Me aro ki te hā o Hineahuone – a national evaluation of breast and cervical Screening Support Services

28 June 2021. Final Report

Shea Pita
& Associates

ABOUT THE EVALUATORS

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ATTRIBUTION

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HE MIHI

To all those who have lost loved ones to breast and cervical cancer. We see and acknowledge you.

E te kirimate o rātou kua ngaro i te mate ūtaetae me te mate waha kōpū. Kei tō mātou aroaro koutou. Tēnei mātou e mihi atu.

To all those who care for women and their families, who have breast or cervical cancer. We see and acknowledge you.

E koutou e tiaki i a rātou kua pākia ki te mate ūtaetae me te mate waha kōpū, me ō rātou whānau. Kei tō mātou aroaro koutou. Tēnei mātou e mihi atu.

To all women of Aotearoa. We acknowledge your strengths, your roles and your contribution to the past, present and future wellbeing of families and communities. We see you; we acknowledge you and we wish you well.

E koutou, e ngā wāhine katoa o Aotearoa. E mihi atu nei ki ō koutou mārohirohinga, ō koutou mahinga, ō koutou whakapau werawera mō te whakatairanga o te whānau me te hapori. Kei tō mātou aroaro koutou. Tēnei mātou e mihi atu, kia ora koutou katoa.

As a Kaupapa Māori organisation and evaluation team, evaluations of this nature are dear to our hearts as they enable us to promote mana wāhine Māori, and the mana of all wāhine in Aotearoa. This evaluation relied on the generosity, empathy, and compassion of many people who kindly shared their time and wisdom.

We acknowledge the women and wāhine (and their families/whānau) who agreed to be interviewed, the National Screening Unit of the Ministry of Health who funded this evaluation, the Screening Support Services (SSS) who work hard to make a positive difference in the lives of priority group women, Partner Providers who work with SSS to deliver screening, and multiple subject matter experts who offered us valuable insights and advice.

Thank you for your awhi. We hope the findings and recommendations in this report uplift those who need our support the most.

Ngā mihi aroha,

The Shea Pita Evaluation Team.

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 Māori women. From the beginning of time was Papatūānuku, the Earth Mother, then Hineahuone the first human created a woman. I sneezed and therefore I live!

This whakatauki honours the mana of priority group women – the mana of wāhine Māori as Tangata Whenua and the mana of Pacific and Asian women as Tangata Tiriti. The principle *Hiki mana i ngā wāhine katoa i Aotearoa* reflects the inherent mana of all women and was used by our team to 'pay heed to the dignity' of all women.

Introduction and purpose of this evaluation report

The National Screening Unit (NSU) of the Ministry of Health (the Ministry) commissioned Shea Pita & Associates Ltd to evaluate breast and cervical cancer Screening Support Services (SSS). The overall purpose of this evaluation is to understand whether SSS are effective. It includes insights about screening support services' specific contribution to equitable screening, models of good practice and opportunities to strengthen future delivery. Furthermore, it includes sector views about the possibility of expanding SSS to support bowel screening.

Equity is a key feature of this evaluation for two reasons. Firstly, despite best intent and some gains, breast and cervical cancer and screening inequities exist for three priority groups: wāhine Māori, Pacific women and, more recently, Asian women. Secondly, the Ministry expects that all providers who deliver cervical and breast screening programmes contribute to achieving equity. This includes the National Cervical Screening Programme (NCSP), BreastScreen Aotearoa (BSA) and SSS. SSS are funded to support the two national screening programmes to achieve equity for priority group women.

During this evaluation, it became clear that it was not possible to evaluate SSS in isolation of observations about the broader screening system. Insights from thematic analysis and other data, reflect a complex and dynamic interplay between priority group women with SSS, General Practice, Primary Healthcare Organisations, District Health Boards, the Ministry, and others. Therefore, we have included observations and recommendations about the screening system, as well as SSS.

The NSU intends to use this report to shape the future of SSS. This report sets out a range of findings and recommendations that reflect, in our view, what effective SSS (and the broader screening system) looks like. It also includes recommendations about what it takes to achieve equity for priority group women. In this regard, the evaluation team has designed a new framework called Te Hā. Te Hā is offered to guide future SSS design and system wide improvement. The framework is outlined later in this summary.

Method

This evaluation was conducted over 10 months (June 2020-March 2021). It is a process and short-term outcome evaluation. The evaluation team used a mixed method approach which comprised collecting and analysing quantitative and qualitative data. The team used contractual performance data, thematic analysis, provider profiles and the voice of priority group women to evaluate SSS effectiveness.

This evaluation is framed by and privileges a te ao Māori world view. It also braids evaluative techniques based on te ao Māori and western science.

Background and the screening landscape

Data about breast and cervical cancer in Aotearoa

Mate pukupuku is a national and global burden. In Aotearoa, cancer is a leading cause of death, and the burden of cancer is increasing year after year. Breast and cervical cancer data provide a tale of improvement and a tale of persistent inequities.

At a population level, evidence suggests that NCSP and BSA have contributed to improving health outcomes for all women in Aotearoa. However, persistent inequities exist for priority group women. Incidence, mortality, and survival rates for cervical and breast cancer are worse for wāhine Māori and Pacific women than for all Other women. Data suggests that wāhine Māori and Pacific women are more likely to die from cervical cancer than others, and the estimated excess mortality for wāhine Māori with cervical cancer is 44% (Gurney et al, 2019).

Breast cancer rates for all women in Aotearoa have increased over time; and the rate for wāhine Māori remains higher than non-Māori. Furthermore, both wāhine Māori and Pacific women have higher mortality rates for breast cancer compared to non-Māori, non-Pacific, and non-Asian peoples. The estimated excess mortality for wāhine Māori with breast cancer is 37% (Gurney et al, 2019).

At a population level, Asian women do not experience inequity of outcome like wāhine Māori and Pacific women. However, breast cancer is one of their most common cancers.

The national breast (BSA) and cervical (NCSP) screening programmes

The NSU funds the following national screening programmes – NCSP and BSA. Their overarching objectives are to reduce mortality from cervical and breast cancer (respectively). Both programmes offer screening for eligible women to detect cancer as early as possible and support access to treatment, which reduces the likelihood of death (MoH, 2015).

NCSP is mainly delivered by General Practice and BSA is delivered by eight Lead Providers across Aotearoa. NCSP offers cervical screening to women or people with a cervix[1], particularly if women are aged between 25-69 years and have ever been sexually active. Women are invited to have a cervical screen once every three years. BSA offers free, two-yearly mammograms and follow-up for asymptomatic women aged between 45-69 years.

Priority group women for cervical screening are wāhine Māori and Pacific women, based on population and screening programme inequity. At a programme level, as of December 2020, the equity gap[2] for wāhine Māori and Pacific women engaged in NCSP was -14% and -12% respectively. Asian women are also a priority for cervical screening. As of December 2020, the equity gap for Asian women was -15% (greater than Māori and Pacific).

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[1] This includes trans or non-binary people. In this report, we respectfully refer to women and/or people for NCSP interchangeably.

[2] The equity gap is calculated by the Ministry by subtracting the programme performance for the comparator population (non-Māori) from the programme performance for the population of interest (Māori). An equity matrix is published each month to monitor equity and performance data.

Priority group women for breast cancer screening are wāhine Māori and Pacific women, based on persistent population and screening programme inequity. At a programme level, wāhine Māori had the lowest coverage rates of all women over the last decade. As of December 2020, the equity gap for wāhine Māori was -7%.

Screening Support Services (SSS)

The NSU funds 12 SSS services across Aotearoa. SSS are a strategic response to inequities in the screening system. They prioritise supporting priority group women to be regularly screened. Support is also available to women who are unscreened or under-screened. SSS has six objectives. The objectives range from contributing to equitable access and outcomes for priority group women through to delivering high-quality services that are safe, innovative, flexible, empowering, and which reduce the financial and social burden of cancer.

The current SSS contracts have been in place since 2016. However, SSS have been funded for many years. Annually, the Ministry invests approximately $3.5m in SSS.

Key Findings

Key findings are grouped into three categories: current delivery, future delivery and insights on bowel screening, models of effective engagement, and contracting processes.

Current Delivery

Despite some gains, inequities persist

Population and national screening programme level data reflect persistent inequities. Overall, the screening system is not meeting the needs of priority group women and must continue to do more to deliver equitable outcomes. SSS primarily exist because inequities persist.

Asian women should be a priority group, alongside wāhine Māori and Pacific women

Although Asian women do not experience inequity of outcome like Māori and Pacific women, there are reasons why SSS should continue to support Asian women. Firstly, NCSP performance data suggests an emerging equity gap. Secondly, Asian women represent a large and growing number of women needing to be screened. Thirdly, literature and Asian women interviewed for this evaluation, suggest specific barriers and enablers that impact upon their access and utilisation of universal screening services.

More work needs to be done at multiple levels among SSS providers (and the wider system)

Many SSS providers demonstrated their commitment and ability to uplift the mana of priority group women. All SSS providers interviewed are passionate about their services, their approach, and the role they play to eliminate inequity and support wellbeing.

Priority group women spoke of enabling environments and positive experiences of SSS (and in some cases, the broader screening system). They referred to providers that understood their past experiences, met their cultural preferences, and delivered care that was relational, values- and strengths-based.

In contrast, interviewees shared what did not work (in SSS and the wider system) and spoke of mana disabling environments and practices. Examples of this included provider-centric approaches; experiences of racism, discrimination, and bias; and poor provider processes which reduced service flexibility.

More needs to be done to improve SSS, and the wider system.

Collectively, SSS are effective and engage well with women

In our view, SSS are effective. They fulfil a valuable role mitigating inequities in the current screening system and programmes. Based on the SSS outcome framework and quantitative contractual data, we find that, collectively, SSS deliver improved outcomes and quality services to priority group women.

Between 2017-2020, nearly 35,000 priority group women were screened who may not have been screened otherwise. This is a positive outcome. Between 2017-2020, around 50% of women were successfully engaged in both pathways, which equated to nearly 73,000 women. Overall, engagement data for both screening programmes improved over the three years. This points to the quality of engagement.

In line with a quality experience (and as noted earlier) many priority group women shared positive experiences of SSS. In addition to those noted earlier, positive experiences included access to women- and whānau-centred models of care – care that was culturally safe and respectful, providers honouring Te Tiriti, the mana of wāhine, and meeting Pacific and Asian women specific preferences and needs.

Partner providers stated that they valued the role of SSS. Some provider partners suggested improvements which ranged from SSS providing more flexible screening options through to general discussion about the pros and cons of focusing on priority group women, better use of data, and improving SSS capabilities.

SSS service configuration depends on the local needs of the diverse communities they serve

SSS service delivery is configured in multiple ways. For example, there are multiple provider types (i.e. DHBs, PHOs, smaller NGOs, Kaupapa Māori, Pacific providers, universal providers[3]); different contracting models (e.g. some providers hold the contract and deliver the SSS service and others sub-contract out delivery); geographic differences (i.e. rural vs. urban); and different levels of capability and capacity (i.e. some SSS providers had exceptional referral and working relationships with Partner Providers and others did not; some were struggling financially; some lacked sufficient workforce to flex in times of need; and some had comprehensive IT systems). Many SSS providers also stated that their configuration and model was designed to meet unique local circumstances and women's specific needs.

Therefore, it is not possible to compare which configuration is most effective, as there are too many variables. As a result, the evaluation team concentrated on identifying the characteristics of effective SSS services (and systems). These characteristics are in the Future Delivery section (below).

SSS providers deliver value-add activities and outcomes over and above screening

SSS providers identified six categories of value-add outcomes which reflect value-add activities. The outcomes include improved Access and Participation; Experience; Health and Social; Health System; Capability Building Benefits for the Social Sector; and Societal and Community outcomes. Detail about each outcome is contained in the body of this report. Many of the outcomes were aligned

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[3] Universal services are those that present themselves as available to anyone with no or little attention paid to meeting cultural preferences, needs or safety. These types of services are often called Mainstream. The evaluation team prefer to not use the term 'mainstream' as it tends to 'other' alternative providers or models of care such as Kaupapa Māori, Pacific, Asian or community-based NGOs.

with Whānau Ora. The team could not validate the outcomes but accept the providers' view in good faith.

Future Delivery

The mana of wāhine/women must be upheld by SSS and the wider screening system

All and any inequities impact negatively upon the mana of wāhine and other priority group women. This is unacceptable. Systems and services must be held accountable for eliminating inequities. The NSU has a key role to play as the main funder and commissioner.

Four core themes inform models of good practice

Detailed thematic analysis brought to the surface four core themes: Caring and supportive relationships with women; Women- and whānau-centred models; Cultural safety; and Proactive Partnerships. Components of each theme apply to SSS and, or the broader screening system. Each core theme is supported by explanatory factors.

Other insights – bowel screening, contracting and other models of effective engagement

There is support for SSS to include bowel screening. However, there are caveats

73% of partner providers surveyed, agree that SSS should support bowel screening and most SSS providers concur. Thematic analysis revealed multiple pros and cons. Most cons related to ensuring appropriate resourcing was available and that existing services were not compromised.

More work is needed to review the current contracting approach and move towards commissioning

There were mixed views about the current contracting approach. Barriers and enablers ranged from lack of trust and failure to consider Whānau Ora, through to requests to review the outcome framework and contractual metrics. There is more work to be done.

There are strong health system reform signals that a move towards a Kaupapa Māori and culturally nuanced commissioning approach is required. This type of approach would incorporate a te ao Māori lens to uplift the specific mana of Māori wāhine pursuant to Te Tiriti, and this aligns with policy and strategy, such as the Ministry's Māori Health Action Plan – Whakamaua.

Trust-based and relational contracting and contract management, informed by a mana wāhine and 'hiki i ngā mana' outcome framework, could also be a feature of the future. The Ministry is in an excellent position to frame the future commissioning of SSS (and broader screening system programmes) using insights from this evaluation.

Indigenous and other models of effective engagement are available for implementation

The Ministry asked for information about other models of effective engagement. *Te Piringa* (Savage et al, 2020 and 2020a) provides recent insights into effective primary care for Māori and Pacific Peoples. The research suggests there are three interconnected layers which support effective delivery: Whānau, Whānau-centred service and practices, and Government.

At a Whānau level, key enablers ranged from valuing whānau diversity and mātauranga through to the importance of kaupapa Māori values, decolonisation, healing, and holistic health experiences. Key barriers ranged from intergenerational exposure to health compromising conditions and feelings of whakamā, through to limited service delivery options and choices.

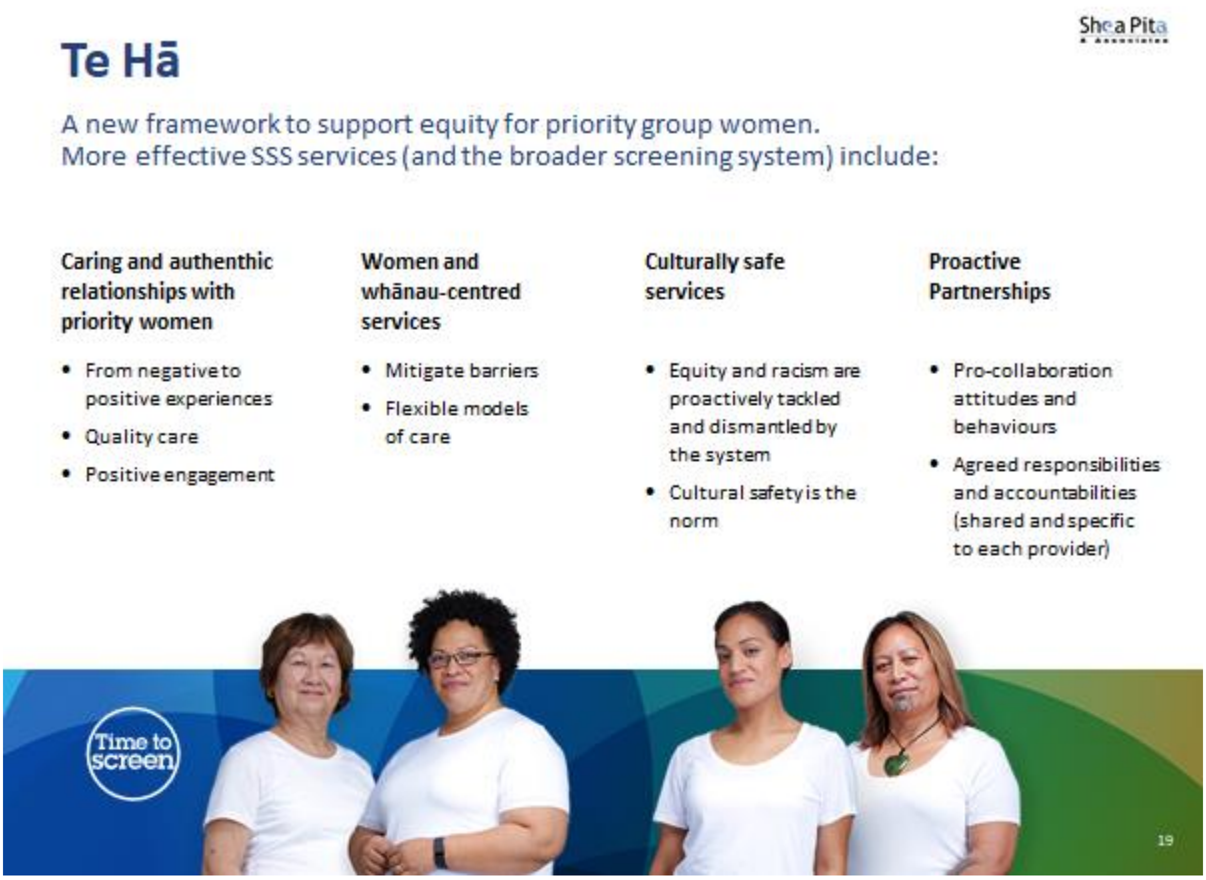
At a Whānau-centred service and practice level, key enablers ranged from a clear whānau-centric model of practice, practising kaupapa Māori values and cultural safety. Key barriers ranged from lack of a clear model of practice through to power imbalances, poor contracting approaches, and unsustainable funding.

At a Government level, key enablers ranged from a whole system approach, adherence to Te Tiriti and Whānau Ora, through to the lack of Government fulfilling its partnership obligations and a failure to collect and use data to improve Māori health.

This research has informed the recommendations in this report.

Te Hā - a new framework to support equity for priority group women

Based on the findings of this evaluation, the team has developed a new framework called Te Hā. The purpose of Te Hā is to breathe new life into future SSS and the broader screening system. It offers fresh insight into what good SSS looks like, inclusive of a pro-Tiriti and pro-equity lens. By understanding what 'good looks like', the NSU and providers can co-construct new or enhanced strategies and actions designed to improve equity of access, experience, and outcome for priority group women. The framework is outlined below:



Te Hā

A new framework to support equity for priority group women.
More effective SSS services (and the broader screening system) include:

Caring and authenthic relationships with priority women

- From negative to positive experiences
- Quality care
- Positive engagement

Women and whānau-centred services

- Mitigate barriers
- Flexible models of care

Culturally safe services

- Equity and racism are proactively tackled and dismantled by the system
- Cultural safety is the norm

Proactive Partnerships

- Pro-collaboration attitudes and behaviours
- Agreed responsibilities and accountabilities (shared and specific to each provider)

Figure 1: Te Hā – a new framework to improve screening outcomes for priority group women

Photo source: NSU Time to Screen website.

The framework adapts the four themes from the thematic analysis and outlines the most common characteristics of effective SSS. It is noted that many SSS providers already display several of these characteristics. However, persistent inequities at population and programme levels, coupled with variable contractual performance by some SSS providers, suggest that these characteristics may not be universally applied – by either SSS or the wider system.

Some of these characteristics may also apply to the NSU as the funder. (See Table 9 in the report for a detailed overview of the framework.)

Recommendations

These recommendations aim to support service and system changes to achieve equity for priority group women. Based on the Key Findings and insights in this report, the evaluation team recommends that NSU action the following:

In the next 6-12 months

1. **Adopt Te Hā and use it to generate fresh thinking about SSS and system wide change.**

   Suggestions about the use of this framework are threaded through the recommendations below.

2. **Continue to fund SSS services for existing priority group women.**

   This is based on data linked to persistent and emerging inequities.

3. **Consider scaling and reframing SSS services as proactive disruptors vs equity backstops.**

   The body of this report highlights what works and there are also examples of opportunities for improvement - across SSS and the broader system. Despite potential new ways to strengthen SSS, we are clear that collectively SSS services are already effective. The NSU is strongly encouraged to enhance their effectiveness by extending their reach and scale. This will require new investment and support to understand issues such as optimal geographic coverage, provider and workforce development, equitable funding, reporting, volumes, and targets. This will need to happen alongside further work regarding whole system effectiveness.

   In addition, the framing of SSS focuses on their role as equity 'backstops' as they are funded to fill the screening system's performance and equity gap. If the Ministry reframed SSS as a disruptor which models what good looks like, this is a more strengths- and mana-enhancing approach to equity. It also supports the principle that what works for priority group women, will work for others. This approach celebrates indigenous and culturally inspired models as the 'gold standard', not the marginal or 'other' model. This is a mindset shift for some, and a real opportunity for the NSU to demonstrate proactive leadership for equity.

4. **Investigate immediate ways to improve equity and accountability across the whole system.**

   The NSU could bring together a group of willing stakeholders, including SSS providers, across or within each of the two screening programmes to brainstorm new ideas about 'what works.' It could use Te Hā and the findings in this report to broker new thinking about pro-Tiriti and pro-equity. Short-term strategies and actions (quick wins) could be identified that use existing levers in services and systems. If stakeholders use existing levers, actions should be implemented within the next 12 months. Examples of 'quick wins' might include: a 1-page Charter that commits system stakeholders to work more collaboratively to improve outcomes for priority group women, agreement to safely share data and pinpoint actual or emerging inequity 'hotspots', agreement to quickly mobilise responses and resources to prevent 'hotspot' inequity escalating or developing.

5. **Pursue a new and more explicit pro-Tiriti approach to commissioning SSS for wāhine Māori.**

   The NSU could enhance its existing approach by partnering with Māori (expert advisors, providers, wāhine and whānau) to revise how it commissions. A pro-Tiriti commissioning approach could include:

   a. The Articles and Principles of Te Tiriti – identifying how to fulfil the promise of these obligations and opportunities. Noting that achieving equity for Māori women is one of several principles of Te Tiriti
   b. Mana Wāhine Māori – use the insights in this report about wāhine Māori needs, aspirations, and preferences to influence future model of care design, outcome framework and contractual performance metric updates
   c. Mātauranga Māori – incorporate Mātauranga Māori into future model of care design thinking and metrics, which is led and guided by Māori
   d. Kaupapa Māori – incorporate Kaupapa Māori into future model of care design thinking which is led and guided by Māori
   e. Take action linked to 'quick wins'. Examples may include enabling SSS providers to report additional quantitative or qualitative data to the Ministry which showcases their points of difference and other value-add outcomes; and/or holding a workshop with SSS providers to reinforce the NSU's commitment to mana wāhine and agree how to use Te Hā to improve equity; and/or identify new ways to incorporate mana wāhine voice into assessing service effectiveness from Ministry to provider levels; and/or agree new and consistent ways to streamline referral systems and processes to reduce the current administrative burden of 'poor' referrals on SSS; and/or host a rapid model of care design workshop with SSS providers and priority group women to focus on what works, what does not work, and future opportunities to strengthen screening.

6. **Pursue a new and more explicit pro-equity approach to commissioning for Pacific and Asian women.**

   The NSU could also enhance its existing approach by partnering with Pacific and Asian stakeholders (expert advisors, providers, women, and families) to revise how it commissions. A pro-equity approach could include consideration of the following:

   a. Hiki mana i ngā wāhine katoa ki Aotearoa – how this principle is factored into future design thinking
   b. Pacific and Asian peoples' notions of wellbeing - ensuring that wellbeing specific to cultural nuances and preferences feature in models of care and service configuration design thinking
   c. Actions linked to 'quick wins' (as noted above in Recommendation #5).

Noting that components of Recommendations 5 and 6 are not mutually exclusive. There are positive crossovers.

7. **Consider expanding SSS to include bowel screening.**

   This recommendation is based on the appetite of the system to consider SSS expansion to support bowel screening. If pursued, the pros and cons expressed in this report will be valuable insights for the NSU to consider.

8. **Find ways to work with SSS providers to celebrate success.**

   Whilst it is important to tackle what is not working, it is equally important to scale what is working and therefore successful. A balanced approach to service development is required. The NSU is encouraged to invest in new communication or engagement methodologies that support frequent shared messaging and collaboration for success.

In the long-term

9. **Initiate a formal review of NCSP and BSA and the broader screening system to incorporate an enhanced pro-Tiriti and pro-equity lens.**

   This review will lever off the findings in this report and could use Te Hā as a focal point.

10. **Adopt a Kaupapa Māori investment approach.**

    A Kaupapa Māori investment approach prioritises a pro-Tiriti methodology that results in equitable commissioning of services which prioritise kaupapa Māori and a Māori worldview. Components may include ringfenced and indexed funding for SSS[4], including a long-term and sustainable funding investment model for Kaupapa Māori providers[5].

11. **Adopt a Pro-equity investment approach.**

    This recommendation is like the recommendation above, but it is focused on Pacific and Asian priority group women within the context of Equity.

12. **Think about building intersectoral commissioning agreements that support a joined-up commissioning approach with SSS providers who already have multiple intersectoral funders and contracts.**

    This recommendation recognises that many SSS providers hold multiple contracts with multiple funders. The administrative burden alongside the general siloed impact of this approach is counterintuitive to a joined up and streamlined system that is women- and whānau- centred. This challenge is for government agencies and funders to resolve.

Conclusion

Globally, New Zealand has a positive reputation for delivery of its national screening programmes. (MoH, 2020; OECD[6]). Effective screening programmes impact on population outcomes as they contribute to reducing mortality and morbidity from cancer. Research in this report suggests that both NCSP and BSA have contributed to improving population outcomes for all women in New Zealand. It also shows that at a programme level, hundreds of thousands of women have been

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[4] Other payment and funding setting models may be adopted but the point is that funding is protected and targeted towards Māori wellbeing using a kaupapa Māori approach. Indexed funding refers to a mechanism that ensures the funding pool grows over time based on need and equity compared to a stagnant pool of funding.

[5] This is likely to include specific provider and workforce development investment.

[6] Source: https://stats.oecd.org/index.aspx?queryid=30159. Accessed June 2021.

screened. A showcase equity story for BSA was achieving equitable screening rates for Pacific women in December 2020. These results are good news stories, and the Ministry should be acknowledged for funding and managing successful programmes at a whole population level.

However, it would be irresponsible to let macro success mask serious and persistent inequities experienced by priority group women. Findings in this report clearly demonstrate that whilst successful for some women, the national screening programmes are not as successful as they should be for wāhine Māori, Pacific women and, more recently, Asian women.

The NSU knows this. They have multiple strategies to effect equity, ranging from policy and strategy commitments through to clinical quality guidelines and active performance improvement of contracted services. A key pro-equity investment for NSU is SSS.

SSS are specifically funded to support improved screening system equity (in geographic areas). Based on what we saw, SSS work hard to support priority group women to be successfully screened. As a collective, we believe SSS are effective. If SSS did not exist, thousands of priority group women may not have been screened at all. Furthermore, they are likely to deliver broader outcomes over and above screening, many of which are aligned to Whānau Ora.

Whilst relatively small in scale compared to the whole screening system, we suggest SSS deliver significant value and are a justified spend. As noted by the NSU, they are designed to have a significant impact on a small number of valued women.

Could SSS improve? Absolutely. No provider or service is perfect. Findings revealed several ways to improve SSS services. It is important to remember, however, that SSS operate as part of a broader screening system. As noted in the report, effective services require effective systems (and vice versa). Therefore, the broader screening system also needs to ‘lift its equity game.’

Looking to the future, the new health sector reforms will impact upon what the NSU can do post July 2022. Irrespective of structural and system changes, priority group women need and the effectiveness (or not) of the screening system will remain. In our view, reform signals support the recommendations outlined in this report and the ongoing leadership required of government agencies to support the health and wellbeing of priority group women. Therefore, this report and what the NSU does with it matters; perhaps even more than usual as we are in an environment that is inviting reform and new ideas for improvement.

The NSU can facilitate innovative and fresh thinking about how to improve SSS and the wider screening system. Te Hā is offered to NSU, SSS and system partners as part of an improvement journey. Perhaps the ultimate objective may be to eliminate the need for SSS – at least in its current form. The future opportunity may be to ‘flip the script’ and, as noted in the recommendations, to view the most optimal SSS not as an equity backstop but as the future ‘gold standard.’

Whilst all priority group women are valued in this report, the plight of wāhine Māori is of particular concern. Generally, they fare the worst. As Tangata Whenua, wāhine Māori are not only entitled to have their needs met, but they are also entitled to have their rights met pursuant to Te Tiriti o Waitangi. At present, it seems that neither needs nor rights are being fully met.

Finally, from an indigenous perspective, it is clear that the unacceptable price of inequity is unfair and unjust wāhine Māori mortality. How much longer must wāhine Māori pay this price? In our view, the time to act is now and disrupt the disadvantage. The future wellbeing of indigenous wāhine and all women in New Zealand deserves continued investment, nurturing, and prioritisation.

WĀHANGA TUARUA: OVERVIEW AND METHOD

This section provides an overview of the evaluation, including the evaluation type, duration, method, and other relevant factors.

A te ao Māori worldview and approach

This evaluation prioritises a te ao Māori worldview. Te ao Māori is expressed in three ways: through framing this evaluation by a whakatauki, by using Mātauranga Māori and Kaupapa Māori to understand mana wāhine needs, aspirations and preferences, and applying Kaupapa Māori values throughout the evaluation process.

Whakatauki

Whakatauki are a rich and important taonga of te ao Māori. As evaluators, we believe whakatauki enrich us with knowledge about values, behaviours, principles, and lessons. They have multiple purposes, the least of which is to teach and share wisdom from the past for contemporary learning, adaptation, and application.

This evaluation is framed by the following whakatauki:

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 Māori women. From the beginning of time was Papatūānuku, the Earth Mother, then Hineahuone the first human created a woman. I sneezed and therefore I live!

This whakatauki provides a tika platform for this evaluation. It speaks to the mana of women and their importance. All women should be respected for their role to influence the past, present and future Oranga of their families, friends, and communities.

Mātauranga Māori

Mātauranga Māori is an important whāriki for this evaluation. Mātauranga Māori reflects a wide expanse of Māori knowledge. As Broughton (2015) states:

> *"Mātauranga Māori (mātauranga) is the Indigenous knowledge system of these lands. It is dynamic, innovative and generative." (p.83)*

Kaupapa Māori

Kaupapa Māori privileges a te ao Māori worldview. It is the antithesis of a monocultural or ethnocentric way of being, thinking, and doing. It recognises that racism and prejudice, which can also be expressed through 'othering' (Hapeta et al, 2018, HDSR, 2020) is an issue that needs to be tackled both globally and in Aotearoa. We use a Kaupapa Māori approach in this evaluation. We define this as a Māori way of being, thinking, owning, and doing. The evaluation team also defines a Kaupapa Māori investment approach as one that values, prioritises, and invests in kaupapa Māori to support intergenerational wellbeing.

Kaupapa Māori values

This evaluation was conducted according to Kaupapa Māori values. The following values and principles were applied:

- **Rangatiratanga:** supporting and respecting each other's authority, intelligence, and mana.
- **Manaakitanga:** acting in a caring and supportive way to each other.
- **Whanaungatanga:** respecting kaupapa and whakapapa whānau bonds and mutuality.
- **Paeheretanga:** creating and nurturing positive working relationships and results for a common purpose.

When engaging with Māori providers and all interviewees, the team used the most appropriate te reo me ona tikanga. The team was also guided by mana whenua and local tikanga and kawa.

Mana Wāhine

There is an in-depth discourse about the kupu and concept of Mana Wāhine. For this evaluation, the team reserves the term Mana Wāhine for Māori women. However, the team also recognises the inherent mana of all women and articulates a principle for this called *Hiki mana i ngā wāhine katoa ki Aotearoa* (outlined later in this section).

The evaluation team suggests that mana and wāhine represent a frame to celebrate Māori (and other women's) knowledge and authority. Accordingly, this evaluation:

- privileges Māori wāhine voice as Tangata Whenua
- celebrates and prioritises 'herstories' which reflect wāhine preferences, views, and lived experiences (Irwin, 1992a)
- acknowledges the positive intersect between mana wāhine and mana whānau, mana whenua, mana atua and mana tāne (Simmonds, 2011)
- contests monocultural, ethnocentric, patriarchal, and racist views that attempt to redefine and reshape the realities of Māori women (Simmonds, 2009)
- understands and values the authority and strength of women and the many positive roles and responsibilities women have in whānau, hapū, iwi and society
- acknowledges wāhine as Te Whare Tangata - creators and nurturers of life and protectors of whakapapa. Like Papatūānuku, who was the creator of all life; Te Whare Tangata affirms that the life-giving role that wāhine have is a core part of generating one's sense of value, self-esteem, and self-respect. It is often translated as the House of Humanity[7]
- honours wāhine who represent the strengths and values of Atua Wāhine via knowledge sharing and lessons imparted through whakatauki and pūrakau narratives (Sharman, 2019).

The Mana of all Women - Hiki mana i ngā wāhine katoa ki Aotearoa

All women in Aotearoa should be valued and respected. We have created the following to guide respect for all women - *Hiki mana i ngā wāhine katoa ki Aotearoa*. This principle means that we value and support all women in Aotearoa. The evaluation team has adopted Mana Wāhine and the Mana of all Women to guide this evaluation.

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[7] Source: https://www.tepou.co.nz/stories/he-tapu-te-whare-tangata---exploration-of-the-cervical-screening-clinical-pathway. Accessed April 2021.

Approach and Method

Evaluation type and timeframe

The National Screening Unit (NSU) of the Ministry of Health (the Ministry) commissioned Shea Pita & Associates to evaluate the breast and cervical Screening Support Services (SSS). The Ministry intends to use this evaluation to inform the future commissioning of SSS. Shea Pita commenced the evaluation in June 2020, and it was completed in March 2021.

The Ministry commissioned a process and short-term outcome evaluation. The process evaluation focused on understanding how SSS providers delivered their services and 'what worked'. The short-term outcome evaluation focused on whether wāhine Māori, Pacific, and Asian women (referred to as priority group women) were 'better off' (had they been successfully screened).

Evaluation objectives and insights

The objectives of this evaluation are:

- To assess the effectiveness of SSS. This includes understanding equity of access, experience, and outcomes, the participation of priority group women (Māori, Pacific and Asian) in screening, and service configurations that support successful delivery.
- To understand models of good practice and other 'value added' activities.
- To assess and identify opportunities to strengthen the screening pathway for priority group women.
- To identify other models of effective engagement over and above the current providers.
- To explore sector views of broadening the scope of SSS to include bowel screening services.

The Ministry also sought a range of insights about SSS delivery processes, client outcomes and the Ministry's contracting approach with SSS providers. Insights are outlined in the body of this report.

Equity

The Ministry requested a focus on equity in this evaluation. We have used Ministry of Health's definition of Equity:

> *"In Aotearoa New Zealand, people have differences in health that are not only avoidable but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes."*[8]

A mixed-method and staged approach

This evaluation was implemented in eight stages:

- Stage 1 –Evaluation planning including scoping the Kaupapa Māori approach
- Stage 2 – A literature scan
- Stage 3 – Desktop analysis of data
- Stage 4 – Collect additional data

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[8] Source: https://www.health.govt.nz/about-ministry/what-we-do/work-programme-2019-20/achieving-equity. Accessed January 2021.

- Stage 5 – Analysis
- Stage 6 – Report drafting
- Stage 7 – Final report submission to the Ministry of Health
- Stage 8 – Exit

We used a mixed method approach. Data collection and analysis included a mix of the following: a literature scan, interviews with 18 priority group women (qualitative, semi-structured), interviews with all SSS providers and, where relevant, their sub-contractors (qualitative, semi-structured interviews), interviews with three Ministry of Health and five Subject Matter Experts (qualitative, semi-structured interviews), 33 Partner Provider survey respondents (customised survey), documentation and data analysis. Further information is contained in Te Tāpiritanga Tuarua.

External peer review

The logic and quality of this report was peer reviewed by Associate Professor Terryann Clark. Associate Professor Clark did not participate in the data collection or analysis. She was purposefully kept at 'arms-length' to enable her to constructively critique the report. Multiple draft reports were also critiqued by the Ministry.

Ethics

All internal and external interviewees were supplied with information about the evaluation prior to giving informed consent. Interviewees were advised that their involvement was voluntary, and they could withdraw at any stage prior to their data being incorporated into thematic and other analyses. No interviewees exited the evaluation. The evaluation team sought advice from the Ministry's Health and Disability Ethics Committees (HDEC). The Team were advised that this evaluation did not require HDEC approval or review.

Out of scope

There are a variety of issues which are out of scope. They include:

- A system level evaluation
- Symptomatic pathways
- Screening programme policy and strategy review
- The viability and efficacy of HPV self-testing
- Outcome framework redesign and continuous quality improvement
- Other NSU or MoH screening programmes
- Clinical analysis of the quality or effectiveness of screening pathways
- Third party data validation
- Performance monitoring and contract re-design linked to SSS
- Interviewing providers in areas that do not have SSS contracts

SSS Outcome Framework

Figure 2 outlines the SSS outcome framework. It includes population and client outcomes, with associated data sets. The framework is sourced from the SSS outcome agreements and has been adapted and updated by the evaluators to highlight client outcomes that have the most direct (contributory) line of sight to population wellbeing.

The outcome framework is informed by Results Based Accountability™ (RBA)[9] which is the Government's framework of choice in outcome agreements with NGOs[10]. For an overview of RBA, refer to Te Tāpiritanga Tuatahi.

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[9] Ibid.

[10] https://www.procurement.govt.nz/procurement/specialised-procurement/social-services-procurement/developing-a-social-services-procurement-plan/how-to-measure-outcomes-and-outputs/. Accessed February 2021.

SSS Outcome Framework

Population outcome: All women in New Zealand live longer, healthier lives

Population Accountability

Who is the priority sub-population that is specific to breast and/or cervical cancer screening? Māori, Pacific and/or Asian women/people with a cervix (priority group women). Including those in the population who are unscreened and/or under-screened.

What would be different in the future? – We would see women and people with a cervix from priority groups (Māori, Pacific and Asian) equitably screened for breast and cervical cancer and the impact of cancer on wāhine, women, their families and communities would be reduced. The mana of wāhine and women is honoured and prioritised. Inherent in this future is a commitment to supporting oranga wāhine, healthy women, equity (access, experience and outcomes) and fulfilment of Te Tiriti o Waitangi commitments.

How would we know this population outcome is being achieved? By measuring the selected population indicators and targets (as appropriate)

- (1) Coverage rates of breast and cervical screening (by ethnicity). Targets achieved.
- (2) Incidence of breast and cervical cancer (by ethnicity)
- (3) Mortality rates for breast and cervical cancer (by ethnicity)

Who is accountable for achieving this population outcome and what roles do they have to play? At a population level, accountability is shared across multiple partners who are working towards this outcome, in particular, accountability is shared amongst relevant health system partners which range from the MoH through to DHBs, PHOs, NGOs, SSS providers, BSA Lead providers and others. Intersectoral partners will also have a role to play.

The MoH funds, manages and monitors multiple providers that deliver services and supports linked to national cervical and breast cancer screening pathways. Multiple providers are contracted to fulfil dedicated roles along the pathways and are expected to deliver outcomes to their direct clients. If multiple providers achieve client outcomes, together, this should contribute to achieving the population outcome and turning the population indicators in the right direction. This includes shifting the 'equity dial'.

SSS are funded as part of the suite of services along the screening pathways. MoH enters into outcome agreements with 12 SSS providers that specify *priority group women* client outcomes, which is a niche role. SSS providers are accountable for delivering outcomes to their clients and contributing to population outcomes.

Client outcomes: All priority group women who are unscreened or under-screened are supported by SSS to be screened

Performance Accountability

Who are the clients of the SSS services? Māori, Pacific and/or Asian women who are unscreened or under-screened, and who are referred, identified and successfully contacted

What are SSS providers contracted to deliver? Support services to priority group women who experience barriers to access and engagement in breast and/or cervical screening pathways. Priority women for cervical cancer screening are Māori, Pacific and Asian; for breast cancer are Māori and Pacific.

How do we know client outcomes are achieved? Through measuring and monitoring three types of performance measures:

(1) How much service was delivered?	(2) How well was service delivered?	(3) Are SSS clients better off?
Example measures: # of priority group women referred and identified/ethnicity # of priority group women successfully contacted/ethnicity	Example measures: % of priority group women successfully contacted/ethnicity	Example measures: % of priority group women successfully contacted who were screened/ethnicity

Figure 2: SSS outcome Framework

Source: Ministry of Health SSS contracts. Adapted and updated by the Evaluation Team, for the purposes of this evaluation.

Evaluation team

The evaluation team comprised the following people:

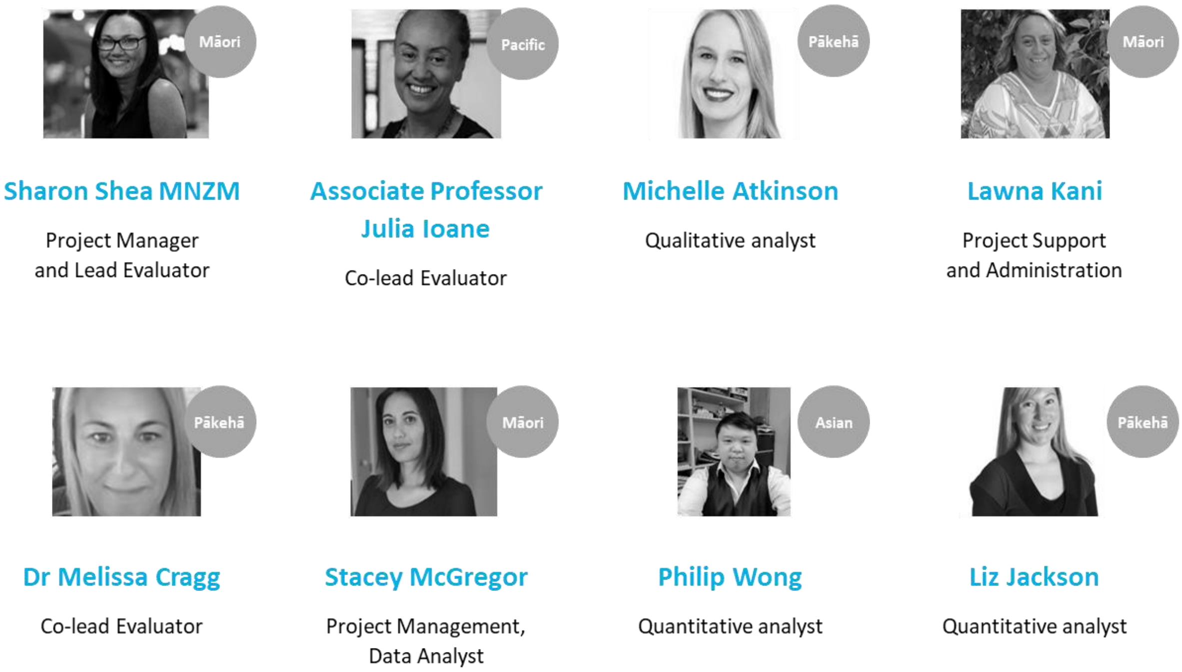

Figure 3: SPA Evaluation Team

The team was fortunate to receive cultural advice and guidance from two experts – Tui Ah Loo and Bronson Perich.

Limitations

The limitations of this evaluation are:

- **No formative component** – this was a retrospective evaluation.
- **Sample size and diversity of women interviewed** – eighteen women were interviewed for this evaluation. The sample size was relatively small, and the group was not as diverse as it could have been. For example, we did not interview LGBTQI women or people with a cervix who did not identify as a woman. Nor did we interview women who did not engage in the system at all. However, the team received rich insights from the priority group women they engaged with.
- **Poor quality of some performance measurement data** – some data supplied by SSS providers was inconsistent or incorrect. The team adjusted data sets to compensate for this, and final data sets were approved by the Ministry for use. The team is confident the final data set used in this report is as reliable as possible.

Conflict of interest

Sharon Shea is Chair of the Bay of Plenty District Health Board (one of the 12 SSS providers). The interest was declared to the Ministry prior to the project commencing, and Sharon Shea played no role in the DHB's interview or data analysis. In addition, draft and final reports were peer reviewed by the Ministry and an external reviewer, to ensure analysis and findings were fair and unbiased.

WĀHANGA TUATORU: CONTEXT AND BACKGROUND

This section provides context and background to the evaluation. It includes a summary of cancer and screening programme data, an overview of the breast and cervical screening landscape, an introduction to Screening Support Services (SSS), and a brief overview of strategy, policy, and literature.

Mate Pukupuku is a global and local burden

In 2020, the World Health Organisation (WHO) estimated there were 9.95m deaths related to Cancer[11]. Cancer is a leading cause of mortality across the World, and the burden of this disease is increasing year on year. Not only does Cancer have a large economic impact[12], global inequities by ethnicity or race are also common (Zavala et al, 2020).

In Aotearoa, Mate Pukupuku is a leading cause of death (MoH, 2019, Te Aho o Te Kahu, 2021; Allemani et al, 2018; Tin et al, 2018). As New Zealand's population ages and grows, the number of people with cancer is set to increase. In 2016, 66 people in New Zealand were diagnosed with Cancer every day. In the next twenty years, the number of people diagnosed with Cancer is likely to double to around 52,000 people or 142 people a day (Te Aho o Te Kahu, 2021). The most common cancers in New Zealand are breast, lung, prostate, and colorectal.

Cervical and Breast Cancer in Aotearoa

A simple description of cervical and breast cancer

Cervical cancer is cancer of a woman's cervix[13]. The majority (99%) of cervical cancer is linked to the high-risk human papillomaviruses, commonly known as hrHPV (NSU, 2020; WHO[14]). Cervical cancer develops over a long period of time; on average, between 10-20 years. Breast cancer is cancer of the breast. There are many types of breast cancer, and it can affect both men and women[15].

Cervical cancer incidence, mortality, and survival rates – population outcome data

Incidence

At a population level, evidence suggests that NCSP has contributed to improving health outcomes for all women in Aotearoa. For example, NCSP has contributed to reducing the incidence of cervical cancer for all women aged 25 and over (NSU, 2020). Further, the Ministry suggests that since NCSP was introduced, cervical cancer incidence has reduced by ~50%, and mortality by 60%[16].

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[11] International Agency for Research on Cancer. Source: www.who.int. Accessed January 2021.

[12] The World Health Organisation (WHO) suggests that in 2010, the annual economic cost of cancer was ~ US$ 1.16 trillion (Stewart and Wild, 2014).

[13] The cervix is the entranceway to the uterus from the vagina.

[14] Source: https://www.who.int/health-topics/cervical-cancer#tab=tab_1. Accessed January 2021.

[15] Around 25 men per annum are diagnosed with breast cancer in New Zealand. Ibid.

[16] Source: https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme. Accessed February 2021.

The New Zealand Cancer Control Agency, Te Aho o Te Kahu (2021), recently reported that between 1996-2017, Māori and non-Māori have experienced large reductions in the rates of cervical cancers (Figure 4 below). However, despite overall gains, there remain persistent disparities linked to the incidence of, and mortality from cervical cancer. This is especially so when comparing Māori and non-Māori women. Findings from Te Aho o Te Kahu are supported by Sykes et al (2019)[17].

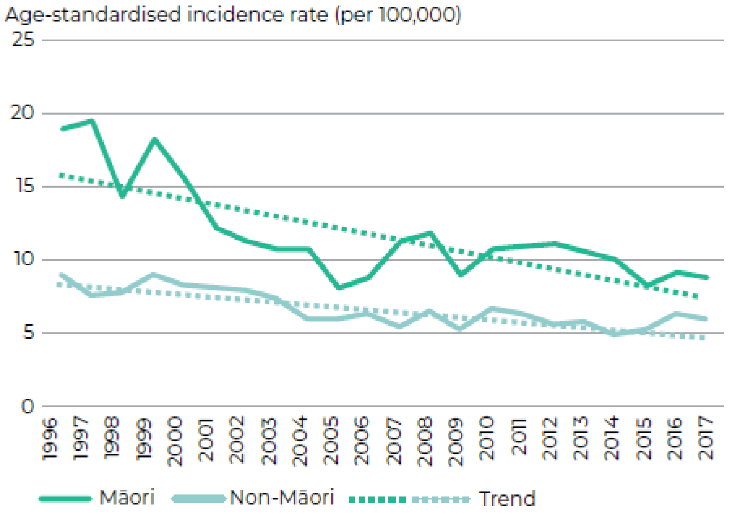

Figure 4: Cervical cancer incidence in Aotearoa, 1996–2017.

Source: Te Aho o Te Kahu (2021).

Mortality

Data from 2010-2012 showed that Māori women had a cervical cancer registration rate at twice that of non-Māori women. Furthermore, Māori women were 2.5 times more likely to die from cervical cancer than non-Māori (MoH, 2015). In 2018, almost a quarter (23%) of cervical cancer registrations were Māori[18]. Figure 5 (below) shows persistent inequities in mortality rates for wāhine Māori and Pacific women, compared to all Other women.

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[17] Based upon a review of cervical cancer occurrences between January 2013 and December 2017, Sykes et al found that the overall age-standardised rate for Māori was almost double (with 8.1 per 100,000 female population compared to 4.4 among non-Māori). Further, the peak of cervical cancer occurrences was among an older age group for Māori (45-49) compared to non-Māori (30-39); and Māori women with cancer lived in areas of lower socio-economic deprivation compared to non-Māori. This review had a low number of Pacific or Asian women and therefore analyses of these groups were not undertaken.

[18] Source: New Zealand Cancer Registry 2018. https://www.health.govt.nz/publication/new-cancer-registrations-2018. Accessed February 2021.

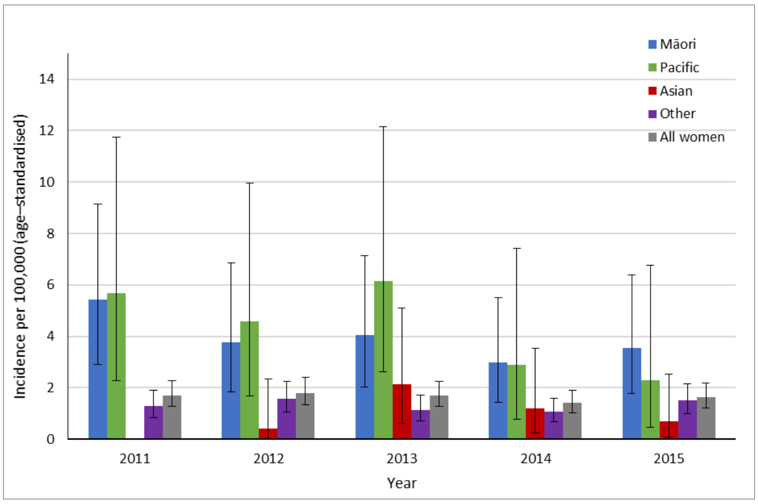

Figure 5: Age-standardised cervical cancer mortality rates by ethnicity, 2011–2015.

Source: NSU, 2020.[19]

Survival

Gurney et al (2020, 2020a) suggest that overall survival rates have improved. However, there are persistent disparities in survival rates between Māori and non-Māori. Figure 8 provides an overview of comparative (Māori and non-Māori) survival rates. For Māori, the excess mortality compared to non-Māori for cervical cancer was approximately 44%.

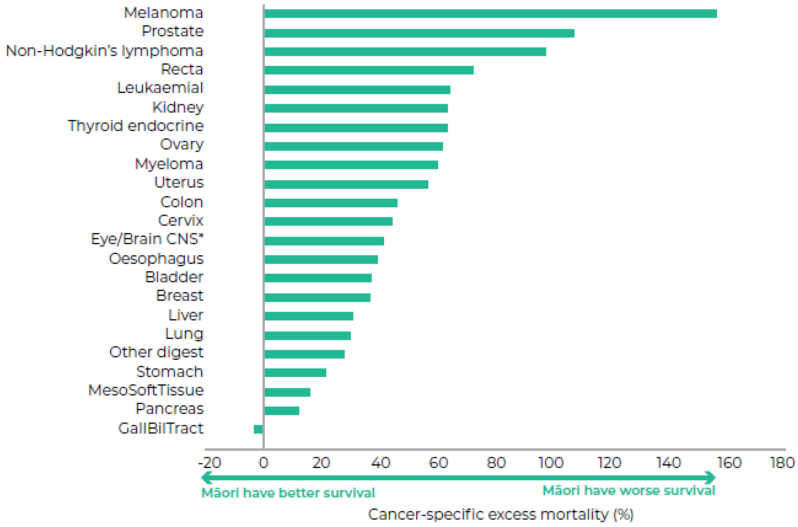

Figure 6: Survival disparity between Māori and non-Māori for the most common cancers among Māori, 2007–2016.

Source: Gurney et al 2020 as noted in Te Aho o Te Kahu, 2021

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[19] Note that vertical bars represent 95 percent confidence intervals, and no deaths were recorded for Asian people in 2011.

Breast cancer incidence, mortality, and survival – population outcome data

Incidence

Breast cancer is one of the most common cancers for women in Aotearoa (Te Aho o Te Kahu, 2021). It is the leading cause of non-tobacco-attributable cancer deaths (MoH, 2013). According to the Ministry (2019), since the introduction of the national breast screening programme, overall breast cancer mortality has reduced by approximately 30%. Recent evidence shows there may be a specific mortality benefit for women aged 70–74 years.

Over the last 20 years, breast cancer rates for all women have increased. The rate for Māori is consistently higher than for non-Māori:

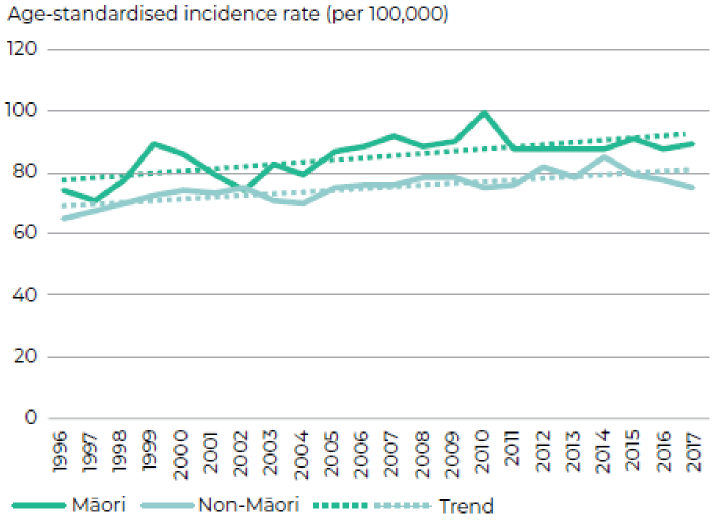

Figure 7: Female breast cancer incidence in Aotearoa, 1996–2017.

Source: Te Aho o Te Kahu, 2021.

Mortality Data

Data from 2010-2012 showed that Māori women had breast cancer registration rates at 1.4 times that of non-Māori. Furthermore, Māori women were 1.5 times more likely to die from breast cancer compared to non-Māori women (MoH, 2015). In 2018, Māori women had a breast cancer registration rate of 124.9 cases per 100,000 compared to 97.4 cases per 100,000 for non-Māori women[20]. A recent study in 2018 found that Māori and Pacific women were almost twice as likely to die from breast cancer when compared with non-Māori and non-Pacific women (Tin et al, 2018). This is consistent with previous studies in Aotearoa and internationally[21].

Cancer-related mortality for wāhine Māori has increased markedly over time, compared to New Zealand European/Other populations (Teng et al, 2016). Mortality rates for Māori compared to non-Māori, non-Pacific Peoples, and non-Asian were higher for most common cancers in Aotearoa. Wāhine Māori experience significant disparities linked to breast cancer mortality (Gurney et al, 2020). Disparities in incidence and mortality rates for wāhine Māori and Pacific women were also reported upon by Te Aho o Te Kahu (2021):

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[20] New Zealand Cancer Registry 2018.

[21] Ibid.

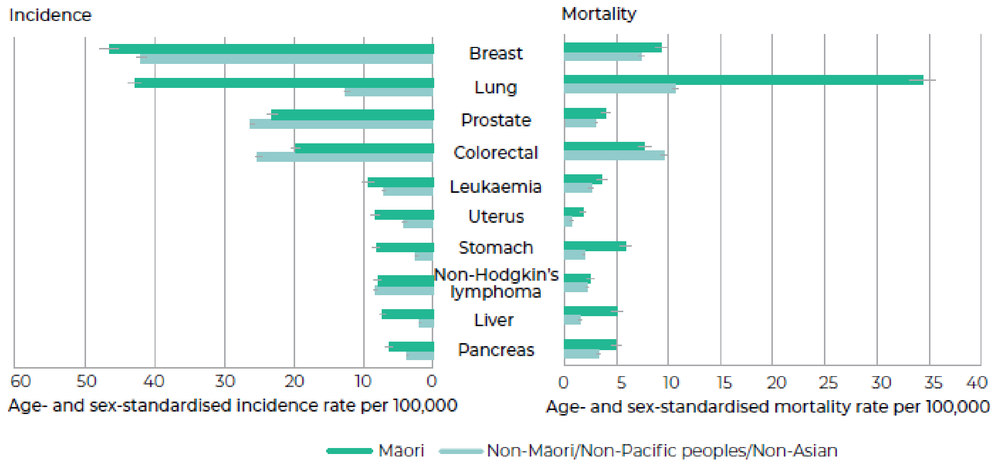

Figure 8: Māori specific age- and sex-standardised incidence and mortality data, 2007–2017.

Source: Te Aho o Te Kahu, 2021.

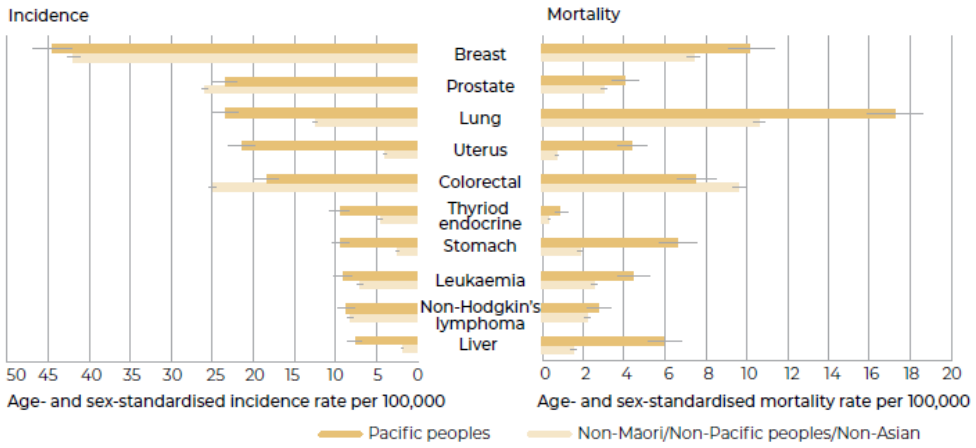

Figure 9: Pacific and non Pacific peoples-specific age- and sex-standardised incidence and mortality data, 2007–2017.

Source: Te Aho o Te Kahu, 2021.

One of the most common cancers for Asian peoples is breast cancer; although mortality and incidence rates are lower than non-Māori/non-Pacific/non-Asian (Te Aho te Kahu, 2021).

Survival

As noted for cervical cancer, Gurney et al (2020, 2020a) suggest that there are significant persistent disparities in survival rates between Māori and non-Māori. Figure 7 provides an overview of comparative (Māori and non-Māori) survival rates. For Māori, the excess mortality compared to non-Māori for breast cancer was 37%.

The breast and cervical screening landscape

The Funder - National Screening Unit, Ministry of Health

The National Screening Unit (NSU) of the Ministry of Health funds and manages multiple screening programmes in Aotearoa. The two most relevant for this evaluation are BreastScreen Aotearoa (BSA) and the National Cervical Screening Programme (NCSP). The NSU vision is “high-quality, equitable and accessible national screening programmes”. It is committed to meeting Te Tiriti o Waitangi obligations and tackling persistent inequities. The NSU has multiple functions, which range from national coordination, funding, and advice about national screening programmes to leading research and evaluation, designing policies, processes, and standards, building the screening workforce, and managing system and service performance. The Unit advocates for improved access to, and the effectiveness of, multiple screening programmes for eligible people.

The Unit has five national advisory groups comprising priority group women (wāhine Māori, Pacific, and Asian women), clinical and academic advisors. A representative of the Māori Monitoring and Equity Group (MMEG) was interviewed for this evaluation.

National Screening Programmes – NCSP & BSA

A brief overview of the National Cervical Screening Programme

The National Cervical Screening Programme (NCSP) was introduced in 1990 and is reinforced by its own legislation[22]. The purpose of NCSP is to reduce the incidence and mortality rate of cervical cancer for people/women in Aotearoa[23]. NCSP promotes regular (once every three years) screening, particularly to women between the ages of 25-69[24]. Screening is designed to pick up changes in precancerous squamous cells which, if not treated, may turn into cancer (NSU, 2020).

The national screening coverage rate target for all eligible women/people is 80%. Priority group women for NCSP are wāhine Māori, Pacific and Asian. Women who are unscreened or under-screened are also a priority[25]. In June 2018, Asian women were prioritised due to their growing population size and more recently, programme performance data is showing emerging disparities.

The cervical screening pathway has multiple components. It includes:

- An invitation to be screened
- Information about the procedure
- Enrolment in the NCSP Register

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[22] Part 4A, Health Act 1956 and the Health (National Cervical Screening Programme) Amendment Act (2004) supports the NCSP to co-ordinate and deliver a high-quality programme in Aotearoa.

[23] The term ‘people’ refers to a person with a cervix or vagina, who has been sexually active (ever) including people who are transgender or non-binary. Sexual orientation is irrelevant. The term People and Women are used interchangeably in this report.

[24] In general, when a woman has their very first cervical screening test or they have not had a cervical screening test within five years, a second cervical screening test is recommended within one year and then three-yearly after that if the results are normal. For women aged 70+, regular smears are recommended if they had a history of unscreened or under screened. For women aged under 25, if they have already been screened, they should be treated the same as the 26-69 group. The national guidelines (NSU, 2020) provide a range of flowcharts for clinicians to use as part of the programme’s quality assurance approach.

[25] Unscreened is defined as women who have either never been screened or have not been screened for five years. Under-screened is defined as women whose coverage and participation rates are well below those of the total eligible population.

- Information about the importance of regular screening, including the risk and benefits of participation
- A cervical screening test
- Receiving results
- Referral to colposcopy for follow-up and treatment if required

The table below provides a high-level summary of the cervical screening system (excluding SSS, health promotion, post-diagnosis treatment and the registry):

What	Role	Who
NCSP regional coordination	To lead the health sector to achieve an 80% target for cervical screening coverage. To work with primary health care to achieve equitable screening coverage for priority group women. To support coverage improvements for priority group women by using data.	15 District Health Boards
Cervical Smear or Sample Takers	To deliver cervical screening test services to all eligible women/people in Aotearoa.	~7,300 mainly General Practitioners and Nurses
Cytology, HPV and Histology testing services	To provide testing linked to cytology (cells), histology (tissue) and HPV.	7 Laboratories
Colposcopy	To provide colposcopy services to eligible women, including cervical screening and laboratory services for histology.	20 District Health Boards

Cervical screening can only be delivered by an accredited sample taker[26]. Most sample takers in New Zealand are Nurses or General Practitioners. According to the NSU, there are around 7,300 sample takers in Aotearoa. Subject to adherence to quality guidelines, a cervical screening test can be delivered in almost any location (e.g. at home, in a community-based clinic or setting, in a mobile unit, in a primary care practice).

NCSP performance data - cervical cancer screening coverage, particularly for priority group women

Many women are eligible to be screened. In 2020, this equated to over 1.3m women. Since 2006, the national screening coverage target has not been met. As of December 2020, the current overall 3-year coverage rate was 70.7%, a -9.3% gap to performance target.

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[26] For more information see https://www.nsu.govt.nz/health-professionals/national-cervical-screening-programme/ncsp-workforce/smear-takers. Accessed February 2021.

Programme coverage for priority group women is outlined below.

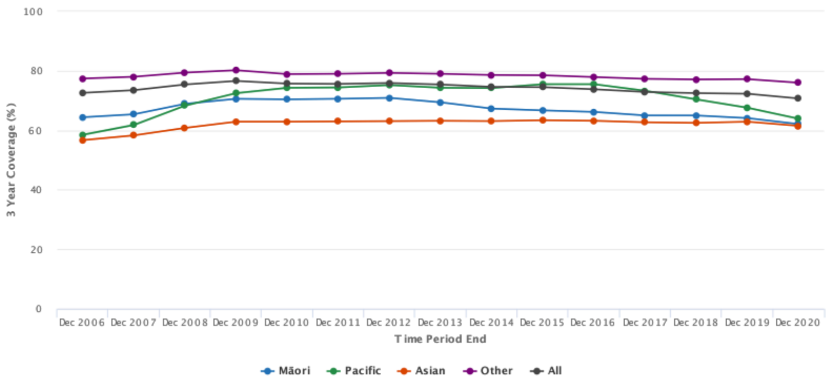

Figure 10: 3-year Coverage by Ethnicity, New Zealand, 25-69, Cervical, Dec 2006-Dec 2020.

Source: https://minhealthnz.shinyapps.io/nsu-ncsp-coverage/[27]

Since 2006, there have been consistent disparities in coverage. Pacific women generally have higher coverage than Māori and Asian women, and Asian women seem to have the lowest coverage. Although there was a convergence of 'low' coverage rates in December 2020.

Equity Matrix

The Ministry use an Equity Matrix to track NCSP performance. The matrix plots two measures, one for equity and one for programme performance. As defined by the NSU:

- **Performance** is the difference (percentage point) between the population of interest (i.e. wāhine Māori) and the programme target (80%)
- **Equity** is the difference (percentage point) between the performance of the population of interest (i.e. Māori) and the reference population (non-Māori, non-Pacific, and non-Asian women)[28]

As of December 2020, the equity and performance data targets for priority group women are summarised below. There are equity and programme performance gaps for all priority group women. Asian women have the largest disparity, followed by wāhine Māori and then Pacific women.

DHB	Ethnicity	Coverage	Gap to Equity (%)	Gap to Performance Target (%)
All	Māori	62.1	-14	-18
All	Pacific	63.9	-12	-16
All	Asian	61.5	-15	-19
All	Other	76.0	-	-
All	Total	70.7	-	-9.3

Table 1: Equity and performance matrix showing cervical screening coverage rate disparities for wāhine Māori, Pacific and Asian women compared to Other and Total, Dec 2020. All DHBs.

Source: https://minhealthnz.shinyapps.io/nsu-ncsp-coverage/[29]

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[27] Accessed 10 February 2021.

[28] Source: https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/. Accessed February 2021.

[29] Accessed 10 February 2021.

A brief overview of the BreastScreen Aotearoa programme

BreastScreen Aotearoa (BSA) was launched in 1998. The Ministry began managing the programme in 2000 (NSU, 2013). The purpose of BSA is to reduce breast cancer mortality in Aotearoa (MoH, 2015). BSA offers free mammograms and follow-up for asymptomatic women aged between 45-69 years[30]. Routine and regular screening is designed to identify cancer early to optimise survival.

The national screening coverage rate target is 70% for people aged between 50-69 years (for two-yearly screening). Priority group women for BSA are wāhine Māori and Pacific women.

The breast screening pathway has multiple components. It includes:

- screening promotion
- health education (i.e. breast cancer, screening, and treatment)
- identification and invitation of eligible people
- invitation and recall of people eligible for screening every two years
- mammography
- multidisciplinary assessment for screened women (i.e. clinical examination, ultrasound, biopsy, and pathology services)
- communication of screening results to people and their primary health care provider
- support and counselling for people who are being assessed
- referral to treatment for people with breast cancer
- an information system which supports the programme
- quality assurance, audit, monitoring and evaluation

The NSU contracts eight Lead Providers to deliver BSA. The providers are assigned areas to cover, which are determined by DHB boundaries. The BSA Lead Providers are contracted to:

- recruit and retain eligible people
- invite people for screening
- complete mammographic screening
- assess the screen
- refer people to treatment (where cancer is present)
- provide quality assurance

Mammographic screening requires expensive technology and can only be delivered in certain settings. This is usually in a centralised breast screening service (including those in DHBs and private providers) or in a mobile breast screening bus. Assessment is usually provided at a centralised location. Mammograms are delivered by a Medical Radiation Technologist (MRT). The MRT provides the screen and is accountable for providing an “acceptable screening experience”[31]. According to the NSU, for most women attending BSA, the MRT is the main health professional they interact with.

BSA programme performance data - breast cancer screening coverage, particularly for priority group women

Many women are eligible to be screened. In 2020, this equated to around 823,000 women. BSA aims to screen 70% of eligible women between 50-69 years (a subset of the total eligible age range of 45-

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[30] In July 2004, the age range was extended from 50-64 to 45-69 based on evidence of effectiveness

[31] Source: https://www.nsu.govt.nz/health-professionals/breastscreen-aotearoa/breastscreen-aotearoa-workforce/role-medical-radiation. Accessed February 2021.

69 years). There is no overall coverage target. Ministry of Health data to December 2020, showed that the national coverage target for women aged between 50-69 years was not met by 1.9 percentage points (68.1% compared to 70%)[32].

Programme coverage for priority group women is outlined below:

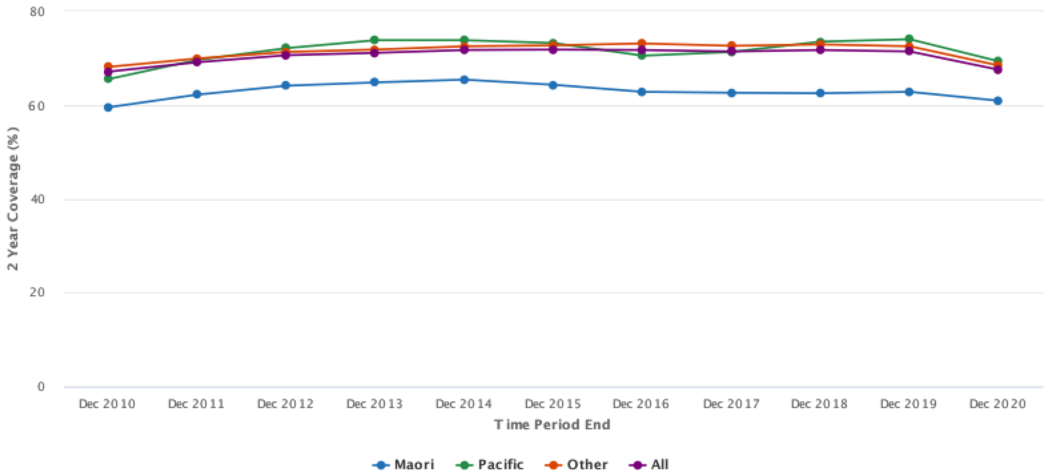

Figure 11: 2-year Coverage, BSA, All DHBs, By Ethnicity, 45-69 years, Breast, December 2010-December 2020.

Source: https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/[30]

Since 2010, there have been consistent disparities in coverage primarily for wāhine Māori. Wāhine Māori have consistently had the lowest coverage compared to All Other women over the last decade. In contrast, Pacific women have similar and sometimes slightly better coverage than All Other women. This is a welcome and positive result for Pacific women from an equity perspective.

Equity Matrix

As for NCSP, BSA uses an Equity Matrix to track performance. As of December 2020, there are gaps to equity and performance targets for wāhine Māori.

DHB	Ethnicity	Gap to Equity (%)	Gap to Performance Target (%)
All	Māori	-7	-9
All	Pacific	+1	-1

Table 2: Equity and performance matrix showing breast screening coverage rate disparities for wāhine Māori and Pacific women compared to Other and Total, Dec 2020. All DHBs.

In contrast, for Pacific women, the targets continue to progress in a positive direction. There was effectively no inequity for Pacific women. This is an excellent equity story for the BSA programme.

Relevant strategy and policy settings

Strategy and policy influence SSS, NCSP and BSA services and programmes. A brief synopsis of selected strategies and plans are outlined in Te Tāpiritanga Tuawhā. The documents summarised include the Health and Disability System Review 2019 and 2020, the New Zealand Cancer Action Plan 2019–2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029, Whakamaua – the National

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[32] Source: https://minhealthnz.shinyapps.io/nsu-bsa-coverage-dhb/ Accessed February 2021.

Māori Health Action Plan 2020-2025, 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018 and Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025, Wai 2575 – Health Services and Outcomes Kaupapa Inquiry and the Inquiry into health inequities for Māori: Report of the Māori Affairs Committee. Collectively, these documents support a future system that is pro-Tiriti, pro-equity and pro-high performance.

Literature on barriers, enablers, and what works

A summary of a literature is outlined in Te Tāpiritanga Tuatoru. The scan identifies barriers, enablers and what works for priority group women linked to both cervical and breast screening pathways. The scan has informed the findings and recommendations in this report.

WĀHANGA TUAWHĀ: SCREENING SUPPORT SERVICES

This section provides a detailed overview of breast and cervical Screening Support Services (SSS). It includes a summary of the SSS role, scope and function, a summary profile of the SSS providers and an overview of their collective impact between July 2017 to December 2020.

Purpose and roles

SSS services are one of several Ministry of Health strategies to improve outcomes and equity for priority group women. SSS have been funded for 18 years and the current SSS providers commenced in 2016. SSS prioritise screening support to wāhine Māori and Pacific for breast screening, and to all priority group women for cervical screening. For both screening pathways, SSS can also support any women who is unscreened or underscreened. The Ministry spends ~$3.5m on SSS.

As niche equity providers supporting the screening pathways, SSS are designed to make "a big difference to a small group of women" (NSU, 2020b, p.1). They have six objectives:

1. To increase access to screening for priority group women and deliver services in a culturally safe, flexible, and mobile way. SSS should provide women with choices.
2. To facilitate seamless access to screening services through collaboration.
3. To contribute to reducing equity gaps.
4. To empower women to engage with the health system with improved confidence and health literacy.
5. To support NCSP and BSA to reduce the social and financial burden of breast and cervical cancer.
6. To be innovative.

Key service components include:

Component	Description of what this may include
Improve access to services	• Support for enrolment and ongoing participation in screening pathways • Outreach screening • Collaboration with partner providers to improve referral processes to SSS • Receipt of referrals to support other providers that have difficulty reaching priority group women • Identifying new opportunities and approaches to reach priority group women • Providing alternative community-based, culturally safe screening for priority group women; particularly for those women not enrolled in a PHO or engaging with general practice
Provide support to improve access	• Providing personal support, e.g. emotional support • Providing practical support, e.g. transport or childcare • Providing information to ensure women are fully informed • Supporting women to provide informed consent
Develop collaborative working relationships	• Active engagement with provider partners • Supporting and/or lead regional and/or DHB specific screening projects • Inputting into DHB or regional BSA/NCSP coordination plans

Component	Description of what this may include
Refer priority group women to other services	- Referring women and their family to other health and social services as required
Build community awareness	- Implementing community awareness raising activities

Table 3: Contracted components of SSS

SSS provider overview

The NSU contracts with 12 SSS providers across the country. The table below summarises the SSS providers and their sub-contractors.

Some providers (i.e. Midlands Regional Health Network and Te Pou Matakana) are contracted to provide services across multiple DHB areas; one provider (Well Women Family Trust) is contracted to provide services across two DHB areas, and one DHB area has two SSS providers.

Most providers deliver services to support both breast and cervical cancer screening; two providers (BreastScreen Otago and He Waka Tapu) are contracted to deliver support to only one screening pathway.

A supplementary document is available which contains more detailed profiles of each provider. It is held by the Ministry and is available upon request.

There are no funded SSS services in Whanganui, Wairarapa, Nelson and West Coast DHB areas.

The table below summarises the type and distribution of screening support services:

Name	Provider Type	DHB Area(s)	Other Services based on 'lead' provider	Sub-contractor(s)	BSA Lead Provider	Breast	Cervical
1. Te Hāuora o Te Hiku o Te Ika	Kaupapa Māori Charitable Trust	Northland	Whānau ora Multiple sectors	Northland Pacific Island Charitable Trust Ki A Ora Ngatiwai Ngāti Hine Health Trust Te Hā o Te Oranga o Ngāti Whatua	BS Waitemata Northland	✓	✓
2. Well Women & Family Trust	Charitable Trust	Auckland Waitemata		-	BS Auckland Ltd	✓	✓
3. Counties Manukau Health	DHB	Counties Manukau	NCSP Co-ordinator BSA Lead Provider Colposcopy	-	BS Counties Manukau	✓	✓
4. Midlands Regional Health Network (#1)	Charitable Trust (co-owned by a PHO and two Māori organisations)	Waikato		Ngā Miro Health South Waikato Pacific Health Raukawa Charitable Trust Taumaranui Community Kokiri Trust Otorohanga Support House Whare	BS Midland	✓	✓
Midland Regional Health Network (#2)	PHO	Taranaki		Te Rere o Te Manu	BS Coast to Coast	✓	-
5. Hauraki PHO	PHO	Waikato		-	BS Midland	✓	✓
6. Bay of Plenty DHB	DHB	Bay of Plenty	Colposcopy	Western BOP PHO	BS Midland	✓	✓
7. Te Pou Matakana (#1)	Whānau Ora Commissioning Agency	Tairāwhiti	Whānau Ora Multiple sectors	Te Runanga o Ngāti Porou Turanga Health Ngāti Porou Hauora	BS Coast to Coast	✓	✓
Te Pou Matakana (#2)		MidCentral		Te Tihi o Ruahine Whānau Ora Collective Rangitāne o Tamaki nui a Rua	BS Coast to Coast	✓	✓
Te Pou Matakana (#3)		Lakes		Te Arawa Whānau Ora Collective Tuwharetoa Health Charitable Trust	BS Midland	✓	✓

8. Hawkes Bay DHB	DHB	Hawkes Bay	NCSP Co-ordinator BSA Lead Provider Colposcopy	Kahungunu Executive Te Kupenga Hauora Ahuriri Choices Te Taiwhenua o Heretaunga	BS Coast to Coast	✓	✓
9. Mana Wāhine Alliance	Kaupapa Māori NGO	Capital Coast Hutt Valley	Multiple sectors	Ora Toa Health Unit Koraunui Marae Te Turuma Hauora Hora Te Pia Health Services Kokiri Marae Health & Social Services	BS Central	✓	✓
10. Central Pacific Collective	Pacific NGO	Capital Coast Hutt Valley	Multiple sectors	Pacific Health Service Hutt Valley Inc. Pacific Health Service Porirua Inc. Atamu EFKS Inc.	BS Central	✓	✓
11. He Waka Tapu	Kaupapa Māori NGO	Canterbury	Multiple sectors Whānau Ora	-		-	✓
12. BreastScreen Otago	Private Provider	Southern	BSA Lead Provider	-	BS Otago South	✓	

Table 4: Summary of SSS providers across Aotearoa by DHB area and type of cancer pathway supported. December 2020.

Outcomes and better off data

The SSS outcome framework is outlined on p.22 of this report. SSS are contracted to deliver three outcomes – equitable access to screening, equitable and timely access to diagnosis and results for cervical and breast screening (Table 5). These client outcomes are measured by Better Off performance data, as summarised below:

Narrative description	Better off performance measure
Equitable access to screening	#/% of successfully contacted priority group women (referred or identified[33]) who were screened / ethnicity
Equitable and timely access to diagnosis and results - cervical	#/% of priority group women who attend their colposcopy appointments
Equitable and timely access to diagnosis and results - breast	#/% of priority group women who attend their BSA assessment and/or results appointment

Table 5: Summary of Better Off performance measures and contractual targets

SSS providers have contractual performance targets. The initial targets were based on:

- **BSA** – 20% of the shortfall needed to reach the target of 70% coverage in the DHB area for priority group women
- **NCSP** - 15% of the shortfall needed to reach the target of 80% coverage in the DHB area for priority group women

SSS performance and effectiveness

Performance monitoring data was analysed over three financial years: 2017-2018, 2018-2019 and 2019-2020. Collectively, SSS providers have supported tens of thousands of women over the last 3 years. A summary of collective data is outlined below.

Data category	Summary of metrics
How much service was delivered across all providers?	• "How much" data measured the quantity of provider effort. • In this case, the measure was linked to clients of the support services. • Over the last three years, approximately 144,000 women in total had been referred to, or identified for, support services. • Of those 144,000 women, 57,000 (40%) required support for breast cancer screening, and 87,000 (60%) required support for cervical screening. • Most of the women were wāhine Māori 52.4% (75482/144175), followed by Other 19.0%, (27445/144175), Pacific 16.4%, 23653/144175) and Asian 12.2%, (17595/144175).
How well were all services delivered?	• "How well" data measured the quality of provider effort. • In this case, the measure was linked to the quality of engagement with priority group women and the provider's ability to successfully engage women in the screening pathway process.

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[33] Referred women relate to women who are referred to SSS from external providers. Identified women relate to women who are referred to SSS from within the SSS provider (internally).

Data category	Summary of metrics
	• Over the last three years, on average, 50% (72295/144175) of women referred or identified were successfully contacted and, therefore, engaged in the screening pathway of their choice. • By ethnicity, engagement success has varied. SSS was most successful engaging with Māori women (54%, 39012/72295), followed by Other 18% (12843/72295), Asian (14%, 10114/72295) and Pacific women (14%, 10326/72295).
Are priority group women better off?	• Ae/Yes. • “Better off” data represents the quality and quantity of provider effectiveness. • In this case, the measure is focused on the proportion of priority group women who were screened. • If women were screened, they were Better Off. • Combined, the SSS providers significantly exceeded their contractual breast screening targets by 290% (16689/5755). • For cervical, the providers did not fully meet the target but delivered nearly 18,000 screens and achieved 87% of the target (17855/20466).

Table 6: A summary of RBA performance data for all SSS providers

Tāpiritanga Tuarima sets out a detailed data table aggregated for all providers between 2017-2020.

Tables 7 and 8 provide a snapshot of outcome data for individual providers for breast and cervical screening. They use traffic lights to show performance against outcome-focused contractual targets.

For clarity, there are 14 providers noted (although there are 11 unique providers of SSS for breast and cervical). There are 14 providers in the tables below because one unique provider reported data by three distinct areas and one provider reported one set of data for two areas. One provider was excluded from the analysis in Table 7 as it did not have targets.

Provider	Target 2017-18	Target 2018-19	Target 2019-20	Actual # 2017-18	Actual # 2018-19	Actual # 2019-20	Actual % 2017-18	Actual % 2018-19	Actual % 2019-20	Actual % over 2017-2020
A	123	123	123	1932	1455	1228	1571%	1183%	998%	1251%
B	154	360	360	567	739	528	368%	205%	147%	210%
C	52	152	152	203	359	91	390%	236%	60%	183%
D	52	150	150	875	905	882	1683%	603%	588%	756%
E	86	86	86	23	33	37	27%	38%	43%	36%
F	N/A	N/A	N/A	0	0	14	N/A	N/A	N/A	N/A
G	213	150	150	112	180	280	53%	120%	187%	112%
H	64	150	150	140	56	0	219%	37%	0%	54%
I	159	292	292	338	498	234	213%	171%	80%	144%
J	107	257	257	490	323	257	458%	126%	100%	172%
K	52	52	52	0	204	198	0%	392%	381%	258%
L	52	150	150	189	106	25	363%	71%	17%	91%
M	52	150	150	93	149	500	179%	99%	333%	211%
N	85	180	180	691	984	771	813%	547%	428%	550%
TOTAL	**1251**	**2252**	**2252**	**5653**	**5991**	**5045**	**452%**	**266%**	**224%**	**290%**
							101+%	**100%**	**75-99%**	**74% and under**

Table 7: # priority group women screened, per financial year, 2017-2020, by SSS provider, by contractual targets, Breast screening.

With respect to breast screening:

- 77% (10/13) of providers **achieved** their overall target. Some providers exceeded their targets by significant proportions
- 23% (3/13) of providers **did not achieve** their overall targets

- 38% (5/13 providers) **consistently achieved** their targets, **year on year**
- 8% (1/13) providers **did not achieve** any targets, year on year

Table 8 presents data for cervical screening:

Provider	Target 2017-18	Target 2018-19	Target 2019-20	Actual # 2017-18	Actual # 2018-19	Actual # 2019-20	Actual % 2017-18	Actual % 2018-19	Actual % 2019-20	Actual % over 2017-2020
A	1105	1105	1105	1236	1945	982	112%	176%	89%	126%
B	336	372	372	463	794	386	138%	213%	104%	152%
C	336	336	336	278	529	161	83%	157%	48%	96%
D	336	400	400	1013	383	297	301%	96%	74%	149%
E	396	396	396	483	325	178	122%	82%	45%	83%
F	500	440	440	0	0	318	0%	0%	72%	23%
G	2366	1500	1500	472	1541	1556	20%	103%	104%	67%
H	296	296	296	126	117	44	43%	40%	15%	32%
I	325	325	325	265	366	248	82%	113%	76%	90%
J	325	325	325	266	215	228	82%	66%	70%	73%
K	220	220	220	0	20	194	0%	9%	88%	32%
L	250	250	250	255	211	430	102%	84%	172%	119%
M	285	285	285	610	250	208	214%	88%	73%	125%
N	320	285	285	163	115	184	51%	40%	65%	52%
TOTAL	**7396**	**6535**	**6535**	**5630**	**6811**	**5414**	**76%**	**104%**	**83%**	**87%**
							101+%	**100%**	**75-99%**	**74% and under**

Table 8: # priority group women screened, per financial year, 2017-2020, by SSS provider, by contractual targets, Cervical Screening.

With respect to cervical screening:

- 36% (5/14) of providers **achieved** their overall target
- 64% (9/14) of providers **did not achieve** their overall targets. However, 21% (3/14) of the providers were **close to achieving** their targets at between 83-96%
- 7% (1/14) of providers **achieved** their targets, **year on year**
- 36% (5/14) of providers **did not achieve** any of their targets, **year on year**

Partner Provider views of SSS

Partner Providers are providers who work with SSS across NCSP and BSA. Partner providers were surveyed and asked to provide their views about SSS, and how to improve SSS and the screening pathways. Partner Providers included NCSP Coordinators, BSA Lead Providers, PHOs, Colposcopy services and other respondents who had asked to be part of the survey. Seventy-one respondents were invited to complete the survey. 33 out of 71 providers responded (a survey response rate of 46%). Most respondents were engaged in the cervical screening pathway compared to breast screening.

Insights

Overall, respondents valued the role SSS had to play, and some provided advice about future system and service improvements. The following are insights based on responses, and where appropriate, they are ranked according to the magnitude of the response[34]:

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[34] Note that denominators vary based on how many respondents answered the questions.

	Majority	Many	Minority
	More than 75%	Between 50-74%	Less than 49%
1. **Working partnerships** with SSS providers are **'Good or Very Good'** (**20/24, 83%).**	✓		
2. It is important that all **priority group women continue to be a focus** for SSS (83-87%)[35]	✓		
3. SSS services **contribute to equitable access, experience, and outcomes** for priority group women (regardless of ethnicity or pathway). (81/109, 74%)		✓	
4. SSS **should be expanded to include bowel screening** (73%, 16/22)		✓	
5. **Overarching pathways meet** priority group women needs (breast screening - **48%, 15/31** and c**ervical screening - 46%, 36/78**).			✓

Partner Providers offered several suggestions about how to improve SSS. The 'top 5' suggestions are outlined below and ranked from the most to least common suggestions[36].

1. **Flexible screening options** - must be provided to meet multiple priority group women needs. Options suggested included (more) community-based clinics, after-hours clinics, in-home visits, and transportation.
2. **More resources** - required to support effective screening pathways tailored to priority group women. Example resources included time, money, staff, and training.
3. **Understand the pros and cons of prioritising priority group women** – some respondents suggested that focusing on existing priority groups 'distracted' from providing support to other women in need (e.g. women at greater clinical risk and 'other' hard to reach women). Conversely, some respondents were concerned that priority groups were not adequately prioritised or catered for; and that some ethnicities within priority groups were emphasised over others.
4. **Better use of data** - improving access to and the flow of data across screening pathways was important.
5. **Improved SSS capability** - more needs to be done to improve SSS capability (i.e. poor visibility or systems), which may include greater flexibility about who can provide SSS, such as more provision by DHBs or BSA Lead Providers.

Bowel Screening

Partner Providers were very positive about SSS providing bowel screening support. There were, however, some caveats. Respondents emphasised the importance of maximising opportunities to support priority group women; this included priority group women family/whānau. Some respondents' shared concerns about men being part of SSS, and the potential impact of a male presence on an otherwise female service. It was also suggested that more resources and support

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[35] 83% of respondents agreed for both Pacific and Asian women; 87% agreed for wāhine Māori.

[36] The first two themes were each present in approximately 25% of responses, and the next three most common themes were each present in more than 10% of all responses.

were required to adequately provide bowel screening support, in addition to breast and cervical screening support.

WĀHANGA RIMA: THEMATIC ANALYSIS

This section outlines themes from interviews with priority group women, experts, SSS providers and the Ministry. The data set is rich, diverse and of a substantial size. Interviewees were asked a range of process and outcome focused questions aligned to the evaluation objectives. They were asked to provide their views about what works, what does not work and what could work in the future.

Questions were focused on SSS. However, interviewees spoke about SSS, NCSP, BSA, other Provider Partners, the broader screening, and other systems. Primarily because SSS is not delivered in isolation and successful screening delivery is reliant on more than effective SSS. Where themes are specific to SSS, we have tried to make that clear. Otherwise, themes are specific to multiple providers and the system. Also, most themes apply to both breast and cervical screening, however some are specific to a pathway.

Quotes are colour-coded for ease of reading. The green font are quotes from priority group women, orange font are quotes from SSS providers, purple font are quotes from subject matter experts and blue are quotes from the Ministry of Health.

Four core themes

Thematic analysis generated four main themes:

1. **Caring and authentic relationships with priority group women**
2. **Women and whānau-centred models**
3. **Cultural safety**
4. **Proactive partnerships**

Theme 1: Caring and authentic relationships with priority group women

Caring relationships are essential to screening. Explanatory factors linked to this theme are summarised below.

Caring and authentic relationships

- Negative experiences compromise care
- Quality care is based on values, strengths and relationships
- Building rapport breaks down barriers
- The way you contact women matters
- 'Building up' women incresaes knowledge, confidence and supports motivation

Negative experiences compromise care

Common negative experiences are exposure to racism; unfriendly staff and services; feeling judged; lack of aroha; lack of respect for dignity and modesty; and culturally unsafe services. Screening, especially cervical screening, could prompt feelings of whakamā and shame. This was particularly so for Māori and Pacific women.

> *"My first mammogram, I didn't know that... I was going to take my bra and everything off and put my boob in on a thing and they were going to compress it. I didn't know that was gonna happen." - Priority Group Woman.*

For women who have experienced trauma, cervical screening could trigger feelings associated with sexual abuse.

> *"[It] can be off putting if they don't acknowledge that where someone's been in their history, the mamae that they've been through. It's usually the ones that have had sexual abuse that... struggle a little bit more [so it's important to find] out their background as to why wāhine won't have it at the start." - SSS Provider.*
>
> *"Historical trauma is one of the barriers, right? And experiences accessing health services. So, you know, there's some really bad experiences, if not their own then their mother's, their sister's. As whānau, we share our stories, whether they're good or bad... we know that trauma impacts on the sisters, [it's] wider reaching, it's not just specific to this." - SSS Provider.*

Wāhine Māori and Pacific women spoke of cultural and spiritual discomfort during universal cervical screening experiences. Cultural discomfort is linked to services not understanding or valuing a woman's culture. For wāhine Māori, this can be linked to services not understanding or adjusting screening processes to acknowledge cultural concepts such as Te Whare Tangata.

> *"The biggest challenge, and especially for our Māori women and our Pacific women, is the nature of the [cervical screening] itself. It's the fact that it is an invasive test. They do need to expose their area of the body that they don't normally go around exposing to a stranger in a brightly lit room." - SSS Provider.*

Some interviewees described screening as transactional and impersonal. For cervical screening, services were described as cold, sterile, and uncaring with a physically rough approach and inattention to discomfort. For breast screening, services were described as painful, uncomfortable, with no rapport building. In these cases, services were transactional and impersonal.

Screening literacy is a barrier. Interviewees spoke of a general lack of awareness about services; screening procedures; what results mean; and how to navigate the healthcare system (particularly for new migrants); and fear. If whānau had a negative experience, this also influenced women's views. This was particularly so, for wāhine Māori and Pacific women.

Quality care is based on values, strengths, and relationships

Examples of values-based care include:

- Whanaungatanga – take a genuine interest, share about oneself, and connect as women rather than as a professional and patient.
- Aroha - for women and their whānau, and a passion for their wellbeing. Truly valuing the woman.
- Manaakitanga – is a way of showing aroha inclusive of acts of caring, support, and valuing women. This included kai, and support for issues outside of screening. Making women feel special was important. For example, small gifts or koha for women after screening acknowledged their value and the decision to be screened.
- Rangatiratanga - respect and honour women and their families.

Examples of relationship-based or relational care include:

- Treat women as a whole person: understand and pay attention to other priorities, needs and aspirations for herself and her whānau.

- Listen and understand women's barriers to screening, offer as much time as they need, validate thoughts, feelings, and experiences, reassure and address fears.
- Provide a judgment-free environment, including when women choose not to engage, or cancel appointments.
- Respect mana and agency – encourage women but do not force them. This includes commitment and perseverance to make the first contact, to build a relationship, and to persuade women to be screened. Find the balance between encouragement but not pressure.
- Protect dignity with the use of gown and pay attention to discomfort, including the size and use of the speculum for cervical screening.

Examples of strengths-based care include:

- Use positive language to frame screening such as valuing herself; being healthy; for whakapapa rather than fear or obligation.
- Recognise the mana and dignity of women and their families/whānau.
- Treat women as individuals, with individual preferences and needs.
- Use humour (where appropriate).
- Offer choices, e.g. group-based screening.
- Respect cultural preferences.

> *"'I felt valued, I felt that my voice was heard, I felt important'. Those are the things that I talk about when I mean 'mana enhancing', and I think what we do is... an inspirational approach allows us to foster a mana enhancing approach when working with whānau, and we recognise some of the issues that they deal with on a day-to-day basis, so we don't judge them." - SSS Provider.*

Building rapport breaks down barriers

Rapport was described as essential to success. Examples of how SSS providers build rapport with women include: offering an all-female staff; having the 'right' staff member for women and their whānau or referring to a colleague if needed; ensuring cultural and language matches (including te reo, native language speakers or interpreters for women who were not fluent in English) and providing a consistent person and team.

> *"Aroha has a lot of meanings towards that. So, it's about making our woman feel that they are important because they are and to encourage them to attend these appointments. It could be 20 times before they decide to go to those appointments, but the thing is with mana wāhine we come from this the real mauri of woman." - SSS Provider.*

The way you contact women matters

SSS providers emphasised it was important to make women feel comfortable and valued from the outset of their SSS journey. Example approaches include matching women with staff who could speak their language; a personalised phone call to build rapport or a home visit if appropriate; multiple forms of communication that work for the woman; making the first contact at times that suit women (e.g. phone calls after hours or visiting the home during the day or after business hours); making the first contact through other organisations that have an existing relationship with the woman; locating and engaging referred women through community or hapū networks. This last point was especially true for Kaupapa Māori and smaller providers.

> *"She genuinely cares about you and your wellbeing and getting you there... She treats you like an individual, not just a statistic. She does it because she enjoys doing what she is doing. It's like a friend from way back that you never met." - Priority Group Woman.*

> *"I found her persistence was really great. She persisted; she didn't give up. I had been getting mammograms from other people and I just go 'I am not coming in'. I hang up and that's it." - Priority Group Woman.*

'Building up' women increased knowledge, confidence, and supported motivation

Interviewees, particularly those in Kaupapa Māori and smaller service providers, describe 'building up' women they work with to restore a sense of their own value and self-worth.

> *"You need someone like [SSS staff] to build your esteem to come along to these things. Otherwise, we just switch off and say 'oh, nah, we're all right, we don't want to flop our tits out and do all this squishy squashy stuff'." - Priority Group Woman.*

'Building up' includes the following:

Building knowledge of…	**Building confidence in…**	**Identifying motivators…**
• Reproductive system • HPV - minimising stigma associated with screening • Importance of screening • Screening procedures • What results mean • Interventions • Services available (for screening and more generally)	• Navigating services • Rights and entitlements • Engaging in screening • Engaging with primary care • Engaging with health and social services more generally • Advocating for herself	• The woman's own sense of value and looking after her health (particularly for Māori women) • Whakapapa • Mokopuna • Family • Whānau experience with cervical cancer • A role model • Incentives or koha - for some women it meant putting kai on the table that night

> *"Talking on behalf of my daughter was the voucher that pushed her over the line, because she's always bad experiences with her screenings. But the gift card pushed her over the line for sure, that extra twenty bucks to put kai on the table." - Priority Group Woman.*

Theme 2: Women and whānau-centred models

Women- and whānau-centred models are the antithesis of provider-centric delivery. These models meet women's needs, preferences and acknowledge their context. One notable factor is engaging with women based on the norms of their community and culture.

> *"I have to acknowledge the service because I had an abnormal reading at the beginning of the year. And because of my family history, they removed my ovaries and part of my fallopian tubes as a precautionary measure. So, yes, [if] I'd been*

> *somewhere else I would have been avoiding it... I could have ended up in the same fate as my mother [dying from cervical cancer]." - Priority Group Woman.*

Explanatory factors are summarised below.

Women- and whānau-centered models	Access barriers exist
	'Life' barriers exist
	Flexible models of care

Access barriers exist

Interviewees describe access barriers predominantly linked to the system and service delivery processes. Examples include failure to understand women's needs; provider-centricity; difficulty navigating a complex health system; ineffective communication (texts or letters that do not reach women); difficulty arranging or rearranging appointments; difficulty accessing services due to rurality; long waiting times; affordability issues (co-pays for cervical screening); disability unfriendly services; and limited choice of screening locations, times, and providers.

> *"After the [cervical smear] I have bleeding for three days. I am very reluctant to do the same test. And then I heard [about SSS provider]. The next time I choose to [screen] with them, that experience is totally different. 'Feel anything? Any pain?' Yeah, maybe a little bit, but not painful at all." - Priority Group Woman.*

SSS providers spoke of poor quality, complex and unwarranted variation in referral pathways. Poor processes create access barriers[37]. Examples include:

- Variation in the quality of referrals – some referrals are incorrect, out of date, for women who are ineligible (they have had a hysterectomy or passed on) or short-notice.
- Poor quality pre-referral engagement processes - these include referrers using communication or engagement processes that were not conducive to building relationships, e.g. letters not received; automated reminders or no reminders when letters are unanswered; impersonal processes which result in 'did not attend'; large volumes of paper referrals to SSS providers[38].
- Technology gaps and registry issues **–** examples include lack of system-wide data sharing, poor quality screening registers and an inability to match women's data across the registers, DHB and PHO patient management systems. Most SSS providers reported they did not have direct access to registries, technology, or resources to data match, compared to larger organisations such as DHBs and BSA Lead Providers. This led to several SSS providers managing large volumes of paper-based referrals which impacts on time available to deliver frontline services.

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[37] SSS providers receive external referrals (from primary care practices, breast screening providers, colposcopy clinics, DHB screening coordinators, via data shared from breast and cervical screening registers) and internal referrals from their own client databases.

[38] SSS providers noted that some referrers have subsequently improved their processes. For example, a breast screening provider piloted phone calls to priority group women to reduce referrals to SSS.

> *"[DNR referral forms] come at the beginning of each month, they can be anywhere from 80 to... 150 a month. They come as a paper copy. And so, the pile arrives, it's really admin intensive... They need to be [entered] manually, every single one. And then they need to be allocated to the person, which is normally the administrator, to deal with... Sometimes the phone numbers might not be correct, so then we need to go to the GP clinics, and see if they have different information." - SSS Provider.*

Some SSS providers discussed the possibility of introducing referral thresholds. 'Low' thresholds comprise women with low levels of complexity, and limited effort is required to ensure a successful screen. 'High' thresholds relate to women who have multiple unmet needs. Considerable effort is required to ensure a successful screen. This may be a way to streamline effort.

Some SSS providers accept referrals for ineligible women. The eligibility criteria for SSS have caused some tension for providers, as they are loathe to decline women. In some cases, ineligible women are fully engaged but not necessarily reported to the Ministry.

Interviewees also spoke of rurality as an access barrier. This includes distance to services and limited choice of services.

'Life' barriers exist

Screening is not always a top priority for women due to competing needs. Interviewees describe a number of 'life barriers' that compete with a decision to screen. Life barriers include the ongoing impact of trauma and disadvantage; work; whānau commitments; dealing with abuse, no kai, unstable housing, lack of income; and consequent lack of motivation to engage with services that do not offer positive experiences.

> *"Our barriers here, they're across the board, from economic, socio, business, single parenting, transport, timing. Some women are working, some women are the ones that are bringing the bread to the table." - SSS Provider.*

Flexible models of care

Inflexible models of care are rigid, institutional, and authoritarian. Some interviewees said breast screening is inflexible. For example, providers refusing to offer appointments after 3.30 pm, or not accepting drop-ins at a mobile bus in a rural community, or experiences of institutional racism.

> *"The [screening provider said] appointments are finishing at 3:30. That was the latest appointment... That was the only thing that was stopping [women] from coming." - SSS Provider.*

> *"My view is that breast screening is provider-driven and cervical screening is more whānau or person-centric." - Subject Matter Expert.*

There are examples of positive SSS provider experiences with BSA including trialling a more accessible booking system to meet priority group women needs[39]; protecting appointments for priority group women; offering a choice of times within business hours; creating the ability to rearrange appointments; and co-facilitating access to mobile screening.

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[39] In one area, a new electronic system was being trialled which allowed a SSS provider to directly book breast screening appointments reserved for priority group women.

> *"The breast clinic has had very quite authoritarian approach. In the past, they were only available 'this, this and this'. They have changed the rule. So, they say, 'Get hold us when you make the appointment and then tell us when you can get around'... working around the woman rather than working around the clinic." - SSS Provider.*

Flexible services offer women genuine choices. Examples of flexible and accessible SSS services include:

- Cultural and language specific services.
- Easy ways to book appointments.
- Practical assistance to attend the screening – which includes transport; support to attend specialist diagnosis or treatment; childcare; access to low or no cost cervical screening[40]; a support person along the pathway; advocacy and support to navigate the system.

> *"We've got a six-hour round trip that we have to make from [rural area to specialists] so our support ladies [do a] three-hour drive [to the] appointment then three hours back." -SSS Provider*

- Visible SSS services to ensure women know about and can access SSS – this includes community engagement and networking; service and screening champions; female health promoters of diverse ethnicities; word of mouth; social media; information pamphlets (culture and language-specific); use of other organisation’s networks to connect with women; and educating primary care practices.
- Easy access for women who are not formally referred – this includes screening whānau and friends of priority group women, including women in the same household; intergenerational engagement for screening through Kaupapa Māori and Pacific approaches; screening women through outreach into community groups (cervical); opportunistic screens[41]; women screened through successful outreach in rural areas and running a competition between primary care practices in screening month to get as many priority group women screened as possible.
- Planned, opportunistic, and home-based clinics for cervical screening.

Planned, opportunistic and home-based cervical screening clinics are good examples of current flexible delivery. Planned clinics are delivered after-hours, as drop-ins and they are culture- and language-specific. At these clinics, some SSS providers offer a choice of screening staff (gender and ethnicity) and locations such as community venues; marae; places of worship; various primary care centres and large, well-known primary and secondary health centres.

> *"We start our clinics at eight o'clock in the morning, so they can come before work if they're working. We have clinics until seven o'clock at night, so they can come after work, even on the Friday night, and... we've got them all over the place." - SSS Provider.*

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[40] Breast screening is free.

[41] A SSS provider provides opportunistic screening at Waitangi, Northland. They described a wāhine Māori who had a breast screen at a mobile bus, The screen detected cancer in an early stage. Her shared experience motivated other wāhine to be screened the following years. They were motivated by her story and her experience.

Opportunistic clinics are one-off and delivered in multiple settings such as playgroups, workplaces, women's refuge; special events (i.e. one event was put on for formerly incarcerated women); widely advertised drop-in environments; at holistic health 'promotional days' and marae.

> *"We'll go to the Samoan playgroup, [colleague] might go and talk to them... and then I might come on the second or third visit and we'll set up a clinic next door, and the mums will look after each other's kids, and they'll nip next door and have their cervical smear." - SSS Provider.*

Home-based screening is based upon a woman's preference. Women describe this experience very positively. It is comfortable, culturally safe, convenient and less anxiety-provoking. Cervical screening at home is particularly important to wāhine Māori and Pacific women,

> *"When you go into the doctors, they're just being professional – but body is not respected. At home, they respect you and your body." - Priority Group Woman.*

> *"... Kaiawhina know who the women are, they're familiar with the culture, with the Māori world, the Māori values, they have the networks, the relationships, and they're comfortable … navigating that world." - MoH Interviewee.*

Theme 3: Cultural Safety

Cultural Safety requires providers and practitioners to understand and tackle personal biases, mental models and behaviours that negatively impact on others (overtly or covertly). This includes tackling racism, prejudice, conscious and unconscious biases. SSS providers and other system partners are committed to implementing Cultural Safety, but more work is required. Explanatory factors linked to this theme are summarised below.

Cultural Safety

- System failures exacerbate peristent inequities
- Systemic racism
- Lack of Cultural Safety is a significant barrier
- Cultturally safe services should be the status quo
- Honouring Mana Wāhine
- Honouring Pacific Women

System failures exacerbate persistent inequities

Some interviewees said inequity was accepted in the health system. Strategies to address inequity had failed and there was minimal change. At the national level, some interviewees also said that equity was given "lip service" and that the wider health system structure has led to a "failure for equity". System structural issues include services are siloed, focused on the individual, transactional, difficult to navigate, and rigid.

For some, the current primary care model is viewed as incongruent with equity as it perpetuates private ownership interests over women-centred needs; healthcare professionals lack time to engage with patients and this results in cold and transactional services. Universal screening models in primary care are viewed as the major driver of inequities in screening.

Interviewees cautioned against 'tack on' efforts to reduce barriers and address equity. They sought meaningful action or change rather than perceived 'tack on' efforts to engage Māori and other priority group women.

> *"Our history is to set up a national screening program and add on some things to brown it up a little." - Subject Matter Expert.*

> *"Once we've set up this population screening, then we'll get on to the Māori bit." - Subject Matter Expert.*

Systemic racism

Interviewees suggest that systemic racism is embedded in society and creates a cumulative disadvantage for wāhine Māori (and other non-Pākehā ethnicities and cultures). Interviewees spoke about the intergenerational trauma of colonisation (a practical expression of racism), racist narratives, and how colonisation causes cultural disconnection and socio-economic disadvantage.

> *"There should be dedicated resource put in to help improve access, experience and outcomes for priority women. I'd expect a dedicated team to be focusing on it. And it's... also looking within the [screening] provider because otherwise, how do you address these issues that people might choose to not admit around the institutional racism? The service needs to start within to look at itself to see what they can be doing differently." - MoH interviewee*

Interviewees spoke of wāhine Māori being the subject of racist public discourse and treatment.

> *"Public discourse shapes this narrative about Māori, you know, like they're uneducated, and they're unemployed, and they're on the benefit, and they have too many kids, and they smoke and they're pregnant, and they drink when they're pregnant. And you know, there's this constant bombardment of Māori women, that society somehow positions them as less worthy." - Subject Matter Expert.*

Interviewees said that systemic racism contributes to inequity. Examples of systemic racism (which are specific to the screening system and broader societal issues) 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 and being asked to validate achievements in the absence of similar challenges to non-Māori providers.

According to interviewees, wāhine Māori are more likely to experience poor outcomes in breast and cervical cancer partly due to cumulative disadvantage in the broader cancer pathways. Eliminating disparities between wāhine Māori and others require strong quality improvement approaches that 'design out' unfair or avoidable variability.

> *"What most of the Māori cancer experts will talk about is that we need strong quality improvement approaches where we design out … variability at every step along the pathway. And that's actually what happened for a while with breast cancer, which is why the symptomatic pathway was actually producing better results for Māori women." - Subject Matter Expert*

Interviewees comment that instances of institutional racism and racist behaviour negatively affect partnerships between kaupapa Māori SSS providers and other Partner Providers. They suggest that the Ministry is not aware of the extent of racism and associated dynamics between some organisations.

A disturbing quote from a wāhine Māori highlighted historical experiences of systemic racism. As a young woman, she was in 'Borstal' (a youth detention centre) where they were forced to have sexually transmitted disease checks. She recalled the kōrero from the Borstal staff, where they said:

"This is what you dirty little Māori do." - Priority Group Woman.

Lack of Cultural Safety is a significant barrier

Universal services are described as culturally unsafe, cold, transactional, racist, and rushed. This was coupled with kōrero about the difficulty of navigating the system for new migrants and women for whom English was not the first language.

Aspects of culturally unsafe settings and services were described as follows:

- Did not cater for feelings of embarrassment, shame, and a desire to protect modesty (which was common to all priority group ethnicities)
- Did not consider that screening "isn't talked about" leading to varying levels of knowledge
- Did not tackle the stigma associated with cervical screening and HPV
- Did not consider the cultural beliefs of wāhine Māori and Pacific women regarding the significance, sacredness, and tapu of the body

"It's understanding from a Māori perspective what a wāhine means to a whānau. And that is very different for cultures, and what a body means, and the body parts of your body mean, and so therefore how you approach any screening or practice towards that part of the body matters. And that difference differs specifically for Māori." - SSS Provider.

Culturally safe services should be the status quo

All SSS providers state that culturally safe services, for priority group women, are fundamental to service design and delivery. Cultural Safety is described as an attitude rather than a model, and it requires constant self-reflection and change. Women and SSS providers describe culturally safe delivery and enablers as:

- Building trust – between the provider and women. This includes working at the woman's pace with cultural sensitivity and (in time) providing a safe context for the woman to engage in screening or other services.
- Whānau or provider support – facilitating a whānau support person or the provider offers cultural support.
- Language and culturally diverse health promotion, screening, and education[42].

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[42] A standout example was use of a 3D model of the reproductive system. One provider held group-based education for Pacific women to increase knowledge of the reproductive system and minimise the stigma around HPV. The 3D model was used to visually demonstrate the female anatomy, and out of respect for the sanctity of a women's body, it was kept wrapped in a lavalava, treated with respect, and used with gentleness.

- The 'right' workforce – examples included a female workforce that mirrored priority group women; culturally diverse staff, in particular sample takers; linguistically diverse staff and /or access to interpreters (not relying solely on family members).

> *"If they hear some voice in their mother tongue coming, it's really important. So, like in a promotion… in a comfortable language, and personal content makes a huge difference." - Priority Group Woman.*

- A trained and skilled workforce – all providers, and in particular, non-Māori and non-Pacific providers, spoke about investing in cultural safety and cultural competence training.
- Providing culture and language-specific clinics and events.

> *"We might run 15 clinics a week or have 15 events a week, but they're all run slightly differently. And the people that are involved. You know, if [staff member] is running a clinic in a marae it will be really, really different than if we're running a van clinic at one outside one of the hospitals or in, you know, in a car park somewhere outside Salvation Army." - SSS Provider.*

> *"Our [sub-contractor] have their own clinic and space and everything, and people know that it's a clinic, but they also know it's Pacific." - SSS Provider.*

> *"[Kaupapa Māori screening] days are working really, really well. And on the flip side, we have cervical screening clinics… for Asian women, one hundred percent attendance, no DNA." - SSS Provider.*

Honouring Mana Wāhine

SSS providers and wāhine Māori believe that services should understand and appreciate the tapu and the sacredness of the female body and ngā wāhine roles with respect to creation and intergenerational wellbeing.

> *"It's a house for our babies." - Priority Group Woman.*

> *"Actually, getting to the appointment is such a small part of a huge journey. [Screening is] a huge process, an intergenerational process, and the more wāhine that are supported into screening, that has a knock-on effect for whānau as well. And I've read so many stories and heard of so many amazing stories through our kaimahi across the three regions of whānau attending screening together, nana, mama and the pepe all going, and one falls down and whānau lift them up." - SSS Provider.*

Examples of mana enhancing services include:

- Delivering screening aligned with kaupapa Māori values, tikanga and kawa
- Respectful of kuia who have a special and unique place in te ao Māori
- Understanding the importance of kai. The offering of kai is a significant part of expressing manaaki and aroha to others
- Understanding the role of koha, as one of several ways to acknowledge women

> *"We would go [to the DHB on kaupapa Māori priority days] and we would actually put a banquet of kai eh, because kai, that's us Māori, kai, cup of tea. And*

then you have your support workers there and actually making the women feel important. So that was that was awesome to see." - SSS Provider.

Honouring Pacific Women

Like earlier statements about honouring Mana Wāhine, SSS providers and Pacific women believe that services should understand and appreciate how Pacific women view the reproductive system as tapu or sā.

> *“They’re sacred areas… you don’t flop yourself out for anybody.” - Priority Group Woman.*

Honouring Pacific women is also a priority in Aotearoa because 60% of Pacific peoples are now born in New Zealand and Pacific communities are fast-growing, young, and dynamic (Ministry for Pacific Peoples, 2018).

Examples of services that honour Pacific Women include:

- Understanding the cultural principle of Vā. It is important to invest time into building genuine relationships with Pacific women, so they feel comfortable and respected. This requires knowledge and practice of cultural and spiritual protocols of engagement specific to Pacific women.

> *"Being Pacific when we ask, how are you? We're not sort of talking just about your physical self. But we're, it means how's your job? How's your home? How’s your family?" - SSS Provider.*

- Understanding what motivates Pacific women. The practice of screening is seen as akin to a mealofa or gift by women to their children and future generations.
- Understanding the importance of hosting and hospitality as part of the appointment process. For example, offering of food during an appointment is one way of expressing the concept of reciprocity. Pacific women respond to this by ‘giving back’ to the professional and attending their appointment(s).
- Providing information that is language, age, and gender specific. This enables Pacific women to share information across their aiga and ethnic communities.
- Understanding the intergenerational and collective nature of Pacific communities. SSS and screening is not just about the individual women, it is also about other Pacific women and their families. Pacific peoples’ identity is relational and about relationships.

Theme 4: Proactive partnerships

Working in partnership, across the whole screening system, for the benefit of priority group women is viewed as essential to success.

Explanatory factors linked to this theme are summarised below.

Proactive Partnerhips	Rigidity and non-collaborative attitudes and behaviours
	Unclear reponsibilities
	Unresolved tension and reliance on goodwill
	Collaborative activites exist
	Building beneficial relationships with the community
	Common goals and passion to make a difference

Rigidity and non-collaborative attitudes and behaviours

Examples of rigid and authoritarian provider behaviours are mentioned in an earlier theme. Additional examples of behaviours by Partner Providers towards SSS providers include mobile services declining to visit localities that suit priority group women; inflexibility linked to co-location of services in regional collaboration work; declining to share data; non-collaboration in rural areas when designing screening promotions; SSS provider suggestions being ignored; and instances where SSS were not invited to 'the table'.

Observations of competitive behaviours between SSS providers was discussed. For example, larger providers received preferential access to mobile breast services; sub-contracting models favoured the lead provider (not sub-contractors); and organisations did not refer to particular SSS due to negative attitudes between the organisations.

Unclear responsibilities

Interviewees said that responsibilities across the system are unclear and there is minimal national guidance and accountability. As one Subject Matter Expert states:

> *"I'd like to look at how can we make integration stronger within the programme so that there are clearly recognised roles to play and accountability held for that within breast screening because there are a number of players [such as] the lead [screening] providers... primary care for identifying women and referring them and encouraging them to participate, Māori and Pacific providers for contract, screening, or just working with the same population that we want to come into the programme. All of those players have a role to play. Some are funded, some are not funded. And I think it would be great if we can more clearly articulate the roles of each and give more formal recognition as to how they fit within the programme." - MoH interviewee*

Unresolved tension and reliance on goodwill

Some SSS providers experience tense relationships with Partner Providers. Tension is caused by challenging culturally unsafe practices; feeling alienated when large organisations fail to progress collaborative projects; poor historic relationships or competitive behaviours between organisations; SSS viewed as threat to primary care screening rather than an enabler.

Interviewees spoke of over-reliance on individual relationships to support service coordination. This is risky as it is vulnerable to personnel change versus coordination that is formally embedded into the system.

Collaborative activities between Partner Providers and SSS

Despite barriers, interviewees shared examples of a wide range of positive collaboration in the system:

- SSS providers building 'universal' provider organisational capacity – Some SSS providers work with primary care to build their capability to support priority group women screening. Practices supported are those with low screening rates, a large number of priority group women, and low-income practices. Capability building activities include using data to identify priority group women; improving screening processes and ways to approach women; running competitions to get as many priority group women screened as possible; supporting screening promotion; running opportunistic clinics; and celebrating primary care staff who champion priority group women screening.
- Mutual organisational capacity development and service improvement – examples include new data sharing systems; formal and informal regional collaboration to review models of good practice; using data to understand collective and individual provider performance; improving referral pathways and service coordination; providing more flexible service delivery options.
- Equity leadership – examples include sharing capacity to lead equity improvements; giving feedback to one another regarding effective processes and people; contributing to one another's strategies and workplans and producing a regional strategy.
- Joined up work to improve Cultural Safety – examples include Kaupapa Māori and Pacific SSS providers partnering with others to build their capability to understand te ao Māori and Pacific cultures; deliver training or cultural advice; to develop Kaupapa Māori cervical and breast screening events.
- Workforce development – examples include sharing access to workforce development training; providing training sessions to one another about each organisation's processes, role, and expertise; structured catchups and review groups to provide peer supervision and 'bounce ideas'; targeted support for frontline staff and informal mentoring.

Building beneficial relationships with the community

Partnering and building beneficial relationships with iwi, hapū, marae, churches, small community organisations, and community leaders (to name a few) helps embed SSS in the community. Examples include investing in structured relationships, such as attending a particular community group every few months to screen women in their community, and informal relationships with individuals in many different community groups and community services.

Common goals and passion to make a difference

Interviewees said that successful partnerships require shared goals and passion, coupled with a genuine aroha for the wellbeing of women and whānau. Shared goals include a desire to remove barriers to screening, make screening a seamless experience, to deliver services in women and whānau-centred ways, and meet women and whānau needs.

> *"It's dependent on staff... Some days, you'll get no one and other days, you'll get [lots of women screened], and that is very much depending on the passion of the person involved. And we know who those passionate people are." - SSS Provider.*

Minor themes

Several minor themes were identified. They are:

- Value-add outcomes including Whānau Ora
- SSS model of care, contracting and reporting
- A common or refreshed understanding of equity, eligibility, and prioritisation
- Perverse consequences and moral hazards in the screening pathways
- Inadequate funding
- Workforce and leadership development
- Understanding the pros and cons of provider types and configurations

Explanatory data for these themes is outlined in Te Tāpiritanga Tuaono. However, detail about Value-add outcomes and the SSS model, contracting and reporting approach are outlined below as they relate to evaluation objectives.

Value-add outcomes including Whānau Ora

SSS providers and some women spoke of 'value-add' outcomes over and above outcomes defined in the contractual specifications, such as, being screened. These include:

- Uplifting the mana of women – wāhine were supported to realise and 'awaken' to their value. This was particularly so for wāhine Māori accessing Kaupapa Māori SSS. Kōrero was noted about how SSS can build wāhine sense of self-worth.

> *"If you can, bestow mana and a mana enhancing service [will] validate what they did today is really important, and a huge taonga for the family, that they've done this thing for everybody. I think there must be a way that even though the procedures aren't very nice, that the service that you received was really mana enhancing, and made you feel really good about your decision. And that it wasn't a given, that wasn't something we take lightly. Actually, it was huge. And you should feel really good about yourself today for doing it." - SSS Provider.*

- Access and participation outcomes –once successfully engaged in SSS, women engaged in the broader screening pathway and other health services. Examples include women and whānau accessing wider health and social services (e.g. immunisation); accessing more than one service; and enrolling in primary care.
- Experience outcomes – suggested examples include women reported feeling cared for and valued; culturally safe; being treated with dignity; having a racism-free experience; being supported to address the determinants of inequity; and having better experiences with other health and social services because of partnerships with SSS.
- Health and social outcomes – suggested health outcomes include early detection; a contribution to reduced mortality; a contribution to improved survival rates; improved health outcomes through engagement with services (i.e. reported reduced hospitalisations, safe housing).
- Intersectoral outcomes **–** suggested intersectoral outcomes include improved social conditions, such as new housing; immediate needs were met through grants (e.g. kai and hygiene packs)
- Increased knowledge **–** example knowledge gain topics include the reproductive system; HPV; screening procedures; results; diagnostics and treatment; services available; how to navigate services and human rights.
- Increased confidence **–** suggested examples include increased confidence to navigate systems and advocate for self and whānau.

- System outcomes – suggested examples include bridging health system failures and building wider capability building across the social sector.
- Improved societal and community outcomes – a suggested example is that well women are more able to contribute positively to society and communities.

> *"When we're taking a Whānau Ora approach, you can't separate people into their various body parts. You're providing support to whānau for whatever service they need and ensuring that people are aware of what's available to them... " - MoH Interviewee.*

As the quote above suggests, many of these examples are aligned with Whānau Ora. Several SSS providers (lead or sub-contracted) are also Whānau Ora providers.

SSS model of care, contracting and reporting

There are mixed views about the current SSS model of care, contracting and reporting approach. Some interviewees highlighted positive aspects and others negative. The summary below focuses on interviewee suggestions about improvements:

- **SSS model of care –** enable more opportunities to design and deliver a culturally informed, holistic model that does not have to fit into Western framework to secure contract and funding.

> *"If we look at all the models in screening, they're not, you know they're not our models really, you know, we've adopted them from overseas or we've taken pieces from here and there and, I think if we turn it around and design ourselves, you know, the model of care, and then that will just work for the rest of the population." - Subject Matter Expert.*

- **An enabling contract structure** – design a contract structure that supports (more) innovation, holistic delivery, reflects Kaupapa Māori and Pacific focused approaches and measurement.
- **Contracts longer than 3 years** – implement longer-term contracts to support long-term planning and financial security.
- **Data collection** – provide extra support to some providers to capture and report on data. This may include a formal system to support data capture.
- **More transparency about how targets are set**
- **Greater clarity about contractual accountabilities –** across the screening pathways and system.
- **An enhanced way to tell the delivery story from inputs to outcomes** – this includes ways to capture the considerable input that goes into building relationships, getting women screened, and working toward holistic outcomes. Some SSS providers said that they had conveyed the type of work involved to the Ministry and had received a supportive response.

> *"Those [SSS] providers that do provide those really intensive engagements and transports, are we really recognising and valuing that? Because they might not reach their targets, but they might be doing really important and valuable work for some of those women who would not get to the service otherwise." - MoH Interviewee.*

- **More meaningful contract reporting –** develop new or enhance existing reporting to include the amount of time and resources invested to engage and support women and track a range of ‘value-add’ outcomes (outlined earlier) for women and their whānau.

> *"We will need to specify the outcomes that we want. That would probably be a joint co-design process so that the outcomes aren’t top down, they are agreed around what a whānau need and what would we expect to demonstrate good value for money." - MoH Interviewee.*

Bowel Screening

Most interviewees supported SSS providers expanding their support to bowel screening. However, there were caveats. They are summarised below.

Benefits of expanding SSS

Interviewees reported that SSS providers were uniquely placed to deliver high-quality bowel screening support. Reasons for this included:

- **SSS already deliver holistic, whole-of-whānau approaches**

> *“The household approach for bowel screening… seems like a natural thing to be added on, because [we’re] starting to show that we are looking at the whole family, that everyone matters.” - SSS Provider.*

- **SSS have existing frameworks in place to support screening**

> *“We've already got the eco-environment to deliver it. Why we silo things up is beyond me.” - SSS Provider.*

- **SSS have existing relationships and engagement pathways**
- **SSS staff have transferable skills and attributes**

Risks and barriers

Risks and challenges are identified below.

- **An unintended opportunity cost for equity**

> *“If I look at breast and cervical… when you've got too many balls juggling, often you will drop one. And I can see cervical being dropped again. If we got this right and achieved equity and improved access to our screening programmes for both breast and cervical, then there would be another conversation.” - Subject Matter Expert.*

- **It may compromise a wāhine-centred approach**

> *“[The] nature of breast and cervical, the way they do things… chatting on the phone, like girlfriends, and that kind of thing is not what the bowel screening service is going to want.” - SSS Provider*

- **The current (predominantly) female SSS workforce may not be fit-for-purpose for bowel screening support** – male staff would need to be recruited

- **Additional training is required** – this will incur cost and time

Enablers

A wide variety of enablers were discussed to implement effective bowel screening support. These include:

- **Adequate funding**
- **Workforce recruitment, retention, training, and development**
- **A service co-designed with men, whānau and communities**
- **Collaboration with clear parameters, roles, and responsibilities for the different organisations involved**
- **Understanding and mitigating systemic barriers to achieving equity –** some providers were concerned about extant systemic barriers linked to inequity in screening generally. A key issue noted for bowel screening was the eligibility age range, particularly for Māori

> *"For Māori and equity, I just don't know what to say about [not lowering the age eligibility]. We're all really on the back foot for bowel screening." - SSS Provider.*

WĀHANGA TUAONO: KEY FINDINGS AND RECOMMENDATIONS

This section outlines key findings, proposes a new approach to effective SSS and the broader screening system and makes recommendations for NSU consideration.

Key Findings

Key findings are grouped into three categories: those which are specific to current delivery, those which may inform future delivery and insights on bowel screening, models of effective engagement and contracting processes.

Current Delivery

Despite some gains, inequities persist

Population and national screening programme level data demonstrate persistent inequities. The data for wāhine Māori, is disturbing. Excess mortality rates for Māori breast and cervical cancer are 44% and 37% respectively (Gurney et al, 2019). Gains are acknowledged, particularly for Pacific women in breast screening. However, long-standing inequities reflect a screening system that is not meeting the needs of priority group women. The whole system (including SSS) must continue to do more to deliver equitable outcomes for priority group women. Ironically, SSS only exist because inequities prevail in universal screening systems.

Asian women should be a priority group, alongside wāhine Māori and Pacific women

Although Asian women do not experience inequity like Māori and Pacific women, there are reasons why SSS should continue to support Asian women. First, recent NCSP performance data suggests an emerging equity gap. Second, Asian women represent a large and growing number of women to be screened. For example, Statistics New Zealand suggests that between 2018 and 2043, the Asian ethnic group in Aotearoa is projected to rise from 16% (770,000) to 26% (1.5m)[43]. Third, literature and Asian women interviewed for this evaluation confirm there are specific barriers and enablers that impact upon their access and use of screening services.

More work needs to be done at multiple levels among SSS providers and the wider system

SSS providers are passionate about what they do and committed to delivering outcomes to priority group women. There were positive and negative examples of quality service delivery. However, the drivers of quality delivery are complex and interwoven with women-, service- and system-level drivers. Many SSS providers demonstrated their ability to uplift the mana of priority group women. They provided insights and examples of what works and showcased their models of care which were designed to be culturally safe and respond to the needs of priority group women. All SSS providers interviewed were dedicated to role they played to eliminate inequity and support wellbeing.

Priority group women spoke of enabling environments and positive experiences of SSS (and in some cases, the broader screening system). They spoke of experiencing providers understanding their past

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[43] Source: https://www.stats.govt.nz/news/population-projected-to-become-more-ethnically-diverse . Statistics New Zealand. Accessed March 2021. Note this is all Asian peoples, not women only. However, it can be assumed that ~50% of this number will be female. The data is used for illustrative purposes only.

experiences, meeting their cultural preferences, and delivering models of care that were relational, values- and strengths-based.

In contrast, interviewees also shared what did not work and spoke about mana disabling environments and practices. Some examples included provider-centric approaches; experiences of racism, discrimination, and bias; and poor provider processes which reduced service flexibility.

In some cases, the examples of what worked and what did not, were specific to SSS. In many cases, examples were related to the broader screening system. There is a complex interplay between services and the screening system. For many interviewees, that interplay meant it was not always possible to divorce insights about SSS from the broader system. However, it was clear that more needs to be done to improve SSS and system capability to uplift the mana of all women.

Collectively, SSS are effective and engage well with women

In our view, SSS are effective. They fulfil a valuable role mitigating inequities in the current screening system and programmes. Based on the SSS outcome framework and quantitative contractual data, we find that collectively, SSS deliver improved outcomes and quality services to priority group women.

Outcome or ‘better off’ data comprised the number and percentage of women successfully screened based upon agreed targets. Between 2017-2020, collectively, the SSS providers exceeded their breast screening targets by nearly 300%. This equated to 16,700 priority group women screened for breast cancer. The providers did not meet their cervical screening target, but they achieved nearly 90%. This equated to around 18,000 cervical screens for priority group women. Considering the complexities of priority group women and the invasive nature of cervical screening, on the whole, this is a good result. Overall, nearly 35,000 priority group women were screened who may not have been screened at all.

The quality of SSS delivery was assessed using ‘how well’ data. How well data comprised the number and percentage of women successfully engaged in a screening pathway. Between 2017-2020, around 50% of women were successfully engaged in both pathways, which equated to nearly 73,000 women. Overall, engagement data for both screening programmes improved over the three years. It is hoped that higher levels of engagement are achieved in the future.

Many priority group women shared positive experiences of SSS. Positive experiences included access to women- and whānau-centred models of care, care that was culturally safe and respectful, providers services honouring Te Tiriti and therefore the mana of wāhine, and services meeting Pacific and Asian women preferences and needs.

Partner providers stated that they valued the role of SSS. Survey results showed that most partners working with SSS valued their role and reported ‘good or very good’ working partnerships. Some provider partners suggested improvements which ranged from SSS providing more flexible screening options through to general discussion about the pros and cons of focusing on priority group women, better use of data and improving SSS capability.

SSS service configuration depends on the local needs of the diverse communities they serve

SSS service delivery is configured in multiple ways. For example, there are multiple provider types (i.e. DHBs, PHOs, smaller NGOs, Kaupapa Māori, Pacific providers, universal providers); different contracting models (e.g. some providers hold the contract and deliver the SSS service and others sub-contract out delivery); geographic differences (i.e. rural vs. urban); and different levels of capability and capacity (i.e. some SSS providers had exceptional referral and working relationships with Partner Providers and others did not; some were struggling financially; some lacked sufficient workforce to flex in times of need; and some had comprehensive IT systems). In addition, many SSS providers stated that their configuration and model was designed to meet local circumstances and women's needs. Implying that configurations were driven by unique local circumstances and therefore not able to be compared. Based on these issues, we decided it was not possible to compare which configuration is most effective, as there are too many variables. Therefore, we concentrated on identifying the characteristics of effective SSS services (and systems). These characteristics are outlined in the Future Delivery section (below).

SSS providers deliver value-add activities and outcomes over and above screening

SSS providers identified six categories of value-add outcomes which reflect value-add activities. The outcomes include improved Access and Participation; Experience; Health and Social; Health System; Capability Building Benefits for the Social Sector; Societal and Community. Detail about each outcome is contained in the body of this report. Many of the outcomes were aligned with Whānau Ora. The team could not validate the outcomes but accept the providers view in good faith.

Future Delivery

The mana of women must be upheld by SSS and the wider screening system

All and any inequities impact upon the mana of women and are therefore unacceptable. Systems and services must be held accountable for eliminating inequities. The NSU has a key role to play as the main funder and commissioner.

Four core themes inform models of good practice

Detailed thematic analysis surfaced four core themes: Caring and supportive relationships with women; Women- and whānau-centred models; Cultural safety and Proactive Partnerships. The themes may apply to SSS and the broader screening system.

Each core theme is supported by explanatory factors. Themes and factors are summarised below:

Caring and authentic relationships	Negative experiences compromise care
	Quality care is based on values, strengths and relationships
	Building rapport breaks down barriers
	The way you contact women matters
	'Building up' women incresae knowledge, confidence and supported motivation
Women- and whānau-centred models	Access barriers exist
	'Life' barriers exist
	Flexible models of care
Cultural Safety	System failures exacerbate persistent inequities
	Systemic racism
	Lack of Cultural Safety is a significant barrier
	Culturally safe services should be the status quo
	Honouring Mana Wāhine
	Honouring Pacific Women
Proactive Partnerhips	Rigidity and non-collaborative attitudes and behaviours
	Unclear reponsibilities
	Unresolved tension and reliance on goodwill
	Collaborative activites exist
	Building beneficial relationships with the community
	Relationships and rural screening
	Shared goals, passion and influencers

The themes have been used by the evaluators to develop a new framework called Te Hā (discussed later this section).

Other insights – bowel screening, contracting and other models of effective engagement

There is support to expand SSS to include bowel screening. However, there are caveats

73% of partner providers surveyed, agreed that SSS should support bowel screening. and most SSS providers also agreed it was a good idea. Thematic analysis revealed multiple pros and cons. Most cons related to ensuring appropriate resourcing was available and that existing services were not compromised.

More work is needed to review the current contracting approach and move towards commissioning

There were mixed views about the current contracting approach. Some were positive and some were negative. Providers suggested multiple ways to improve the approach. Barriers ranged from lack of trust and consideration of Whānau Ora through to requests to review the outcome framework and contractual metrics.

The evaluation highlighted a wide range of factors (barriers, enablers, and opportunities) linked to system, service, and women, and whānau needs. The complex interconnectedness of these factors impacts on the contracting of SSS (and broader screening pathways).

The recent Health and Disability System Review (HDSR, 2019 and 2020) discussed multiple issues linked to contracting and a potential whole system move to commissioning. Commissioning was defined as:

> *"…a strategic and ongoing process to translate population health objectives into effective responsive services … [which involves] purposefully planning, developing, sourcing, and monitoring service delivery systems to achieve the best outcomes for the population." (HDSR, 2020, pp.72-73).*

The final HDSR Report (2020) outlined a commissioning approach that included specialist understanding of Kaupapa Māori (and other culturally endorsed models), fulfilling Te Tiriti obligations, outcome-focused, locally informed, transparent, and evidence-based.

At the time of completing this evaluation, the Minister of Health had announced the Government's decision regarding health system reforms. This included the establishment of a Māori Health Authority (MHA) and Health New Zealand (HNZ) as future commissioners of services from July 2022. In the future, it is anticipated that SSS services will be commissioned by HNZ in partnership with the MHA or the MHA. This may involve considering a te ao Māori informed commissioning approach. In our view, this approach would prioritise a te ao Māori lens (inclusive of Kaupapa and Mātauranga Māori) to uplift the specific mana of Māori wāhine pursuant to Te Tiriti and supportive policy and strategy (i.e. Whakamaua: The Māori Health Action Plan 2020-2025).

This approach would consider barriers, enablers, and opportunities to strengthen the overarching system and SSS services, as outlined in this evaluation. The voices and preferences of priority group women would drive the approach as much as population, system, and service level data. Trust-based relational contracting and contract management, informed by a mana wāhine and 'hiki i ngā mana' outcome framework, could also be a feature.

The Ministry is in an excellent position to frame the future commissioning of SSS (and broader screening system programmes) using insights from this evaluation. Further, signals from the system strongly support a Kaupapa Māori and culturally nuanced approach to future commissioning.

Indigenous and other models of effective engagement are available for implementation

The Ministry asked for information about other models of effective engagement. *Te Piringa* (Savage et al, 2020 and 2020a) provides recent insights into effective primary care for Māori and Pacific Peoples. The research suggests there are three interconnected layers which support effective delivery: Whānau, Whānau-centred service and practices and Government.

At a Whānau level, key enablers ranged from valuing whānau diversity and mātauranga through to the importance of kaupapa Māori values, decolonisation, healing, and holistic health experiences. Key barriers ranged from intergenerational exposure to health compromising conditions and feelings of whakamā through to limited service delivery options and choices.

At a Whānau-centred service and practice level, key enablers ranged from a clear whānau-centric model of practice, practising kaupapa Māori values and cultural safety. Key barriers ranged from lack of a clear model of practice through to power imbalances, poor contracting approaches, and unsustainable funding.

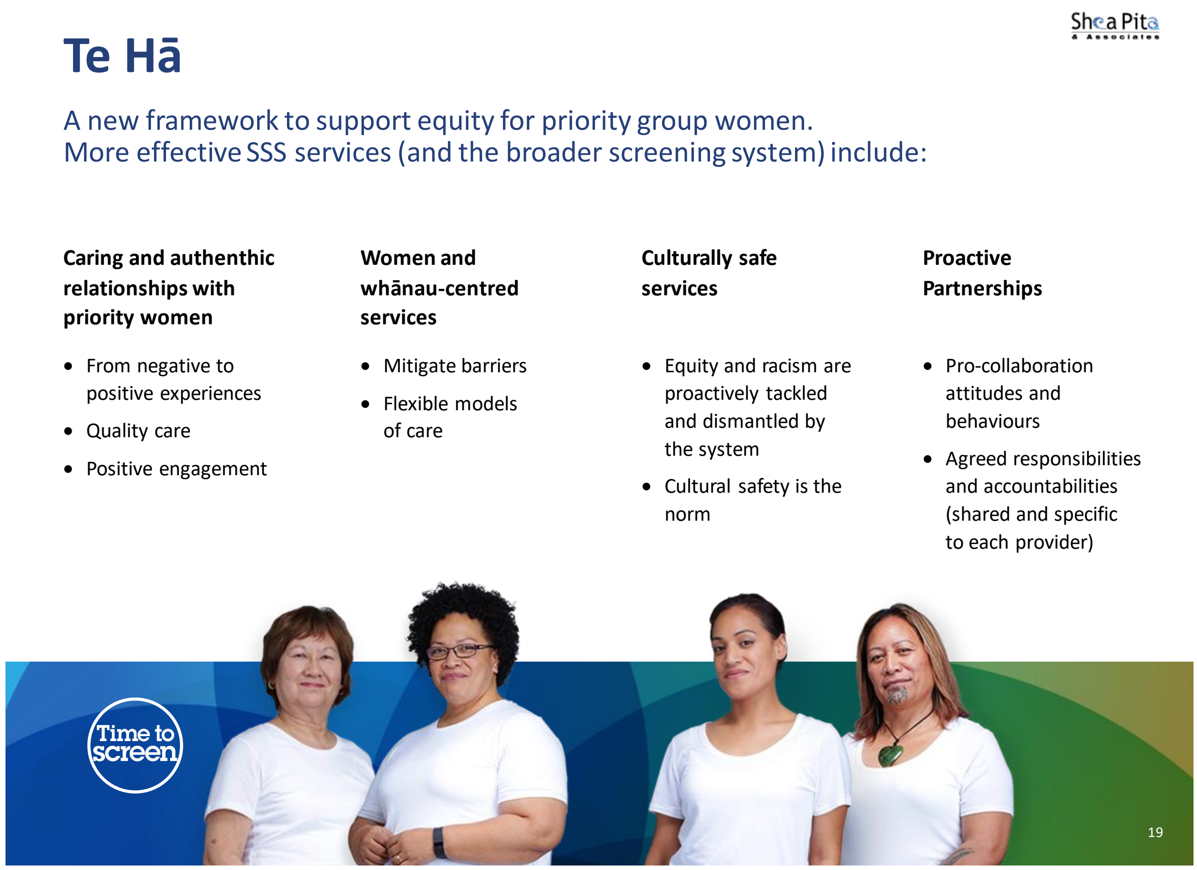
At a Government level, key enablers ranged from a whole system approach, adherence to Te Tiriti and Whānau Ora through to lack of Government fulfilling its partnership obligations and failure to collect and use data to improve Māori health.

Insights from Te Piringa align with insights in this evaluation and are reflected in our synthesis of opportunities for improvement and our proposed framework.

Te Hā - a new framework to support equity for priority group women

The evaluation team has designed a new framework called Te Hā. The purpose of Te Hā is to breathe new life into future SSS and the broader screening system. It offers fresh insight into what pro-Tiriti and pro-equity services and systems look like. By understanding what ‘good looks like’, the NSU and providers can co-construct new or enhanced strategies and actions designed to improve equity of access, experience, and outcome for priority group women.

The framework is outlined below:



Te Hā

A new framework to support equity for priority group women.
More effective SSS services (and the broader screening system) include:

Caring and authenthic relationships with priority women

- From negative to positive experiences
- Quality care
- Positive engagement

Women and whānau-centred services

- Mitigate barriers
- Flexible models of care

Culturally safe services

- Equity and racism are proactively tackled and dismantled by the system
- Cultural safety is the norm

Proactive Partnerships

- Pro-collaboration attitudes and behaviours
- Agreed responsibilities and accountabilities (shared and specific to each provider)

Figure 1: Te Hā – an overview of the framework to improve outcomes for priority group women

Photo source: NSU Time to Screen website.

The framework adapts the four themes from the thematic analysis and outlines the most common characteristics of effective SSS. It is noted that many SSS providers already display several of these characteristics. However, persistent inequities at population and programme levels, coupled with variable contractual performance by some SSS providers, suggest that these characteristics are not universally applied.

Some of these characteristics may also apply to the NSU as the funder. Also, characteristics are not mutually exclusive to a theme and are associated with either women and, or provider capacity and capability.

Factors	Characteristics of effective SSS and the broader screening system
Theme 1 – Caring and authentic relationships	
From negative to positive experiences	Screening is racism-free, friendly, judgement-free, transformational not transactional, personalised, culturally safe, supports body autonomy, respects modesty, mitigates fear, and builds wāhine and whānau service and system literacy. Cervical screening is trauma informed, demonstrates aroha, supports dignity, is pain-free, comfortable, and caring.

Factors	Characteristics of effective SSS and the broader screening system
Quality care is values-, strengths- and relationship-based	Screening is values driven. Values such as whanaungatanga, aroha, manaakitanga and rangatiratanga are regularly practised.
	Screening providers build positive relationships with wāhine and whānau; treat women like a whole person; listen, validate, and respect mana and agency, offers women the time they need; and offers legitimate delivery options and choices (e.g. a Kaupapa Māori provider, a Pacific provider, after hours).
	Screening is strengths-based and uses positive language and framing for motivation; understands and meets women's preferences and needs; delivers services using humour and fun (where appropriate); and offers flexible delivery options (e.g. group based).
Promotes positive engagement with women and whānau	Screening offers women the 'right' staff (e.g. cultural and language matching); provides a consistent team; uses multiple communication channels that best suit the woman; offers flexible timeframes, uses community networks including iwi and hapū, builds up women's knowledge and confidence to support women-centric motivation.
Theme 2: Women and whānau-centred models	
Recognises and mitigates barriers	Barriers for wāhine and whānau occur at personal, service and system levels. These may range from access and quality through to 'life' barriers (e.g. overcoming competing priorities to screening), and 'dealing with' the negative impacts of trauma and intersectoral barriers. Referral processes will be seamless, of a high quality and user-friendly. Technology gaps will be fulfilled, and 'clean' data will be shared to benefit women.
From inflexible to flexible models of care	Screening is flexible, models of care are agile and promote non-authoritarian behaviours; Kaupapa Māori and Pacific models of care are the norm; community relationships are prioritised and embedded in models of care; models offer choice and flexibility (e.g. joined up breast and cervical clinics are available based on demand); it is easy to book an appointment; technology is used to support access; practical assistance is available to support attendance (e.g. transport, personal support, child care); SSS are visible (known) to women; SSS implement multiple activities to support formal and informal referrals; there is proactive collaboration between providers in the system to support access. For cervical screening, multiple options are available to women (e.g. planned, home, community-based, workplace, event-based and culture- and language-specific clinics). Women can choose their preferred staff – gender and ethnicity. For breast screening, there are more after-hours options, drop-ins, and mobile services, especially in rural communities. There are reduced waiting times and more targeted appointments for priority group women.
Theme 3 – Cultural Safety	
Equity and racism are proactively tackled and	Screening is pro-Tiriti and pro-equity. Inherent in this approach is a commitment to being pro-mana wāhine and pro-hiki mana i ngā wāhine katoa ki Aotearoa approach. Systemic racism is acknowledged and tackled. The impact of broader societal racist narrative and actions across multiple systems,

Factors	Characteristics of effective SSS and the broader screening system
dismantled by the system	including health, are known, and collectively tackled. Strong quality improvement eradicates unwarranted variation based on lack of Cultural Safety (and for other reasons).
Cultural safety is the norm	Screening is Culturally Safe. Practitioners and providers tackle biases and adopt positive mental models and practices. Cultural capital and competency are invested in, which ranges from learning and using appropriate language (te reo) through to practising delivery that aligns with cultural customs (tikanga, kawa, vā and sā). A trained and skilled workforce is critical to implementing cultural safety.
Theme 4 – Proactive Partnerships	
Pro-collaboration attitudes and behaviours	Screening stakeholders collaborate. Partnerships are based on shared goals and a passion to ensure women achieve equity of access, experience, and outcome. This includes SSS and Partner Providers enhancing existing collaboration and finding new ways to overcome historical tension and over-reliance on goodwill. Proactive relationships with community stakeholders are prioritised as are relationships with specific parts of the community (e.g. prioritising partnership development in rural communities).
Agreed responsibilities and accountabilities (shared and specific to each provider)	Funder(s) and provider(s) agree and clarify responsibilities and accountabilities across for services, screening pathways and the system. Shared and specific accountabilities (by provider) are clarified and measured to enable performance to be monitored fairly and accurately. There is transparent, open and 'no surprises' communication aligned with a solutions-focused approach. Effort is put towards focusing on the common purpose, which includes a refreshed and co-owned outcome framework, performance metrics and commissioning approach. The commissioning approach prioritises the voices of priority group women alongside evidence. Co-development of an enhanced delivery approach and contractual relationship is agreed that supports outcome-focused and relational contracting, with flexibility for effective delivery if the agreed outcomes are met.
Indigenous and culturally inspired models of care are framed as the 'gold standard'	Indigenous and culturally inspired models of care, that are priority group women centred, are framed as the 'gold standard'. Long-term and sustainable investment is made in these models to promote effectiveness. They are used to influence whole system effectiveness and valued as driving innovation and high-quality service delivery that sets the standard for the system. They are celebrated globally.

Table 9: Te Hā – a detailed overview of the characteristics of effective SSS and a broader screening system

Recommendations

The team has developed a range of recommendations. The recommendations aim to support system and service changes that achieve equity for priority group women. The recommendations springboard off key findings and insights in this report. They also lever off research and evidence.

Recommendations prioritise the needs, aspirations, and preferences of priority group women by placing them at the centre of screening, alongside their families/whānau. Naturally, this includes an overt commitment to pro-Tiriti and pro-equity SSS and the broader screening system.

It is prudent to invest time and energy into what is currently working and to wherever possible, tackle and challenge long-standing barriers for priority group women.

These recommendations aim to support service and system changes to achieve equity for priority group women. Based on the Key Findings and insights in this report, the evaluation team recommends that NSU action the following:

In the next 6-12 months:

1. **Adopt Te Hā and use it to generate fresh thinking about SSS and system wide change.** Suggestions about use of this framework +are threaded through the recommendations below.
2. **Continue to fund SSS services for existing priority group women**. This is based on data linked to persistent and emerging inequities.
3. **Consider scaling and reframing SSS services as proactive disruptors vs equity backstops.** Collectively, SSS services are effective. As with all services (including universal screening services) there is room for performance improvement. However, extended reach and consequent outcomes will benefit the whole system.

   In addition, the framing of SSS focuses on their role as equity 'backstops'. They are funded to fill the equity gap. If the Ministry reframed SSS as a disruptor which models what good looks like, this is a more strengths- and mana-enhancing approach to equity. It also supports the principle that what works for priority group women, will work for others. This approach celebrates indigenous and culturally inspired models as the 'gold standard' not the marginal or 'other' model. This is a mindset shift for some, and a real opportunity for the NSU to demonstrate proactive leadership for equity.
4. **Investigate immediate ways to improve equity and accountability across the whole system.** The NSU could bring together a group of willing stakeholders, including SSS providers, across or within each of the two screening programmes to brainstorm new ideas about 'what works'. It could use Te Hā and the findings in this report to broker new thinking about pro-Tiriti and pro-equity. Short-term strategies and actions (quick wins) could be identified that use existing levers in services and systems. If stakeholders use existing levers, actions should be implemented within the next 12 months. Examples of 'quick wins' might include: a 1-page Charter that commits system stakeholders to work more collaboratively to improve outcomes for priority group women; agreement to safely share data and pinpoint actual or emerging inequity 'hotspots'; agreement to quickly mobilise responses and resources to prevent 'hotspot' inequity escalating or developing.
5. **Pursue a new and more explicit pro-Tiriti approach to commissioning SSS for wāhine Māori.** The NSU could enhance its existing approach by partnering with Māori (expert advisors, providers, wāhine and whānau) to revise how it commissions. A pro-Tiriti commissioning approach could include:
   a. The Articles and Principles of Te Tiriti – identifying how to fulfil the promise of these obligations and opportunities. Noting that achieving equity for Māori women is one of several principles of Te Tiriti
   b. Mana Wāhine Māori – use the insights in this report about wāhine Māori needs, aspirations and preferences to influence future model of care design, outcome framework and contractual performance metric updates
   c. Mātauranga Māori – incorporate Mātauranga Māori into future model of care design thinking and metrics, which is led and guided by Māori

   d. Kaupapa Māori – incorporate Kaupapa Māori into future model of care design thinking which is led and guided by Māori
   e. Take action linked to 'quick wins'. Examples may include enabling SSS providers to report additional quantitative or qualitative data to the Ministry which showcases their points of difference and other value-add outcomes; and, or holding a workshop with SSS providers to reinforce the NSU's commitment to mana wāhine and agree how to use Te Hā to improve equity; and, or identify new ways to incorporate mana wāhine voice into assessing service effectiveness from Ministry to provider levels; and, or agree new and consistent ways to streamline referral systems and processes to reduce the current administrative burden of 'poor' referrals on SSS; and, or host a rapid model of care design workshop with SSS providers and priority group women to focus on what works, what does not work and future opportunities to strengthen screening

6. **Pursue a new and more explicit pro-equity approach to commissioning for Pacific and Asian women.** The NSU could also enhance its existing approach by partnering with Pacific and Asian stakeholders (expert advisors, providers, women, and families) to revise how it commissions. A pro-equity approach could include consideration of the following:
   a. Hiki mana I ngā wāhine katoa ki Aotearoa – how this principle is factored into future design thinking
   b. Pacific and Asian peoples' notions of wellbeing – ensuring that wellbeing specific to cultural nuances and preferences feature in models of care and service configuration design thinking
   c. Actions linked to 'quick wins' (as noted above in Recommendation #4)

   Noting that components of Recommendations 5 and 6 are not mutually exclusive. There are positive crossovers.
7. **Consider expanding SSS to include bowel screening –** taking into account the pros and cons expressed in this report.
8. **Find ways to work with SSS providers to celebrate success** – this may require investment in new communication or engagement methodologies that support frequent shared messaging and collaboration for success.

In the longer term

9. **Initiate a formal review of the two screening programmes and the broader screening system to incorporate an enhanced pro-Tiriti and pro-equity lens.**
10. **Adopt a Kaupapa Māori investment approach** which considers ringfencing and indexing funding for SSS and work towards a long-term and sustainable funding investment model for Kaupapa Māori providers.
11. **Adopt a Pro-equity investment approach** – similar to the recommendation above but focused on Pacific and Asian priority group women.
12. **Think about building intersectoral commissioning agreements that support a joined-up commissioning approach with SSS providers who already have multiple intersectoral funders and contracts.**
    The new health sector reforms will impact upon what the NSU can do post July 2022. However, in our view, reform signals support the recommendations outlined in this report Noting that components of Recommendations 5 and 6 are not mutually exclusive. There are positive crossovers.

The new health sector reforms will impact upon what the NSU can do post July 2022. However, in our view, reform signals support the recommendations outlined in this report.

WĀHANGA TUAWHITU - CONCLUSION

New Zealand has a very positive global reputation for delivery of its national screening programmes. New Zealand's population coverage rates for breast and cervical screening, are often ranked in the top 5-10 countries in the World (MoH, 2020; OECD[44]). Effective screening impacts on population outcomes as they contribute to reducing mortality and morbidity from cancer.

Research in this report suggests that both NCSP and BSA have contributed to improving population outcomes for all women in New Zealand. It also shows that at a programme level, hundreds of thousands of women have been screened. A showcase equity story for BSA was achieving equitable screening rates for Pacific women in December 2020. These results are good news stories, and the Ministry should be acknowledged for funding and managing successful programmes at a whole population level.

However, it would be irresponsible to let macro success mask serious and persistent inequities experienced by priority group women. Findings in this report clearly demonstrate that whilst successful for some women, the national screening programmes are not as successful as they should be for wāhine Māori, Pacific women and, more recently, Asian women.

The NSU knows this. They have multiple strategies to effect equity, ranging from policy and strategy commitments through to clinical quality guidelines and active performance improvement of contracted services.

A key pro-equity investment for NSU is SSS. SSS are specifically funded to support improved screening system equity (in geographic areas). Based on what we observed, SSS work hard to support priority group women to be successfully screened. As a collective, we believe SSS are effective. They exceeded their breast screening targets and nearly achieved their cervical screening targets. If SSS did not exist, thousands of priority group women may not have been screened at all.

Further, it is likely they deliver a much broader range of outcomes to women over and above screening. Some of which are aligned to Whānau Ora. Evidence suggests that when delivered well, Whānau Ora as a philosophy and an approach achieves improved whānau outcomes (Independent Whānau Ora Review Panel, 2018)[45]:

> *"The Whānau Ora commissioning approach creates positive change for whānau. …we have seen whānau progress towards achieving their self-identified priorities …We believe that the intentions of Whānau Ora, aiming to build resilience and capability within whānau to be self-managing and to be the architects of their own solutions, create the conditions to achieve sustainable change." (p.6-7)*

Kaupapa Māori providers spoke of their ability to deliver indigenous informed models which focus on mana wāhine and intergenerational wellbeing, Pacific and other providers showcased their culturally inspired care prioritising vā and aiga approaches, and other SSS providers shared their ability to deliver integrated services across the screening continuum (where services were co-located

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[44] Source: https://stats.oecd.org/index.aspx?queryid=30159. Accessed June 2021.

[45] Independent Whānau Ora Review Panel. 2018. Whānau Ora Review – Tipu Matoro ki te Ao. Final Report to Minister for Whānau Ora. Source: https://www.tpk.govt.nz/docs/tpk-wo-review-2019.pdf. Accessed April 2021.

in DHBs, for example), their desire to deliver flexible screening options and choices, and services that catered specifically to the needs of Asian women.

Whilst relatively small in scale compared to the whole screening system, we suggest SSS deliver significant value and are a justified expenditure. As noted by the NSU, they are designed to have a big impact on a small number of valued women.

Could SSS improve? Absolutely. No provider or service is perfect. Findings showed variable provider performance (based on contractual data). In addition, thematic analysis highlighted some areas for SSS improvement. It is important to remember, however, that SSS operate as part of a broader screening system. As noted in the report, effective services require effective systems (and vice versa). Therefore, the broader screening system also needs to ‘lift its equity game’.

Looking to the future, it is our view that the NSU can facilitate innovative and fresh thinking about how to improve SSS and the wider screening system. Te Hā is offered to NSU, SSS and system partners as part of an improvement journey. Te Hā levers off shared insights and evidence in this report. It articulates what ‘good looks like’. It is not a panacea and will not resolve inequities in its own right. It is simply a tool that NSU and the system can use to test thinking, creativity, and appetite to make a difference.

In fact, the ultimate objective may be to eliminate the need for SSS – at least in its current form. Perhaps the opportunity is to ‘flip the script’ and as noted in the recommendations, to view the most optimal SSS not as an equity backstop but as the future ‘gold standard’.

Whilst all priority group women are valued in this report, the plight of wāhine Māori is of particular concern. Generally, they are the group that seems to fare the worst. As Tangata Whenua, wāhine Māori are not only entitled to have their needs met, but they are also entitled to have their rights met pursuant to Te Tiriti o Waitangi. This means, amongst other things, partnerships, active protection of taonga tuku iho, and the right to express rangatiratanga and mana motuhake when engaged in the health system. At present, it seems that neither needs nor rights are being fully met.

KUPUTAKA/GLOSSARY

Māori or Pacific Languages	English
Awhi	Help, support
Aiga	Family
Aotearoa	New Zealand
Awhi	Support
Hapū	Sub-tribe
Hiki mana i ngā wāhine katoa ki Aotearoa	To value and support all women in Aotearoa
Hineahuone	The first woman created by Tāne-nui-a-rangi, a son of Papatūānuku. Hineahuone means a woman formed by earth
Hinengaro	Mind, mental health, and wellbeing
Hoa	Friend
Iwi	Tribe
Kaupapa Māori	A Māori way of being, thinking, owning, and doing
Kaupapa Māori investment	An approach that values, prioritises, and invests in Kaupapa Māori to support intergenerational wellbeing
Kōrero	Discussion
Korowai aroha	Cloak of love and respect
Kuia	Older woman
Kupu	Word Or Words
Māmā	Mother
Mana	Prestige, authority
Mana Motuhake	Autonomy
Mana Wāhine	The mana of Māori women
Manaaki	Support, hosting, to look after
Mātauranga Māori	All forms of Māori knowledge systems
Mate pukupuku	Cancer
Mauri ora	Healthy individuals
Meealofa	Gift
Oranga	Whānau, Whakapapa, Whenua and Whaikaha
Pacific	Pacific
Pae Ora	Healthy futures for Māori
Pākehā	European
Papatūānuku	Earth Mother
Pūrākau	Māori Creation Stories
Rangatiratanga	Authority
Sā	Sacred
Talanoa	Meeting or gathering; equivalent to a hui
Tāne-nui-a-rangi	Tāne-te-waiora and Tāne-matua, he helped separate Rangi-nui and Papa-tū-ā-nuku so the sun would shine on their children. He also ascended to Te Toi-o-ngā-rangi to bring back the three kits of knowledge
Tangata	Person
Tāngata	People
Tāpiritanga	Te Tāpiritanga
Te ao Māori	The Māori world
Te reo me ona tikanga	Māori language and customs

Māori or Pacific Languages	**English**
Taonga tuku iho	Treasures of Māori heritage
Teina	Younger sister, cousin
Te Tiriti o Waitangi	The Treaty of Waitangi
Tika	Correct, appropriate
Tinana	Body, physical wellbeing
Tuakana	Older sister/cousin
Tuatahi	One
Tuarua	Two
Tuatoru	Three
Tuawhā	Four
Tuarima	Five
Tuaono	Six
Tuawhiti	Seven
Vā	The space between people and things that represents and supports relatedness and relationships. It is both tangible and intangible
Wāhanga	Section
Wai ora	Healthy environments
Wairua	Spiritual Essence
Whakamā	Shame, embarrassment, behaviours that are linked to colonisation or other forms of trauma
Whakamaua	The Ministry of Health's Māori Health Action Plan, 2020-2025
Whakapapa	Genealogy
Whakāro	Thoughts, thinking
Whānau	Family
whānau ora	Family wellbeing, healthy families
Whānau Ora	The Whānau Ora policy or framework
Whāriki	Mat or foundation
Whenua	Land

TE TĀPIRITANGA TUATAHI: UNDERSTANDING RBA

Results Based Performance Accountability™ (RBA) is an outcome methodology that is used internationally and domestically. It has been a preferred framework in New Zealand since 2006 (Shea, 2018)[46].

RBA comprises three key concepts, which are categorised as 2-3-7[47]:

- **2** types of Accountabilities – Population and Performance
- **3** types of Performance Measures
- **7** questions which enable Ends (Outcome) to Means (Implementation) thinking

Each of these are described briefly below:

- **Population Accountability** – is about results or outcomes for a whole population of people, who are also usually defined by a geographic area (e.g. people who live in a community, families who live in a city, citizens of a country). As these outcomes are 'high-level' and involve the wellbeing of a whole population, accountability for achieving the same is always shared across multiple partners working towards a common purpose. Population outcomes are measured using data which are called Indicators.
- **Indicators** – are quantitative data that relate to defined populations compared to clients of services (see Performance Measures below). As they relate to populations, they are data of a certain scale (e.g. prevalence rates) and are usually collected by government agencies (e.g. Statistics New Zealand or the Ministry of Health).
- **Performance Accountability –** focuses on client outcomes (compared to the whole of population outcomes). As these outcomes are specific to defined clients of a service, provider organisation or government agency (for example), accountability is held by that team, organisation, or agency for improving their defined client outcomes[48][49]. Client outcomes and service delivery outputs are measured using data which are called Performance Measures.
- **Performance Measures** – Performance measures are data that count the quantity and quality of delivery effort and the quantity and quality of the delivery effect. There are three types of performance measures:
    - How much did we do? Quantity of effort – inputs and/or outputs.
    - How well did we do it? Quality of effort – quality of inputs and/or outputs.
    - Is anyone better off? quantity and quality of effect – client outcomes.

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[46] Shea, S. (2018) Mahitahi - A synopsis of social sector stakeholder views on Social Investment, Results Based Accountability™ and ideas that could benefit Investing for Social Wellbeing (Shea Pita: Auckland). Source: http://resultsaccountability.com/wp-content/uploads/2021/04/2018-Mahitahi-report-on-RBA-and-social-wellbeing-New-Zealand-author-Sharon-Shea.pdf?fbclid=IwAR0g-EqUpeawf53d8q0f8WwxPjVNiYDbOANqoq8qGALt-ghXQFP3hnJmphQ. Accessed March 2021.

[47] Shea Pita & Associates Ltd emphasise 2-3-7 as a critical success factor to understanding and successfully applying RBA.

[48] Note that accountability must be applied in fair and reasonable ways, taking into account the complexities of attribution and client agency. This will be reliant on mature contract and performance management aligned with prudent use of the 7 Questions outlined in the RBA methodology.

[49] Note that performance accountability also applies at a Systems level. Systems-level outcome framework design is not yet in scope for the SAB.

- **7 Questions** – a key part of the utility of RBA, occurs post-design of the outcome framework and involves using the indicator and/or performance measurement data to drive success. The 7 questions (and in particular, questions 4-7) introduce a common way of thinking which enables organisations to unpack their data to understand causal factors or drivers (question 4), partners (question 5), ‘what works’ (question 6) and then use all of that information to support decision-making about effective strategies and actions (question 7).

TE TĀPIRITANGA TUARUA: INFORMATION ABOUT THE DATA USED IN THIS REPORT

A summary of the data used in this report is as follows:

Type	How many	Interviewees	Stakeholder Category	When	How
Qualitative	12	SSS providers and their sub-contractors (where relevant)	SSS Providers	Oct-Dec 2020	Zoom
	10	Māori wāhine		Nov 2020	Zoom and phone
	2	Pacific women		Nov 2020	Phone
	4	Asian women		Nov 2020	Zoom
	2	Other women (Indian, European)		Nov 2020	Zoom
	3	Ministry of Health NSU management and contract managers	Ministry of Health Leadership	Nov 2020	Zoom
	4	Independent advisors	Subject Matter Experts	Oct-Nov 2020	Zoom
	1	Māori Monitoring & Equity Group, NSU	Subject Matter Expert	Nov 2020	Zoom
	33	Partner provider survey and respondents	SSS Partners	Nov 2020	Survey
Quantitative	12	SSS provider contractual performance measure data analysis, 2017-2020	-	Oct-Dec 2020	Descriptive statistics

Table 10: Summary of data collection and method

Priority group women were recruited via SSS providers, the Ministry, a DHB and the evaluator's own networks. Priority group women were offered a $75 koha (food or petrol voucher) to acknowledge their time and expertise.

All qualitative interviews were recorded and transcribed. Transcripts were coded using NVivo 12 and thematically analysed. Themes were compared and merged where appropriate. Thematic analysis was critiqued by a senior evaluator and discussed amongst the team. The volume of qualitative data analysed was significant. Around 250,000 words were analysed for the qualitative interviews.

TE TĀPIRITANGA TUATORU: ADDITIONAL CONTEXTUAL INFORMATION AND A LITERATURE SCAN

Additional facts about Mate Pukupuku

Many cancer deaths can be prevented and, in some cases, eliminated by implementing high quality and evidence-based prevention strategies (such as screening and vaccination). Cancer can also be mitigated by modifying or avoiding key risk factors (such as diet, weight, exercise, safe sex, tobacco, alcohol, and others). The WHO suggests that cervical cancer can be eliminated within a generation with comprehensive prevention, screening, and treatment approaches[50].

Incidence trends have changed over the past 20 years. For example, both Māori and non-Māori have experienced a reduction in the incidence of lung cancer since 1996. However, Māori rates are still substantially higher than non-Māori rates. Recent evidence about survival trends suggests New Zealand's progress is falling behind comparative countries. However, since 1988, there are more than 80% survival rates at five years for cancers such as breast, prostate, melanoma, thyroid, testis, and Hodgkin's lymphoma.

Unfortunately, there is a substantial gap in Māori compared to non-Māori survival rates. Māori experience poorer survival rates across nearly all the most common cancers. Gurney et al (2020) suggest that for the most common cancers, Māori experience between 12-156% higher mortality compared with non-Māori. Pacific Peoples also experience survival rate disparities due to late diagnosis, deprivation and differential access and quality of services post-diagnosis.

In New Zealand, around 9,000 people die from cancer every year. Fortunately, the overall mortality rate for cancer deaths has decreased over time (from 140.6/100,000 in 2004 to 122.6/100,000 in 2016). The mortality rate decline is likely to be associated with multiple issues ranging from more responsive health systems (screening, early diagnosis, and treatment) to tackling avoidable determinants (e.g. smoking, weight, alcohol).

There are persistent inequities in Aotearoa. Inequities are experienced at multiple steps of the cancer continuum. Māori are more likely than others (non-Māori) to be diagnosed with a wide range of cancers (breast, liver, lung, pancreatic, stomach and uterine). Māori are also around 20% more likely to be diagnosed with cancer compared to non-Māori and 20% more likely to die.

Pacific and Asian Peoples also suffer from persistent inequities. Pacific Peoples have greater incidence and mortality rates for multiple cancers compared to non-Pacific, non-Māori, with significantly high rates of uterine cancer.

Inequities are also experienced by people who are socio economically deprived and, those with mental illness and/or addiction issues. It is likely that disabled, rural and whānau who are SOGIESC[51] (Te Aho o Te Kahu, 2021) also suffer from inequities. More data and research are required to unpack inequities for the population cohorts.

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[50] Ibid.

[51] SOGIESC is an acronym that stands for sexual orientation, gender identity and expression, and sex characteristics.

Kaupapa Māori

The kupu 'kaupapa' has multiple meanings. It can mean a topic, policy, plan, purpose, programme, agenda (or other things)[52]. Te Puni Kōkiri defines kaupapa Māori as "taking a Māori approach" (TPK, 2019). Pihama (2015) describes kaupapa Māori as a theoretical framework that prioritises cultural integrity when analysing issues. Kaupapa Māori also provides a framework to understand the cultural, political, and historical context of Aotearoa (Pihama 2015).

Smith (2005) suggests that kaupapa Māori is:

- about 'being Māori'
- reflects Māori philosophy and principles
- validates and legitimises being Māori as the norm
- normalises the importance of Māori language and culture
- continues the 'struggle for autonomy over our cultural wellbeing'

Cram[53] proposes that kaupapa Māori analysis is about:

- critical thinking
- critiquing Pākehā (non-Māori) constructs and definitions of Māori
- affirming Māori self-definitions and self-valuations

Mana Wāhine

Mana Wāhine is often associated with Māori feminist discourse. It examines the intersection of being Māori and female; it challenges historical and contemporary views that 'Other' Māori women and validates mātauranga wāhine and mātauranga Māori (Simmonds, 2011).

Mana Wāhine is also associated with Atua Wāhine and, creation. As Higgins and Meredith state:

> *"All Mana is sourced from the atua (gods). For Māori women, the sources of this mana (Mana Wāhine) include te ara uwha o Tahu (the heavenly female path of Tahu), the primary parent Papatūānuku (the earth mother, and creator of all life) and other female deities". Papatūānuku (Earth Mother), Hineahuone (the wife of Tane and the mother of Hinetitama/Hinenui-i-te-po) and Taranga (Maui's Grandmother) all demonstrated strengths such as: intelligence, empathy, creativity, and resilience. Not only were they eponymous ancestors for Māori, they created a legacy of strong Māori women whose characteristics can be drawn upon to support strong Māori women of today.*

The two words Mana and Wāhine carry significant meaning. Mana is a multidimensional concept that is more than a literal translation in English (Pere 1991). Some interpretations of mana suggest that it is generated and bestowed upon a person by other people (Henare 1998, cited in Pihama 2001), but most consider it to be transferred to the person not by other people but by the Atua themselves (Marsden 2003; Yates-Smith 1998; Pere 1997). It can be increased by strong actions and exceptional talent shown by the person (Moko Mead 2003) and is the quality of a person that others are aware of (Pere 1997). Mana can include prestige, control, power, and influence (Te Aka, 2019).

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[52] Source: www.maoridictionary.co.nz. Accessed 20 January 2021.
[53] Source: http://www.katoa.net.nz/kaupapa-maori. Access 1 February 2021.

The word Wāhine is a combination of two words: wā and hine. Wā relates to notions of time and space and Hine to the female essence (Pihama 2001). The word implies a balance and a blending of the female essence over time (past, present and future).

Literature scan

Below is a scan of international and domestic insights from published and grey literature. The literature outlines barriers (what does not work) and enablers (what does work) of effective breast and cervical screening programmes. The insights are grouped into three levels: Systems, Services, Wāhine and whānau centred. Whilst some literature is specific to Māori, the principles of working with Māori patients and their whānau are generalisable to working with people from other cultures[54].

Insights are not necessarily mutually exclusive to one level. They may impact multiple aspects of a women's journey through screening, e.g. workforce development issues traverse system, service and wāhine-whānau centred.

Summary

- Insights were gathered from international and domestic literature about concepts linked to te ao Māori, what works (enablers) and what does not work (barriers) for priority group women.
- Te ao Māori concepts supported the evaluation methodology and overarching approach.
- Insights were categorised into three levels: system, service and wāhine and whānau-centred.
- Insights are not mutually exclusive to levels, for example, a wāhine's views about screening impact on service and system-level communications and workforce development.
- For all women, barriers ranged from poor communication and a culturally unsafe workforce to issues about privacy, confidentiality, fear, modesty, and age-specific issues. Enablers ranged from culturally safe systems and services that tailored screening to meet wāhine and women's preferences through to affordable, friendly, and supportive services that proactively respond to women's life circumstances and support options.
- For wāhine Māori, barriers ranged from experiences of sexism, racism, discrimination, bias, and monoculturalism through to systems and services that did not respond to wāhine cultural preferences and desire for body autonomy. Barriers affected older and younger wāhine and services failed to adapt to wāhine life circumstances, in particular, understanding notions of whakamā and previous experiences of trauma. Enablers ranged from more pro-Tiriti and pro-equity systems and services, packages and models of care that supported a more holistic approach, through to Māori engaged in commissioning the services, targeted investment in literacy and trust-based models, more Māori leadership and workforce, and targeted public health, and more kaupapa Māori services with flexible and agile service delivery.
- For Pacific women, barriers ranged from lack of Pacific leadership and workforce development through to lack of models that meet Pacific women's preferences, better communications, and Pacific-value based delivery. Enablers ranged from a pro-equity approach through to acknowledging fear, co-commissioning with Pacific leaders,

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[54] Elder H. Te Iho Website – A Psychiatric Registrar's Viewpoint: Hinemoa Elder (www.teiho.org) cited in Medical Council of New Zealand, 2008.

intersectoral action to tackle social determinant drivers, and Pacific family-centred care models.

- For Asian women, barriers ranged from lack of workforce development and cultural safety through to fulfilling knowledge gaps, assuring privacy and confidentiality, maintenance of wellness and targeted communications.
- Recent research about what works for whānau-centred Māori and Pacific People primary care offers similar and additional insights to those already highlighted above.
- It is always helpful to understand, adopt and adapt relevant evidence about what works from other sectors.

Barriers and enablers of effective services and systems

The tables below outline barriers and enablers grouped by cohorts of women.

All priority group women

	SYSTEM LEVEL	SERVICE LEVEL	WĀHINE & WHĀNAU-CENTRED LEVEL
Barriers	Communications not tailored to women's realities. Lack of workforce development.	Concerns about privacy and confidentiality.	Knowledge gaps and communications issues. Failure to recognise and adapt to the negative impact of life circumstances. Views about inevitable ill health and a diminished future. Lack of whole person approach. Fear. Lack of support for maintaining modesty. Barriers specific to cervical screening for young Māori, Pacific, and Asian women.
Enablers	Cultural safety. Acknowledging women's desire for bodily autonomy and modesty. Associating cervical screening with wellbeing. A prevention focus. A culture shift. Service integration. Affordable access. Clarifying accountability and expecting higher performance. Tailoring services to meet needs of young Māori, Pacific, and Asian women. Pro-equity. Improved workforce development strategy and implementation. National campaigns, e.g. communication, engagement, behavioural change.	Implementing strategies and actions targeted to improve access. Proactively responding to the impact of life circumstances. Improved and targeted communications. A credible provider entity. Acknowledging women's desire for bodily autonomy and modesty. Support options and choices – agile and flexible services. Co-messaging and access to multiple services. Pro-equity. Tailoring services to meet needs of young Māori, Pacific, and Asian women. More sophisticated data and digital resources. Supporting Māori leadership and co-ownership. Workforce development. A commitment to quality assurance. Eliminating affordability issues.	Understand and prioritise motivation that matters to women. Improved and targeted communications. Whole of women models of care. Affordable services Customise screening services to meet the needs of young Māori, Pacific, and Asian women. Friendly and conducive environments.

Wāhine Māori

	SYSTEM LEVEL	SERVICE LEVEL	WĀHINE & WHĀNAU-CENTRED LEVEL
Barriers	Existence of sexism, racism, discrimination, bias and monoculturalism. Failure to effect whole system change. Failure to support self-determination. Inequitable access. Poor communication and information. Affordability issues. Poor quality of service delivery across the system.	Failure to recognise and adapt to the negative impact of life circumstances. Poor communication and engagement. Poor quality and failure to deliver upon Māori preferences and what is important to Māori, including a lack of cultural safety and/or competency. Failure to recognise modesty and bodily autonomy.	Affordability. Fear of and/or negative experiences with screening. Whakamā or embarrassment. Barriers specific to young Māori wāhine. Barriers specific to older Māori wāhine. Failure to recognise and adapt to the negative impact of life circumstances.
Enablers	A culturally safe system. A pro-equity, pro-Te Tiriti system. Enabling, valuing, and aligning with proactive Māori leadership and models. Understanding, supporting, and tackling broader enablers. Understanding the most important packages of care including service integration. Achieving equity is possible – sharing and scaling successful approaches. More sophisticated data and digital resources. Targeted national campaigns. Māori leadership in co-commissioning / commissioning	Friendly and conducive environment. Scaling Māori provider development and investment in Kaupapa Māori services and/or ways of delivery. Trust-based and enhancing care models. Proactively responding to the impact of life circumstances – including whole of person approaches. Targeted health literacy and knowledge gain processes. Supporting Māori leadership in service design and delivery. Improved and targeted communications. Importance of incorporating a mana wāhine worldview in service delivery. Targeted Māori public health. High quality navigation support.	Strategies and actions that support older Māori women. Strategies and actions that support younger Māori women. Proactively responding to the impact of life circumstances – including whole of person approaches. Celebrating success. Improved and targeted communications. Support options and choices – agile and flexible services. Cultural safety.

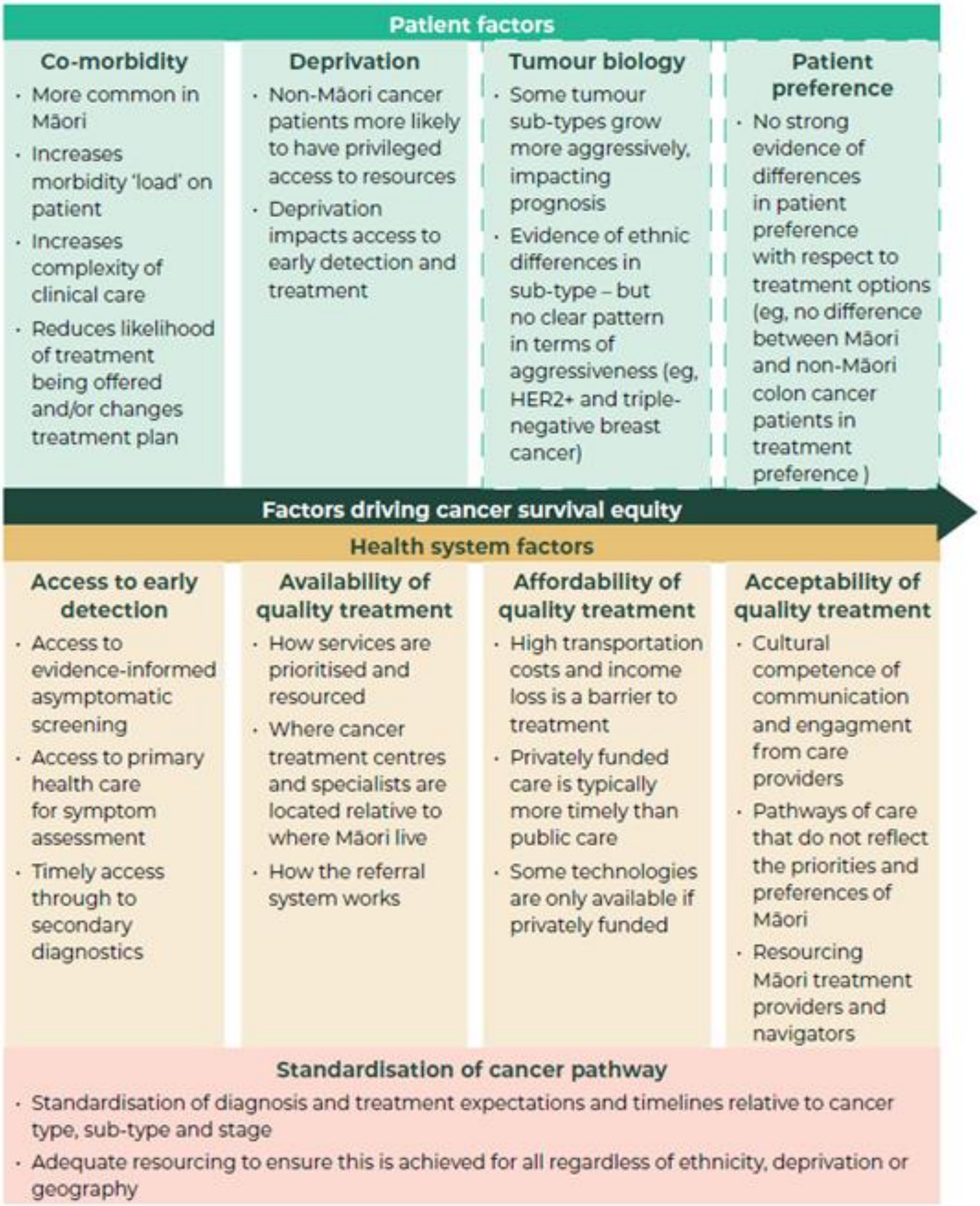
Pacific Women

	SYSTEM LEVEL	SERVICE LEVEL	WĀHINE & WHĀNAU-CENTRED LEVEL
Barriers	Failure to recognise modesty and cultural beliefs and views. Fear. Knowledge gaps.	Fear. Limited knowledge. Poor communication and dissemination of information. Failure to recognise and adapt to the negative impact of life circumstances.	
Enablers	Respecting and enabling Pacific leadership. Workforce development. More sophisticated data and digital resources tailored to Pacific needs and solutions. Co-commissioning. Pro-equity. Intersectoral action to tackle drivers.	Models that meet Pacific women preferences.	Improved and targeted communications. Pacific values-based service delivery. Building health literacy and knowledge. Pacific family-centred care. Pacific and general screening workforce development.

Asian Women

	SERVICE LEVEL	WĀHINE & WHĀNAU-CENTRED LEVEL
Barriers	Lack of workforce development.	Knowledge gaps. Lack of engagement. Lack of privacy and confidentiality.
Enablers	Workforce development and cultural safety.	Maintaining wellness. Improved and targeted communications.

The summary above is complemented by Gurney et al (2020) who summarised patient, health system and quality parameters that drive disparities and survival between Māori and non-Māori who have cancer.



Patient factors

Co-morbidity
- More common in Māori
- Increases morbidity 'load' on patient
- Increases complexity of clinical care
- Reduces likelihood of treatment being offered and/or changes treatment plan

Deprivation
- Non-Māori cancer patients more likely to have privileged access to resources
- Deprivation impacts access to early detection and treatment

Tumour biology
- Some tumour sub-types grow more aggressively, impacting prognosis
- Evidence of ethnic differences in sub-type – but no clear pattern in terms of aggressiveness (eg, HER2+ and triple-negative breast cancer)

Patient preference
- No strong evidence of differences in patient preference with respect to treatment options (eg, no difference between Māori and non-Māori colon cancer patients in treatment preference)

Factors driving cancer survival equity

Health system factors

Access to early detection
- Access to evidence-informed asymptomatic screening
- Access to primary health care for symptom assessment
- Timely access through to secondary diagnostics

Availability of quality treatment
- How services are prioritised and resourced
- Where cancer treatment centres and specialists are located relative to where Māori live
- How the referral system works

Affordability of quality treatment
- High transportation costs and income loss is a barrier to treatment
- Privately funded care is typically more timely than public care
- Some technologies are only available if privately funded

Acceptability of quality treatment
- Cultural competence of communication and engagment from care providers
- Pathways of care that do not reflect the priorities and preferences of Māori
- Resourcing Māori treatment providers and navigators

Standardisation of cancer pathway
- Standardisation of diagnosis and treatment expectations and timelines relative to cancer type, sub-type and stage
- Adequate resourcing to ensure this is achieved for all regardless of ethnicity, deprivation or geography

Figure 12: The main factors driving disparities in cancer survival between Māori and non-Māori.

Note: Boxes with dashed lines indicate factors with limited or conflicting evidence. Source: Gurney et al 2019

Te Aho o Te Kahu also summarised drivers of equitable cancer outcomes for indigenous people, as follows:

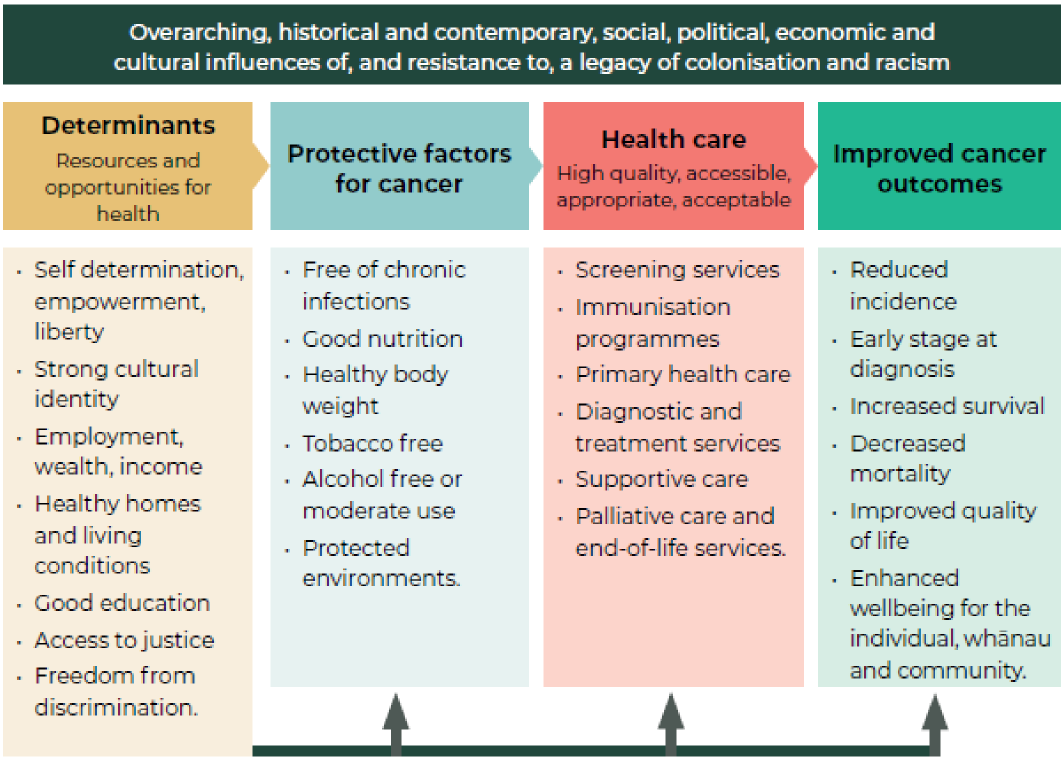


Figure 13: Drivers of equitable cancer outcomes among indigenous peoples.

Source: Te Aho o Te Kahu (2021), p.30

Whānau-centred primary care – recent research about what works for Māori and Pacific People

The MoH requested information about models of effective engagement over and above the current screening support services. Te Piringa is a recent and excellent resource that provides insight into ‘what works’ for Māori and Pacific Peoples in whānau-centred primary care.

Te Piringa comprises two reports. The first is an integrative literature review[55]. The second is a set of case studies of whānau-centred, Māori and Pacific led primary health care models[56]. Together, both reports outline aspects of effective whānau-centred approaches to primary health care and how these approaches could support improved Māori and Pacific health and wellbeing outcomes.

The report outlines three ecologically linked layers:

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[55] Savage, C.; Hynds, A.; Kus-Harbord, L.; Leonard, J.; Malungahu, G.; Fa’alili-Fidow and Jensen, S. 2020. Te Piringa insights into ensuring effective whānau-centred, primary health care services and support. Te Puni Kokiri: Wellington.

[56] Savage, C.; Hynds, A.; Kus-Harbord, L.; Leonard, J.; Malungahu, G.; Fa’alili-Fidow; Jensen, S; Pipi, K.; Were, L. and Paipa, K. 2020a. Te Piringa: Whānau-centred Māori and Pacific Led Primary Health Care Case Studies. Te Puni Kokiri: Wellington.

Figure 14: Layers impacting upon whānau-centred primary healthcare.

Source: Te Piringa Literature Review, 2020.

The three layers represent interrelationships that can impact either positively or negatively on whānau-centred models of care. Each layer has both enablers and barriers. A summary of these is outlined below:

Enablers	Barriers
Layer: Whānau	
• The importance and value of whānau diversity. • Whānau mātauranga and expertise. • Whānau rangatiratanga. • Resilient whānau that access cultural, social, financial resources. • Whakawhanaungatanga and community support for whānau. • Wāhine and tāne as change agents. • Decolonising, collective healing, holistic health experiences.	• Intergenerational exposure to health compromising conditions which cause ‘vulnerable’ or ‘victim’ whānau, e.g. colonisation, co-morbidities, inequities. • Whakamā and fear. • Whānau experiences of poverty. • The physical location of whānau in ‘deprived’ areas, e.g. isolated, or rural areas. • Limited options for whānau with lived experience of disability, e.g. ableism[57], persistent inequities.
Layer: Whānau-centred services and practices	

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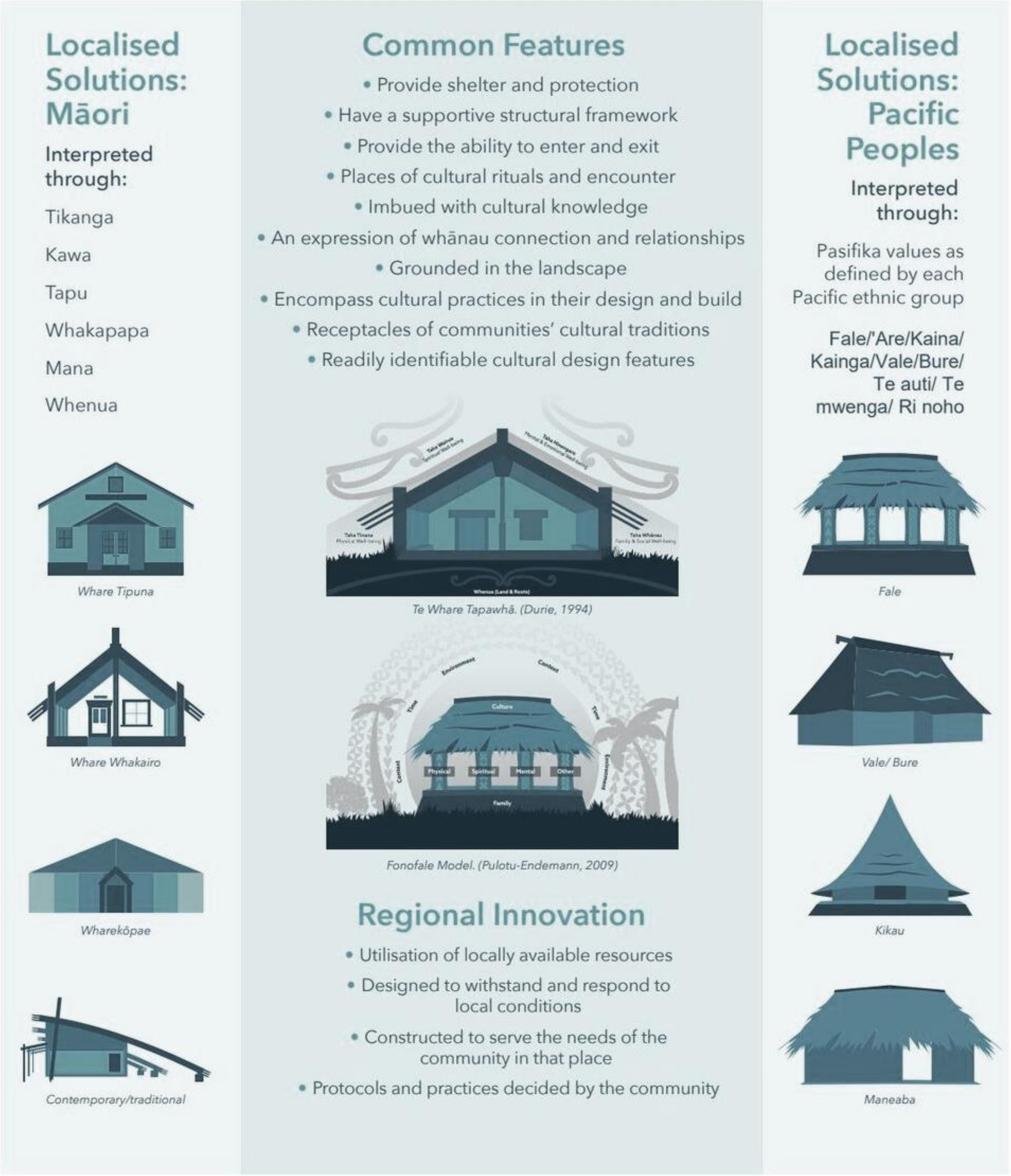
[57] Discrimination or prejudice against people with a disability (Te Piringa, 2020).

• A clear definition of and model of practice for whānau-centred primary health care. • Whanaungatanga – quality and strengths-based relationships. • Fusing mātauranga Māori and clinical approaches. • A flexible approach. • Whānau-centred tools, resources and processes that are holistic and strengths-based to support rangatiratanga. • A shared vision, values, and relational trust. • A culturally safe, competent, capable workforce and provision. • Reflective, relational, and evidence-based practices. • Fit for purpose information systems, data collection and monitoring and evaluation. • Effective governance structures and leadership.	• Lack of a clear definition of and model of practice for whānau-centred primary health care. • Power imbalances – too much emphasis on the professional and not enough on whānau as experts and valuing their diversity (from gender and sexuality through to socio-economic circumstances and lived experience). • Funding, contracting, and reporting requirement difficulties, e.g. updating measures regularly. • Funding that does not sustain or develop a culturally competent and capable workforce.
Layer: Government policies and funding	
• A whole-system approach. • Adherence to Te Tiriti and policies such as Whānau Ora. • Improve and act upon evidence-based policy directions (linked to adherence).	Failure of Crown agencies to: • Adhere to Te Tiriti. • Support Māori health provision. • Collect and use data to improve Māori health outcomes.

Table 11: A summary of barriers and enablers for each layer affecting whānau-centred primary health care.

Source: Te Piringa Literature Review. 2020.

Te Piringa case study report summarises six Māori and Pacific whānau-centred primary care services. Common and unique features of the Māori and Pacific models of care are summarised as follows:



Localised Solutions: Māori

Interpreted through:

Tikanga

Kawa

Tapu

Whakapapa

Mana

Whenua

Common Features

- Provide shelter and protection
- Have a supportive structural framework
- Provide the ability to enter and exit
- Places of cultural rituals and encounter
- Imbued with cultural knowledge
- An expression of whānau connection and relationships
- Grounded in the landscape
- Encompass cultural practices in their design and build
- Receptacles of communities' cultural traditions
- Readily identifiable cultural design features

Te Whare Tapawhā. (Durie, 1994)

Fonofale Model. (Pulotu-Endemann, 2009)

Regional Innovation

- Utilisation of locally available resources
- Designed to withstand and respond to local conditions
- Constructed to serve the needs of the community in that place
- Protocols and practices decided by the community

Localised Solutions: Pacific Peoples

Interpreted through:

Pasifika values as defined by each Pacific ethnic group

Fale/'Are/Kaina/ Kainga/Vale/Bure/ Te auti/ Te mwenga/ Ri noho

Figure 15: Overview of common and unique features for Māori and Pacific Peoples' models of care and solutions from the Piringa case studies.

Source: Te Piringa Case Studies. 2020.

TE TĀPIRITANGA TUAWHĀ: STRATEGY AND POLICY SETTINGS

Health and Disability System Review

The Health and Disability System Review (HDSR, 2019, 2020) recommends multiple system-level changes to ensure sustainable, improved, and equitable outcomes for New Zealanders. The objective is to shift the system from illness towards wellbeing. The Review made multiple recommendations regarding future settings, services, and enablers. Many recommendations sought to benefit the system with respect to Māori, Pacific, and Asian populations.

Example recommendations ranged from placing consumers, whānau and communities at the heart of the system and a culture shift which promotes diverse and connected leadership through to long-term strategic planning, service reconfiguration, prioritisation of prevention and population health and improved digital and data systems.

With respect to Māori as indigenous peoples of Aotearoa, the report stated:

> *"Improving equity and wellbeing for Māori requires immediate improvements in the way the system delivers for Māori, a growth in the range and distribution of kaupapa Māori services and providers, and enhancements to rangatiratanga and mana motuhake." (HDSR, 2020, p.23)*

Key recommendations that are relevant to this evaluation include:

- A range of mechanisms to incorporate Te Tiriti o Waitangi principles into the system, e.g. an independent Māori Health Authority, Health New Zealand Te Tiriti board partnership
- Embedding mātauranga Māori into systems, services, and enablers
- Scaling kaupapa Māori providers
- Growing the Māori workforce
- Strengthening a Māori population health approach

At the time of writing this report, the Minister of Health had yet to confirm the final range of accepted recommendations.

New Zealand Cancer Action Plan 2019–2029 – Te Mahere mō te Mate Pukupuku o Aotearoa 2019–2029

Te Mahere mō te Mate Pukupuku o Aotearoa sets out a 10-year strategic direction for New Zealand's health system[58]. It has four goals:

1. New Zealanders have a system that delivers consistent and modern cancer care
2. New Zealanders experience equitable cancer outcomes
3. New Zealanders have fewer cancers
4. New Zealanders have better cancer survival, supportive care, and end-of-life care

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[58] Source: https://www.health.govt.nz/publication/new-zealand-cancer-action-plan-2019-2029. Accessed January 2021.

The Cancer Action Plan is aligned with the New Zealand Cancer Control Strategy 2003, which set out wide-ranging goals and objectives (MoH, 2003).

Te Aho o Te Kahu (New Zealand Cancer Control Agency) is an independent, departmental agency (hosted by the Ministry of Health). It was established in 2020 to lead the Cancer Action plan implementation (www.teaho.govt.nz).

Whakamaua – the National Māori Health Action Plan 2020-2025

This national action plan (Ministry, 2020b) provides an implementation plan for He Korowai Oranga, New Zealand's Māori Health Strategy (MoH, 2014). The He Korowai Oranga vision is Pae Ora – Health Future for Māori. Pae Ora has three components: Whānau Ora (Healthy Families), Wai Ora (Healthy Environments) and Mauri Ora (Healthy Individuals).

Whakamaua guides the health and disability systems about how to meet its Te Tiriti o Waitangi obligations by putting into a practice strategy that aligns with the principles of Te Tiriti. It has four key objectives:

1. Accelerate and spread the delivery of kaupapa Māori and whānau-centred services
2. Shift cultural and social norms
3. Reduce health inequities and health loss for Māori
4. Strengthen system accountability settings

It also has 8 priority areas:

1. Māori-Crown partnerships	2. Māori leadership	3. Māori health & disability workforce	4. Māori health sector development
5. Cross-sector action	6. Quality and safety	7. Insights and evidence	8. Performance and accountability

'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018 and Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025

'Ala Mo'ui (Minister of Health and Minister of Pacific Island Affairs, 2101) is the national strategic plan for Pacific Peoples. It is complemented by a recent action plan which will guide the delivery of the strategy over the next five years (MoH, 2020b).

The vision of Ola Manuia is Pacific families are thriving in Aotearoa New Zealand (p.14). The plan focuses on four system enablers and three outcomes:

System enablers	Outcomes
1. Leadership	1. Pacific people lead independent and resilient lives
2. Workforce	2. Pacific people live longer in good health
3. Organisational infrastructure capacity	3. Pacific people have equitable health outcomes
4. Funding and investment	

Wai 2575 – Health Services and Outcomes Kaupapa Inquiry

This Waitangi Tribunal inquiry (Waitangi Tribunal, 2019) focuses on claims about complaints and injustices regarding health services and outcomes for Māori. The claims relate to the health and disability system, overall health services, inequity, primary healthcare, disability, mental health and alcohol, tobacco, and substance abuse.

The first (of three) stages focused on the primary healthcare system. Of note were arguments linked to racism, equity, legislative and policy framework failures, breaches of Te Tiriti o Waitangi, poor accountability frameworks, lack of equitable funding, failure to fulfil its commitments pursuant to the United Nations Declaration on the Rights of Indigenous Peoples and many other key issues.

The Tribunal requested that the stage one claimants and the Crown to address four issues: legislative and policy framework design that adhered to Te Tiriti compliance; understanding historical funding issues linked to Māori and primary health care; accountability arrangements for primary health care and future Te Tiriti partnership arrangements including the potential of a Māori health authority.

At the time of writing this report, the claimants and Crown continue to work on the issues.

Inquiry into health inequities for Māori: Report of the Māori Affairs Committee

In August 2020, the Māori Affairs Committee published their report on health inequities for Māori. Entitled *Pakirehua e Pā Ana ki ngā Taumahatanga Hauora mō Ngāi Māori: Pūrongo a te Komiti Whiriwhiri Take Māori: Inquiry into Health Inequities for Māori: Report of the Māori Affairs Committee* (Tirikatene, R. 2020), the report outlines a wide range of recommendations to the Government about how to tackle persistent and unacceptable inequities.

Nineteen recommendations ranged from systemic issues (e.g. establish and resource a specific Māori health entity) through to service-specific issues (e.g. establish and fund health literacy programmes). Several recommendations were made that were specific to cancer, and those most relevant to this evaluation include:

- Deliver equitable Māori health outcomes
- Regular review of the Cancer Plan
- Ensure that all Māori women can access breast cancer screening, particularly those from rural areas
- Health literacy
- A te ao Māori health promotion agency
- Kaupapa Māori cancer navigation roles
- Grow and build the Māori health workforce

TE TĀPIRITANGA TUARIMA: AGGREGATED RBA DATA FOR ALL SSS PROVIDERS

RBA Aggregated Data																		
2017-2018 to 2019-2020 (3 fiscal years)																		
Measure																		
HOW MUCH SERVICE WAS DELIVERED?	**BREAST**								**CERVICAL**									
	Dec-17	**Jun-18**	**Dec-18**	**Jun-19**	**Dec-19**	**Jun-20**	**TREND**	**TOTAL**	**Dec-17**	**Jun-18**	**Dec-18**	**Jun-19**	**Dec-19**	**Jun-20**	**TREND**	**TOTAL**	**TOTAL/3 YEARS**	**% OVER 3 YEARS**
Total # of PGW referred for support services	**6219**	**7466**	**7857**	**7745**	**5840**	**4761**		**39888**	**6485**	**8227**	**10588**	**11860**	**11226**	**10819**		**59205**	**99093**	
Total # of Māori PGW referred for support services	3087	4598	4972	5432	4167	3595		25851	3203	3864	4322	5274	5413	4016		26092	51943	52%
Total # of Pacific PGW referred for support services	1372	1251	1014	757	703	522		5619	1217	1799	2174	2191	1563	1175		10119	15738	16%
Total # of Asian PGW referred for support services									903	1065	2210	2371	2240	1851		10640	10640	11%
Total # of Other PGW referred for support services	1760	1617	1871	1556	970	644		8418	1162	1499	1882	2024	2010	3777		12354	20772	21%
Total # of PGW identified for support services	**2768**	**3961**	**3280**	**3633**	**2008**	**1641**		**17291**	**2196**	**8062**	**6280**	**5550**	**4175**	**1528**		**27791**	**45082**	
Total # of Māori PGW identified for support services	1684	2034	2370	2385	1095	843		10411	1342	3676	2804	2686	2039	581		13128	23539	52%
Total # of Pacific PGW identified for support services	433	1068	438	768	415	602		3724	242	1768	810	677	476	218		4191	7915	18%
Total # of Asian PGW identified for support services									382	1810	1703	1565	1041	454		6955	6955	15%
Total # of Other PGW identified for support services	651	859	472	480	498	196		3156	230	808	963	622	619	275		3517	6673	15%
HOW WELL WERE SERVICES DELIVERED?	**Dec-17**	**Jun-18**	**Dec-18**	**Jun-19**	**Dec-19**	**Jun-20**	**TREND**	**TOTAL**	**Dec-17**	**Jun-18**	**Dec-18**	**Jun-19**	**Dec-19**	**Jun-20**	**TREND**	**TOTAL**		
Total % of PGW referred who were successfully contacted	**63%**	**55%**	**51%**	**59%**	**58%**	**75%**		**59%**	**51%**	**56%**	**50%**	**42%**	**53%**	**34%**		**47%**		**52%**
Total % of Māori PGW referred who were successfully contacted	76%	59%	53%	62%	59%	76%		63%	59%	62%	52%	37%	53%	40%		50%		56%
Total % of Pacific PGW referred who were successfully contacted	44%	39%	51%	58%	61%	68%		50%	42%	45%	37%	32%	41%	39%		39%		43%
Total % of Asian PGW referred who were successfully contacted									50%	52%	56%	49%	60%	37%		51%		51%
Total % of Other PGW referred who were successfully contacted	57%	55%	47%	51%	50%	0%		54%	41%	60%	55%	58%	53%	26%		45%		49%
Total % of PGW identified who were successfully contacted	**38%**	**31%**	**39%**	**40%**	**43%**	**38%**		**38%**	**73%**	**39%**	**48%**	**47%**	**67%**	**66%**		**51%**		**46%**
Total % of Māori PGW identified who were successfully contacted	40%	20%	42%	26%	26%	39%		38%	64%	33%	39%	42%	60%	58%		45%		42%
Total % of Pacific PGW identified who were successfully contacted	37%	40%	46%	43%	43%	38%		41%	107%	30%	53%	54%	62%	86%		49%		45%
Total % of Asian PGW identified who were successfully contacted									0%	61%	64%	54%	86%	86%		67%		67%
Total % of Other PGW identified who were successfully contacted	31%	27%	39%	47%	39%	36%		35%	61%	42%	38%	45%	62%	35%		46%		40%
ARE PGW BETTER OFF?	**Dec-17**	**Jun-18**	**Dec-18**	**Jun-19**	**Dec-19**	**Jun-20**	**TREND**	**TOTAL**	**Dec-17**	**Jun-18**	**Dec-18**	**Jun-19**	**Dec-19**	**Jun-20**	**TREND**	**TOTAL**		
Total # of all successfully contacted PGW (referred or identified) who were screened	**2768**	**2885**	**2587**	**3404**	**2523**	**2522**		**16689**	**2224**	**3406**	**3594**	**3217**	**3353**	**2061**		**17855**	**34544**	
Total # of successfully contacted Māori PGW (referred or identified) who were screened	1484	1868	1496	2281	1672	2007		10808	1243	1554	1127	1123	1377	851		7275	18083	52%
Total # of successfully contacted Pacific PGW (referred or identified) who were screened	594	485	400	455	390	317		2641	205	435	788	399	416	285		2528	5169	15%
Total # of successfully contacted Asian PGW (referred or identified) who were screened									450	804	1089	994	1052	484		4873	4873	14%
Total # of successfully contacted Other PGW (referred or identified) who were screened	690	532	691	668	461	198		3240	326	613	590	701	508	441		3179	6419	19%
Total % of all successfully contacted PGW (referred or identified) who were screened	**55%**	**54%**	**49%**	**56%**	**59%**	**60%**		**55%**	**45%**	**44%**	**43%**	**42%**	**38%**	**44%**		**42%**		**48%**
Total % of successfully contacted Māori PGW (referred or identified) who were screened	49%	57%	42%	53%	57%	66%		**54%**	45%	43%	34%	37%	33%	44%		39%		46%
Total % of successfully contacted Pacific PGW (referred or identified) who were screened	77%	54%	56%	58%	63%	54%		**60%**	27%	33%	64%	38%	45%	44%		42%		50%
Total % of successfully contacted Asian PGW (referred or identified) who were screened									55%	49%	47%	49%	47%	45%		48%		48%
Total % of successfully contacted Other PGW (referred or identified) who were screened	58%	48%	67%	66%	64%	35%		**58%**	53%	50%	42%	48%	35%	42%		44%		50%

Table 12: Aggregated RBA data, Collective Impact view, 2017-2020, all SSS providers

TE TĀPIRITANGA TUAONO: MINOR THEMES

This section outlines minor themes from the thematic analysis.

A common or refreshed understanding of equity, eligibility, and prioritisation

Interviewees want a common definition of equity and how it applies to existing priority group women and potentially other 'vulnerable' women. SSS providers widely reported screening women who fell outside SSS criteria as they felt they should be screened. Examples of ineligible women screened included women with a previous high-grade cervical screen who had not been followed up; referred by whānau; disconnected from primary care; who did not access care due to financial or social constraints; and women who returned to SSS as their preferred sample taker.

Currently, there is no guideline for SSS providers to follow regarding prioritising referrals. Guidance can, however, be taken from current eligibility criteria. Some providers described several other factors they considered when prioritising referrals, including clinical risk, a history of sexual abuse, immunosuppression, socio-economic status, and time elapsed since last screening.

Perverse consequences and moral hazards in the screening pathways

Interviewees suggest there are several perverse consequences and moral hazards in the current screening system. They include:

- **Shifting accountability** – several interviewees suggested a negative consequence of SSS was that the costs associated with screening priority group women and responsibility were shifted from primary care to another part of the system. It also created a moral hazard because primary care could choose to screen the most easily engaged women and refer the 'hard to reach' women to SSS.
- **National screening targets** – removal of the national cervical screening target from primary care performance measures was seen as deprioritising screening. It was also linked to an increased and unfair expectation that SSS providers would hold accountability for achieving or maintaining cervical screening coverage of priority group women.
- **Funding** – it was suggested that the quantum of funding for SSS was partly determined by screening rates in DHB catchments. It was thought that this created a perverse consequence in that a successful SSS service, which contributed to improved screening rates, could be penalised (i.e. when need reduced, so did funding).
- **Potential perverse power dynamics** – concern was expressed by some about power dynamics between large versus small SSS providers (including sub-contractors). It was suggested that some of the larger SSS providers did not treat sub-contractors fairly. For example, there was an incentive to remove funding from the subcontractor to enhance the lead providers role. There were, however, several alternative examples of larger SSS providers resourcing sub-contracted NGOs appropriately to deliver grassroots models of care.
- **Removing cost as a barrier is a moral issue –** unlike other national screening programmes, the cervical screening programme is governed by specific legislation. Cervical screening is the only national screening programme for which there is a charge to the patient. This is $15. However, many women access cervical screening through GP appointments (some not

knowing that they can be screened without one) and pay the full appointment fee. Interviewees and in particular, women interviewed, stated that cost can be a barrier and cervical screening should be free.

"For cervical, it's just a complete anomaly that women have to pay for that." - Subject Matter Expert.

- **A legislative right** – interviewees suggest that legislation that supports cervical screening states that women have the right to choose where they are screened. According to some interviewees, the way SSS is set up infringed upon a woman's right to choose SSS support (i.e. eligibility criteria determined access).

Inadequate funding

Interviewees suggest that funding is not sufficient for SSS. This includes:

- **Overarching funding is not sufficient** – the funding formula was unclear to SSS providers, and they considered funding for the service to be inadequate. Although acknowledged or implied in the contract, interviewees reported that they did not receive adequate resource for population size and growth; complexity of women served, including offering both breast and cervical screening support; large geographic areas; meeting the needs of multiple distinct cultures and ethnicities; costs of providing holistic support to women and their whānau; the time spent building relationships and administrative duties, such as data cleaning.

"I suspect that [success] will be in spite of, not because of, what we've paid them… [SSS] providers [are] forced to be innovative because they're functioning literally on the smell of an oily rag." - MoH Interviewee.

- **Cross-subsidisation** – all SSS interviewees reported subsidising the service with funding from other sources.
- **Inequitable funding** – kaupapa Māori SSS organisations stated they were not funded equitably, with contracts stripped back over time which, in turn, affected service and workforce sustainability. The evaluators note that some of the examples conveyed, may not associated with the Ministry but have more to do with sub-contracting relationships.

Workforce and leadership development

Interviewees suggest work is required to build the screening workforce. Some of these issues are outlined earlier. They include:

- **Recognising that workforce are change agents; not just 'staff'** – this referred to multiple issues. Several examples included, staff working to change the system, champions of cultural safety and equity, working with women and their families, to effect positive life changes.

"They are our change agents." – SSS Provider.

- **Recruitment and retention** –challenges linked to recruitment and retention included high workload and low pay; burnout; insufficient numbers of clinical staff (particularly relevant for smaller and more rural services) and not enough culturally diverse staff, especially for larger and urban services where client populations are likely to be more culturally diverse.
- **The need to invest in workforce development and supports –** this included flexible working conditions, development planning and peer support, mentoring and shadowing.

- **Characteristics of great staff** – were identified by interviewees. They ranged from staff that were culturally safe, competent, and knowledgeable about screening through to staff who could build relationships, read people, were connected to community and services, and who were persistent and passionate about the kaupapa (to name a few).

> *"She's connected in many of the hapū, across all of the community groups, and in her own right as an icon and a leader amongst her own people. So, you know the 'who' component, particularly in terms of the workforce component, is crucially important. And I think the reason she got the model of care to work so well was because of all the engagement that was occurring before we got to the actual day... Although she's talked to general practice, you know, there's also the relationships that exist across Iwi, Hapū, NGOs." - SSS Provider.*

> *"They are very professional, makes me feel I will trust [them]. " -Priority Group Woman.*

- **Roles –** interviewees identified a range of roles and skillsets that were key to successful support services. They included health promotion, kaiawhina/kaimahi; administration; adult educators; cervical screeners and lived experience roles.
- **A constructive workplace culture**
- **More leadership at multiple levels including national, clinical, data, Māori, and Pacific**

> *“When we have more Māori in [leadership] roles, we begin to normalize the equity discussions. It's not one person on your own fighting a battle, it actually just becomes a normal conversation to have.” -Subject Matter Expert.*

Understanding the pros and cons of provider types and configuration

SSS providers described their different models and provider configurations. There were common and unique aspects, as follows:

- **There was a common commitment to high quality, wellbeing-focused delivery**
- **Pros and cons of larger, more urban providers –** pros of larger and more urban SSS providers (mainly DHBs, PHOs and larger NGOs) included an ability to deliver holistic, flexible services due to shared management and co-location of multiple services delivered by the same organisation (e.g. some DHBs deliver NCSP coordination, colposcopy, BSA and SSS); a bigger resource pool (including petty cash and workforce); a larger infrastructure; ability to run joint clinics or events without the ‘usual’ institutional barriers; an ability to more easily subsidise (perceived) unfunded aspects of the model (e.g. transport); resources to offer flexible (e.g. drop-in) screening clinics in larger, well-known community health venues, and the ability to opportunistically meet other health needs whilst women and their whānau were at their services; after-hours clinics with staff who were compensated appropriately (independent of relying on goodwill).

  PHOs stated they had positive relationships with primary care practices, integrated systems, and easy access to practice data and support to ‘clean’ it. Larger NGOs stated that their size and scale provided benefits. Larger and more urban providers also tended to have more discrete activities to engage with Asian women, compared to smaller providers. This was probably due to a larger Asian population in their area, a pool of resources and access to a workforce with which to develop Asian-specific initiatives.

> *"We're all on the same level of the super clinic. If we've got any questions, we can just go down to colposcopy." SSS Provider.*

Comments that focused on the cons of larger providers included that some PHOs only focused on their enrolled population; that larger providers could not reach into communities; that staff in large organisations and in urban areas were less embedded in the community; that staff were more likely to not be of priority group women descent; that staff did not appear to spend as much time engaging the "very hard to reach" women who required more time; that services run by large institutions were incapable of delivering services in a kaupapa Māori, or Pacific way compared to NGOs.

- **Pros and cons of smaller, more rural providers –** pros of smaller, more rural SSS providers (mainly kaupapa Māori providers, a Pacific provider, and smaller NGOs)[59] included that they were able to deliver more flexible, holistic services; were more agile due to their size; had minimal red tape; had fewer institutional barriers, and could 'fly under the radar' and get the mahi done; were more embedded in their communities and well known; had close working relationships with other community-based services and groups in their areas; staff were more reflective of the community; smaller non-Māori, non-Pacific organisations seemed to be more immersed in Māori and Pacific culture than some larger providers.

  Suggested cons of smaller providers included they faced additional barriers and potentially did not have the resources to deal with them (e.g. time spent transporting women to appointments in town); had to deal with extra work to coordinate with mobile buses that may only visit once a year; had limited choice of primary care practices and screening providers, which meant that SSS were the only alternative service; had limited infrastructure including manual systems which increased workload; were financially vulnerable due to size and scale; relied upon staff goodwill to provide flexible and responsive services; had difficulty recruiting to rural areas or smaller providers; in general, were less competent or experienced in delivering services to Asian women.

> *"It is individual dependent... the pivotal role with the aunties out there, who were respected in the community, who could have really tough conversations and be respected by people we're trying to provide services to and their whānau. They would listen to their voices. I suspect that is far more important than what the structure is and who we are contracting with." - MoH interviewee.*

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[59] These are generalisations about the types of providers, and do not necessarily apply to every provider within a category.

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Social media

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