other rural areas for Māori women. Lead providers should not pull resources and opportunities from these areas, they need to engage with the community around what works for them.'

Pasifika models of screening

The development of Pasifika and Pasifika-family centred models of care is also a priority for the BSA programme to meet its obligations under the Government's Interim Policy Statement on Health 2022–2024.[10] The policy statement specifies Pasifika must be actively involved in the development and implementation of policies and services concerning their health and wellbeing, including testing and implementing new models of care that provide integrated support for people and support for connections between service areas. An evaluation of breast and cervical screening services in 2021 found that barriers linked to breast cancer screening for Pasifika women included a failure to understand women's needs, limited service delivery options and choices, and a lack of models that met Pasifika women's preferences and Pasifika-based value delivery.[17]

Including and engaging with Pasifika in service development is essential; this was a consistent theme from interviewees (see [Wāhanga Tuawhā \(Section Four\): Voice of Consumers and Whānau](#)). Along with Māori models, the NSU and BSA providers need to work in partnership with local communities, Pasifika health providers, and screening support services providers to determine what works best for local communities, to share models that work well for Pasifika women and their families; these models need to be appropriately resourced and prioritised.

Strategic documents

Ngā whakatutukinga me te noho haepapa – performance and accountability

Published policies and plans appear to have minimal content expressing comprehensive commitment to te Tiriti, Māori health equity and equity. The NSU's Strategic Plan has not been updated since 2015, and has no reference to te Tiriti o Waitangi or 'Māori health equity'. [40] However, there is a clear focus on equity in the plan with the main goal (vision) being 'high-quality, equitable and accessible national screening programmes'.

The BSA National Policy and Quality Standards (NPQS) were developed at the establishment of the BSA Programme.[18] The standards were fully revised and updated in 2013. The NSU notes that further revisions were published in 2016 and 2020; lead providers stated that most revisions recommended since 2013 are still in draft. The NPQS document determines the minimum requirements for BSA service providers. Despite recent revisions, the wording is out of date regarding equity and te Tiriti o Waitangi. For example, the standards reference 'reducing inequalities' rather than eliminating inequities or achieving equity, and the standards have not been updated to include the principles outlined in the Waitangi Tribunal Hauora Report 2019.[3]

A BSA Equity and Performance Matrix, published in 2019, states that targets are seen as "In line with the policy direction of the Ministry of Health, legislation and Treaty obligation and all programmes should target a zero-equity gap in service delivery".[47] The performance matrix has been included in an equity reporting template for lead providers, however it is unclear if this template is systematically used and how NSU has responded to any reports.

It is also important to note that published policies and plans appear to have minimal content expressing comprehensive commitment to Pasifika health equity. The NSU's Strategic Plan has no reference to Pasifika health equity beyond 2015.

The panel heard strong feedback about the need for the system to be overhauled and changes made across the screening programme as a whole.

'Responsibility needs to be taken for what the system needs to do. There are major flaws in system design, resourcing, governance, ownership and leadership commitment. These are fundamental issues that are causing inequity. Unless Te Whatu Ora leadership is on board this will languish. This needs to be championed not just in NSU.'

Interviewees were critical about reviews not going anywhere, and issues not being addressed despite directions on what to do.

'From the many recommendations over the years few have been implemented they go into a pot never to be seen again.'

Suggested improvements from interviewees included the development of frameworks to strengthen the accountability functions, noting that "It's not just the governance model that needs to be looked at. The NSU operating model needs to be reviewed".

It was very clear from stakeholders that improved accountability and performance transparency within the BSA and NSU will need inbuilt and long-term Māori health equity and Pasifika health equity.

'The NSU needs help and direction to develop, implement and evaluate equity strategies.'

'We need a horizon scanning, strategic framework developed for a 10-year vision – what services and the programme will look like in 10 years with a strong Māori equity focus, including an evidence-based prioritisation framework.'

'There needs to be an evidence-based prioritisation framework for each cancer screening programme. The prioritisation framework needs to be clearly communicated – well articulated/clearly and explicitly explained to the community.'

COVID-19 screening response

The development of a Māori specific COVID-19 cancer screening response and recovery plan is a te Tiriti o Waitangi requirement. The rapid decline in access to cancer screening due to the COVID-19 pandemic is likely to have a devastating impact for many whānau – the result being more avoidable breast cancer deaths for Māori. The differences in cancer screening rates during the pandemic forewarn increases in the already large and unacceptable cancer inequities in Aotearoa New Zealand.

A planned and adequately resourced response could rapidly improve access to cancer screening for Māori. The panel considers this response is required as a matter of urgency. The collaborative development of a Māori-specific COVID-19 cancer screening response and recovery plan will require the NSU to work in partnership with Māori to quickly identify areas of concern, develop and test solutions, and provide rapid feedback.

Collaborative partners for development of this response should include Hei Āhuru Mōwai, the Māori Monitoring Equity Group, Te Aho o Te Kahu, the National Screening Unit and the Ministry of Health.

'The experience from COVID shows that the response can be dramatic if it needs to be and doesn't have to be 'one size fits all' approach.'

Transparency of information

Ngā kitenga me ngā taunakitanga – insights and evidence

'We have no idea what is happening for wāhine Māori in the BSA programme outside of coverage rates. Coverage rates are the only equity indicator being published.'

'Information is a taonga that should be shared and implemented.'

Effective equity monitoring requires high quality ethnicity data that is made accessible to whānau, hapū, iwi, Māori organisations and screening and health service providers. Māori data sovereignty principals needs to be enacted through data governance, planning and practice, including collecting and monitoring. This is necessary to realise true partnership, and to influence and inform system innovation and change, policy development, service design and delivery, and use of Māori models of care.

There are issues with ethnicity data quality in health databases which means there is significant undercounting and under-representation of Māori and Pasifika in health and disability sector data.[20-22] This is because of two issues: Māori are disproportionately underrepresented in primary care (PHO) enrolments (Māori had a lower PHO enrolment rate – 91% compared to 94% for NZ European/Other in 2019)[20]; and because the current Bowel Screening Register and the primary care enrolment registers draw ethnicity data from NHI, and misclassification of Māori in NHI data means that 21% of the actual Māori population are unable to be identified as Māori on the register.[21, 22] Therefore, even when Māori do make it on to a register, 21% of Māori cannot be found because they have not been recorded as Māori.

Undercounting and underrepresentation has a major impact on the ability to identify and monitor access to, and quality of, screening for wāhine Māori and Pasifika, and for identifying and monitoring inequities between Māori and non-Māori, and Pasifika and non-Pasifika, along breast screening pathways of care. Following the consistent use of Ethnicity Data Protocols for the health and disability sector and existing tools such as the primary care data audit toolkit, could improve data quality.[11, 48] This would provide more assurance that the BSA programme is counting and reaching women who are eligible for screening and is reporting outcomes that give a true indication of Māori and Pasifika health and wellbeing.

‘There are access issues all the way along the pathway, these need to be continuously monitored, for example time from screening to access and screen to treatment. The NSU is not looking at this by ethnicity and frequency.’

‘There needs to be a deep dive into the governance of Māori Monitoring, there needs to be clarity of roles, accountability, scope, purpose from a Māori perspective.’

‘Equity needs to be monitored properly, not just by coverage rates. Currently coverage rates are used as the sole equity endpoint.’

‘Time from screening to assessment needs regular, early monitoring by ethnicity and be advised to lead providers. Need a more nuanced approach to monitoring’

Interviewees emphasised the paucity of available data and evidence for tangata whaikaha, therefore issues around equity and ableism are not identified or monitored.

‘There’s a terrible understanding of what is happening for tangata whaikaha. There needs to be a deep dive into tangata whaikaha data, this should be led by them.’

‘The NSU doesn’t share information with lead providers and is not meeting the needs of wāhine Māori. We only know about coverage but not anything else. This is a programme not a bums on seats exercise.’

Workforce

Ngā kaimahi o te rāngai hauora Māori me te whakawhanaketanga o ngā kaimahi hauora a meake nei – The Māori workforce and developing the future health workforce

The Māori workforce needs to be nurtured to ensure Māori values, philosophies and tikanga are prevalent across all levels of the breast screening programme. As a priority, recruitment and retention strategies, training opportunities, and pathways to develop Māori staff need to be established. Feedback from interviewees was clear about the need for Māori clinical leadership along with fostering growth of the Māori health workforce. Targets to increase the Māori workforce need to be incorporated into the breast screening programme.

'The NSU needs clear values and goals to support the workforce and enable Māori development. Strong engagement of the workforce.'

'Noted there is an issue with Māori capacity, in reality there are too few Māori clinicians – too few of us for multiple structures.'

Currently, there is no clear structure for ensuring there is an equitable representation of Māori health and Pasifika health expertise within the NSU and within the BSA programme. There are no specific roles that are designated as 'equity' lead or advisor roles. There are only five Māori staff within the NSU, with no Pasifika staff. Further, these Māori staff are recent positions within the last 3-18 months. Many Māori clinical and screening leaders the panel spoke with had been 'burned' by their past engagement with the NSU.

Given this lack of 'critical mass' of Māori and Pasifika in the NSU and BSA workforce, considerable effort will be required to grow a workforce that is sufficiently able to address and achieve equitable outcomes. It is also important that human resources management systems can collect and record accurate staff ethnicity data to be able to ascertain a full picture of the workforce, including members on governance groups.

Interviewees stressed the importance of personalised services that were holistic, consistent, and catered to the needs of wāhine Māori – reflecting Māori values and models. To achieve this requires more culturally safe care, support for wāhine, and services and systems working in partnership with Māori.

'Māori Women [kaimahi] leading Recruitment Strategies/Māori Health Providers need to lead recruitment, enrolment, need to be empowered.'

Wāhine Māori are seeking services that offer support to navigate the demands of the screening process from the beginning, with an expectation that information is more accessible and available in a wider range of formats and communicated more clearly to them.

The NSU has commenced workforce capacity planning, commissioning the development of a draft workforce strategy. This has not been co-designed and does not meet requirements for Māori and Pasifika. Further development of a workforce strategy and action plan needs to be done using a co-design approach that privileges Māori and Pasifika voices.

The Health Workforce Advisory Board 2021 Annual Report to the Minister of Health (January 2022 [49] notes that several critical workforce issues are impacting on health care services during COVID-19 and post the pandemic, including, most immediately labour force availability, and workforce wellbeing. The report states that both these issues “highlight the critical need for focused health workforce retention strategies, and a targeted and purposeful approach to the retention and development of new health workforces in the kaimanaaki and peer, lived experience spaces.” [49 p4] The BSA needs to work closely with lead providers and screening support services providers to prioritise initiatives that focus on health workforce retention and recruitment.

Developing a culturally safe and competent non-Māori workforce in breast screening is also important. Currently, there is no systematic, comprehensive training for the BSA’s non-Māori workforce in the understandings of te reo me ona tikanga (Māori language and protocols) and te ao Māori (Māori ways of life). Similarly, it is important that there is training in cultural safety and health literacy. Cultural safety moves beyond cultural competency by having a transformative component which ‘involves a critique of power imbalances and critical self-reflection’.[50]

‘The workforce is predominantly non-Māori – how do we ensure they understand the need for equity?’

Staff working across all levels of the BSA programme need to have access to, and complete, anti-racism training, and cultural safety and competency training. This needs to form part of the accreditation process for breast screening providers. Measures of staff competency in each of these areas need to be developed and efforts made to improve them. Individual practitioners will require upskilling, and BSA programme leaders should review the programme’s cultural safety and their role in supporting or maintaining institutional racism and working to eliminate racism in all forms.

RECOMMENDATIONS

Te Tiriti o Waitangi

- Appoint a Pae Whakaterere comprising two to three suitably qualified people to oversee, guide and monitor the implementation of the BSA quality improvement review recommendations and co-governance model. The Pae Whakaterere will:
 - aim to ensure the recommendations from this review are implemented in a timely way including overseeing the development of a co-governance model
 - be a joint appointment by Te Whatu Ora and Te Aka Whai Ora for a two-year term, and report directly to the National Director, National Public Health Service, Te Whatu Ora
 - develop a business case and prioritised implementation plan to ensure the implementation of these recommendations are adequately resourced
 - arrange for an evaluation of the implementation of these recommendations prior to the end of its term
- Establish an expert working group to support the Pae Whakaterere. Involve a wide group of Māori stakeholders including MMEG members, Hei Āhuru Mōwai, wāhine and whānau, and Māori screening and epidemiology experts.
- Resource a wānanga for Māori stakeholders and partners to explore how best to establish a kaupapa Māori community of practice with a comprehensive range of skills and experience from which to enter governance arrangements with the NSU at all levels of the organisation.

Equity

- Resource a Pasifika-led co-design process to develop a strategy and action plan to identify and address Pasifika priorities for breast cancer screening including Pasifika representation and participation at all levels of the programme
- Develop a national programme of work to rapidly increase participation in the BSA programme for wāhine Māori and Pasifika to at least 70%. This programme is to be evidence based and developed with Māori and Pasifika health experts and whānau.
- Co-design Māori and Pasifika plans to formalise approaches to achieving equity. The plans will include kaupapa Māori, and Pasifika-designed, travel assistance initiatives, and a review of the capacity and availability of mobile screening units with a view to communities having more control. The development and implementation of approaches to achieving equity will be evidenced within an equity monitoring and reporting framework (eg, quarterly targets) and linked to funding.
- Develop a Māori specific, and a Pasifika specific, COVID-19 and cancer screening response and recovery plan.

Monitoring, research and evaluation

- Apply Māori data sovereignty principles to the NSU and BSA programme's data collection, analytics, monitoring and reporting frameworks.
- Ensure that quality ethnicity data are collected and used to enable the BSA to make decisions based on the most accurate data possible. This means the HISO 10001:2017 Ethnicity Data Protocols need to be adhered to through all levels of the screening programme and incorporated into the standards, training, ethnicity data audits and quality improvement mechanisms.
- Develop a monitoring and reporting framework for the BSA programme with Māori, consumers and service providers that includes:
 - governance for the framework
 - a clear rationale and process for selecting and prioritising monitoring indicators
 - a process for monitoring and publishing indicator results
 - an ongoing process for ensuring indicators remain relevant, are evidence-based and support quality improvement
 - consistent, regular and timely monitoring and reporting
 - ensuring that monitoring and reporting is transparent with all reports made publicly available in a timely manner
 - identifying where indicator monitoring and reporting work aligns with other agencies such as Te Aho o Te Kahu – Cancer Control Agency and the Breast Cancer Foundation, and how duplication of effort and resources will be avoided and collaboration enhanced
 - collecting, monitoring and reporting data, insights and evidence by ethnicity, disability, social deprivation, rurality and other known priority groups wherever possible
- Monitor and continuously update the evidence-base for development of the programme and make this transparent with regular, timely publication

- Develop and implement a plan to fund research into improving screening pathways (eg, improved coverage, co-location of services, extending screening age, kaupapa Māori led screening centres, holistic care models) for wāhine Māori, Pasifika women, tangata whaikaha and consumers with lived experience of disability, other groups at increased risk of breast cancer death and also underserved by the screening programme; and report annually on progress.

Workforce

- Develop and implement cultural safety and multi-level anti-racism workforce programmes and training for all staff in the BSA programme including lead providers.
- Co-design and implement a dedicated recruitment and retention strategy that includes training opportunities, and pathways to recruit and develop Māori staff, Pasifika staff and staff with lived experience of disability. This will require dedicated Māori health, Pasifika health, and equity positions to be created within the NSU and lead providers. Development of the Māori and Pasifika health workforce and Māori clinical leadership should be a priority.
- Co-design a kaupapa Māori accreditation programme for breast screening providers.

4. WĀHANGA TUAWHĀ: VOICE OF CONSUMERS AND WHĀNAU

Te kanoahi ngaro;
whākorekore noa rā koi
ngaro ana

The unseen face is
thought not to exist

This section addresses the following questions:

- What systems and processes are in place to manage the consumer/whānau voice across the BSA programme?
- Are these systems, policies and processes being operated effectively?
- Are these systems, policies and processes meeting the needs of Māori and Pasifika people?
- Is there clarity about roles and responsibilities in relation to these systems, policies, and processes across the BSA programme?

“Patients bring the lived experience, as well as knowledge about how well the healthcare system functions to meet their needs. In order to provide truly excellent health care, we must have the input of consumers, many consumers, because no one person can speak for the experiences of all.”[51]

Findings

- BSA policy documents provide a good framework for managing consumer and whānau voice across the BSA programme. The NSU acknowledges it needs to improve its approach to consumer and whānau engagement and intends to develop a consumer and whānau engagement strategy.
- The systems, policies and processes for managing consumer and whānau voice are not being operated effectively. Improvement is needed to strengthen consumer and whānau engagement and participation across the programme including in governance and decision making.
- The systems, policies and processes for managing consumer and whānau voice are not meeting the needs of wāhine Māori and Pasifika.
- Roles and responsibilities in relation to these systems, policies and processes need to be clarified.

Discussion

This review has prompted BSA to reflect on its approach to consumer and whānau engagement within its programme. The NSU concedes there is much room for improvement. The review panel agrees with this assessment; many consumers and whānau interviewed for this review described limited understanding of, and attention given to, this critical aspect of quality improvement within the programme.

The lack of focus on consumer and whānau engagement is not unique to BSA; many health services, providers and government agencies struggle with this particularly with the implementation or 'action' needed. The cultural shift in thinking and behaviour needed to drive engagement is often lacking.

Acknowledging the plight of services to engage consumers and whānau, in 2015 the Health Quality & Safety Commission (HQSC) produced a guide to support engagement.[52] Through panel members' work with the health and disability sector on consumer engagement, it is apparent that the 'why, and how' of consumer engagement are not fully understood or accepted in parts of the sector. Some services are actively seeking to improve consumer engagement but others are struggling.[52]

In Aotearoa New Zealand, the rights of consumers, whānau and communities when engaging with health entities are protected by legislation. The Code of Health and Disability Services Consumers' Rights (Code of Rights) is a regulation under the Health and Disability Commissioner Act, 1996²⁵. The Code of Rights established the rights of consumers and obligations of health entities when delivering services. The Code is primarily used by consumers who are dissatisfied with the care and treatment they receive and want to make a complaint about their care.

A new code has recently been released that recognises the need to engage consumers and whānau in health services. The Code of expectations for health entities' engagement with consumers and whānau (Code of Engagement), published in August 2022, specifies how health entities must work with consumers, whānau and communities in the planning, design, delivery and evaluation of health services. [2] All health entities are required to act in accordance with the Code of Engagement under the Pae Ora (Healthy Futures) Act 2022. Health entities must apply the Code of Engagement expectations by co-designing with consumers, whānau and communities so there is collective development of organisational priorities, processes and evaluation, and consumers, whānau and communities are involved at all levels. [23] The Health Quality & Safety Commission offers an open access introduction to co-design.

The National Screening Unit (NSU) has three key documents which refer to consumer engagement: the NSU Strategic Plan 2010–2015, the NSU Quality Framework 2015, and the BSA National Policy and Quality Standards 2013 (Revised September 2020) (NPQS). Although the strategy and quality framework are out of date, these documents provide a useful starting point for the NSU's intended consumer engagement strategy. Three further policies complement this consumer engagement framework: the NSU's Open Communication, Adverse Event Management, and Complaints Management policies. These policy documents are discussed in [Wāhanga Tuao \(Section 6\): Identification and Reporting](#).

The panel conducted interviews with consumers and consumer advocacy groups. From these interviews, several key themes were evident:

- The need to progress equity for Māori, Pasifika, rural and people living with disability
- Challenges with enrolment and eligibility
- Strengthening consumer participation across the BSA programme including governance
- Improving consumer information
- Building and maintaining strong relationships with consumer advocacy groups

25 Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996. Available at: <https://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>

Improving equity for consumers and whānau

Delivering a breast screening programme that leads to equitable outcomes is a key priority for the BSA programme. All three of the NSU's key consumer engagement documents highlight the need to improve equity within the screening programme. The NSU Quality Framework 2015 states "National screening programmes will achieve equitable access to screening and equitable outcomes for all population groups".[53 p4] The NSU Strategic Plan 2010–2015 specifically mentions the target of having "...no significant variation in coverage and access between priority population groups and the rest of the eligible population".[40 p9] And criterion 1.3 of the NPQS specifically states "the provider ensures that their services are responsive to the needs of Māori women and their whānau".[18 p15]

Progress towards achieving equity of outcomes for wāhine Māori, Pasifika and other underserved groups is discussed in [Wāhanga Tuatoru \(Section Three\): Te Tiriti o Waitangi and Equity](#).

Wāhine Māori experience

It is clear the needs of wāhine Māori are not currently being met by the BSA programme despite the NSU's goals and criterion. Interviewed wāhine reported equity issues across the screening pathway from enrolment through to assessment.

Screening Pathway issues – opt-in self-enrolment and eligibility

'The BSA programme is working well for the majority of women who are enrolled, but the issue is so many eligible women are not enrolled and are missing out.'

The NPQS states that for the programme to be successful, 'high levels of programme enrolment and participation' are required (p.6). A significant issue highlighted by wāhine Māori is enrolment into the programme; this is a consistent theme across consumer interviews.

Currently there is no national system in place that identifies and enrolls all eligible women for breast screening. This means participation in breast screening relies on women 'opting in' the screening programme by contacting the breast screening service themselves, or health providers encouraging and assisting in enrolling women eligible for screening.[54] All of the interviewed consumers reported the programme generally worked well for women who were enrolled; however, the current opt-in self-enrolment system was consistently identified as a significant barrier for many women particularly for wāhine Māori.

Consumers described the many steps involved prior to attending an appointment, all of which had potential barriers. These included finding out about the programme, understanding if you are eligible, enrolling, confirming eligibility and receiving an appointment. Interviewed consumers highlighted the biggest barrier to enrolment for many consumers was finding out if they are eligible. This is a significant issue for consumers who are not enrolled with a GP.

'If the system relies on primary care to encourage women to opt on to the screening program ...how is BSA ensuring that unenrolled women are supported to engage with screening?'

Wāhine Māori and consumers expressed feeling frustrated by the opt-in system as it relies on individuals knowing they are eligible, having access to the internet and a phone and initiating the process themselves. Wāhine Māori highlighted how external pressures, such as shift work and a commitment to putting children and the wider whānau before themselves, meant eligible wāhine do not enrol when they become eligible at 45 years old.

'The current systems put everything back on to individual women – you are responsible for finding information regarding eligibility and enrolling – this is wrong!'

The lack of a national breast screening register with a list of all eligible women was identified as a significant barrier to wāhine Māori participation in the review of the programme in 2011.[5] An ICT system that enables a national breast screening register with an 'opt-off' system is an imperative if the programme is going to achieve the $\geq 70\%$ screening target for wāhine Māori. A new BSA programme ICT platform scheduled for implementation in 2024 aims to provide such a system.

'The ICT system is not fit for purpose. We cannot wait three years for an ICT system with a register and opt-off system, we need to act now to create capacity, block out appointments, allow providers to book appointments directly. This needs to happen nationally.'

Alongside the theme of enrolment, consumers also felt little was being done to understand, from wāhine Māori and consumers, why they are not enrolling. The importance of listening to and understanding the lived experience of wāhine Māori is essential to understanding how to address barriers to access and maximise wāhine Māori participation in the programme.

'We should be seeking to understand how and what we can do differently to improve screening for these women...The programme needs to understand the barriers to screening better – don't presume we know what the issues are, [we] need to talk to women especially those who do not participate. Some barriers are mistrust in the health system or specifically with screening, technology, shame or embarrassment, costs, lack of out of hours' access.'

Interviewees emphasised that a lot of assumptions are made by the NSU and lead providers as to why priority groups are not attending screening. There have been few studies to understand the issues from their perspective.

Screening pathway issues – once enrolled

Wāhine Māori also face barriers attending screening appointments once enrolled into the programme. These include physical barriers such as lack of transport, logistical barriers such as childcare or inability to take time off work, through to structural barriers including inflexible appointment time, location of fixed sites, infrequency of mobiles in high needs areas and racism. One wāhine Māori told of her poor experience when attending a mammogram appointment at a fixed site where the reception staff were rude and unhelpful. This impacted her and members of her whānau who were put off from attending their mammogram appointments based on her experience.

'Māori don't go to places where we don't feel welcome.'

Access to results after a mammogram had been completed was an additional issue for wāhine Māori. While some women reported receiving a letter explaining their negative result in the mail, others reported needing to make an appointment to see their GP to get their result.

This was highlighted as a two-fold barrier for wāhine Māori – first, not all are enrolled with a GP; and second, the cost of attending a GP appointment is prohibitive for them.

The acceptability and enthusiasm for events where wāhine could have multiple screening tests done at once, for example breast and cervical screening, was another key theme from interviews with wāhine Māori. Interviewees felt these events made good use of a wāhine time especially if located at events or locations wāhine would be frequenting anyway, for example schools, churches or kapa haka events. One interviewee described a positive experience having an overall health check which included breast screening aligned with a kaupapa Māori world view, stating “stop treating people as individual body parts, treat us a whole person”.

Some lead providers have successfully developed and delivered integrated screening events (offering both breast and cervical screening), for example Counties Manukau hold Mana Wāhine Days for priority women each month on a Saturday. However not all similar initiatives have been supported. One interviewee reported an opportunity to have a mobile screening unit doing combined breast and cervical screening at a stadium during a national event was not supported by the lead provider or NSU. The interviewee explained “underpinning this were feelings from them [local lead provider and NSU] that they know best and racism – undervaluing our position and no idea of understanding solutions to achieving equity”.

Pasifika experience

*‘There is a disconnect between the NSU and those at the coal face.
They make decisions at their level without any understanding about what we think.
I am a Pasifika woman, ask me about Pasifika people.’*

Despite being a priority group, there is no Pasifika representation within the NSU, nor an overarching strategy for increasing Pasifika participation within the programme. There had previously been a sole Pasifika person within the NSU which was recognised as being insufficient, however since this person left there has been no Pasifika voice within the NSU. The opportunity to develop Pasifika leadership in the BSA programme is timely and necessary.

The review panel heard from interviewees that Pasifika women had been neglected and a focus on Pasifika women was imperative.

A consistent theme from Pasifika interviewees was that health services underestimate the importance of ‘including and engaging with Pasifika in service development’. A group of Pasifika consumers who met at a Health Quality & Safety Commission (HQSC) workshop in May 2021, to gather insights into the health system and how it works for Pasifika people, made the following observation:

*‘The need to be inclusive, understanding and deliberate in how we engage with
and care for the many ethnicities within Pacific peoples is fundamental
to mobilising change.’²⁶*

The HQSC workshop noted that growing Pacific representation in critical governance roles will generate important Pacific influence across the health sector²⁷. The importance of inclusive understanding and deliberate engagement with Pasifika was also emphasised by interviewees for this review; interviewees described a need for services that were tailored for, and met the needs of, Pasifika women, as well as a focus on building a representative workforce and engagement of Pasifika at all levels of the BSA programme.

²⁶ https://www.hqsc.govt.nz/assets/Consumer-hub/Partners-in-Care/Publications-resources/Improving-health-outcomes-BS-talanoa_web.pdf p2.

²⁷ https://www.hqsc.govt.nz/assets/Consumer-hub/Partners-in-Care/Publications-resources/Improving-health-outcomes-BS-talanoa_web.pdf, p6.

'There is a lack of Pasifika representation within NSU. There was one Pasifika person at NSU who was the sole voice. They left and now there is no one.'

'There is a lot of work that could be done to improve the programme for Pasifika women, especially who do not currently take part in the programme.'

'Pasifika weren't at NSU before COVID, so it's not just COVID that's caused the lack of a Pasifika voice.'

At the lead provider level, there are Pasifika people working within the BSA programme and there are initiatives to increase Pasifika participation, but this varies from provider to provider. Innovations to improve Pasifika women's participation in the BSA Programme were highlighted, with more targeted thinking required about where to locate services, and the design of these services to best meet the needs of Pasifika women to increase access and improve coverage.

The panel received feedback from a Pasifika person working at lead provider level regarding the need for NSU to lead and coordinate resources for Pasifika and other under-served groups to ensure consistent information and 'brand' awareness. They also expressed the need for NSU to improve information sharing forums between lead providers.

'I look to NSU as the source and would like them to develop consistent, nationwide resources for Pacific and other groups'

'We need to work together but there are no formal forums for information sharing with other lead providers'

The panel heard of several examples of work which has successfully increased Pasifika participation in breast screening within Counties Manukau. These include locating a new fixed site in Mangere, an area with a high Pasifika population which is highly accessible, along with the 'Me and My Mum' initiative and strengthening relationships with local churches. While these initiatives have been successful on a small scale, there have been difficulties in gaining support from the NSU to scale up these projects.

'Location of fixed sites – 'Locate fixed sites in areas with large Pasifika populations and that have easy access (parking and public transport option). E.g., Mangere site – since opening this site the DNA and DNR rates have dropped for Pasifika women in the area. The site is accessible and close to home.'

The importance of following up with women who had previously opted out of breast screening was highlighted by a Pasifika lead provider as crucial for increasing Pasifika participation in breast screening. They spoke about the importance of identifying and re-engaging with these women, as peoples' circumstances and reasons for not participating can change over time. For example, a woman may not have previously attended screening appointment because of transportation or childcare issues, but these barriers may have improved or resolved.

'It's very time consuming but it's important to look back at women who opted out and see if we can engage them.'

A Pasifika interviewee highlighted the need to trust in Pasifika people to deliver services to their people, citing the success of Pasifika model in the COVID-19 response.

'COVID has given us an opportunity to learn, to listen, to trust. We know we can do these things ourselves, Pacific and Māori have demonstrated this. We need to put Pacific and Māori at high levels of decision making.'

Trust was also identified as a crucial element in Pasifika women accessing breast screening services. An interviewee emphasised the importance of trust in the system and the care and empathy of people in the services:

'If people feel cared about they will be more willing to engage with services.'

Interviewees noted that developing trust is particularly important because health is not the priority for Pasifika women, others come first: 'it's the last thing on the list of priorities for Pacific women'.

Trust in GPs was considered to be high among Pasifika, as was trust in well-known Pasifika presenters such as those who broadcast on Radio Samoa. Education sessions on radio given by a health professional focussing on breast cancer, the impact of this on whānau and the role of screening in saving lives, were cited as useful ways of reaching Pasifika communities.

With respect to the BSA programme workforce, interviewees felt that it wasn't necessary for the workforce to be all Pasifika when providing services to Pasifika women, rather staff need to be respectful of cultural and religious beliefs that are important to Pasifika.

'I don't think we necessarily need a Pacific workforce – we just need people who are passionate about the cause. My mother had a non-Māori, non-Pacific person do the mammogram and had such a good experience. She commented that the radiographer didn't need to be Pacific as long as they were kind, caring and considerate. She felt she had a great experience.'

Experience of other underserved groups

The need to achieve equity for other priority groups was highlighted in consumer interviews.

The panel sought views from a disability perspective through an informal phone conversation with a disability advocate which led to further email contact with another source. A paper on access to screening services for people living with disability identified three main areas of concern for those interviewed: accessibility, service environment and information.[55]

Improving accessibility, particularly of mobile screening units, was a key equity theme for people living with disability. The design of new mobile units is a key example where the voices of people living with disability should have been consulted. One of the consumers interviewed (who did not have a disability) nonetheless spoke about new mobile units that are smaller and designed to suit rural roads. Consumers with mobility issues find these new units, which are higher off the ground and don't have provision for a hoist, are much more difficult to access.

Improving equity for rural consumers was highlighted by both consumers and a rural GP. The main issue highlighted for rural consumers was accessing a mobile screening unit. The issue is three-fold: frequency of mobile unit visits at locations, inflexible appointments and consumers on special pathways such as annual screening or the symptomatic pathway cannot access local mammography services. In one rural location the mobile unit visits every two years for a three-week period and this, combined with inflexible appointments, means consumers whose mammogram is not due cannot use the mobile service when it is in their area. For example, if a local consumer had a mammogram 19 months prior, they would not meet the 20-month minimum re-screen interval eligibility criteria for a BSA programme mammogram. The NSU advised that "providers, especially in the South Island, seek NSU advice for women in this circumstance so that a practical approach can be taken, and the NSU's agreement is not unreasonably withheld". However, this does not appear to have been clearly communicated to all providers, GPs and consumers.

High risk rural consumers on special pathways, for example annual mammograms due to whānau history or the symptomatic pathway, also faced significant barriers. In the BSA programme consumers are only eligible to have a mammogram once every two years, while consumers on the symptomatic pathway are excluded from the programme. In these cases, even if the mobile is in area, consumers cannot book an appointment locally and instead face a six-hour round trip to the nearest hospital where mammography is available.

Alongside the theme of enrolment, consumers also felt little was being done to understand, from them, why they are not enrolling.

'There are a lot of assumptions made by lead providers and NSU as to why people in the priority groups are not attending screening. However, there have been few attempts to reach out to those groups to understand the issues from their perspective.'

'If the system relies on primary care to encourage women to opt on to the screening program ...how is BSA ensuring that unenrolled women are supported to engage with screening?'

Strengthening consumer participation across the BSA programme including governance

The Code of expectations for health entities' engagement with consumer and whānau sets an imperative for all entities involved in the BSA programme to engage with and involve consumers at all levels of the screening programme. There is an opportunity for the BSA programme to address this imperative by working with consumers to co-design an approach to consumer and whānau engagement. This will improve the mechanism for communication between the NSU, providers, and multiple and diverse community voices.

There is an urgent need to establish consumer participation within the BSA programme. The NSU states that this is underway as part of the BreastScreen Aotearoa New Zealand Advisory Group (BSAAG) changes and 'the co-design project'. The panel also notes that BSAAG is an advisory group only, this does not provide for shared decision-making and partnership with consumers. Consumers interviewed by the panel were not aware of the changes NSU has made to the BSAAG. The urgent need to establish consumer participation was highlighted during consumer interviews with one interviewee noting 'they seem to have forgotten they are screening people'.

Alongside the need for participation, consumer advocates noted the need for greater transparency in the recruitment process for consumer positions to ensure the recruited consumers either have experience (personal or whānau) of breast cancer, or they have significant experience of the health system (this aligns with the NSU Quality Framework 2015). Consumers also noted the need for diversity, noting the current lack of Pasifika and people living with disability voices. Finally, consumers expressed a desire to have a stronger position within groups, being part of decision-making rather than being just advisors.

'We need more than to be on advisory groups, it's great to sit at the table, but we need to be in power.'

Another consumer made this suggestion:

'Ideally the BSA should establish a consumer panel and most importantly be open to hearing their different points of view. The nominations and appointments for the panel should be broad, ultimately you want a lot of different views at the table, including ethnic diversity. Breast cancer NGOs should also be invited to nominate members as they will bring system-wide and data driven perspectives.'

The NSU's Quality Framework 2015 highlights 'consumer-centred partnership' as a key requirement for the screening programmes' clinical governance.[6 p9] The framework specifies the need to bring in the 'knowledge and experience of consumers at the governance level' to improve acceptability, access and participation in screening.[6 p9] The limitations of having a sole consumer voice at a governance level are acknowledged, and therefore the framework supports having two consumer advisors on advisory groups with 'experience of the condition(s) screened for and the health system'.[6 p4]

Health entities' lack of engagement with consumers and whānau at governance levels has been identified as problematic by Dr Janice Wilson, Chief Executive of HQSC:

"One area where we need to concentrate our efforts to increase consumer engagement is at the governance and policy level. Poor performance in this area negatively affects quality improvement processes and outcomes, in terms of creating policy that is not appropriate or creates risks for consumers. By including consumer perspectives, health providers will spend more wisely and policies will be fit for purpose because consumers have been actively involved."[52 p3]

Key informant interviews revealed substantial improvements are needed to strengthen consumer participation in governance of the BSA programme. One consumer noted:

'In general, the consumer voice and influence in the BSA programme has reduced over time; it is not as strong and active as it once was. This is multifactorial – less budget, now a mature/ well-established programme and individual lead providers have greater control. Now that the BSA Advisory Group has been dis-established, there is no consumer voice across the board.'

Improving consumer information

'Information for consumers needs to be developed with consumer input – BSA needs to have [an] open mind and wide inputs.'

The NSU Quality Framework 2015 specifies informed consent as a key quality principal to be maintained throughout the screening pathway. This document states 'full information' should be provided, whilst acknowledging the importance of addressing 'cultural and health literacy differences' when providing information to support informed consent.[6 p4] The Framework also highlights consumer feedback mechanisms and public reporting as important components of the quality improvement cycle.[6 pp14-15]

Interviews with consumers revealed the current provision of consumer information was lacking/troublesome and could be improved on several fronts. Consumer involvement is often too late and too often consumers are involved just at specific points, for example review a brochure before publication. Consumers emphasised they need to be involved from the start.

Interviewees suggested the following improvements for consumer information:

- Information is written in simple language, use bullet points, avoid significant amounts of texts, include pictures and colours
- Information clearly outlines the following – What is screening? What is a mammogram? Does it hurt? What happens if a cancer is detected?
- Information is delivered through a variety of mediums – post, text, internet, TV adverts, radio, social media, churches, schools etc
- Information addresses the needs of women with English as a second language or a preferred language that is not English. Given the Māori and Pasifika inequities in breast cancer screening, it would make sense to prioritise te reo Māori and Pasifika languages

'Communications from BSA to women needs to reflect the way that women communicate these days – mail is probably least favoured – need to also consider email, text, phone calls, social media, and needs to be at no cost to the women'

The need to communicate the benefits of the screening programme better was a key theme from consumers' interviews and interviews with consumer advocacy groups. Interviews revealed consumers were receiving mixed messages regarding the benefits of screening, with many interviewees commenting that information is too often focused on the risks of screening (for example investigating a lump that turns out to be benign). Breast cancer awareness groups were particularly keen to ensure the benefits of screening are emphasised and highlighted as outweighing the risks. Too much information regarding risks leads to mixed messaging and ultimately reduces trust in the programme.

Key informant interviews revealed consumers want and appreciate open and honest communication from the NSU/BSA and lead providers, especially regarding mammography delays. Breast cancer awareness groups reported anecdotal evidence of poor communication with consumers regarding time delays. This was congruent with findings from interviews with consumers impacted by time delays in the 2DHB incidents who waited up to two years²⁸ from enrolment in the programme to receiving their first mammogram[1] During this period, consumers received no communication regarding the delays from either the lead provider or NSU but received several reminders from their GP to enrol and attend their screening appointment. This highlights that information regarding delays in accessing appointments and long wait lists was not shared with primary care providers.

'I wish they had been honest and said we can't screen everyone right now'

Consumers also spoke about their expectation that their health information would be shared – they expressed surprise their screening information was not readily available to other health professionals. No consumers interviewed expressed concerns about their information being shared for the purposes of monitoring; in fact, consumers were surprised this was not already occurring.

Building and maintaining strong relationships with consumer advocacy

The panel interviewed members from two key breast cancer not-for-profit organisations in Aotearoa New Zealand – The Breast Cancer Foundation New Zealand (BCFNZ), and Breast Cancer Aotearoa Coalition (BCAC). Both organisations reported having reasonable, long-standing relationships with the BSA programme leadership, but little to do with lead providers. Both organisations reported their regular, bi-annual meetings with the BSA managers had been disrupted due to COVID-19.

The BCFNZ has recently re-established their regular meetings with BSA, however for the BCAC the meetings remain ad-hoc and usually at their request. Both organisations expressed a desire to maintain strong relationships with the programme, with the Chair of BCFNZ highlighting the importance of ensuring their Pink October messaging complements the programme. BCFNZ stated it has a good relationship with BSA; BCAC previously had a good relationship but its relationship has declined in recent years. Both NGOs have limited/ no relationships with lead providers.

It is timely to strengthen and build these relationships. Consumers who were interviewed for this review, and who have experience advocating across all facets of breast cancer screening and treatment, raised issues they believe warrant further exploration. Some of these include broadening the objectives of the screening programme, reassessing tools used in risk stratification, age extension and measuring and reporting breast density. While some of these issues are outside the scope of this review, they merit further exploration as they are central to wider discussions about cancer screening.

From consumers who were interviewed for this review, there is a desire to work proactively and productively with the NSU, providers and other consumers to develop a more tailored and flexible programme. The opportunity to engage more intentionally using the knowledge and experience of consumers and whānau needs to be acted on; the panel has recommended setting up a consumer and whānau panel and developing a Consumer and Whānau Engagement Framework based on the Code of Engagement.

²⁸ The 2DHB service and review team were unable to identify any eligible client who waited nearly two years, except at mobile sites. Throughout the country, it is not rare for rural women to wait this long for a first screen via a BreastScreen Aotearoa New Zealand mobile site as a mobile unit may visit a remote site only once every two years.

RECOMMENDATIONS

- Set up a consumer and whānau panel to oversee the redesign of the BSA governance structure and provide advice on issues identified in this review (for example, inequities, barriers to access and participation, information for consumers and whānau, processes for recruiting consumers to participate in governance, and communication of delays). Wāhine Māori and Pasifika women must have a strong voice on this panel.
- Partner with the Health Quality & Safety Commission to develop a consumer and whānau engagement framework based on the Code of expectations for health entities' engagement with consumers and whānau, with an action plan for the next six months to implement the framework.

5. WĀHANGA TUARIMA: CLINICAL QUALITY AND SAFETY

Ehara ko te ia o te wai
Ehara hoki ko te pupuhi o te hau
Engari ko te whakarite kē o ngā rā
Ka tae to tātou waka ki uta

It is not the way the current flows
Nor is it the way the wind blows
Rather it is the way we set our sails
That will enable us to reach the
shore

This section addresses the following questions:

- What systems, policies and processes (including monitoring, audit and clinical governance, clinical expertise and input) are in place to manage equity, consumer/whānau voice, clinical quality and safety across the BSA programme?
- Are these systems, policies and processes being operated effectively?
- Are these systems, policies and processes meeting the needs of Māori and Pasifika people?
- Is there clarity about roles and responsibilities in relation to these systems, policies, and processes across the BSA programme?
- What arrangements are in place to manage relationships between the NSU and BSA lead provider managers and clinical directors?
- Are there any recommendations for improving these relationships and how the teams work together?

Findings

- The BSA programme has some but not all the substantial elements in place to manage clinical quality and safety. Of note is the lack of Māori clinical governance.
- Elements of clinical governance are not operating effectively.
- Systems, policies and processes do not meet the needs of Māori and Pasifika people.
- Key strategic policies are out of date and do not reflect te Tiriti principles and the Government's priorities. There should be a comprehensive set of BSA-specific strategic policies.
- Roles and responsibilities are clearly described but not clearly understood. A redesign of the programme's governance structure is an opportunity to review the clinical governance model and co-design different ways clinicians can be involved in the programme's governance.
- The principles of co-design, shared decision-making and distributive leadership should be applied in any governance redesign, and the panel strongly encourages a co-design process that is inclusive of all groups in the design model including consumers and providers.

Discussion

The BSA programme needs to build on opportunities for improvement. It can develop a more cohesive approach to clinical quality and safety with systematic, continuous learning and improvement, and transparency.

Key opportunities for improvement identified by the review panel are set out below.

Governance

Governance is fundamental to ensuring quality and safety and enabling continuous improvement. The BSA programme's current governance system is set out in Figure 9. Current advisory group and UDG structure for the BSA programme, July 2022.

Breastscreen Aotearoa Advisory Group and UDG Structure

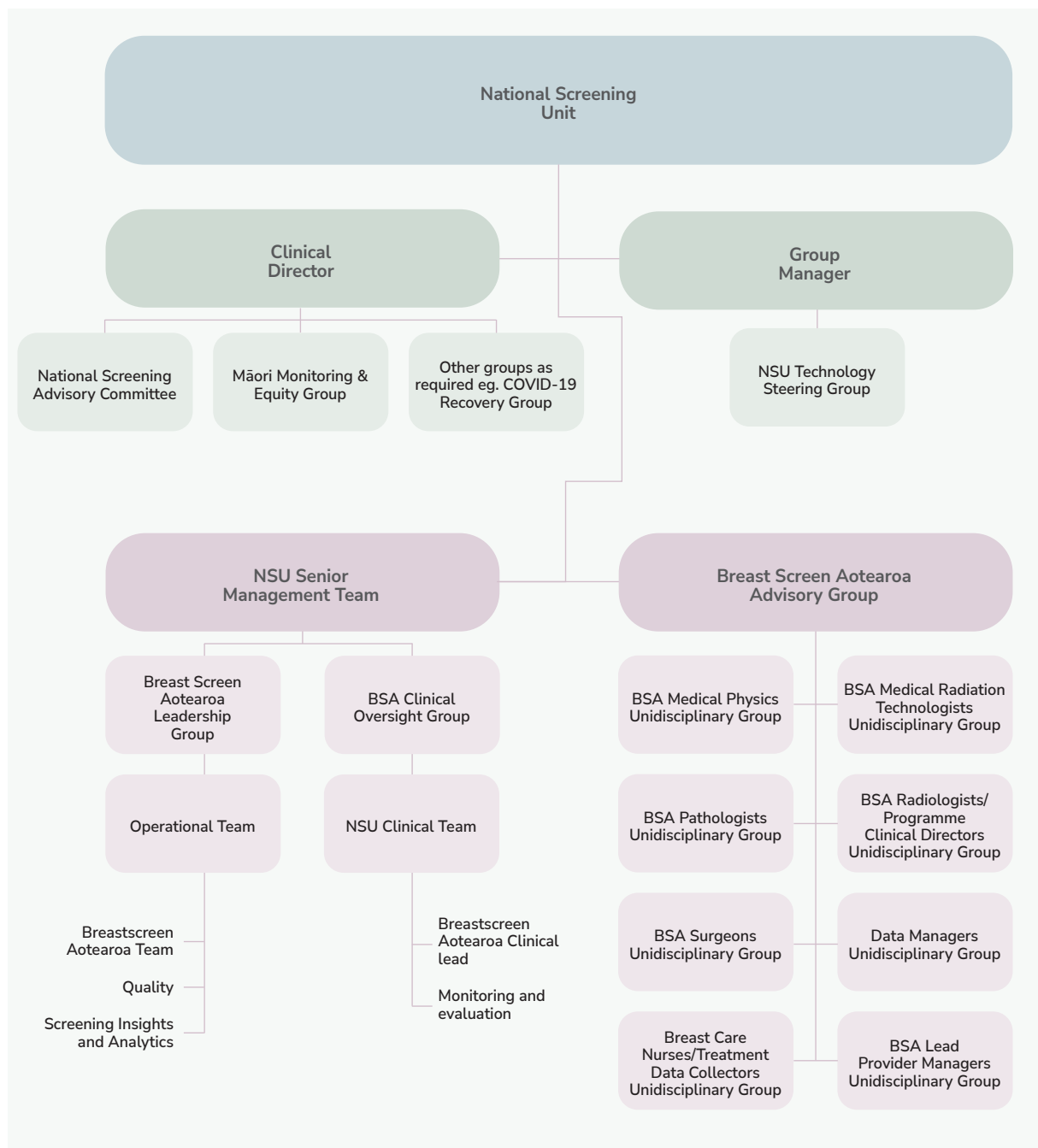


Figure 9. Current advisory group and UDG structure for the BSA programme, July 2022

A description of the roles and responsibilities of the current governance groups is set out in [Appendix 6](#).

The review panel acknowledges significant changes are being made to BSA's governance structure. There are opportunities to improve the clinical governance of the programme as part of the redesign of the NSU and BSA's governance model. Issues that need to be addressed include:

- The governance system does not give effect to te Tiriti and the principles of the Pae Ora (Healthy Futures) Act 2022. It does not sufficiently value and recognise the centrality and importance of whānau in te ao Māori and provide opportunities for Māori to exercise decision – making authority (see [Wāhanga Tuatoru \(Section 3\): Te Tiriti o Waitangi and Equity](#)).
- The governance system does not reflect the principles of shared decision-making, partnership and co-design. All the governance groups with Māori, Pasifika, consumer and/or provider members are advisory, with no shared decision-making.
- Currently there is no wāhine Māori, Pasifika and consumer involvement within the programme's governance.
- The Clinical Oversight Group has decision-making power for all clinical decisions. NSU staff make up all but one of members (the Clinical Lead role is the only clinician member who also works outside of the NSU).
- Responsibilities and lines of accountability, including who and how decisions are made, are not clear even to those participating in the governance groups.
- The clinical advisory groups (uni- and multidisciplinary groups) do not meet according to the specified NPQS schedule, and meetings are not structured for quality improvement.
- Expertise in screening programmes is highly distributed in Aotearoa New Zealand, governance needs to be as inclusive as possible, particularly involving Māori and Pasifika expertise.

Te Tiriti Governance Partnership Model

The review panel commends the NSU and MMEG for commencing a process to review and inform the NSU's governance and develop and implement a Tiriti Governance Partnership Model over all the national screening programmes (as discussed in [Wāhanga Tuatoru \(Section Three\): Te Tiriti o Waitangi and Equity](#)). Inequities for Māori wāhine are serious, longstanding and have been exacerbated by COVID-19; a well-developed governance structure with strong leadership at every level of the programme could have a significant, positive impact for Māori wāhine accessing and participating in the BSA programme.

It is important to note that many of the interviewees for this review, including Māori, were unaware of the governance re-design work happening and wanted to be informed and involved. Consultation with BSA programme key stakeholders including consumers, screening support services, and lead providers is necessary to ensure that this occurs.

Consumer and whānau engagement

Aotearoa New Zealand's Code of expectations for health entities' engagement with consumers and whānau (the Code of Engagement) recognises an imperative to engage with those with greater health needs, particularly Māori, Pasifika and people living with disability.[2] Consumers, whānau and communities must be involved at all levels, and health entities must share leadership, acknowledging and valuing equally the knowledge, expertise and lived experience of consumers, whānau and communities.

Consumers interviewed for this review all stated that consumers and whānau are not involved at all levels of the programme and there is no active support for them to be involved. There are currently two consumer roles in the NSU governance structure, both are members of the National Screening Advisory Committee, a high-level advisory committee across all NSU screening programmes. There are no consumer roles specifically in the governance of the BSA programme. For wāhine Māori, decision-making authority was described as essential. Wāhine Māori stated they felt the NSU does not value and recognise the importance of wāhine Māori and provide decision-making opportunities.

'Māori involvement in the BSA programme should be business as usual. It should not be optional or nice to have.'

Consumers described wanting to be partners with the NSU, be part of shared decision-making, and co-design the programme's strategy, priorities, and service improvement. Consumers also noted that they are often not seen as partners by lead providers. There is no consistent standard of consumer involvement at the lead provider level, it is essentially up to each provider to determine how they involve consumers.

'Co-designing with consumers would greatly improve the consumer experiences.'

The NSU has acknowledged the need for much greater involvement of consumers in the BSA programme. BSA will need to ensure consumers, whānau and communities have access to resources to enable them to contribute and engage meaningfully. BSA policies will need to reflect the programme's commitment to the Code of Engagement. And BSA needs to systematically listen to and value the lived experience of its consumers, whānau and communities.

It is also important that the governance redesign work considers how the other groups in the BSA governance structure fit in a new model, for example the Clinical Oversight Group (COG) and the uni- and multidisciplinary groups. Consideration also needs to be given to the relationship the new co-governance structure has with Te Aka Whai Ora.

'When thinking about leadership groups, they can be widespread but disconnected with a wide variety of advisory groups, there needs to be a way of getting connected.'

Clinical leadership

'Clinicians are at the centre of an organisation's clinical governance arrangements. Their leadership and commitment are crucial.[9]

Māori clinical leadership

Currently there are only five Māori staff working in the NSU and there are no Māori clinician members of MMEG.

Engagement and partnership with Māori clinician leaders is critical to the success of a revised NSU and BSA governance structure. There is a need for skilled Māori leadership with screening expertise. Māori interviewees noted that many Māori leaders who could help, have had bad experiences working in or with the NSU over the years (including a number of the interviewees), and they would never go back due to these poor experiences. This is a big problem because there is a very small pool of people with the relevant competencies.

Development of the Māori health workforce and clinical leadership for the BSA programme must be given a high priority.[10] The BSA has recently commissioned the development of a workforce strategy and action plan.[56-58] Further work to develop the Māori health workforce needs to be led by Māori under the new co-governance model.

'We need to build more capacity as there aren't enough Māori to go around. We're widespread and disconnected and we need to understand who and where leadership groups are and connect with them. This is on the radar. It's hard to keep connected – there's a failure/gap to report back, connect and coordinate to each other when there are so many groups.'

BSA clinical lead role and lead provider clinicians

Under the current structure, there is a BSA clinical lead role and there are nine uni- or multidisciplinary advisory groups (UDGs), representing each of the programme's professional groups (for example, clinical directors (radiologists), lead provider managers, medical imaging technologists, breast nurses). The UDGs are the key means for managing the relationship between NSU and the lead provider clinical directors, managers and other clinicians.

The Clinical Lead role is considered an important role by all stakeholders. The Clinical Lead is a member of the BSA's Clinical Oversight Group (COG). According to its terms of reference, the COG has decision-making authority for all clinical aspects of the programme. Previous programme reviews have identified the importance of this role being filled by a radiologist because the programme is essentially a radiology-based (mammography) programme that requires radiologists' specialist knowledge and experience.

A radiologist has not been in the Clinical Lead role since 2009. Difficulties in recruiting a radiologist to the role were highlighted in the review of the programme in 2011 and the review recommended a radiologist be appointed part-time to the role.[5] Lead provider radiologists acknowledge that none of them have wanted to take up the role for several reasons (including remuneration, time-commitment required and relationships with NSU staff), and that this has made clinical governance of the programme challenging for the NSU. Clinical directors and lead providers describe their meetings with the NSU as not constructive and at times hostile.

'We [clinical directors] get summoned to UDG meeting, the NSU do most of the talking, they surprise us with decisions made.'

'The disestablishment of BSAAG [BreastScreen Aotearoa New Zealand Advisory Group] was a fait accompli, there was no discussion with the clinical directors.'

Other unidisciplinary groups also said the programme's governance structure wasn't working effectively. For example, UDG members were confused about group reporting lines and did not know what the Clinical Oversight Group does, and how the groups relate; they felt meetings were not well structured; and some of the UDGs met irregularly or had not met for several years and were unsure why this happened. The programme's standards specify a schedule of UDG meetings, which should be at least once a year.[18] One of the groups, the Data Managers' UDG, has not met for the past six years.

A redesign of the programme's governance structure is an opportunity to review the clinical governance model and co-design with clinical directors different ways they can be involved in the programme's governance instead of relying on one national clinical lead role.

The principles of co-design and distributive leadership are important to ensure the highly distributed expertise in the programme is included in governance. A co-design process should be inclusive of all unidisciplinary groups in the design of the model. Governance group meetings should be structured with meeting agendas included in a co-design process.

Performance and accountability

Policies and planning documents

The NSU has a set of quality and safety policies that provide a solid framework for the management of clinical quality and safety across the screening programmes. Key policies include the NSU Strategic Plan 2010–2015 (published in 2010); the NSU Quality Framework 2015 (published December 2015); and, for the BSA, the National Policy Quality Standards 2013 (Revised September 2020).

The policies are not up-to-date and there should be a set of BSA programme-specific policies in addition to the broader set of NSU policies. The policies need to reflect the health sector's commitment to te Tiriti, the aims of He Korowai Oranga (Māori Health Strategy) and the priorities and actions in Whakamaua: Māori Health Action Plan 2020–2025; the principles of the Pae Ora (Healthy Futures) Act 2022; and the priorities in the Interim Government Policy Statement on Health 2022–2024. [10, 35, 59]

'In order for the programme to be cohesive, the programme must know where it is going. NSU has not articulated where BSA programme is going.'

A BSA programme-specific strategic plan is an expectation specified in the NSU's 2010–2015 strategic plan. Several interviewees stated that there is no clear vision for the BSA programme, and current aims and objectives are not clear. An up-to-date BSA strategic plan should be co-designed with Māori co-governance partners, Pasifika, consumers, and other stakeholders. The plan should clearly describe the programme's quality and safety vision and objectives.

Other key strategic policies including the NSU Quality Framework 2015, the BSA Data Management Manual 2010, and the BSA National Policy and Quality Standards 2013 (Revised September 2020) (NPQS), are also out of date.

A comprehensive set of BSA programme policies should be published on the NSU website. The set should include a BSA Programme:

- strategic plan
- quality strategy and a quality action plan
- quality standards
- data monitoring framework
- data monitoring and reporting plan
- research plan
- communication plan

There should also be clear, transparent reporting of the BSA's performance according to its strategic plan and quality plan, for example in the form of an annual report.

Roles and responsibilities

The current roles and responsibilities of the NSU, BSA leaders, and lead providers are clearly described,²⁹ however, these are not clearly understood. There is a spectrum of views about what the key responsibilities are, what should be the focus, and whether there should be distributive leadership and shared decision-making.

Providers consistently expressed the view that the NSU is focused on providers' contractual performance, and this creates a "punitive" environment that detracts from programme coordination and improvement. This was also strong theme in the programme's 2011 review.[5]

The NSU emphasised the importance of it being 'independent' so that it could monitor providers and hold them to account. The NSU highlighted to the panel the impact that COVID-19 has had on its ability to fulfil its functions over the last two years.

The panel acknowledges that during the COVID-19 period the NSU experienced a significant reduction in FTE (from over 70 to less than 20) as staff were seconded to support the health sectors' COVID-19 response, and this has been hard for the small number of staff sustaining the screening programmes. However, it is also noted that many of the concerns about the role and focus of the NSU are long-standing and will therefore not be addressed solely by resourcing. A re-design of the BSA programme's governance model and development of a BSA strategic plan, is an opportunity to review and revise roles and responsibilities in the context of a shared decision making, distributive leadership model.

In addition, Te Aka Whai Ora and Te Whatu Ora structures bring an opportunity to work better as one system. Both can support and enable the NSU to re-focus its role on performance through continuous quality improvement – supporting providers to engage with consumers to plan, design and improve services.

'The NSU needs to lead the development and support of a continuous quality improvement mind-set across the programme – encourage and allow ideas to flourish, enable and support change to happen.'

²⁹ The roles and responsibilities of the NSU are set out in the NSU's Strategic Plan 2010–2015, and Quality Framework 2015. The roles and responsibilities of lead providers are set out in the National Policy Quality and Standards (NPQS). The roles and responsibilities of screening support service providers are set out in the contracts between the NSU and the providers; this information is not available publicly.

Monitoring, reporting, audit, evaluation and research

Standards and indicators

The BSA's National Policy and Quality Standards 2013 (Revised September 2020) (NPQS) together with a Data Management Manual 2010[18, 60], set out standards for the management of quality and safety of the programme along with indicators and targets; the documents are out of date.

'The latest version of the data manual is 2010 – this is too out of date. Some current elements of the data manual do not fit well with current clinical practice which has evolved considerably since 2010.'

The NPQS includes more than 350 standards and applies to all service providers who are “contractually obliged” to meet the standards. The NPQS is also the basis for the NSU's programme monitoring and provider compliance audit. The NPQS was revised and updated in 2020 but providers interviewed said it is not clear to them what changed as a result of this review.

'The NPQS was meant to become an online document 15 years ago with a front page describing the changes. On the current NSU website there's nothing. Changes are not visible to the lead providers. Lead providers are not informed about current requirements so I don't know what to tell staff. We need to know what is the current version to be able to train staff.'

'2013 was the last review of NPQS. Clinical directors were not involved and not aware of a review of NPQS in 2020, it may have been just an update of what had changed in past.'

The BSA programme has a large number of indicators: the NPQS together with the Data Management Manual identify 42 indicators for regular monitoring with targets for 34 of these indicators. There is no clear prioritisation of the standards and indicators. The indicators have a stated rationale but do not include references to published evidence that the indicator can improve outcomes for the women being screened.

The NSU reported undertaking periodic reviews of the screening pathway and indicator review to identify key performance indicators for each screening programme but evidence for this was not provided to the panel. Prioritisation of the indicators would allow providers to better focus their efforts and respond when sentinel indicators are below target.

Consumers have not been directly involved in the development of the BSA programme indicators. And the NSU does not systematically measure patient-reported experience (PREs/PREMs) and patient reported outcomes (PROs/PROMs), it is up to each lead provider to measure and monitor this data.

A clear process and timetable for selecting, prioritising and reviewing indicators would help give lead providers, the wider health sector and consumers and whānau, confidence in the indicators and the value of the programme. Consumers and whānau should be included in the process of determining which outcome measures are reported, what is most important to them, and how information is presented. The NSU ICT project[19] will include technology to communicate directly with consumers; designing measures to capture and report PRO and PRE data to inform quality improvement should be given high priority and be included in the implementation of this project.

'We need updated performance indicators, digital data dictionary, NPQS and data management manual – hopefully in time to enable the new BSA ICT programme to design the corresponding data fields.'

The panel also notes that treatment outcome indicators are reported not only by the BSA programme but also by Te Aho o Te Kahu – the Cancer Control Agency, and by the Breast Cancer Foundation via its registry. Alignment of definitions and data collection efforts would avoid duplication, reduce potential confusion and ensure good stewardship of public resources.

Monitoring, reporting and transparency

The NSU states that “there is a comprehensive suite of monitoring and reporting tools that support best practice performance and quality improvement. These reports provide a range of different lens on the programme effectiveness and equity”. However, what this ‘suite’ comprises is not clear and transparent to consumers and providers.

This review has identified a number of opportunities to improve the way the programme is monitored and reported.

The BSA programme does not, but should,³⁰ have a monitoring framework that includes clearly defined indicators that are prioritised, describes the frequency of reporting and where indicators will be reported, and escalation protocols if an indicator is out of line. The NSU provided, to the panel, a ‘Monitoring and Evaluation Plan’ that describes when monitoring reports are due and their status. The plan is not published on the NSU website www.nsu.govt.nz and it has not been shared with lead providers.

Reporting of indicators is not regular and timely. The programme monitoring reports are summarised in **Appendix 7**. Lead providers reported that they found the data difficult to source for the monitoring reports they must complete for the NSU, and the reporting provided by NSU is too slow (coming out up to a year or more later) to be of practical use in their local programme work. Small providers found the data needed to monitor their work particularly difficult to source.

Most monitoring reports produced by NSU are overdue. The last mortality evaluation report published by the NSU was in 2015 for data from 1999–2011;^[16] and the last interval cancer report was published in 2018 for data from 2008–2009 (the Data Management Manual states interval cancers will be reported annually).^[61] The NSU states that the volume of interval cancers in Aotearoa New Zealand is not sufficient to report annually so the decision was made to report on a two year period cycle. However, this has not happened, and the last report included interval cancer data from 13 years ago.

³⁰ The NSU Quality Framework 2015 states that each screening programme should have a monitoring framework.

The 2015 BSA breast mortality evaluation report looked at a key aspect of the BSA programme, which was how much more mortality reduction might be achieved if coverage was improved to target (including ethnic specific). This is a useful way to consider expectations of future mortality improvement with improvements in coverage. The report also noted that there were not ethnic-specific differences in the pathway and outcomes of screen-detected women: this is important reassurance that once in the programme there is equitable diagnostic/treatment access, and that the focus should be on improving coverage. Repeating the mortality evaluation to continue to provide this assurance would be useful.

Overall breast cancer mortality is available annually as part of general cancer mortality reporting by the Ministry of Health via the New Zealand Cancer Registry (NZCR).³¹ The latest report covers 1948 – 2018 and reports 685 deaths due to breast cancer in 2018; this data is not reported by ethnicity nor age. There is no link from the NSU breast cancer website to this report. The NSU reports cancer mortality by time series (including ethnicity and age) as a routine part of the National Cervical Screening Programme with the latest report (2022) reporting mortality from cervical cancer to 31 December 2019.[13] Similar annual time series mortality reporting should be part of routine reporting for the BSA programme.

The exception to delayed reporting is reporting of coverage data including an equity matrix that is presented in a BSA Coverage App on the NSU website.³² Given the aim of the BSA programme is to reduce mortality, it is not acceptable for BSA reporting and publication of mortality data to be so out of date.

Transparency of reporting is essential for quality, safety, accountability, and informed decision making. [62] Interviewees emphasised transparency of this information and timely publication by the NSU is essential for building and sustaining consumers trust in the programme; for providers so they can provide consumers with robust information for informed consent and identify opportunities for improvement; and for researchers who can test and validate the strength of the evidence supporting the programme. While some monitoring reports have been made available on the NSU website in an area labelled “For Health Professionals” (the latest report was posted in 2019), there is no programme monitoring information made available specifically for consumers and whānau.

The panel notes that the NSU has not published the evidence eg epidemiological analysis, supporting its screening prioritisation criteria despite lead providers repeatedly asking NSU to share this information. Detailed analysis supporting significant decisions made by the NSU, including prioritisation decisions, should be shared with lead providers, consumers and the public in a timely manner.

31 Available at: <https://www.health.govt.nz/publication/cancer-historical-summary-1948-2018>

32 BreastScreen Aotearoa New Zealand DHB Coverage Report. Available at: <https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/>

Audit, evaluation and research

'The audit system is not working well; it needs to be fixed.'

'There needs to be a complimentary audit system at national and local/region level.'

The NPQS require lead providers to undertake regular internal monitoring and auditing of quality within their service. The results of these audits are reported to NSU through the six-monthly management reporting templates. Learnings from these audits may be shared with other lead providers through UDG meetings, but are not shared in a systematic way. No public reporting of these findings is made.

The NPQS also requires the NSU to coordinate external auditing of lead providers every three years. The most recent external audit cycle round was carried out by a new auditor between February 2021 and September 2022. Prior to this, there was a nine-year period (2012–2021) when no external auditing occurred.

Lead Providers described a number of concerns about external audits: the NSU changed the external auditor without consultation; the NSU did not provide auditors with relevant data prior to the audit and auditing did not identify non-compliance with NPQS indicators; auditing felt too much of a tick box exercise; and there is no timely systematic sharing and learning from audits provided by the NSU to the lead providers.

A review of external auditing needs to be undertaken in consultation with lead providers with a view to developing more effective and efficient audits focused on what is most important including priority indicators and clinical risk.

Evaluation and research are also an important part of a screening programme's clinical quality and safety system. Ongoing evaluation should be a routine and regular practice as part of the operations of the BSA programme. The panel considers it extraordinary that it had to engage an epidemiologist to evaluate the outcomes of the BSA programme; this should have been readily available to the panel (and public). The NSU should ensure a regular (yearly or two yearly) epidemiology evaluation of the screening programme is carried out, rather than episodic evaluation based on issues. To allow better evaluation of the programme, linkages need to be made between BSA data, clinical records on all breast cancer patients, and information on breast screening outside the BSA programme.

The NSU does not have a research plan although the NSU's Quality Framework specifies research as a requirement of the NSU as the screening programme's central agency, and in its 2010–2015 strategic plan the NSU undertook to 'operate, by 2015, a robust research and development programme to inform the development of existing and any future programme'. The constantly increasing international scientific knowledge relevant to breast cancer screening needs to be kept under review, especially as it may impact on major aspects of the programme which need further consideration. These aspects include the lower age range, the upper age range, risk stratification of women for screening, and breast density. All these aspects need to be assessed for their impact on equity.

The development of a research plan that is regularly updated is important and needs to be included in the BSA's strategic planning and annual performance reporting process. The research plan should have strong Māori and Pasifika input and needs to address gaps in knowledge about wāhine Māori and Pasifika women's experiences of the breast screening programme (including their journey through diagnosis and treatment), factors that contribute to the late-stage diagnosis of breast cancers and lower survival, and a more in-depth analysis that examines breast cancer outcomes by level 2 ethnicity.

Continuous quality improvement

Culture, teamwork and relationships

The BSA programme was described by several interviewees as a “high trust environment” – an environment with many different interdependent professional groups working across multiple sites and in different settings requiring a high degree of trust between individuals and groups to operate effectively. Most interviewees felt that trust has eroded particularly between lead providers and the NSU, and between the NSU and consumers, and that work needs to be done to build trust and create a positive, ‘one team’ culture across the programme.

Several interviewees recognised the importance of having clear set of programme values and the importance of the values being co-designed with programme stakeholders. And many recognised the opportunity the development of a co-governance model offered to develop a positive culture within and between teams, with strong Māori leadership and stewardship, shared decision making, and distributive leadership.

A draft BSA Workforce Development Strategy 2022–2032 recently commissioned by the NSU recognises forming and maintaining trusted relationships is key to effecting change and that “there needs to be a willingness on the part of all BSA sector players to support collaborative initiatives.” [56] The strategy recommends “skilled relationship building, and management will be necessary to successfully bring all parties along on a shared journey”.

The co-design of new ways of working between the NSU and lead provider clinical directors, managers and the multidisciplinary groups, will help foster a culture of teamwork and build trust. This will be underpinned by having strong, focused governance with shared decision making and broad, diverse involvement of stakeholders at all levels of governance.

The success of a screening programme depends on good governance and a focus on the programme's purpose – for BSA, to decrease mortality for Aotearoa New Zealand's wāhine aged 45–69 years. To do this, the BSA programme needs to reframe the relationship between NSU and providers and with consumers as a relationship based on distributive leadership, shared decision-making and partnership.

Learning system

Developing a learning system is also a critical component of a robust screening programme: a system that:

- uses information from multiple sources eg data reports, complaints/feedback, audits, incidents, in a systematic way to continuously review and improve
- regularly evaluates best practice
- systematically shares information.

‘There are diverse ways breast screen services are provided across the country, there are siloed solutions, there is little sharing across the country.’

The benefits of a well-functioning learning system are multiple and recognised internationally. Benefits include optimising the use of knowledge and evidence for decision-making; reducing unwarranted variation in care; improving relationships and organisational culture; informing research; building consumer trust; improving consumer outcomes and experience; and maximise the benefits of technology and innovation.³³[63]

A strong theme from interviews was the BSA programme is not using information systematically to support learning and continuous quality improvement. Information about how lead providers are engaging with consumers, listening and learning from consumers' lived experience, and examples of successful engagement models, is not visible. There is no systematic shared learning and continuous improvement across the programme.

'The current systems puts everything back on to individual women – you are responsible for finding information regarding eligibility and enrolling – this is wrong!'

There is a lack of effective shared learning coordinated by the NSU across lead providers, lead providers exist in silos and have very little visibility of what other providers are doing to improve services, sharing of information is not timely, and the NSU does not have a system-wide view of quality improvement skills and experience. The NSU states “the NSU have encouraged providers to replicate innovations but have been disappointed that these opportunities are not taken up”. Evidence of this “encouragement” was not apparent to the panel and clearly is not sufficient.

'The NSU should have oversight of the system, asking and knowing are standards being met equally across the country according to the NPQS. This is not happening. The current system is not finding that view across whole country, learning has not been passed on.'

The Te Whatu Ora and Te Aka Whai Ora structures bring an opportunity build a quality and safety learning system across the BSA programme. BSA clinical leaders with broad and diverse representation could engage with the Improvement and Innovation Directorate of Te Whatu Ora and equivalent expertise in Te Aka Whai Ora, to apply training and quality improvement methods, and develop and implement specific quality improvement programmes.

RECOMMENDATIONS

- Include in the design of a BSA co-governance model:
 - a review of the clinical governance model and co-design of different ways in which clinicians can be involved in the programme's governance
 - a review of the roles and responsibilities that reflect the principles of shared decision making and distributive leadership
 - a reset of relationships at all levels of the programme based on the principles of shared decision-making, partnership, co-design, and recognition and respect and a commitment to improvement
- Co-design and publish a comprehensive set of BSA programme policies with Māori co-governance partners, Pasifika, consumers, and other stakeholders that reflects te Tiriti obligations and a comprehensive commitment to Pasifika health equity. The set should include a BSA programme:
 - strategic plan
 - quality strategy and a quality action plan
 - quality standards
 - data monitoring framework
 - data monitoring and reporting plan
 - research plan
 - communication plan
- Review and redesign the BSA's external auditing programme to focus on what is most important, based on priority indicators.
- Co-design and implement a learning system that underpins a new governance structure. The learning system should include the systematic evaluation of best practice, a change of focus from targets to best practice models, systematic sharing of information and continuous improvement.

6. WĀHANGA TUAONO IDENTIFICATION AND REPORTING

Kaua e rangiruatia te
hāpai o te hoe;
e kore tō tātou waka e
ū ki uta

Do not lift the paddle out
of unison or our canoe will
never reach the shore

This section addresses the following questions:

- Do BSA providers have appropriate policies in place to appropriately communicate to impacted people if there are delays, or capacity constraints? Are these consistent with good practice?
- Has the 2DHB review been sufficiently robust to give confidence in the process and outcomes, and to give assurance that all reasonable steps have been taken to identify all impacted people?

Findings

- BSA providers have appropriate policies in place to communicate to impacted people if there are delays or capacity constraints. These are consistent with good practice but the pathways for implementation are not clear.
- Communication to impacted people if there are delays or capacity constraints is likely to be a wider, more systemic issue in the health system given the impact of COVID-19 and there should be a national approach to how to best communicate and provide open disclosure in this situation.
- The 2DHB review has been sufficiently robust to give confidence in the process and outcomes and to give assurance that all reasonable steps have been taken to identify all those people physically impacted by delays in being offered an initial screening. However, improvements have been identified, in particular timely communication with consumers about delays in access to services/treatment; and early engagement and participation of consumers in the adverse event review process.

Definition of impacted people

To answer the above questions, the panel firstly needs to determine the definition of “impacted people”. The panel has chosen to take a broad definition of impacted people to include all consumers who experienced a delay in being offered an initial mammogram appointment (not offered and appointment within the expected standard time) irrespective of the outcome. This contrasts with a narrower definition of impacted people being people who experienced a delay in being offered an appointment and subsequently suffered physical harm (subsequently received a diagnosis of breast cancer).

The expected standard waiting time for consumers newly enrolled in the screening programme to be offered a mammogram appointment is less than 60 working days as set out in the National Policy and Quality Standards (NPQS). Under the standard for timeliness (standard 3), the NPQS states:

3.1.1 “Target: ≥90% of eligible women, once enrolled, are offered an available appointment for a screening mammogram within 60 working days (fixed sites only)”.
[18 p28]

The panel has chosen to adopt a broad definition of ‘impacted’ primarily based on the strong, consistent voice of consumers interviewed for this review.

All the consumers interviewed, including consumers who experienced delays in relation to the 2DHB’s incidents, said they wanted to be (and would appreciate being), informed about long waiting times/ delays in access to services beyond the expected time or a reasonable time, along with the reasons for the delay (for example, capacity issues). They all said that they would like this information irrespective of whether they developed breast cancer or were otherwise physically harmed while awaiting an appointment. (The panel acknowledges it is not possible to generalise and conclude this is the view of all consumers). A consumer was reminded by her GP on a number of occasions that she hadn’t yet had her mammogram; the GP was unaware of the delays in getting an appointment.

Providing consumers who were waiting beyond the expected time with information about the delay, would have allowed them to consider other options, be informed about what to do if they developed breast symptoms, and would have been an opportunity for their GPs to be made aware of the delays so the GPs could appropriately support them.

It appears that the NSU, 2DHB and its lead provider, and the 2DHB adverse event review team, have taken a narrower, more technical approach, and considered impacted consumers to be those who have suffered physical harm (were not offered an appointment within the 60 working day target timeframe and who subsequently received a diagnosis of breast cancer). The relevance of this difference in interpretation of impacted consumers is that the panel considers not “all” consumers impacted as a result of the 2DHB waiting times have been communicated with appropriately. It is the panel’s view that all consumers who experienced a delay in receiving a mammogram beyond the expected standard time should have been informed about the delay in a ‘open, transparent, culturally appropriate and timely’ way (as soon as practical after the delay was identified).

The panel notes that communication and open disclosure about delays and capacity issues is a wider systemic issue within the health system due to impacts from COVID-19 and significant numbers waiting longer for diagnostic and screening services than expected. Therefore, there should be a national approach, inclusive of screening, to respond to people who are delayed for these services.

Policies in place to communicate to impacted consumers

The NSU has an Open Communication Policy for all its screening programmes, and two policies that complement the Open Communication Policy, the Adverse Event Management Policy and the Complaint Management Policy.[64-66] All three policies apply to the NSU and to service providers and contractors.

The Open Communication policy guides: when 'open disclosure' with consumers, their family and whānau is required, including in response to adverse events and complaints; the 'response actions and responsibilities' of NSU staff and screening providers; and how open communication will be conducted. The policy states that the NSU and providers are jointly responsible for ensuring "that all people who are part of the screening pathway receive high quality care where the risk of harm is minimised."

The Open Communication Policy is based on the NSU's commitment to "open, transparent, and timely communication with all consumers, their family and whānau". According to the policy open communication includes: the right to informed consent; the right to effective communication; the right to be fully informed; the right to complain; and the right to services of an appropriate standard.

The Open Communication policy is sound, applying a principle-based approach to open disclosure with all consumers, their family and whānau. The policy refers to research on best practice in an open disclosure process and states that best practice indicates that affected consumers value the following factors in the process:

- Acknowledgement, regret and empathy
- Information, early, repeated and progressive
- A care plan and discussion as to the extent of recovery from the harm event
- Prevention of recurrence – what has been learnt and how it will prevent the occurrence of a similar situation

The policy requires open disclosure in a number of cases, in particular whenever a consumer participating in a screening programme has suffered any harm, or has "been exposed to possible harm resulting from a system error (mistake) that affected a consumer's health outcome and may not be immediately apparent". Harm is not a prerequisite for open disclosure: the policy states "An open disclosure process is used when an adverse event or complaint identifies actual or possibility of harm. It's about ... Being timely & transparent. As soon as practical and can be before harm has been identified".

The principles of open disclosure set out in the policy include:

- Timely acknowledgement when actual or potential harm is identified must occur with the consumer and their support person as soon as possible
- Transparency so that open disclosure and the discussion on the event or complaint is conducted in a transparent and open manner with the consumer and participating staff
- Open communication with consumers, their families and whānau that is culturally appropriate

While the Open Communication Policy is sound in principle and reflects best practice it appears the three policies were not followed in the case of the 2DHB incidents. In July 2020 the 2DHB lead provider notified the NSU that "we are dealing with a high frequency of clients [consumers] waiting to be screened and have received a number of complaints of which many of them include new enrolments". It was not until 22 months later that public disclosure to impacted consumers occurred.

The notification of delays and the notification of complaints received by the 2DHB lead provider in July 2020, should have been recognised by both the lead provider and the NSU as an adverse event: it met the definition of an adverse event according to the NSU's Adverse Event policy³⁴ and, therefore, an investigation should have been initiated, and an open disclosure made to consumers "as soon as possible".

34 Adverse Event is defined as "An event with negative, unfavourable reactions or results that are unintended, unexpected, or unplanned." The policy further states "In practice this is most often understood as an event which results in harm or has the potential to result in harm to a consumer."

Disagreement on how to communicate with consumers

In July 2020 it appears that the NSU and the 2DHB lead provider could not agree on how to communicate with consumers. The 2DHB lead provider requested the NSU approve a letter it wanted to send to new enrollees to advise them about the longer waiting times for their first mammogram screen, and to let them know what to do if they had any breast problems. The NSU did not approve the proposed letter and the letter was not sent to consumers.

There are differing views on when the NSU needs to approve lead provider communications to consumers. All lead providers interviewed for this review understood that the NSU has to approve all their communication to consumers about the BSA programme; the NSU says this is not the case and the NSU only need to be notified (informed) on the basis of a 'no surprises' approach.

Both the adverse event policy and complaints policy suggest the NSU's approval is required: for an adverse event, the provider must inform the NSU of an adverse event (any SAC level) and the NSU "agrees an initial communication plan"; for a complaint, the lead provider prepares a communication plan, if required, with the NSU. None of the policies describe what needs to happen if the NSU and a lead provider do not agree with proposed communication to consumers.

The policies need to be clearer: they need to specify when the NSU needs to approve communication that a lead provider wishes to have with consumers and what happens if the NSU and lead provider do not agree with the proposed communication. The policies need to specify a pathway (process) for a rapid decision about what communication will be given to consumers (eg who will make this decision and within what time) to ensure there is no further delay in communicating with consumers.

Opportunities to recognise an adverse event

The panel notes that there were opportunities prior, and subsequent, to July 2020 for both the NSU and the 2DHB lead provider to recognise there was an adverse event, and therefore instigate an investigation and open disclosure.

Prior to July 2020, if the standard expected waiting time for a mammogram appointment for new enrollees had been monitored, the prolonged waiting times for the 2DHB lead provider could have been identified and consequently an adverse event recognised. The NSU learnt in 2021 by a retrospective review of data, that the prolonged waiting times at the 2DHB lead provider went back to 2018. This was not identified as an issue because the waiting time indicator (NPQS standard 3.1.1 [18]) was not being monitored as part of routine programme monitoring. The NSU states that the failure to monitor this indicator this was an oversight. The NSU has also noted that the prolonged waiting times were not identified as part of a 2021 external audit of the 2DHB Lead provider, which reported standard 3: timelines (including 3.1.1) was fully attained.

Subsequent to July 2020, there were several opportunities for the NSU and 2DHB lead provider to recognise an adverse event. In September 2020 the 2DHB lead provider notified the NSU, in its six-monthly monitoring report, that new enrollees were experiencing long waits due to capacity constraints and because it was prioritising rescreens: "Long waiting times for new enrols due to capacity issues and prioritising on rescreens to meet timeliness targets". And in a six monthly monitoring report submitted to the NSU in January 2021, the 2DHB lead provider again informed the NSU that long waiting times continued for newly enrolling consumers and that there had been limited progress on these waiting times. In May 2021 the NSU was notified by two consumers about "an extensive waiting time for a mammogram appointment at the 2DHB lead provider (2 years) from enrolment as reported by the two women." The NSU subsequently became aware of three further complaints from consumers affected by the delay in getting a mammogram appointment. These were all opportunities where, had the NSU's adverse event and complaint management policies been followed, timely open disclosure to the affected consumers would have occurred. Even when an adverse event was recognised by the NSU (in December 2021) and a formal investigation commenced (February 2022), timely open disclosure did not occur.

It appears the NSU and 2DHB lead provider were focused on identifying whether consumers who had been waiting beyond the 60 working days had been harmed (subsequently received a diagnosis of breast cancer), and they did not consider the need to inform consumers about the delays irrespective of whether physical harm had occurred.

Robustness of 2DHB review process

The panel considers the 2DHB review followed a robust process: the 2DHB engaged an external panel of experts to help identify individuals for whom the delay in receiving an initial mammogram appointment could potentially have affected their diagnosis or treatment for breast cancer. For all those identified as potentially having experienced harm (subsequently received a diagnosis of breast cancer), adverse event reviews were undertaken in accordance with the 2DHB's Adverse Event Management policy and the Health Quality & Safety Commission's National Adverse Events Reporting Policy.[67]

There are two areas the panel would like to comment on.

The first area concerns the issue of all consumers being informed about the delays (longer than expected waiting times), although the panel notes that this issue was likely deemed out of scope of the adverse event review process. As identified above, the review panel is of the view that all consumers who experienced a delay in being offered a mammogram appointment within the 60 working day target timeframes were impacted by the delays and should have been informed about the delays in a timely, open and culturally appropriate way. This is a national issue and therefore there should be a standard approach to communicating with consumers.

The second area concerns the issue of consumer involvement in the 2DHB's adverse event review process. This panel's view is that consumers should have been appointed as a member of the 2DHB external review team. The National Adverse Events Reporting Policy 2017[67] states under the principle of consumer participation that:

“Adverse events need to be considered within the context of the whole consumer and whānau experience of care. Including the consumer perspective in the review process enables a broader understanding of the circumstances surrounding an adverse event. It is expected that, at a minimum, consumers and whānau who have been involved in an adverse event will be offered the opportunity to share their story as part of the review process and that review findings and recommendations will be shared with them. Health and disability service providers should also consider involving independent consumer representatives in the review process.” [67 p3]

The appointment of a Māori and a Pasifika consumer to the 2DHB external review panel would have been consistent with best practice and enhanced the robustness of the review process.

This panel notes that the 2DHB's Serious Event Review Procedure does not refer to the recommendation to have independent consumer representatives involved in a review process although its intention is to be aligned with the national policy.

The panel also notes that the Health Quality & Safety Commission is currently undertaking a review of the National Adverse Events Reporting Policy and proposing to incorporate restorative practice and hohou te rongopai (peace-making from a te ao Māori view) principles and approaches as part of a new policy. Restorative practice approaches provide a framework for restoring wellbeing, relationships and trust through respectful dialogue, collaboration and consensus.³⁵ The panel acknowledges the advantages that restorative practice processes will bring to reviews of adverse events such as the 2DHB incidents.

35 See: Restorative practice | Health Quality & Safety Commission (hqsc.govt.nz)

RECOMMENDATIONS

- Develop a clear pathway to implement the NSU's Open Communication, Adverse Event Management and Complaint Management policies. The pathway should clearly specify:
 - when the NSU's approval for communication with consumers is required
 - what should happen if the NSU and a provider do not agree on the communication plan with consumers (who and in what timeframe will decide what is communicated)
- Provide updated training for all NSU and lead provider staff on the recognition and management of adverse events, and open communication. Training should include information about:
 - early recognition of adverse events
 - recognition of adverse events does not depend on identifying harm to consumers
 - open disclosure and communication with consumers and whānau, which should occur as soon as possible and be honest, transparent and culturally appropriate

7. WĀHANGA TUAWHITU IMPROVEMENT OPPORTUNITIES

Ka pai ki muri, ka pai ki
mua, ka pai ngā mea katoa

Everything works well
when the workers behind
the scenes and the workers
in front do their job well

This section addresses the following questions:

- What opportunities to work better as one system will Te Whatu Ora and Te Aka Whai Ora structures bring? How can these be maximised?
- Whether any changes to systems, policies and process are required to ensure appropriate BSA programme monitoring and quality, including equity and consumer/whānau voice, now and into the future, taking into account the development of the future IT system?

Opportunities to work as one system

- The review panel is mindful that the wider health system is grappling with the challenge of giving effect to te Tiriti and achieving ōritetanga (equity), particularly for Māori and Pasifika, and implementing the Code of expectations for health entities' engagement with consumers and whānau. [2] Similar issues were identified across the health sector by the Waitangi Tribunal in its report on stage one of its Health Services and Outcomes Inquiry (Wai 2575).[3] There are strong findings and recommendations in this report but they should not be taken out of this context. The shortcomings identified reflect health system wide issues that are longstanding. The health system reforms provide the opportunity for Te Whatu Ora in partnership with Te Aka Whai Ora to drive much needed reform across the entire health system.
- Opportunities to work better as one system with Te Whatu Ora and Te Aka Whai Ora structures include:
 - The imperative to focus on te Tiriti and ōritetanga (equity) provides the opportunity to develop a coordinated population-based approach to screening in Aotearoa New Zealand. Screening programmes should be redesigned into a 'single system' with improved linkages between data sets, a single national register, and coordination of recruitment, communication and advertising processes. This work should include the development and testing of holistic models of care, for example cancer screening with other diagnostic and preventive services for cardiovascular disease and diabetes. Te Aka Whai Ora and the Ministry of Health will have the ability to ensure appropriate co-design and governance over such a system and ensure it delivers equitable outcomes for Māori and Pasifika.

- The panel considers the Ministry of Health and Te Aka Whai Ora are appropriate agencies to undertake independent monitoring of the BSA programme. However, they must ensure they have the necessary systems in place to undertake this function. The form and function of the NSU should be reviewed and designed to ensure that it aligns with and supports the ‘one system’ approach, with the necessary skills for relationship building and management to successfully bring all parties along on the shared journey. This will enable the NSU to focus on working with providers as ‘one team’, supporting providers to provide high quality and safe services, rather than focusing on contractual performance. Te Aka Whai Ora will need a monitoring and performance framework over the BSA co-governance system.
- The recent publication of the Code of expectations for health entities’ engagement with consumers and whānau provides an opportunity to co-design an approach to consumer and whānau engagement in the BSA programme. This will address the imperative to engage with and involve consumers at all levels of the programme. The Innovation and Improvement Directorate of Te Whatu Ora and equivalent expertise in Te Aka Whai Ora, along with the Health Quality & Safety Commission, could be engaged to support the co-design approach.
- Te Whatu Ora and Te Aka Whai Ora structures bring an opportunity build a quality and safety learning system across the BSA programme. BSA clinical leaders with broad and diverse representation, could engage with the Innovation and Improvement Directorate of Te Whatu Ora and equivalent expertise in Te Aka Whai Ora, to apply training and quality improvement methods, and develop and implement specific quality improvement programmes.

‘For at least 10 years we’ve been told the breast screening computer programme is old and cannot be updated. This has reduced the process of thinking in a continuous quality Improvement mindset. People have learned no matter what idea they have, it mostly won’t happen and so why bother. New people come into their roles and ask ‘this is not intuitive, why don’t we do this?’, then after a few months in the role they realise nothing is going to change and they give up with their ideas and trying.’

- It is widely agreed that ICT systems for the BSA programme are in urgent need of renewal. This was recognised in the 2011 review of the BSA programme which then recommended urgent replacement. Replacement of new system is now underway. Findings from this review confirm and amplify the concerns identified in the 2011 review. There are multiple inefficiencies as well as opportunities for error, and corresponding benefits that will accrue from a new system if it is well designed with BSA staff and consumers. The ICT replacement project will benefit from close monitoring and support from Te Whatu Ora’s Data and Digital Directorate to ensure the project delivers a fit-for-purpose, modern screening ICT system.

Mā te hē ka tika

By learning from our mistakes
we create opportunities to
make things right

Changes to systems, policies and process:

RECOMMENDATIONS

SYSTEM LEVEL

1. Develop a comprehensive, coordinated population-based approach to all cancer screening services in Aotearoa New Zealand. This should include:
 - a. redesigning the screening programmes into a 'single system' with improved linkages between data sets, a national register, and coordination of recruitment, communication and advertising processes
 - b. review the form and function of the NSU
 - c. re-examining the objectives of the screening programmes
 - d. broaden the focus of the screening programmes to include wellbeing and hauora health gain for individuals, whānau and the community
 - e. a reset of relationships between the NSU, providers, and with Māori, Pasifika, consumers and communities
2. Develop a monitoring and performance framework over the NSU programmes' Tiriti responsive co-governance.
3. Monitor and support the BSA ICT replacement project to ensure the project delivers a fit-for-purpose, modern screening ICT system.

PUBLIC HEALTH DIRECTORATE – NSU LEVEL

Te Tiriti o Waitangi

4. Appoint a Pae Whakaterere comprising two to three suitably qualified people to oversee, guide and monitor the implementation of the BSA quality improvement review recommendations and co-governance model. The Pae Whakaterere will:
 - a. aim to ensure the recommendations from this review are implemented in a timely way including overseeing the development of a co-governance model
 - b. be a joint appointment by Te Whatu Ora and Te Aka Whai Ora for a two-year term, and report directly to the National Director, National Public Health Service, Te Whatu Ora
 - c. develop a business case and prioritised implementation plan to ensure the implementation of these recommendations are adequately resourced
 - d. arrange for an evaluation of the implementation of these recommendations prior to the end of its term
5. Establish an expert working group to support the Pae Whakaterere. Involve a wide group of Māori stakeholders including MMEG members, Hei Āhuru Mōwai, wāhine and whānau, and Māori screening and epidemiology experts.

6. Resource a wānanga for Māori stakeholders and partners to explore how best to establish a kaupapa Māori community of practice with a comprehensive range of skills and experience from which to enter governance arrangements with the NSU at all levels of the organisation.

Equity

7. Resource a Pasifika-led co-design process to develop a strategy and action plan to identify and address Pasifika priorities for breast cancer screening including Pasifika representation and participation at all levels of the programme.
8. Develop a national programme of work to rapidly increase participation in the BSA programme for wāhine Māori and Pasifika to at least 70%. This programme is to be evidence based and developed with Māori and Pasifika health experts and whānau.
9. Co-design Māori and Pasifika plans to formalise approaches to achieving equity. The plans will include kaupapa Māori, and Pasifika-designed travel assistance initiatives, and a review of the capacity and availability of mobile screening units with a view to communities having more control will be evidenced within an equity monitoring and reporting framework (eg, quarterly targets) and linked to funding.
10. Develop a Māori specific, and a Pasifika specific, COVID-19 and cancer screening response and recovery plan.

Monitoring, research and evaluation

11. Apply Māori data sovereignty principles to the NSU and BSA programme's data collection, analytics, monitoring and reporting frameworks.
12. Ensure that quality ethnicity data are collected and used to enable the BSA to make decisions based on the most accurate data possible. This means the HISO 10001:2017 Ethnicity Data Protocols need to be adhered to through all levels of the screening programme and incorporated into the standards, training, ethnicity data audits and quality improvement mechanisms.

13. Develop a monitoring and reporting framework for the BSA programme with Māori, Pasifika, consumers and service providers that includes:
 - a. governance for the framework
 - b. a clear rationale and process for selecting and prioritising monitoring indicators
 - c. a process for monitoring and publishing indicator results
 - d. an ongoing process for ensuring indicators remain relevant, are evidence-based and support quality improvement
 - e. consistent, regular and timely monitoring and reporting
 - f. ensuring that monitoring and reporting is transparent with all reports made publicly available in a timely manner
 - g. identifying where indicator monitoring and reporting work aligns with other agencies such as Te Aho o Te Kahu – Cancer Control Agency and the Breast Cancer Foundation, and how duplication of effort and resources will be avoided and collaboration enhanced
 - h. collecting, monitoring and reporting data, insights and evidence by ethnicity, disability, social deprivation, rurality and other known priority groups wherever possible
14. Monitor and continuously update the evidence-base for development of the programme and make this transparent with regular, timely publication.
15. Develop and implement a plan to fund research into improving screening pathways (eg, improved coverage, co-location of services, extending screening age, kaupapa Māori led screening centres, holistic care models) for wāhine Māori, Pasifika women, tangata whaikaha and consumers with lived experience of disability, other groups at increased risk of breast cancer death and also underserved by the screening programme; and report annually on progress.

Workforce

16. Develop and implement cultural safety and multi-level anti-racism workforce programmes and training for all staff in the BSA programme including lead providers.

17. Co-design and implement a dedicated recruitment and retention strategy, which includes training opportunities, and pathways to recruit and develop Māori staff, Pasifika staff and staff with lived experience of disability. This will require dedicated Māori health, Pasifika health, and equity positions to be created within the NSU and lead providers. Development of the Māori and Pasifika health workforce and Māori clinical leadership should be a priority.
18. Co-design a kaupapa Māori accreditation programme for breast screening providers.
22. Co-design and publish a comprehensive set of BSA programme policies with Māori co-governance partners, Pasifika, consumers, and other stakeholders that reflects te Tiriti obligations and a comprehensive commitment to Pasifika health equity. The set should include a BSA programme:
 - a. strategic plan
 - b. quality strategy and a quality action plan
 - c. quality standards
 - d. data monitoring framework
 - e. data monitoring and reporting plan
 - f. research plan
 - g. communication plan

Consumers

19. Set up a consumer and whānau panel to oversee the redesign of the BSA governance structure and provide advice on issues identified in this review (for example, inequities, barriers to access and participation, information for consumers and whānau, processes for recruiting consumers to participate in governance, communication of delays). Wāhine Māori and Pasifika women must have a strong voice on this panel.
20. Partner with the Health Quality & Safety Commission to develop a consumer and whānau engagement framework based on their Code of expectations for health entities' engagement with consumers and whānau, with an action plan for the next six months to implement the framework.
23. Review and redesign the BSA's external auditing programme to focus on what is most important, based on priority indicators.
24. Co-design and implement a learning system that underpins a new governance structure. The learning system should include the systematic evaluation of best practice, a change of focus from targets to best practice models, systematic sharing of information and continuous improvement.

Identification and reporting adverse events

21. Include in the design of a BSA co-governance model:
 - a. a review of the clinical governance model and co-design of different ways in which clinicians can be involved in the programme's governance
 - b. a review of the roles and responsibilities that reflect the principles of shared decision making and distributive leadership
 - c. a reset of relationships at all levels of the programme based on the principles of shared decision-making, partnership, co-design, and recognition and respect and a commitment to improvement
25. Develop a clear pathway to implement the NSU's Open Communication, Adverse Event Management and Complaint Management policies. The pathway should clearly specify:
 - a. when the NSU's approval for communication with consumers is required
 - b. what should happen if the NSU and a provider do not agree on the communication plan with consumers (who and in what timeframe will decide what is communicated)
26. Provide updated training for all NSU and lead provider staff on the recognition and management of adverse events, and open communication. Training should include information about:
 - a. early recognition of adverse events
 - b. recognition of adverse events does not depend on identifying harm to consumers
 - c. open disclosure and communication with consumers and whānau, which should occur as soon as possible and be honest, transparent and culturally appropriate.

KUPUTAKA: GLOSSARY

Glossary and abbreviations

KEY TERMS	ABBREVIATION	DEFINITION
2DHB review		A review undertaken by local DHBs to investigate screening delays in the Wellington region
Breast Cancer Aotearoa Coalition	BCAC	Non-government organisation providing a united voice and support for New Zealand women who have experience of breast cancer
Breast Cancer Foundation New Zealand	BCFNZ	Non-government organisation providing breast cancer awareness, education and research
BreastScreen Aotearoa New Zealand	BSA	The free national breast screening programme in New Zealand for eligible women aged 45–69 years
BreastScreen Aotearoa New Zealand Advisory Group	BSAAG	A group within the National Screening Unit consisting of representatives from each of the unidisciplinary groups, plus consumer presentation. Disestablished in 2022.
BreastScreen Central	BSC	The lead provider providing breast screening programme services to women residing in the wider Wellington region
Clinical Oversight Group	COG	The Clinical Oversight Group has decision-making authority for all clinical aspects of the BSA programme.
Co-design		Co-design is often used as an umbrella term for participatory, co-creation and open design processes. Key components of a co-design process should involve users and staff in designing solutions, and design decisions should only be made after feedback is gathered ³⁶
Consumer		Person(s) who have used the BSA services. Term has been used interchangeably with wāhine Māori depending on the focus of content.
District health board	DHB	The organisation responsible for providing and/or funding the provision of health services in their district prior to 1 July 2022. Replaced on 1 July 2022 by Te Whatu Ora – Health New Zealand
Eligible wāhine/women		BreastScreen Aotearoa New Zealand offers free mammography every two years to women who: <ul style="list-style-type: none"> ▪ are aged 45–69 years ▪ have not had mammography within the previous 12 months ▪ are not pregnant or breastfeeding ▪ are free from breast cancer ▪ are asymptomatic ▪ are eligible for public health services in New Zealand.
General practitioner	GP	Primary care physician
Hapū		Subtribe

36 Definition from Ko Awatea <https://koawatea.countiesmanukau.health.nz/co-design/> accessed 22 September 2022. See also HQSC learning module available at <https://www.hqsc.govt.nz/consumer-hub/engaging-consumers-and-whanau/co-design/> accessed 22 September 2022

KEY TERMS	ABBREVIATION	DEFINITION
Hauora		An holistic view of health and wellbeing in Te Ao Māori comprising taha tinana (physical well-being), taha hinengaro (mental and emotional well-being), taha whanau (social well-being), and taha wairua (spiritual well-being).
Information and communications technology	ICT	A diverse set of technological tools and resources used to transmit, store, create, share or exchange information
Hei Āhuru Mōwai Māori Cancer Leadership		National network of Māori cancer specialists who are committed to rangatiratanga in cancer control, the elimination of cancer inequities between Māori and non-Māori, and increasing hauora gains for whānau
Health Quality & Safety Commission	HQSC	The agency responsible for assisting health care providers (private and public) to improve service safety and quality and therefore health outcomes
Iho		Heart, essence, inner core, kernel, essential quality
Interval cancer		A cancer diagnosed between a negative screen and the time the next screen would have occurred
Iwi		Tribe
Kaupapa Māori		A Māori way of thinking, being and doing
Kaupapa partner		Stakeholder
Lead provider	LP	One of nine service providers that contract with the National Screening Unit to provide breast-screening services
LGBTQIA+	LGBTQIA+	LGBTQIA+ is an abbreviation for lesbian, gay, bisexual, transgender, queer or questioning, intersex, asexual, and more. These terms are used to describe a person's sexual orientation or gender identity.
Manaakitanga		Kindness, hosting, support, to look after
Māori Monitoring and Equity Group	MMEG	MMEG provides Māori governance to the National Screening Unit, "with critical focus on achieving equity across all screening programmes".
Mātauranga Māori		All forms of Māori knowledge systems
Ministry of Health	MoH	The public service department of New Zealand responsible for healthcare in New Zealand.
National Screening Unit	NSU	A unit within Te Whatu Ora responsible for the development, management and monitoring of six nationally organised population-based screening programmes in New Zealand, including breast cancer screening
National Policy and Quality Standards	NPQS	The policy and quality standards applicable to all providers of the BSA programme.[18]
Ōritetanga		Equity
Pae ora		Healthy futures
Pasifika		A reference to people with genealogical connections to islands within Melanesia, Polynesia, Micronesia, French Polynesia and all others throughout the Pacific Ocean who have chosen to live in Aotearoa New Zealand and identify Aotearoa New Zealand as their home base.

KEY TERMS	ABBREVIATION	DEFINITION
Pae Whakatere		Appointed experts who can lead, navigate, accelerate, mentor
Primary health organisation	PHO	PHOs provide essential primary health care services, mostly through general practices, to people who are enrolled with the PHO. PHOs are funded by Te Whatu Ora – Health New Zealand, which focuses on the health of their population.
Priority groups for screening		Groups identified as a priority for invitation, screening, rescreening and treatment within the BSA programme are: <ul style="list-style-type: none"> ▪ Māori women ▪ Pacific women ▪ unscreened women (women who have either never been screened or have not been screened for five years) ▪ under-screened women (groups of women whose participation is well below those of the total eligible population).
Patient reported experience/ patient reported experience measure	PRE/PREM	A measure of a patient’s perception of their personal experience of the healthcare they have received
Patient report outcome/ patient report outcome measure	PRO/PROM	Patient-reported outcome measures (PROMs) capture a person’s perception of their own health through questionnaires. Patients report on their quality of life, daily functioning, symptoms, and other aspects of their health and well-being to help hospitals and healthcare services provide the care that patients need and want.
Severity assessment score	SAC	A numerical rating which assesses the severity of a patient adverse event and determines the level of reporting required and the type of review to be undertaken for the event.
Tangata		Person
Tāngata		People
Tangata whaikaha		Māori with lived experience of disability
Te ao Māori		The Māori world
Te Whatu Ora – Health New Zealand		The organisation with responsibility for planning and commissioning hospital, primary and community health services in New Zealand from 1 July 2022.
Tino rangatiratanga		Self determination
Unidisciplinary group	UDG	Clinical network groups within BSA which provide clinical advice to the NSU on policy and operational matters affecting BSA as well as an information sharing forum
Wairua		Spiritual essence
Whakawhanaungatanga		Relationship building/relating well to others
Whānau		Family
Whānau ora		Family wellbeing/healthy families
World Health Organization	WHO	A specialized agency of the United Nations responsible for international public health.

TE TĀPIRITANGA TUATAHI: APPENDIX 1 TERMS OF REFERENCE

Terms of reference (FINAL June 2022)

Quality improvement review of clinical safety and quality for BreastScreen Aotearoa New Zealand

Purpose of the review

The purpose of this quality improvement review is to assess whether the arrangements for clinical safety and quality for the BreastScreen Aotearoa New Zealand (BSA) programme are fit for purpose to achieve the objective of the screening programme. This includes determining whether the arrangements have been operationalised equitably and effectively, and providing any recommendations for change or improvement.

Background and alignment

The impetus for the review is the identification that a large number of people in a particular region had been waiting longer than the 60 working day target from enrolment to offered appointment for mammography. For some people, this delay may have led to their cancer becoming more advanced by the time of diagnosis. This specific incident is already being separately investigated, following established processes, and includes independent review team members.

This assurance and quality improvement review of the BSA programme will provide additional information about system-wide aspects of this screening system, and recommendations for where systems can be improved.

Scope

The scope of the review includes the 2017–2022 period and will focus on the systems, processes, and procedures in place for ensuring the clinical safety and quality of the BSA Programme.

Key questions the review will address include:

Insights and analysis

1. What systems, policies, and processes (including monitoring, audit and clinical governance, clinical expertise and input) are in place to manage equity, consumer/whānau voice, clinical quality and safety across the BSA programme, and are they being operationalised effectively?
2. Are systems, policies and processes meeting the needs of Māori and Pasifika people who are enrolled in the programme?
3. Is there clarity about roles and responsibilities in relation to these systems, policies, and processes across the BSA programme?

Relationships and clinical decision-making

4. What arrangements are in place to manage relationships between the NSU and BSA Lead Provider Managers and Clinical Directors?
5. Are there any recommendations for improving these relationships and how the teams work together?

Delays in identification and reporting

6. Do BSA providers have appropriate policies in place to appropriately communicate to impacted people if there are delays, or capacity constraints? Are these consistent with good practice?
7. Has the 2DHB review been sufficiently robust to give confidence in the process and outcomes, and to give assurance that all reasonable steps have been taken to identify all impacted people?

Improvement opportunities

8. What opportunities to work better as one system will HNZ³⁷ and Māori Health Authority structures bring? How can these be maximised?
9. Whether any changes to systems, policies and process are required to ensure appropriate BSA programme monitoring and quality, including equity and consumer/whānau voice, now and into the future, taking into account the development of the future IT system?

Process

The reviewers will review relevant documentation, held by the Ministry of Health, National Screening Unit and DHBs relating to the Programme.

The reviewers may interview former and current Ministry and DHB staff and any other persons as required. This may include engagement with consumer groups and peak bodies, as decided by the reviewers.

In addition to the matters set out under the Purpose, the reviewers may provide advice on any other matters arising in the course of the review.

Exclusions

The review will not re-examine the evidence that supports the current BSA eligibility criteria.

The review will not include other screening programmes managed by the National Screening Unit.

The review will not include the audit or review of individual cases.

Review Group

The review will be led by an appropriately qualified review group, independent of the National Screening Unit. Review Group members will be appointed by, and accountable to, the Chief Executive of Health New Zealand. Members will bring the following expertise

- consumer lived experience
- clinical expertise specific to breast screening
- health service leadership and management
- equity.

Additional reviewer(s) with particular areas of expertise may be appointed to support the panel, as required, such as epidemiology.

Secretariat support

The interim National Public Health Service, within Health New Zealand, will provide expert secretariat support to the review team to ensure timely delivery of the findings. This will include:

- sourcing background materials and documents
- providing agendas and supporting materials for the review group's meetings
- support with analysis, including data analysis, and drafting the group's report and recommendations.

Deliverables

The review group will report to the Chief Executive, Health New Zealand. The group will produce a report that will address the key questions identified in these terms of reference and make recommendations for action as appropriate.

The reviewers will also include interim updates on progress as required to the interim lead, National Public Health Service and/or Chief Executive, Health New Zealand.

The Chief Executive, Health New Zealand will consider the findings of the review and based on this the National Screening Unit will develop an action plan for implementation.

Timeframes

The review group must report to the Chief Executive, Health New Zealand with a draft report provided by 5 September, and a final report provided by 14 October 2022.

Issues, conflicts and risk resolution

Issues and potential conflicts or risks will be identified and documented by review members and escalated to Health NZ as identified.

37 Now known as Te Whatu Ora (Health New Zealand) and Te Aka Whai Ora (Māori Health Authority)

PANEL MEMBER Biographies

Dr Dale Bramley (Chair)

Dale Bramley (Nga Puhī, Ngāti Hine and Whānau Apanui) is National Director, Service Improvement and Innovation, Te Whatu Ora. He is also Chair of the Health Quality & Safety Commission and was a Member of the Māori Expert Advisory Committee advising the Health and Disability Review Group.

He has medical qualifications from the University of Auckland (BHB, MBChB), a Master in Public Health (first MPH class honours) degree and a Master in Business Administration (MBA) degree from Henley, United Kingdom.

He is also a Fellow of the Australasian Faculty of Public Health Medicine and a Fellow of the New Zealand College of Public Health Medicine. A recipient of the international Harkness Fellowship, Dr Bramley has had over 50 papers published in peer reviewed medical journals. He has previously served on the National Health Committee and the National Ethics Committee.

Dr Nina Scott, public health physician

Nina Scott (Ngāpuhi, Ngāti Whātua, Waikato) is a Public Health Physician and Director of Māori Equity Strategy and Research at Te Whatu Ora – Waikato. She has worked with a range of organisations in governance, strategy, service delivery and research contexts to advance Māori health.

Nina has been involved in cancer screening, research and control for many years and is co-chair of Hei Āhuru Mōwai, the national Māori cancer leadership network. Over a decade ago, Nina worked for the National Screening Unit and led a quality improvement project for breast cancer treatment and was an inaugural member of the National Screening Unit Māori Advisory Group.

Dr Sally Urry

Sally is a radiologist living in Auckland. She is the clinical director of BreastScreen Counties Manukau (BSCM), the lead provider of breast screening services in the Counties Manukau region. She also works as a breast radiologist at Astra Radiology (previously Ascot Radiology).

Sally began working at Counties in 1985 as a general radiologist and subsequently developed a special interest in Breast Imaging. She started working with BreastScreen Auckland and North (BSAN) in late 1998, when BSA was established. She was a member of the working group (2004) that looked at the devolution of BSAN to what then became BreastScreen Waitematā and Northland, BSCM and BreastScreen Auckland Ltd. She started her role at BreastScreen Manukau in 2005 when Te Whatu Ora – Counties Manukau (then Counties Manakau DHB) was awarded the contract for the provision of breast screening services for the region. She worked with others establishing this service from the outset. She therefore has a strong knowledge and experience of BreastScreen Aotearoa New Zealand.

Sally held the clinical director role for the radiology department for Counties for 8 years (2009–2018), and currently works in clinical governance, clinical sessions in screening and diagnostic breast radiology.

Dr Christine Walsh – consumer experience

Chris has spent most of her working life in health. She trained initially as a psychiatric nurse before becoming a comprehensive trained nurse. Her undergraduate degree is in education, her Masters in applied social science research and her PhD in nursing.

After clinical nursing and teaching undergraduate nursing her career moved into nursing education at Victoria University, Wellington NZ, where she spent 12 years teaching post graduate nursing students. Much of this teaching was with mental health nurses where the importance of hearing multiple consumer voices guided her teaching and work.

Her consumer work became much more focused when a diagnosis of breast cancer in 2006 prompted an awareness of poorer treatment options and outcomes for NZ women who were diagnosed with breast cancer. As a result of her work around this in 2010 she was awarded a Member of the New Zealand Order of Merit in the New Year's honours for her contribution to women's health.

Until July 2022, Chris worked at the NZ Health Quality & Safety Commission where she was the director leading the consumer engagement programme. She has been instrumental in introducing and actioning the concept of co-design in the work the commission does within the health system. Her belief that consumers need to be 'sitting at the table at the time' to guide and inform service design and delivery has prompted a stronger focus on consumer engagement across services. This has now resulted in the development of a quality and safety marker for consumer engagement, a world first. Chris now does contract work in health, education and research.

TE TĀPIRITANGA TUARUA: APPENDIX 2 LIST OF INTERVIEWEES

Individuals

Tira Albert	Sonja Freese	Kathy Phillips
Gabrielle Baker	Moahuia Goza	Kezia Ralphs
Diana Balog	Maryanne Heather*	Ah-Leen Rayner
Barbara Beckford	Karen Holden	Papaarangi Reid
Sheila Beckers	Christina Kirkwood	Bridget Robson
Nina Bevin	Scott McWilliams	Kerry Sexton
Libby Burgess	Mandy Mackay	Fay Sowerby
Trevor Chan	Maria Marama	Adam Stewart
Stephanie Chapman	Christine Mouat	Gemma Sutherland
Jacquie Copland	Rachael Neumann	Gary Thompson
Pania Coote	Gabrielle Nicholson	Rachel Thomson
Olivia Flannigan	Jane O'Hallahan	Dougal Thorburn
John Fountain	Maree Pierce	Jenny Walker
Helen Framhein-Wong	Kathy Pritchard	Jo Wall
Susie Kite	Pua Tualapini	Madeleine Wall

*written response

Organisations consulted

Breast Cancer Aotearoa New Zealand Coalition
Breast Cancer Foundation New Zealand
BreastScreen Aotearoa New Zealand
Hei Āhuru Mōwai
Mana Wāhine
National Screening Unit
Te Aho o Te Kahu

2DHB Review External Panel and Review Team

Marcel Brew
Briar Coleman
Brian Cox
David Hamilton
David Moss
Zoe O'Riordan

TE TĀPIRITANGA TUATORU: APPENDIX 3 LIST OF DOCUMENTS REVIEWED

List of Documents Reviewed

1. Breast Screening for 45 to 69 Year Olds – Information pamphlet. BreastScreen Aotearoa New Zealand.
2. BreastScreen Aotearoa New Zealand Advisory Group and UDG Structure [Oversight Structure].
3. Terms of Reference of BreastScreen Aotearoa New Zealand Surgeons' Unidisciplinary Group.
4. Terms of Reference of BreastScreen Aotearoa New Zealand Pathologists' Unidisciplinary Group.
5. Terms of Reference of BreastScreen Aotearoa New Zealand Medical Physicists' Unidisciplinary Group.
6. Terms of Reference of BreastScreen Aotearoa New Zealand Lead Provider Managers' Group.
7. Terms of Reference of BreastScreen Aotearoa New Zealand Clinical Directors' Unidisciplinary Group.
8. Terms of Reference of BreastScreen Aotearoa New Zealand Breast Care Nurses' and Treatment Data Collectors' Unidisciplinary Group.
9. Terms of Reference of BreastScreen Aotearoa New Zealand Advisory Group.
10. BreastScreen Aotearoa New Zealand Management Narrative report BreastScreen Counties Manukau 1 Jan 2021 – 30 June 2021.
11. BreastScreen Aotearoa New Zealand National Breast Screening Services Revised reporting template for 6 monthly reporting due 31 August 2020.
12. [Provider] Equity and Improvement Plan 2021 template.
13. BreastScreen Aotearoa New Zealand Management staffing report template.
14. BreastScreen Aotearoa New Zealand Management Narrative report template.
15. Lead Providers Agenda Unidisciplinary Group Agenda Monday 4 July 2022.
16. BSA Workplan 2022–23.
17. BSA Monitoring and Evaluation Plan. Reporting Status.
18. Feedback form on time to screen.
19. Terms of Reference of BreastScreen Aotearoa New Zealand Medical Radiation Technologists' Unidisciplinary Group.
20. Time between Enrolment date and 1st Appointment date – BSC and Lead Providers without BSC. In: National Screening Unit, editor.
21. Tracing the journey: Understanding and improving the experience of Māori women in the BreastScreen Aotearoa New Zealand screening pathway August 2017. 2017 August 2017.
22. Terms of Reference MĀORI MONITORING AND EQUITY GROUP to National Screening Unit. 2018.
23. Terms of Reference Breast Screening Clinical Oversight Group December 2018. 2018.
24. BSA – 2022 Calendar of Events. 2022.
25. BSA – 2021 Calendar of Events. 2021.
26. BSA – 2020 Calendar of Events. 2020.
27. BSA – 2023 Calendar of Events. 2022.
28. BSA – 2018 Calendar of Events. 2018.
29. BSA – 2017 Calendar of Events. 2017.
30. BSA – 2019 Calendar of Events. 2019.
31. Lead Provider clinical strengths and weaknesses: BreastScreen Counties Manukau DRAFT 5 November 2020. 2020.
32. Memo to Deborah Woodley DDG Population Health from Jane O'Hallahan, Clinical Director, National Screening Unit re staffing 20 May 2020. 2020.
33. Lead Provider Strengths and Weakness Comparative Report 25 November 2020. National Screening Unit 2020.
34. Guidance to BreastScreen Aotearoa New Zealand providers for re-commencing breast screening when out of Government COVID Alert Level 4 20 April 2020. Ministry of Health; 2020.

35. COVID 19 National Hospital Response Framework The Process 22 March 2020. Ministry of Health; 2020. Report No.: Version 1.0.
36. Guidance to BreastScreen Aotearoa New Zealand providers for breast screening at various Government COVID Alert Levels 14 August 2020. Ministry of Health; 2020.
37. Guidance to BreastScreen Aotearoa New Zealand providers for breast screening at various Government COVID Alert Levels 14 August 2020. Ministry of Health; 2020.
38. Guidance to BreastScreen Aotearoa New Zealand providers for breast screening at various Government COVID Alert Levels 17 December 2020. Ministry of Health; 2020.
39. BSA breast screening prioritisation for Lead Providers post-COVID 19 December 2020. 2020.
40. Lead Provider clinical strengths and weaknesses: BreastScreen Coast to Coast (BSCC) DRAFT 5 November 2020. 2020.
41. Lead Provider clinical strengths and weaknesses: BreastScreen South Limited DRAFT 5 November 2020. 2020.
42. Lead Provider clinical strengths and weaknesses: BreastScreen Otago Southland DRAFT 24 September 2020. 2020.
43. Lead Provider clinical strengths and weaknesses: BreastScreen Midlands DRAFT 8 September 2020. 2020.
44. Lead Provider clinical strengths and weaknesses: BreastScreen Waitemata Northland DRAFT 24 September 2020. 2020.
45. Lead Provider clinical strengths and weaknesses: BreastScreen Waitemata Northland DRAFT 24 September 2020. 2020.
46. Lead Provider clinical strengths and weaknesses: BreastScreen Central DRAFT 4 November 2020. 2020.
47. BSA breast screening prioritisation post-Covid-19. 8 June 2021. 2021.
48. Guidance to BreastScreen Aotearoa New Zealand providers for breast screening at various Government COVID Alert Levels 16 June 2021. 2021.
49. Written complaint re appointment delay with BreastScreen Central October 2021. 2021.
50. Memo to Breast Clinical and Oversight Group (COG) from Pam Hewlett, Senior Portfolio Manager, National Screening Unit re BreastScreen Lead Providers Quality Assurance Audit Programme 21 July 2021. 2021.
51. NSU Auditing Handbook Part One: General and audit programme requirements For National Screening Unit programmes February 2021. 2021.
52. Preparing for a BreastScreen Aotearoa New Zealand National Screening Programme Audit May 2021. DAA Group; 2021.
53. Wait Times | BreastScreen Central Summary of Meeting 13 December 2021. 2021.
54. BreastScreen Central Production plan presentation 19 December 2021. 2021.
55. BreastScreen Central New Enrols with No Appointment Waiting Times (Production plan presentation) 15 October 2021. 2021.
56. Guidance to BreastScreen Aotearoa New Zealand providers for breast screening at various Government COVID Alert Levels 19 August 2021. Ministry of Health; 2021.
57. BreastScreen Central Adverse Event Indicative Timeline as of 23 May 2022. 2022.
58. BSA Programme clinical safety and quality – Kathy Phillips response August 2022. 2022.
59. NSU summarised feedback on Terms of Reference for BSA Review Panel 29 August 2022. 2022.
60. NSU response to panel questions 11 July 2022. 2022.
61. National Screening Unit. DRAFT: BreastScreen Aotearoa New Zealand (BSA) provisional data based on draft monitoring specification for indicator – time from enrolment to first offer of screening mammogram. 2022.
62. General review report v4 for SERC (draft BSC incident report). 2 September 2022. 2022.
63. BreastScreen Central and MOH minutes 24 March 2022.
64. BreastScreen Central Adverse Event Indicative Timeline as of 16 June 2022. 2022.
65. COVID-19 Breast Screening COVID Response Framework February 2022
66. Aotearoa New Zealand HÄMMCL. Position Statement on Breast Cancer Screening 20 May 2022.
67. Baker G, Talamaivao N. Te Tiriti o Waitangi, (Co-) Governance and the National Screening Unit. Report to Te Tiriti Governance Partnership Model Project, Reference Group (revised May 2022). 2022.
68. Breast Screen Aotearoa New Zealand. BSA Programme Sustainability: Critical Infrastructure Replacement 11 March 2022. Business Case. 2022. Report No.: FINAL.

69. Breastscreen Central. Breast Screening Central Review – interim communications plan for Capital & Coast and Hutt Valley DHBs and interim Health NZ/Ministry of Health 19 May 2022. 2022.
70. Cox J. BreastScreen Aotearoa New Zealand Handbook November 2020 (for internal team use) 13 November 2020. Ministry of Health; 2020. Report No.: Version 0.1 Final draft.
71. Fernhill Solutions Ltd. BreastScreen Aotearoa New Zealand Workforce Development Strategy 2022 – 2032 DRAFT. Interim Health New Zealand.
72. Fernhill Solutions Ltd. BreastScreen Aotearoa New Zealand Workforce Development Strategy 2022 – 2032 Part 2 – Action Plan. Te Whatu Ora.
73. Fernhill Solutions Ltd. BreastScreen Aotearoa New Zealand Workforce Development Strategy 2022 – 2032 Part 1 – Evidence for Change. Te Whatu Ora.
74. Hei Āhuru Mōwai, M.C.L.A., Position Statement on Breast Cancer Screening. Wāhine Māori te tuatahi – Māori women first. 20 May 2022. 2022.
75. Innovation Unit. Co-design and Social Innovation capability building for equitable breast and cervical screening Guidelines, Recommendations & Summary Report RAFT v2. National Screening Unit, Ministry of Health; 2021 November 2021.
76. National Screening Unit. Clinical Team Workplan detailed 2021–2022.
77. National Screening Unit. COVID-19 equity response framework for cancer screening programmes – DRAFT v0.2_15 May 2020.
78. National Screening Unit. Improving Quality: A Framework for Screening Programmes in New Zealand. Wellington: Ministry of Health; 2005.
79. National Screening Unit. National Screening Unit Strategic Plan 2010 to 2015. June 2010. Wellington: Ministry of Health; 2010.
80. National Screening Unit. BreastScreen Aotearoa New Zealand Data Management Manual March 2010. National Screening Unit; 2010. Report No.: Version 4.0.
81. National Screening Unit. BreastScreen Aotearoa New Zealand National Policy and Quality Standards 2013. Revised September 2020. Ministry of Health; 2013.
82. National Screening Unit. National Screening Unit Quality Framework. In: Unit NS, editor. Wellington: Ministry of Health; 2015.
83. National Screening Unit. Interval cancers in BreastScreen Aotearoa New Zealand 2008–2009. 2018.
84. National Screening Unit. Impact analysis: Extending BreastScreen Aotearoa New Zealand to include women aged 70–74 years. 2019 May 2019.
85. National Screening Unit. BreastScreen Aotearoa New Zealand COVID-19 impact and recovery advisory group – Terms of Reference [Final ToR BSA Covid Advisory ratified 7 July 2020]. 2020.
86. National Screening Unit. Terms of Reference Breast Screen Aotearoa New Zealand COVID-19 impact and recovery advisory group DRAFT. 2020.
87. Penno O. Review of screening programmes. A precis of previous screening reviews – national and international. Interim Health New Zealand; 2022.
88. Quality Manager. NSU Complaint Management Policy. In: National Screening Unit, editor. National Screening Unit Policy Framework.
89. Robson B, Ellison-Loschmann L, Jeffreys M, McKenzie F. BreastScreen Aotearoa New Zealand Monitoring Report for women screened between 1 July 2018 and 30 June 2020 DRAFT. 2022.
90. Robson B, Stanley J. BreastScreen Aotearoa New Zealand Programme Monitoring Report For Māori, Pacific and Total women screened during the two or four years to June 2016. National Screening Unit, Ministry of Health; 2017 June 2017.
91. Sense Partners. Breast screening projections 2023–2038 Demand and capacity under different scenarios DRAFT Report. 30 May 2022. 2022.
92. Shea S, Cragg M, Ioane J, Atkinson M, McGregor S. Me aro ki te hā o Hineahuone – a national evaluation of breast and cervical screening support services. Auckland: Shea Pita & Associates Ltd; 2021.
93. Stewart A. BreastScreen Aotearoa New Zealand six-monthly monitoring report 31 Dec 2020. 20 August 2022. 2022.
94. Stewart A. BSA MINI IMR REPORT June 2021. 2022.
95. Thorburn D. National Screening Unit Advisory Groups Principles, Values, and Processes. A kōrero towards a common understanding.
96. Wall J. BreastScreen Aotearoa New Zealand Wait time from enrolment to offer of first appointment for screening mammogram Provisional data for BSA COG meeting 15 July 2021. 2021.

TE TĀPIRITANGA TUAWHĀ: APPENDIX 4 PEER REVIEWERS

REVIEWER	ROLE(S)/AFFILIATION(S)
Libby Burgess MNZM	Chair Breast Cancer Aotearoa Coalition, Patient representative on the Breast Special Interest Group of NZ cancer specialists, Affiliate member of Breast Cancer Trials (Australia and New Zealand), Member of Te Aho o Te Kahu (Cancer Control Agency) Consumer Reference Group He Ara Tangata
Ian Campbell ONZM	Professor, Waikato Clinical Campus Department of Surgery, Faculty of Health Sciences, University of Auckland Breast and General Surgeon
Prof Gregor Coster	Emeritus Professor Gregor Coster CNZM, PhD, FRNZCGP Te Wāhanga Tātai Hauora Wellington Faculty of Health Te Herenga Waka Victoria University of Wellington
Dr Corina Grey	Public Health Physician and Epidemiologist Chief Clinical Advisor Pacific Health Public Health Agency, Manatū Hauora
Dr Julia Peters	Public Health Physician/Medical Officer of Health Auckland Regional Public Health Service Ratonga Hauora-ā-lwi ō Tāmaki Makaurau Te Whatu Ora
Fay Sowerby	Chair Breast Cancer Cure Secretary and Committee Member Breast Cancer Aotearoa Coalition Consumer Representative Breast Special Interest Group Affiliate Breast Cancer Trials (Australia and New Zealand) Working Group Member, Te Aho o Te Kahu National Breast Quality Performance Indicator Working Group Steering Committee Member, Enhancing New Zealand's Clinical Trial Infrastructure, Ministry of Health and Health Research Council
Dr Madeleine Wall (Te Rarawa, Te Aupouri and Ngati Maru descent)	Clinical Director BreastScreen Central Regional Screening Service Capital, Coast, Hutt Valley and Wairarapa
Dr Jenny Walker	Clinical Director BreastScreen Auckland Central, Waitematā
Dr Pete Watson	Te Whatu Ora Interim National Director – Medical and Interim District Director – Counties Manukau
Dr Janice Wilson	Chief executive Tumuaki Health Quality & Safety Commission

TE TĀPIRITANGA TUARIMA: APPENDIX 5 MEMBERSHIP OF MĀORI MONITORING AND EQUITY GROUP (MMEG)

Pania Coote (Ngāi Tahu, Ngāti Kauwhata, Ngāti Raukawa)

Pania is the chair of MMEG, she has extensive experience in both leadership and governance positions. Pania is an independent contractor working in the areas of Māori health/wellbeing, strategy and evaluation, with over 20 years' work experience in the health sector, she has contributed to screening programmes for many years with a strong focus on achieving equitable health outcomes for Māori. Pania holds a Master's degree in Social Welfare and Community Development.

Tira Albert (Nō Te Whānau-A-Apanui, Ngāti Rahiri Ki Hauraki me Te Waipounamu)

Tira is the Kaiwhakahaere for Mana Wāhine collective and Te Mauri – Whakamana Māori Whānau with cancer. Tira has extensive experience in Māori health promotion, working towards equity in breast and cervical screening programmes and providing Māori specific cancer support services. Tira is the Chair for the National Cervical Cancer Screening Programme (NCSP) Advisory and Action group, a member of groups including the Māori Monitoring and Equity Group, the NCSP Media Campaign and Resources Advisory Group, and Hei Āhuru Mōwai – Māori Cancer Leadership Aotearoa New Zealand, and a Board member of Takiri Mai Te Ata – Whānau Ora Collective ki te Ūpoko o te Ika and Cancer Society Wellington division.

Gary Thompson (Ngāti Pāoa and Ngāti Hauā iwi, Ngāti Werewere hapū)

Gary has over 20 years of Māori Health gain experience beginning at Te Whatu Ora Waitematā (previously known as Waitematā DHB) followed by two regional roles across the four Northern DHBs and five Midland DHBs. Together with several colleagues, Gary helped establish Hei Āhuru Mōwai, Māori Cancer Leadership Aotearoa New Zealand and is currently a Co-chair. Gary is a long serving member of the Māori Monitoring and Equity Group (MMEG) and is hugely encouraged by the work currently being done by the NSU and MMEG to embed te Tiriti o Waitangi across the screening unit.

Gary is employed as the Kaiwhakarite for Community Waikato. The role is dedicated to providing capability and capacity building programmes, facilitation, and advice to whānau, hapū and iwi organisations across the greater Tainui waka region. He works closely with Marae Trustees, Ahu Whenua land trusts and with Iwi development initiatives.

Gary is the chair of the Taumata Hauora, Advisory Group to Pinnacle Incorporated and is a Trustee of the Midland Regional Health Network Charitable Trust. Gary is an iwi representative on the Manawhenua Forum and an elected Councillor to the Matamata Piako District Council.

When time allows, Gary is a servant of his marae, Waiti, Kai-a-te-mata and Rukumoana.

Rachel Brown (Ngāti Mutunga ki Wharekauri, Kāi Tahu, Tuahiwi and Kāti Māmoe)

Dr Brown is Chief Executive of the National Hauora Coalition (NHC). Dr Brown has previously worked at the Ministry of Health, Oranga Tamariki, and across three universities and district health boards, iwi and community. Dr Brown holds a PhD in Health Science and a Master's in Health Promotion – Māori Health.

Boyd Broughton (Te Rarawa, Ngāpuhi, Tainui, Ngāti Porou)

Director of Health at Te Rūnanga o Ngāti Whātua.

Amy Hina (Nga Wairiki/Ngati Apa)

Mātanga Tapuhi – Nurse Practitioner with a Master's in Nursing. Amy has extensive experience in Primary Care both urban and rural setting having worked predominantly in an iwi lead organisation over her career and now works for local PHO to support and improve population health and screening. Amy's primary focus is on preventative measures including cervical smears, cancer screening programmes in primary care, immunisations and Māori health across the Whanganui/Rangitikei/Ngati Rangi rohe. Her Māori/European whakapapa allows her to walk in both worlds setting goals to achieve equity and working towards a workforce that can close the equity gap. Her clinical expertise and working the frontline with whānau and communities provides another lens on screening for Aotearoa New Zealand.

TE TĀPIRITANGA TUAONO: APPENDIX 6 ROLES AND RESPONSIBILITIES OF CURRENT NSU GOVERNANCE GROUPS

National governance of the National Screening Unit (all screening programmes) through the:

- National Screening Advisory Committee (NSAC) – provides high level strategic governance and leadership, particularly concerning evidence for new national screening programmes. NSAC has an external chair and NSU provides secretariat support
- Māori Monitoring and Equity Group (MMEG) – provides Māori governance, “with critical focus on achieving equity across all screening programmes”

BSA Programme – level governance:

- BSA Advisory Group (BSAAG) – recently re-established with a new purpose and membership. Historically BSAAG had an important role in monitoring of the programme; it provided feedback on the BSA Annual Monitoring Report, and it endorsed all changes to the BSA National Policy and Quality Standards (NPQS).
- Unidisciplinary Groups (UDGs)– membership includes sector experts from different disciplines within the BSA programme eg BSA lead provider managers, clinical directors, data managers, breast care nurses, medical radiation technologists, medical physicists. The lead provider UDGs are chaired by the NSU BSA team; the Clinical Director UDG is chaired by one of the clinical directors.

Internal to NSU:

- BSA Clinical Oversight Group fortnightly meeting to look at clinical risk issues. This group includes members from NSU Clinicians Screening, BSA Operations Team and data team.
- BSA Leadership Group Meeting (monthly – no formal minutes).

TE TĀPIRITANGA TUAWHITU: APPENDIX 7 BREASTSCREEN AOTEAROA MONITORING REPORTS

Table 3. BreastScreen Aotearoa monitoring reports: summary of monitoring and evaluation national indicator reports commissioned or produced by the National Screening Unit

REPORT	PURPOSE	LATEST VERSION	NOTES
Annual monitoring report	<p>Monitors an agreed set of 42 programme indicators and targets and displays trends over time.</p> <p>Monitoring of BSA programme equity, quality, and regional differences.</p>	<p><i>BreastScreen Aotearoa New Zealand Programme Monitoring Report For Maori, Pacific and Total women screened during the two or four years to June 2016 published 26 June 2017</i>[31]</p> <p><i>BreastScreen Aotearoa New Zealand Monitoring Report for women screened between 1 July 2018 and 30 June 2020</i> May 2022 (not yet published)</p>	<p>Descriptive epidemiology is stratified by prioritised ethnicity, age and BSA lead provider</p> <p>Contracted to Associate Professor Bridget Robson Associate Dean Māori, Te Rōpū Rangahau Hauora a Eru Pōmare/Eru Pōmare Māori Health Research Centre, University of Otago, Wellington.</p>
Six monthly monitoring report	<p>Provides timely reporting of key clinical BSA monitoring indicators.</p> <p>Monitors coverage, two measures of the quality of screening and assessment (assessment rate and positive predictive value) and five measures of early detection of cancer.</p>	<p><i>BreastScreen Aotearoa New Zealand six-monthly monitoring report 31 December 2020</i> e-mailed to lead providers on 29 October 2021</p> <p><i>BreastScreen Aotearoa New Zealand six-monthly monitoring report 30 June 2021</i> e-mailed to lead providers on 5 August 2022</p>	<p>Report prepared by NSU staff for a subset of key indicators that were agreed by the BSA Programme LPs and clinical directors.</p>
Treatment Indicator Audit report	<p>Compares treatment of breast cancer patients referred from BreastScreen Aotearoa New Zealand to those referred from other sources.</p>	<p><i>BreastSurgANZ Quality Audit Report on early and locally advanced breast cancers diagnosed in New Zealand patients in 2016</i> [68] published December 2018</p>	<p>Report previously produced by Royal Australia and NZ College of Surgeons.</p> <p>The Breast Cancer Foundation has been commissioned to develop the 2020 and 2021 treatment outcomes report using their registry data.</p>

REPORT	PURPOSE	LATEST VERSION	NOTES
Interval Cancers Reports	Monitor the effectiveness of a breast cancer screening programme.	<i>Interval cancers in BreastScreen Aotearoa New Zealand 2008–2009</i> published February 2018[61]	A further report is in draft and covers the period 2010 to 2017
Coverage and COVID-19 monitoring reports	Monitoring coverage and the impact of the COVID-19 pandemic on BreastScreen Aotearoa New Zealand. Coverage, numbers needed to screen to reach equity, numbers needed to screen to reach target, and estimates of the impact of COVID-19 on coverage.	BreastScreen Aotearoa New Zealand interactive coverage data tool : https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/ Latest coverage data available for period ending June 2022. Last updated 18 August 2022 with data extracted on 22 August 2022.	Data is updated and published quarterly. COVID-19 impact monitoring added in August 2022.
Programme Evaluation – BSA Mortality Evaluation	Assessment of the impact of New Zealand’s breast screening programme from 1999 to 2011 on breast cancer mortality.	A summary of the BreastScreen Aotearoa New Zealand Mortality Evaluation 1999–2011[16] Cohort and Case Control Analyses of Breast Cancer Mortality: BreastScreen Aotearoa New Zealand 1999–2011[69] published December, 2015	

Table 4. Provider clinician performance monitoring in the BreastScreen Aotearoa programme

REPORT	REPORTING COVERS	REPORT FREQUENCY
BreastScreen Aotearoa New Zealand Management Narrative report	<ul style="list-style-type: none"> ▪ Unresolved issues from previous period and emergent Issues ▪ Indicators (including BSA NPQS indicators) where performance is below target ▪ Results of internal audits/reviews where issues have been identified ▪ Summary of requests or complaints received ▪ Comment on service delivery including workforce ▪ Service configuration (annual report due 31 July) ▪ Opening hours, current scheduled mobile and fixed site screening locations, number of mammography machines (# per fixed site) 	Report due six monthly on 31 July and 31 January.
BreastScreen Aotearoa New Zealand Management staffing report	<ul style="list-style-type: none"> ▪ Budgeted and actual FTE for mandatory and other leadership roles, clinical and admin roles and fulfilment of accreditation and registration requirements where applicable ▪ All subcontracting arrangements and sites with the lead provider's region. 	Report due annually with other reporting due 31 July.
Provider Equity and Improvement Plan template	<ul style="list-style-type: none"> ▪ Overview of current performance ▪ Current Māori and Pacific Health Workforce ▪ Reporting against measures of coverage and rescreening rates for Māori and Pacific and priority groups to achieve equity ▪ Additional provider specific equity activity/ measures ▪ Stakeholder engagement ▪ Other information 	<p>A new report introduced in 2021 to support the goal of achieving equity and improved Provider performance for priority group wāhine.</p> <p>The Equity and Improvement plan first draft was due 1 November 2021, each year thereafter it will be due by April.</p>
Financial report	<ul style="list-style-type: none"> ▪ Expenditure against budget using NSU financial reporting template 	Full report due 31 July each year. Expenditure against budget using NSU financial reporting template due 31 January
Regional coordination plan	<ul style="list-style-type: none"> ▪ Exception reporting to identify issues or challenges providers are experiencing on delivering on activities in the regional coordination plan 	Six monthly with other reporting.

TE TĀPIRITANGA TUAWARU: APPENDIX 8 RECOMMENDATIONS FROM MĀORI GP INTERVIEWS

1. Increased flexibility within the BSA booking system

This is two-fold. GPs would like to be able to refer women directly into the booking system (or be able to refer for mammography via their PHO referral system) and would like greater leeway with interval times. This is particularly important in rural areas where a woman's interval time may not match with the mobile being in the area

2. Surveillance screening for high-risk women should be part of the BSA programme

3. Greater visibility of the BSA programme in areas or events which high priority women attend/ take all opportunities to screen women and giving communities financial incentives for reaching a certain target

4. Improved governance and follow up processes where women have multiple screenings done at once to ensure abnormal results are followed up and acted upon appropriately

5. Audit of who currently receives and who should be receiving annual breast screening. If GPs are expected to do this, BSA needs to provide financial incentives

6. Increasing the number of mobile units and reviewing their capacity and availability. Provide rural Māori communities with more control over mobile units – letting the communities decide where they should be and when

7. Review of the travel assistance criteria to include screening appointments as eligible for financial assistance

8. Review of how BSA communicates with women and how women would like to be communicated with – limit communications by mail and increase social media, texts and email, and ensure no cost on the women.

9. Improve connections and communication with Primary Care, for example GPs would like to be informed of long delays, system capacity and where/when mobiles will be in their area

REFERENCES

1. Te Whatu Ora – Health New Zealand, Capital, Coast & Hutt Valley BreastScreen Central General Review Report. Draft 2022.
2. Health Quality & Safety Commission, Te tikanga mō te mahi tahi a ngā hinonga hauora ki ngā kiritaki me ngā whānau Code of expectations for health entities' engagement with consumers and whānau 2022: <https://www.hqsc.govt.nz/consumer-hub/engaging-consumers-and-whanau/code-of-expectations-for-health-entities-engagement-with-consumers-and-whanau/>.
3. Waitangi Tribunal, HAUORA Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry. 2019, Waitangi Tribunal Report.
4. Gillis, D., People and Culture in the National Screening Unit: Moving Forward, in Review of the BreastScreen Aotearoa Program. 2011, CAMRYD Management Consulting.
5. Muller, J., Review of the BreastScreen Aotearoa Program – Report 1 | National Screening Unit: Future Directions for the National Screening Unit. Working in Partnership with Lead Providers for a Sustainable Quality Program. 2011.
6. National Screening Unit, National Screening Unit Quality Framework. 2015, Ministry of Health: Wellington.
7. Sense Partners, Breast screening projections 2023-2038 Demand and capacity under different scenarios DRAFT Report. 30 May 2022. 2022. p. 14.
8. Elwood, M., Epidemiological aspects of breast cancer screening relevant to Aotearoa New Zealand. 2022.
9. Health Quality & Safety Commission, Clinical Governance – guidance for health and disability providers. 2017.
10. Ministry of Health, Interim Government Policy Statement on Health 2022-2024. 2022.
11. Ministry of Health, HISO 10001:2017 Ethnicity Data Protocols. 2017, Ministry of Health.
12. Kim, A., et al., Patient-reported outcomes associated with cancer screening: a systematic review. BMC Cancer, 2022. 22(1): p. 223.
13. Te Whatu Ora, National Cervical Screening Programme Incidence and Mortality Report 2018 to 2019. August 2022, Te Whatu Ora – Health New Zealand: Wellington.
14. World Health Organization. Regional Office for Europe, Screening programmes: a short guide. Increase effectiveness, maximize benefits and minimize harm. 2020, Copenhagen: World Health Organization. Regional Office for Europe.
15. Ministry of Health, Impact analysis: Extending BreastScreen Aotearoa to include women aged 70-74 years. 2019: Wellington.
16. Ministry of Health, Summary of the BreastScreen Aotearoa Mortality Evaluation 1999–2011. 2015, Ministry of Health: Wellington.
17. Shea, S., et al., Me aro ki te hā o Hineahuone – a national evaluation of breast and cervical Screening Support Services. 2021, Shea Pita & Associates Ltd: Auckland.
18. National Screening Unit, BreastScreen Aotearoa National Policy and Quality Standards Revised September 2020. 2013, Ministry of Health.
19. Breast Screen Aotearoa, BSA Programme Sustainability: Critical Infrastructure Replacement 11 March 2022. 2022.
20. Irurzun-Lopez, M., M. Jeffreys, and J. Cumming, The enrolment gap: who is not enrolling with primary health organizations in Aotearoa New Zealand and what are the implications? An exploration of 2015–2019 administrative data. International Journal for Equity in Health, 2021. 20(1): p. 93.
21. Cleary, L., Using ethnicity data in Health Statistics. 2021, Ministry of Health: Wellington.
22. Harris, R., et al., We still don't count: the under-counting and under-representation of Māori in health and disability sector data. N Z Med J, 2022 in press.
23. Cox, J., BreastScreen Aotearoa Handbook November 2020 (for internal team use) 13 November 2020. 2020, Ministry of Health.

24. Teng, A.M., et al., *Ethnic inequalities in cancer incidence and mortality: census-linked cohort studies with 87 million years of person-time follow-up*. *BMC cancer*, 2016. 16(1): p. 755.
25. Breast Cancer Foundation, N.Z., *30,000 voices: Informing a better future for breast cancer in Aotearoa New Zealand*. 2022, Breast Cancer Foundation NZ.
26. Te Aho o Te Kahu, He Pūrongo Mate Pukupuku o Aotearoa 2020 *The State of Cancer in New Zealand 2020*. 2021.
27. Hei Āhuru Mōwai, M.C.L.A., *Position Statement on Breast Cancer Screening. Wāhine Māori te tuatahi – Māori women first*. 20 May 2022. 2022.
28. Robson, B., et al., *BreastScreen Aotearoa Monitoring Report for women screened between 1 July 2018 and 30 June 2020 DRAFT*. 2022.
29. Lawrenson, R., et al., *Outcomes in different ethnic groups of New Zealand patients with screen-detected vs. non-screen-detected breast cancer*. *J Med Screen*, 2019. 26(4): p. 197-203.
30. Seneviratne, S., et al., *Impact of mammographic screening on ethnic and socioeconomic inequities in breast cancer stage at diagnosis and survival in New Zealand: a cohort study*. *BMC public health*, 2015. 15: p. 46.
31. Robson, B. and J. Stanley, *BreastScreen Aotearoa Programme Monitoring Report For Māori, Pacific and Total women screened during the two or four years to June 2016*. 2017, National Screening Unit, Ministry of Health.
32. Walsh, M. and C. Grey, *The contribution of avoidable mortality to the life expectancy gap in Māori and Pacific populations in New Zealand—a decomposition analysis*. *N Z Med J*, 2019. 132(1492): p. 46-60.
33. Thomson, R.M., S. Crengle, and R. Lawrenson, *Improving participation in breast screening in a rural general practice with a predominately Maori population*. *The New Zealand Medical Journal*, 2009. 122(1291): p. 39-47.
34. Sandiford, P., et al., *Reducing ethnic inequalities in bowel screening participation in New Zealand: A randomised controlled trial of telephone follow-up for non-respondents*. *J Med Screen*, 2019. 26(3): p. 139-146.
35. Ministry of Health, *Whakamaua: Māori Health Action Plan 2020–2025*. 2020, Ministry of Health: Wellington.
36. Ministry of Health, *New Zealand Cancer Action Plan 2019–2029 – Te Mahere Mō Te Mate Pukupuku o Aotearoa 2019–2029. Revised January 2020*. 2019, Ministry of Health: Wellington.
37. Talamaivao, N., et al., *Informing Anti-Racism Health Policy in Aotearoa New Zealand*. *Policy Quarterly*, 2021. 17(4): p. 50-57.
38. Williams, D.R., J.A. Lawrence, and B.A. Davis, *Racism and Health: Evidence and Needed Research*. *Annu Rev Public Health*, 2019. 40: p. 105-125.
39. Jones, C.P., *Levels of racism: a theoretic framework and a gardener's tale*. *American Journal of Public Health*, 2000. 90(8): p. 1212-1215.
40. National Screening Unit, *National Screening Unit Strategic Plan 2010 to 2015*. June 2010. 2010, Ministry of Health: Wellington.
41. Jones, B., et al., *COVID-19, Intersectionality, and Health Equity for Indigenous Peoples with Lived Experience of Disability*. *American Indian Culture and Research Journal*, 2021. 44(2): p. 71-88.
42. Hill Collins, P. and S. Bilge, *Intersectionality*. 2nd ed. *Key Concepts*. 2020, New York: Wiley.
43. Ministry of Health, *BSA New Zealand All District Health Board Coverage Report For the period ending 31 March 2020*. 2020, Ministry of Health: Wellington.
44. Health Quality & Safety Commission, *A window on quality 2021: COVID-19 and impacts on our broader health system – Part 1 | He tirohanga kōunga 2021: me ngā pānga ki te pūnaha hauora whānui – Wāhanga 1*. 2021, Health Quality & Safety Commission: Wellington.
45. Linda Tuhiwai, S., *Decolonizing Methodologies Research and Indigenous Peoples*. 1988, Dunedin: University of Otago Press.
46. Rolleston, A.K., et al., *Seeing the unseen: evidence of kaupapa Māori health interventions*. *AlterNative: An International Journal of Indigenous Peoples*, 2020. 16(2): p. 129-136.
47. National Screening Unit, *Equity and Performance Matrix*. July 2019: https://www.nsu.govt.nz/system/files/resources/equity_matrix.pdf.

48. Ministry of Health, *Primary Care Ethnicity Data Audit Toolkit*, in Ministry of Health NZ. 2013.
49. Health Workforce Advisory Board, *Annual Report to the Minister of Health January 2022*. 2022, Ministry of Health: Wellington.
50. Curtis, E., et al., *Why cultural safety rather than cultural competency is required to achieve health equity: a literature review and recommended definition*. *International journal for equity in health*, 2019. 18(1).
51. Edgman-Levitan, S. and S.C. Schoenbaum, *Patient-centered care: achieving higher quality by designing care through the patient's eyes*. *Israel Journal of Health Policy Research*, 2021. 10(1): p. 21.
52. Health Quality & Safety Commission, *Engaging with consumers: A guide for district health boards*. 2015, Health Quality & Safety Commission.
53. National Screening Unit, *Improving Quality: A Framework for Screening Programmes in New Zealand*. 2005, Ministry of Health: Wellington.
54. Best Practice Advocacy Centre New, Z., *Increasing the uptake of breast screening*. *Best Practice Journal*, 2011(34): p. 32-39.
55. Pearson, J., et al., *Access to and engagement with cervical and breast screening services for women with disabilities in Aotearoa New Zealand*. *Disability and Rehabilitation*, 2022. 44(10): p. 1984-1995.
56. Fernhill Solutions Ltd, *BreastScreen Aotearoa Workforce Development Strategy 2022 – 2032 DRAFT*. Interim Health New Zealand.
57. Fernhill Solutions Ltd, *BreastScreen Aotearoa Workforce Development Strategy 2022 – 2032 Part 2 – Action Plan*. Te Whatu Ora.
58. Fernhill Solutions Ltd, *BreastScreen Aotearoa Workforce Development Strategy 2022 – 2032 Part 1 – Evidence for Change*. Te Whatu Ora.
59. Ministry of Health, He Korowai Oranga. <https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga>.
60. National Screening Unit, *BreastScreen Aotearoa Data Management Manual March 2010*. 2010, National Screening Unit.
61. National Screening Unit, *Interval cancers in BreastScreen Aotearoa 2008-2009*. 2018.
62. Kaplan, G.S., *Building a Culture of Transparency in Health Care*. *Harvard Business Review*, 2018.
63. Taylor, Y.J., et al., *Realizing a learning health system through process, rigor and culture change*. *Healthcare*, 2021. 8: p. 100478.
64. National Screening Unit, *NSU Open Communication Final*, in *National Screening Unit Policy Framework*.
65. National Screening Unit, *NSU Adverse Event Management Policy*, in *National Screening Unit Policy Framework*. 2019.
66. National Screening Unit, *NSU Complaint Management Policy*, in *National Screening Unit Policy Framework*.
67. Health Quality & Safety Commission, *National Adverse Events Reporting Policy 2017 New Zealand health and disability services*. 2017.
68. BreastSurgANZ, *Quality Audit Report on early and locally advanced breast cancers diagnosed in New Zealand patients in 2016*. 2018.
69. Morrell, S., et al., *Cohort and Case Control Analyses of Breast Cancer Mortality: BreastScreen Aotearoa 1999-2011*. 2015.