SHINING A LIGHT ON

CERVICAL SCREENING IN AOTEAROA

2024

SURVEY REPORT

WOMEN'S
HEALTH
ACTION

DISCLAIMER: THIS REPORT REPRESENTS THE VIEWS OF SURVEY RESPONDENTS, NOT NECESSARILY THOSE OF WOMEN'S HEALTH ACTION OR OUR FUNDERS.

WE WOULD LIKE TO ACKNOWLEDGE THE GENEROUS CONTRIBUTION OF OUR PARTICIPANTS WHO TOOK TIME OUT OF THEIR BUSY LIVES TO COMPLETE OUR SURVEY AND SHARE THEIR VIEWS AND EXPERIENCES.

WE ALSO WANT TO THANK THE TEAM AT MOANA CONNECT FOR THEIR ASSISTANCE WITH THE PROJECT DESIGN AND DEVELOPMENT.

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ABOUT WHA

Ina oranga te wāhine, ka ora te whānau, ka ora te hapū, ka ora nga iwi e

When women are in good health, the whānau, hapū and iwi will flourish

We are pleased to present this report exploring people's experiences of cervical screening in Aotearoa. This report provides valuable insights into attitudes and understanding of HPV primary screening, during the early stages of a notable transition in the programme with the introduction of the self-test. We hope that the findings in this report will support the health system to respond to key concerns and barriers for people trying to access and engage with screening.

Women's Health Action (WHA) has been involved in the National Cervical Screening Programme since its inception. We are a charitable trust founded in 1984 by women's health activists Phillida Bunkle and Sandra Coney. The trust's initial focus was on reproductive health and rights, and we came to national prominence with our key role in exposing the 'Unfortunate Experiment' at National Women's Hospital. This resulted in the landmark Cartwright Inquiry and subsequent Cartwright Report in 1987/1988, ultimately leading to the establishment of the National Cervical Screening Programme.

Women's Health Action is a small team supported by a board of trustees. Our services align with health system priorities and directly support the implementation and delivery of the Women's Health Strategy, the National Breastfeeding Strategy, and embedding the Code for consumer and whānau engagement in the health sector.

Our mission is to authentically protect women's health and serve whānau. Our team work with consumers (service users), whānau, hapū, iwi, health professionals and other agencies/providers across the health, social development, education, and justice systems/sectors. We are committed to supporting the health system to provide timely access to quality, safe, and equitable health services. Along with delivering quality health information and initiatives, we engage with diverse communities nationwide to provide insights into the real-time needs of those accessing and delivering health care.

Thank you again to all the people who have contributed to this report.

BACKGROUND

Cervical cancer is a fully preventable disease. In Aotearoa New Zealand, a key part of eliminating cervical cancer is the National Cervical Screening Programme. This programme has a notable history, being the first organised cancer screening programme in the country (Ministry of Health, 2019) It was also born out of the Unfortunate Experiment and subsequent Cartwright Inquiry in 1988, which enshrined several legal rights for consumers of health care. In Aotearoa New Zealand, 180 people a year are diagnosed with cervical cancer. Of those 180, 85% have either never been screened or have not had regular screening (Ministry of Health, 2023).

In May to September 2023, Women's Health Action undertook a social research project to better understand consumers' experiences and attitudes towards cervical screening and further treatment, in Aotearoa New Zealand – alongside parallel research on breast screening.
While many high-level national and regional reports have pointed to wide variances in access to screening and treatment, there is limited (or not publicly available) information about people's experiences of these services.

We believe the information, perspectives and recommendations in this report provide valuable insights that reinforce the existing knowledge base about cervical screening and further treatment. This report highlights some of our findings which come at an important time during wider healthcare system reforms and specific changes to the cervical screening programme, notably the introduction of the self-screening tool in September 2023. Further valuable data has yet to be fully unpacked, and we would welcome the opportunity to undertake a more in-depth analysis of this information in the future.

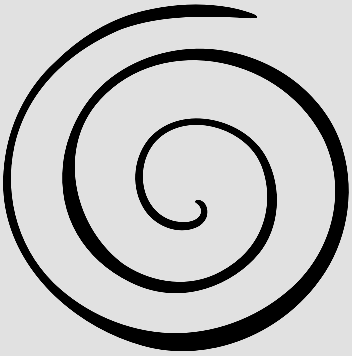
OVERVIEW

Respondents shared their experiences of the current cervical screening programme, both recently and historically. While the data captured many positive experiences, there were also some harrowing stories. As the focus of this report is on how we can improve the way the system operates, this report highlights areas for improvement more than areas of satisfaction.

The data captures people's cautious optimism regarding the introduction of the new self-screening tool and speaks to areas for improvement, such as:

- Communication about results
- Management of pain
- Cost of participation in the screening programme and/or further treatment
- Other barriers include travel, time off work, and childcare

We have included a number of recommendations about improvements at the end of each section on our survey findings. You can view our full list of recommendations at the end of the report.



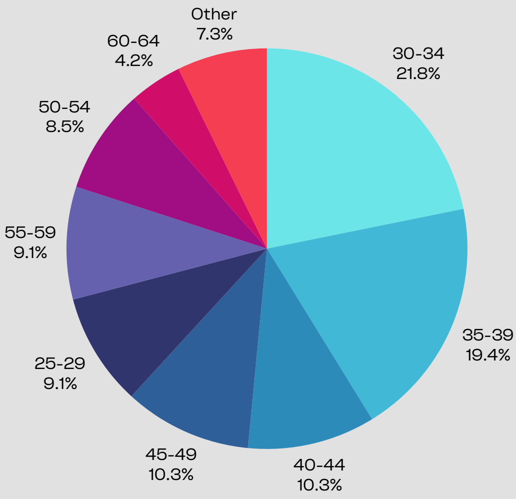
KEY DEMOGRAPHICS

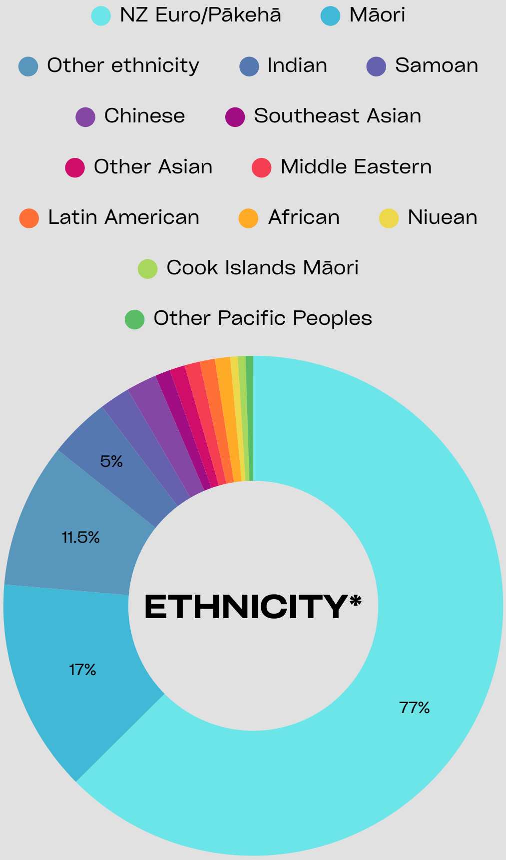
The online survey undertaken by Women's Health Action in late 2023 had 165 respondents

We had good representation from all areas of Aotearoa, with people from all geographic regions taking part in the survey. The largest group, 33%, were living in Auckland, with Wellington next at 13%, closely followed by Manawatu-Wanganui at 12%.

- 77% of respondents identified as NZ European/Pākehā, 16% identified as Māori.
- 99% of respondents identified as female.
- 41% of our respondents were in the 30-39 age range.
- 10% of respondents told us that they had a disability.

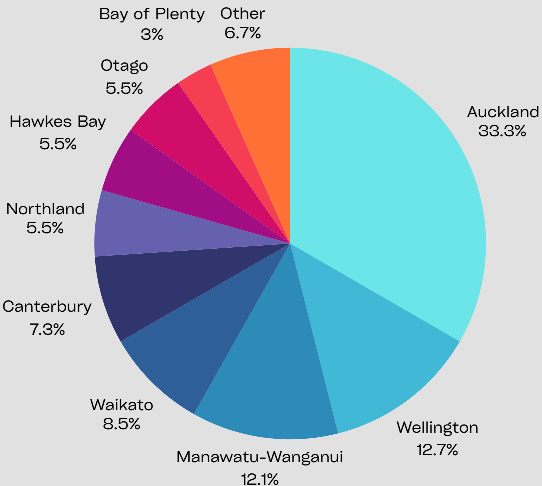
AGE





ETHNICITY*

REGION



- percentages do not total 100 as people could select multiple answers to this question

ACCESS

93%

accessed cervical screening via their GP

14% at Family Planning (now known as Sexual Wellbeing Aotearoa)

7% at a hospital or with an OB/GYN

4.5% at a mobile screening unit

53%

had to pay for some or all of their screening

38.5% did not have to pay

8.5% were unsure

LIMITATIONS

The online nature of this survey likely contributed to lower participation from Pasifika and Asian populations as well as older people. We also had low rates of trans and non-binary people (TGBN) participating in this survey, which may reflect general lower rates of cervical screening among TGBN people (Carroll, Tan, Ker, Byrne, & Veale, 2023). We know these are priority groups within the existing cervical screening programme. Further research should be done amongst these population groups prioritising in-person conversation, which we feel would be a more appropriate means of data collection.

FINDINGS

Our survey findings centre around several key things:

1. Perceptions of the new self-screening tool
2. What's working well
3. Communication about results
4. Taking people's pain seriously
5. Cost
6. People accessing further treatment

1. PERCEPTIONS OF THE NEW SELF SCREENING TOOL

Whilst the new self-screening tool is thought to be a game changer in terms of increasing the reach of the programme - with more than 50% of our survey respondents feeling positive about the tool, it is clear there needs to be further work done to increase people's understanding and confidence in the self-screening process and its effectiveness.

We are pleased to see that most people (69%) who responded to our survey were <u>aware</u> of the introduction of the self-screening tool. We feel this is a high number considering the self-screening tool was rolled out in September 2023, a few months after our survey was first launched. A good number reported that they feel positively about this new tool, and they feel it will increase participation in the screening programme.

65% of respondents (100 people) gave us their specific thoughts on the new self-screening tool. These responses were mainly focused on these key themes:

- Most people feel positively about it (59%). They are happy about the less invasive nature of the test and reported that they are more likely to use it, compared to the traditional smear test.
- Concerns about making errors with the new self-screening tool. People worried they would do it wrong themselves and need to be retested, or that something would be missed.
- Perception that the self-screening test can be done at home. Whilst this is apparent in some of the promotional material, we are not certain that this is offered across all GP practices and screening units.
- Some people raised cost as an issue in terms of accessing the self-screening tool. People are still confused about whether there is a cost for screening; the cost is different depending on if you are in a priority group, where you live or what GP you go to; and there is concern that covering the cost of the under-screened or never screened will encourage people to not access or delay their screening.

59%

feel positive about the new self-screening test

> *I have been invited to do the self test. But it still had to be done in a nurses office at the full cost of the old test. So although it was less invasive it was still inconvenient and expensive.*

I am excited for a self testing option.i work with whānau who have experienced sexual abuse and find smears traumatic and I am hopeful this may help them do testing. I am worried about the longer gap between testing though. I have cervical cancer that developed between my smear tests. My cancer grew rapidly and nearly symptomlessly within 18 months of a normal smear result and if I didn't work in women's health I probably wouldn't have gone to get extra testing done and the cancer would have killed me. I worry how many will fall through the cracks with a 5 year gap between tests.

I hope this will make people more comfortable - I have attempted one screening and due to vaginismus, doubt I will attempt one again in a clinical setting. It was humiliating and painful.

OUR RECOMMENDATIONS

- Continue to publicly promote the new self-screening tool, with communications focusing on where people can use the new tool (e.g. its use is still predominantly at a GP, clinic or marae and not at an in-home setting). Providers who do offer self-screening at an in-home setting should make this very clear and promote it publicly.

- Provide clear, concise and coherent instructions - in both physical and digital formats and in several languages - on how to use the new self-screening tool so that people feel confident that they are doing it correctly. We encourage practices to have posters visible in their bathrooms.

AREAS FOR FURTHER RESEARCH

- Future research should explore the accessibility and acceptability of the self- test for the TGNB population in Aotearoa (Carroll, Tan, Ker, Byrne, & Veale, 2023).

- A further piece of work to come out of this report could be the creation of a national register of screening locations/providers who allow for in-home screening.

2. WHAT'S WORKING WELL

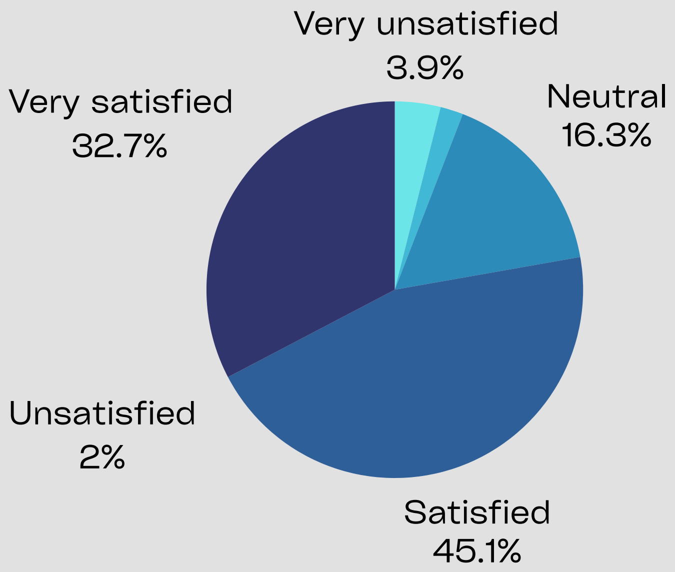
Our survey respondents identified a number of things that are going well in the current national cervical screening programme. These were mostly connected to people's experience of the actual screening appointment itself.

Our survey respondents reported that:

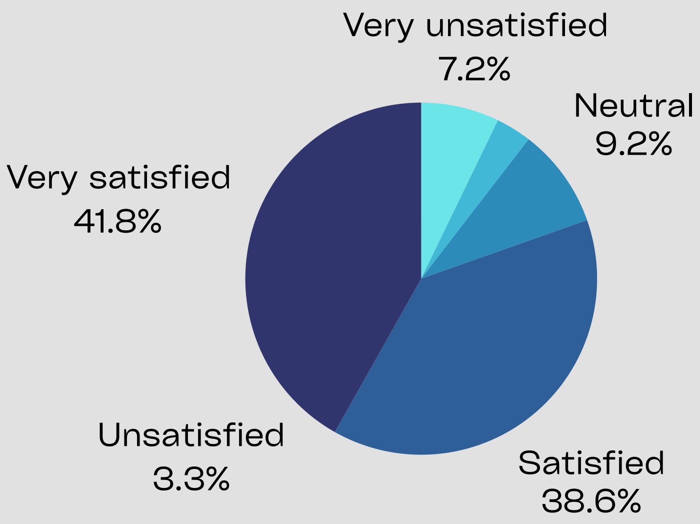
- 78% were satisfied or very satisfied with the length of time the appointment took.
- 75% were satisfied or very satisfied with how they were treated by the reception staff.
- 80% were satisfied or very satisfied with the facilities of the provider.
- 80% were satisfied or very satisfied with how they were treated by the clinical staff.

The metric where people reported lower levels of satisfaction was regarding pain or discomfort that they experienced during screening. Only 45% of people reported a positive experience with this, compared to 10% who were very unsatisfied, 12% who were unsatisfied, and 32% who were neutral. Whilst some level of pain or discomfort is to be expected, in our view it is worthwhile to interrogate this further to understand where improvements could be made.

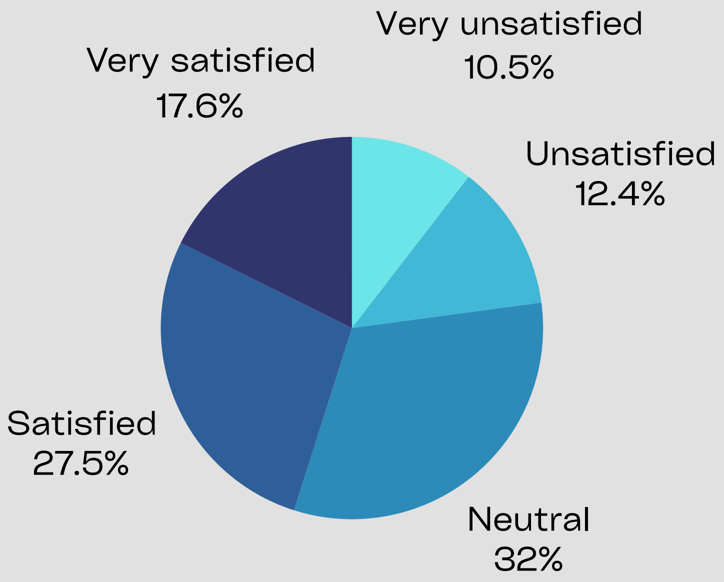
TIME THE APPOINTMENT TOOK



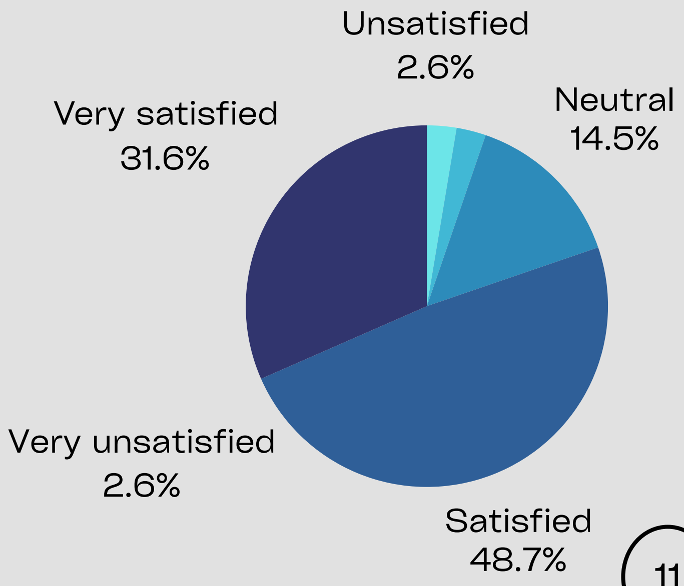
HOW YOU WERE TREATED BY THE CLINICAL STAFF



PAIN OR DISCOMFORT DURING SCREENING



THE FACILITIES OF THE PROVIDER



We were also pleased to see that:

93% were offered a sheet or something to cover themselves with

86% were provided with a comfortable place to change

86% felt they were listened to during their visit

55% Only 55% of people were offered a place to sit and gather themselves after the procedure

However, only 55% of people were offered a place to sit and gather themselves after the procedure, compared to 35% who were not, and 10% who were unsure. This is something that could be improved and would be very impactful in terms of people having a more positive experience.

OUR RECOMMENDATIONS

- Make sure that all providers offer people a place – and the time – to sit after the procedure and gather themselves. Cervical screening can be scary, invasive, and difficult for people for a range of reasons. Doing this can help improve their visit and encourage them not to drop out of the screening programme because of a bad experience.

3. COMMUNICATION ABOUT RESULTS

TIMELINESS

Although a majority (74%) of respondents said that communication about their results was timely, 13% told us that it wasn't, with some saying they heard nothing from their provider. The remaining 13% were unsure.

13%

said communication of their results was not timely

Communication of results varies from service to service, often causing unnecessary concern. Some were told to check their online records for their results; others were told that no news is good news. We heard that people do not know how long to wait; they might wait weeks and think they are in the clear only to get a call later on because of delays in the system, or they do not have proper records to know or remember when they might next be due for screening. This could be further complicated for people who move GP practices, houses or countries.

On one occasion it took 4 weeks for the provider to leave a message about my results which were abnormal.

I was told no news was good news and then a few weeks later I was told my test was inadequate & needed to be repeated.

They only contact you if there is a problem. So do not hear any more about your screening experience.

COMPREHENSION

We also asked people whether they were provided with information about their results that they understood. 81% answered yes, 10% were unsure, and 9% said no. The people who responded no to this question predominantly reported that they were unhappy with how no result was communicated to them at all. Others had to google their results for themselves and try to understand that way.

19%

were not provided with information that they understood (or they were unsure)

I assumed no info meant no issue. This is a scary way GPs operate.

I had to google what it meant

DELIVERY

We asked people if they were satisfied with how their results were communicated to them. 77% said yes, 11% were unsure, and 12% said no. Of those who said no, most of their dissatisfaction centred around results being uploaded to the person's online health portal, but no direct communication being made with them by their health provider.

12%

were unsatisfied with how their results were communicated to them

Was just put in online medical record, not contacted about the result directly

Results were just uploaded to my health portal, they were normal so I assume there is no contact about your results if this is the case

Others talked about how the delivery of the information about their results could have been done in a kinder way.

> *I was told I had an abnormal smear and that I needed a biopsy.*
> *I needed that information told to me kindly and with more detail.*
> *I didn’t understand and I was afraid*

OUR RECOMMENDATIONS

- All people should be contacted by their healthcare provider about their results – regardless of what those results might be. This should be a blanket expectation for all people engaged in the screening programme, and should not differ across localities or providers. Patients should receive documentation that confirms what their result was and when this result was received.

4. TAKING PEOPLE’S PAIN SERIOUSLY

PAIN DURING SCREENING

It is a reality that pain from all procedures connected to cervical screening is one of the biggest concerns for people, with impacts both before, during and after screening. A third (35%) of our respondents reported that they were worried about pain from the screening procedure, and that this was a barrier for them to access screening. 18% reported that they felt shame or embarrassment, and 14% felt fear or uncertainty about the process.

35% were worried about pain from the screening procedure

18% felt shame or embarrassment

14% felt fear or uncertainty about the process

As stated earlier in this report, when we asked people about the pain or discomfort they experienced from the cervical screening procedure itself, 55% responded that they felt either unsatisfied or neutral about the level of pain they experienced. Whilst some level of discomfort might be expected with the traditional smear test, this is an area where we feel improvements could be made.

This could involve more explanation from practitioners about what to expect during screening, advice to take pain relief before screening, and practitioners listening to, validating, and not minimising people's experience when they report pain or discomfort to them. We are hopeful that the introduction of the self-screening tool will also mitigate people's experience of pain, as it is less invasive, and people can do it themselves.

Seemed like a minor issue to them despite me explaining how painful the initial examination had been

My screener (GP) did not listen to my concerns about my excruciating period pain, irregular and heavy cycle. Indicated to me I should just accept the pain as they feel it is normal for women who menstruate to have this level of pain. Gaslit me about my "lifestyle choices" saying the reason I am in such pain every month and bleeding so heavily is due to my weight (I am 5'11 and weigh 87 kilo). I do not feel safe or cared for by my GP and as there are no other GPs enrolling in my area I choose to forego medical care while I wait for a new GP to become available who does not talk down to me or dismiss my concerns about my own body. I am overdue a smear again and with my history of irregular results I feel pressure to go have one but I am not willing to subject myself to the dehumanizing experience of having a GP who doesn't care about me as a person roughly shoving equipment into my vagina and then telling me not to make a fuss when I remark that the roughness is causing me discomfort.

Had bad experience in the past had bleeding afterward

The male obstetrician asked if I was going to be big girl & not need a chaperone. I made a complaint to HDC, who shared no concerns with this statement

PAIN DURING FURTHER TREATMENT

After their cervical screening, <u>20% of people required further treatment.</u> When it came to people receiving further treatment (e.g. LLETZ, colposcopy/cone biopsy, or cancer treatment) there were some particularly harrowing stories about people experiencing pain.

For this group, the main barrier to them accessing treatment was their concern about the pain of the procedure – 45% of respondents raised this as an issue.

Properly informing people about the level of pain that can be expected, and listening to them when they say they are experiencing pain and responding to it appropriately, should be a cornerstone of the cervical screening programme. Whilst we know that most providers will be doing their best and acting appropriately in this area, some people are still being let down.

45% were worried about pain from the procedure

We are concerned that offering no pain relief seems to be standard practice during colposcopy and feel that consumers should be better informed of how to manage pain from this procedure. Encouraging people to take pain relief in adequate time before the procedure would be a good first step.

No one told me it would be so painful. I nearly passed out. I later had an IUD inserted and that hurt less.

I found the colposcopy incredibly painful and I wish I was given gas or something for the pain

I wish they had listened when I said the numbing injections weren't working and I could still feel it. I felt my LLETZ and it was horrific. I have massive trauma around it and now struggle with trust issues and anxiety and panic attacks for all doctor or physio visits involving my genitals.

OUR RECOMMENDATIONS

- Improve people's experience of pain or discomfort during screening. It's important that providers discuss pain management with people before their screening and ask questions to understand a person's background e.g. have they experienced screening before, are they concerned about pain, or are there any relevant factors (like past sexual trauma, a previous bad experience with screening, or other health concerns like endometriosis) which might increase their pain or discomfort. This is particularly important for priority groups, including trans and non-binary people, and perimenopausal/menopausal women. Options for pain management include paracetamol and numbing gel or using a smaller speculum. In our view, more culturally responsive services would also improve this metric.

- Better management of patients' pain by practitioners during follow-up procedures, particularly colposcopy. People should be advised to take pain relief in adequate time before the procedure, regardless of whether a biopsy is going to be performed. The option for numbing gel or spray should also be discussed with people, with studies showing that Lidocaine spray reduces pain during colposcopy-directed cervical biopsy.[1]

5. COST

When we asked people what some of the barriers were to them accessing cervical screening, a quarter of them (25%) said cost was an issue. In our view this is a significant problem in terms of screening all people who are eligible for the screening programme.

25% said cost was a barrier

55% had to pay for some, or all, of their screening

It was expensive! Almost $50 and I take to take time off work to go to the appointment because I have a toddler and only have childcare during my working hours, so it was a huge juggle to make sure my child was in care and then try to work those extra hours back in the evening. I was asked about family violence/domestic abuse which was good. I'm safe at home but I'm glad they asked if I did feel safe and had a supporting husband.

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[1] Wongluecha, T., Tantipalakorn, C., Charoenkwan, K., & Srisomboon, J. (2017). Effect of lidocaine spray during colposcopy-directed cervical biopsy: A randomized controlled trial. The journal of obstetrics and gynaecology research, 43(9), 1460–1464. https://doi.org/10.1111/jog.13380

48% of our survey respondents said they had to pay for their screening, with a further 7% saying there was some cost to them (e.g. discounted GP visit with a Community Services card). With most people accessing screening through their GP (93%), the cost for screening will vary widely for people all around the country, depending on where they live and how much their local GP appointments cost. That is notwithstanding the cost for people getting themselves to their appointments – one respondent told us the closest GP to them was 40km away – or the cost of having to take time off work because appointments are only available during the day.

Distance. My GP is 40km away as I can't get into one closer to my new home

Getting time off work to attend. All appointments in work hours

Cost was also an issue for people accessing further treatment after screening. A lot of the time these costs impacted people who were too sick to work or lived far away from their treatment provider.

I had to quit my job (community midwife) as soon as treatment begun. I was too sick to work, didn't meet criteria for social assistance. My mum had to move in to help look after my 5 children so that my husband could keep working. We used our entire life savings to survive the 12 months that I couldn't work and are still struggling because of it. I have long term chronic fatigue and pain from treatment and cannot return to full time work. We don't qualify for any support and I may never be able to work full time as a midwife again- despite only qualifying 3 years ago and having worked a total of 18months before I got sick. I don't think we will ever be able to recover financially and will likely never own a home because of it. We are a middle income family and because of this there Is no financial support

There was no financial support at all with transport. I live in Pukekohe and treatment was at Auckland Hospital. No financial support for my caregiver I couldn't raise my 2 children while having treatment so my mum had to do everything while my husband worked to pay our bills. I was lucky my dad could drive me to treatment because I was so unwell and mum could stay with my kids. But no one helped us financially at any point

OUR RECOMMENDATIONS

- Fund cervical screening appointments for everyone – not just those in priority groups. This would reduce cost as a barrier, make navigating the system less complex, and greatly improve equity. This is particularly important given the introduction of the self-screening tool, which for some people will require repeat/more visits to their healthcare provider, meaning more cost to them. One in four people surveyed said cost was a concern for them. Currently, the cervical screening programme is the only national screening programme that is not fully funded.

- Reassess the eligibility criteria for financial support for people undergoing cancer treatment. With inflation and the ongoing cost of living crisis, people on middle incomes, people living rurally, and/or with young families are no longer able to afford the cost of someone being out of full-time work and needing to access cancer treatment. The existing eligibility criteria is also hard to find and unnecessarily complex.

6. PEOPLE ACCESSING FURTHER TREATMENT

Of the 164 people who responded to our survey, 20% reported that they required further treatment after their initial cervical screening.

We asked people to tell us which further treatments they had experienced – we asked them to tick all that applied (this is why the total percentages do not equal 100 as some people experienced more than one treatment). Most of this group (77%) underwent a colposcopy and/or cone biopsy, 26% underwent LLETZ, 10% had surgery, and 6% had radiation and/or chemotherapy.

We asked them about the information they received from their treatment provider:

- 68% said it was timely
- 79% said it was easy to understand
- 76% said it was communicated to them with kindness and compassion
- 86% said it was in their own language
- 79% said they received verbal information (from discussion with the provider)
- 67% said they received written information
- Only 22% said they received digital information

22%

Only 22% received digital information about the further treatment that they needed

We asked people if they thought anything could have been done better in terms of the information that they received – almost half (45%) said yes. A lot of the suggested improvements centred around more support and better information for whānau and support people, as well as more information about the risks or impacts from the procedures.

45% thought things could have been done better in terms of the information they received

Someone could have supported my partner and my parents. It was a lot of information to relay. And because my dad was typically the one who drove me he didn't sit in on consults as they were so personal

I wish they told me more about the risks of pain and bleeding after as I ended up in hospital for a few days after due to bleeding

OUR RECOMMENDATIONS

- Provide more digital information, including what the possible risks and side effects are from further treatment. Digital information can easily be shared with whānau and support people, even if they have not been part of the consultation.

OUR FULL LIST OF RECOMMENDATIONS

- Continue to publicly promote the new self-screening tool, with communications focusing on where people can use the new tool (e.g. its use is still predominantly at a GP, clinic or marae and not at an in-home setting). Providers who do offer self-screening at an in-home setting should make this very clear and promote it publicly.

- Provide clear, concise and coherent instructions - in both physical and digital formats and in several languages - on how to use the new self-screening tool so that people feel confident that they are doing it correctly. We encourage practices to have posters visible in their bathrooms.

- Make sure that all providers offer people a place – and the time – to sit after the procedure and gather themselves. Cervical screening can be scary, invasive, and difficult for people for a range of reasons. Doing this can help improve their visit and encourage them not to drop out of the screening programme because of a bad experience.

- All people should be contacted by their healthcare provider about their results – regardless of what those results might be. This should be a blanket expectation for all people engaged in the screening programme, and should not differ across localities or providers. Patients should receive documentation that confirms what their result was and when this result was received.

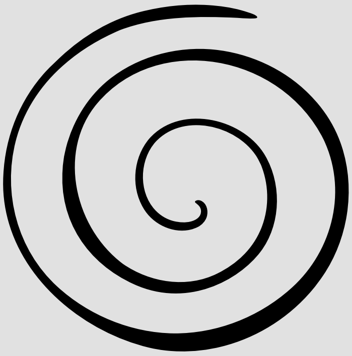
- Improve people's experience of pain or discomfort during screening. It's important that providers discuss pain management with people before their screening and ask questions to understand a person's background e.g. have they experienced screening before, are they concerned about pain, or are there any relevant factors (like past sexual trauma, a previous bad experience with screening, or other health concerns like endometriosis) which might increase their pain or discomfort. This is particularly important for priority groups, including trans and non-binary people, and perimenopausal/menopausal women. Options for pain management include paracetamol and numbing gel or using a smaller speculum. In our view, more culturally responsive services would also improve this metric.

- Better management of patients' pain by practitioners during follow-up procedures, particularly colposcopy. People should be advised to take pain relief in adequate time before the procedure, regardless of whether a biopsy is going to be performed. The option for numbing gel or spray should also be discussed with people, with studies showing that Lidocaine spray reduces pain during colposcopy-directed cervical biopsy

- Fund cervical screening appointments for everyone – not just those in priority groups. This would reduce cost as a barrier, make navigating the system less complex, and greatly improve equity. This is particularly important given the introduction of the self-screening tool, which for some people will require repeat/more visits to their healthcare provider, meaning more cost to them. One in four people surveyed said cost was a concern for them. Currently, the cervical screening programme is the only national screening programme that is not fully funded.

- Reassess the eligibility criteria for financial support for people undergoing cancer treatment. With inflation and the ongoing cost of living crisis, people on middle incomes, people living rurally, and/or with young families are no longer able to afford the cost of someone being out of full-time work and needing to access cancer treatment. The existing eligibility criteria is also hard to find and unnecessarily complex.

- Provide more digital information, including what the possible risks and side effects are from further treatment. Digital information can easily be shared with whānau and support people, even if they have not been part of the consultation.



CONCLUSION

This report has put the spotlight on cervical screening services across Aotearoa. Whilst many people are reporting good experiences with these services – and the introduction of the new self-screening tool is a gamechanger – there is room for improvement.

Better and more consistent approaches to pain management, led by patients and upheld by practitioners, is at the heart of our recommendations for positive change. This should be supported by consistent and timely communication and documentation about results.

We acknowledge the deeply personal stories and insights that our survey participants shared with us in the creation of this report. These people are the experts of their own bodies and their experiences of health systems, and their stories form an important basis from which to make change.