Thematic Feedback Analysis

Public Consultation on Introducing Self-Testing to the Human Papillomavirus (HPV) Primary Screening Clinical Pathway



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# Background

## Purpose

This document outlines the feedback and recommendations from the public consultation undertaken throughout May and June 2021, including 105 written submissions and 11 consultation meetings on the plan for implementing the human papillomavirus (HPV) primary screening pathway, which introduces the option of self-testing. Submissions raised similar themes and issues, and these are summarised within this document, alongside sector recommendations.

The outcome of this consultation has been the development of a final HPV primary screening clinical algorithm, with the option of self-testing. Consultation feedback is also informing the next steps of planning, including designing a detailed information technology (IT) system for implementing the programme and developing guidelines, policy and procedures.

## Context

In May 2014, the then Associate Minister of Health approved policy work to consider a major change to the National Cervical Screening Programme (NCSP). This was changing the primary screening test from liquid-based cytology testing to HPV testing, in line with similar changes in other countries.

In 2015, the NCSP undertook a public consultation in preparation for implementing HPV primary screening. The NCSP released a public consultation document in September 2015 on changing primary cervical cancer screening from liquid-based cytology testing to HPV primary screening.

The 2015 and 2018 parliamentary review committees and Te Rōpū Whakakaupapa Urutā, the National Māori Pandemic Group (2020) recommended that HPV primary screening, including self-testing, be funded and implemented as a matter of urgency. Professional groups (including The Royal New Zealand College of General Practitioners, RNZCGP) and Māori advocacy groups are strongly advocating for implementing HPV primary screening in order to support more equitable health outcomes.

In 2021, the Government announced funding for the NCSP to move to primary HPV screening, with the option of self-testing, from July 2023. This consultation proposed a number of changes to finalise the clinical pathway for HPV primary screening based on emerging international evidence and to consult on the introduction of self-testing.

## Adding a universal option of self testing

The transition to HPV primary screening[[1]](#footnote-1) will give everyone the option of either self-testing or having a clinician-taken sample. New Zealand studies suggest that offering HPV self-testing alongside more comprehensive pathway supports will increase participation and equitable outcomes by reducing barriers to screening.[[2]](#footnote-2)

An HPV test using a swab can be done by either the participant or a clinician, if preferred. The clinician who orders the test will remain responsible for all follow-up. It is important that the clinician provides education and support about cervical screening at the time of the test to ensure the participant is fully informed and understands the importance of ongoing participation in the NCSP.

Modelling undertaken in Australia to assess the impact of self-testing[[3]](#footnote-3) concluded that offering even a single HPV self-test has considerable potential to improve outcomes for un- and under-screened participants. HPV primary screening provides the opportunity for everyone to self-test and the ability to safely adopt a five-year screening interval. This supports increased participation by removing one of the key barriers to screening: the need for a speculum examination. However, anyone who is HPV positive will need a subsequent speculum examination for cytology or colposcopy examination.

## Guiding principles

Guiding principles for the change to primary HPV screening include the following:

* Improve equity of outcomes (cervical cancer incidence and mortality) across all population groups as per Te Tiriti o Waitangi principles identified in the Wai 2575 Hauora report of the Waitangi Tribunal.
* The guarantee of **tino rangatiratanga**, which provides for Māori self-determination and mana motuhake in the design, delivery and monitoring of primary health care.
* The principle of **equity**, which requires the Crown to commit to achieving equitable health outcomes for Māori.
* The principle of **active protection**, which requires the Crown to act, to the fullest extent practicable, to achieve equitable health outcomes for Māori. This includes ensuring that the Crown, its agents and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity.
* The principle of **options**, which requires the Crown to provide for and properly resource kaupapa Māori primary health care services. Furthermore, the Crown is obliged to ensure that all primary health care services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care.
* The principle of **partnership**, which requires the Crown and Māori to work in partnership in the governance, design, delivery and monitoring of primary health care services – Māori must be co-designers, with the Crown, of the primary health care system for Māori[[4]](#footnote-4).
* Deliver a best-practice national cervical screening programme that stands up to international comparison.
* Make screening coverage more equitable across all population groups.
* Maintain and improve the safety and quality of screening for all enrolled participants.
* Maintain a skilled and competent workforce to deliver the national programme.
* Be managed to ensure a smooth transition to the new primary screening pathway.
* Maintain and improve the NCSP Register’s capability to support the programme.
* Allow all participants to choose whether their sample will be taken by self-test or by a clinician.

## Consultation process and responses

Individuals and organisations were invited to make online submissions in response to the revised pathway for primary screening from liquid-based cytology testing to human papillomavirus (HPV) testing, in line with similar changes in other countries. The referral pathway, clinical guidelines, policies and standards inform the core elements of the clinical programme change.

The consultation received 105 written submissions and 11 stakeholder huis were held with key stakeholders to collect feedback. Table 1 below shows the number of submissions received by submitter type. Submissions raised similar themes and issues, and these have been broken down into nine themes as summarised below. For more information on stakeholder feedback, see **Appendix 1**: Consultation Stakeholder Meetings.

The consultation yielded recommendations and discussion on a wider range of topics than the HPV primary screening clinical pathway. Some of the feedback that may have been out of scope for this consultation will be used to support and inform further consultations on the specific changes required to support the implementation of the programme change.

A large number of recommendations are being addressed through core workstreams for implementing HPV primary screening from 2023. There are more workshops planned for over the next six months to further explore and understand sector implementation requirements to support the programme change.

**Table 1: Submissions by submitter type**

| **Submitter type** | **Number of submissions/participants** |
| --- | --- |
| Individuals | 12 |
| District Health Board | 23 |
| Government organisation | 1 |
| Māori provider | 6 |
| Non-governmental organisation (NGO) | 15 |
| Research or academic organisation | 4 |
| Primary health organisation (PHO) | 10 |
| Primary Care Service | 34 |
| **Total** | **105** |

# Executive Summary of Responses

## Themes

### Equity

There is strong support for New Zealand to move toward self-testing for convenience, privacy, empowerment and autonomy over whare tangata[[5]](#footnote-5). The increased acceptability of self-testing, especially in the un- and under-screened populations, will lead to increased uptake among people who have been reluctant to screen to date. This will likely result in a more equitable screening programme and a reduction in the number of cervical cancers.

Organisations consulted advised that the clinical pathway requires a strong focus on the principles found in Te Tiriti o Waitangi and must align with the transformations called for in the Wai 2575 Hauora report of the Waitangi Tribunal[[6]](#footnote-6).

As identified in the Hauora report, the Waitangi Tribunal proposes the following framework of Te Tiriti o Waitangi principles be adopted for the primary health care system.

* Tino rangatiratanga
* Equity
* Active protection
* Options
* Partnership.

### 2. Barriers to accessing primary and other health care services

Like the current cervical screening programme, this proposed pathway plans to offer the HPV screening test in a clinical setting. Replacing the test within the current delivery system presents a significant risk of replicating the inequities known to exist around access and outcomes for Māori and Pacific participants. There are concerns for priority group populations, those not enrolled with a primary health care provider and transient people.

Recommendations were provided to manage routine invitation, follow-up and recall, as well as new capabilities to be built into the IT design for the new National Cervical Screening Programme (NCSP) Register. Participant follow-up must be implemented in an equitable way, as this will be especially important in reducing adverse outcomes (cervical cancer incidence and mortality) among priority populations.

### 3. Cost barriers

The cost implications of the new clinical pathway (initial test and follow-up) for participants must be considered. Cost will potentially still be a barrier, particularly if the NCSP relies on primary care services in any of the screening stages. The sector recommended that funding be redirected to HPV screening and follow-up for at-risk Māori and Pacific peoples and others living in quintile 5 deprivation areas (that is, the most deprived areas) and for the programme to investigate capacity to fund all follow-up investigations for participants where HPV is detected.

### 4. Clinical pathway for high-risk HPV (type 16 or 18)

The algorithm allows a pathway for direct referral to colposcopy to mitigate high-risk participants being lost for follow-up, with the option of adding cytology if the participant chooses. If a participant self-tests for HPV type 16/18, a follow-up visit with a primary health care provider is a good opportunity to provide education and reassurance, even if the participant does not take up cytology testing.

### 5. Pathway education and communication strategy

The transition process from one testing programme to another will need to be well managed and include a comprehensive education campaign. The screening sector recommended a communication strategy at all levels, providing clear, accessible information to support clinicians and participants in understanding how the programme has changed and what steps are involved in the new pathway.

### 6. Self-testing in a clinical setting

Self-testing is an important option to promote access to cervical sampling. However, organisations agree that there are benefits to a clinician-taken sample over a self-test. The risk of self-testing is that some issues that may have been picked up during a speculum examination may not be identified.

The organisations recommended developing guidelines that would help clinicians identify participants who might benefit from a clinician-taken sample and speculum examination rather than completing a self-test and discuss options with the participants so they are making informed decisions regarding their health.

### 7. Considerations related to implementing HPV testing mail-out kits

Some organisations recommended that the HPV primary screening pathway include home-based self-sampling alongside the option for self-sampling in a clinical setting. Some supported a transition to home self-testing and recommended that the programme be designed to enable this in the future.

However, others were wary of home-based testing being rolled out without considering the limitations faced in the mail-out bowel screening programme, as well as the loss of communication and education that is provided when a clinician is involved in discussing options if HPV is detected. It was recommended that the programme implement robust outreach services to reach priority groups who may face challenges in accessing services.

### 8. Workforce impacts

A few workforce impacts were raised relating to the increased demand for self-testing. The skilled cervical screening workforce would shrink as the requirement for cytology tests dropped, and this could impact on the quality of cytology testing. Experts in this area might require extra support and re-training in the future.

Recommendations were provided for the programme to ensure appropriate funding would be available to strengthen laboratory, cytology and colposcopy services.

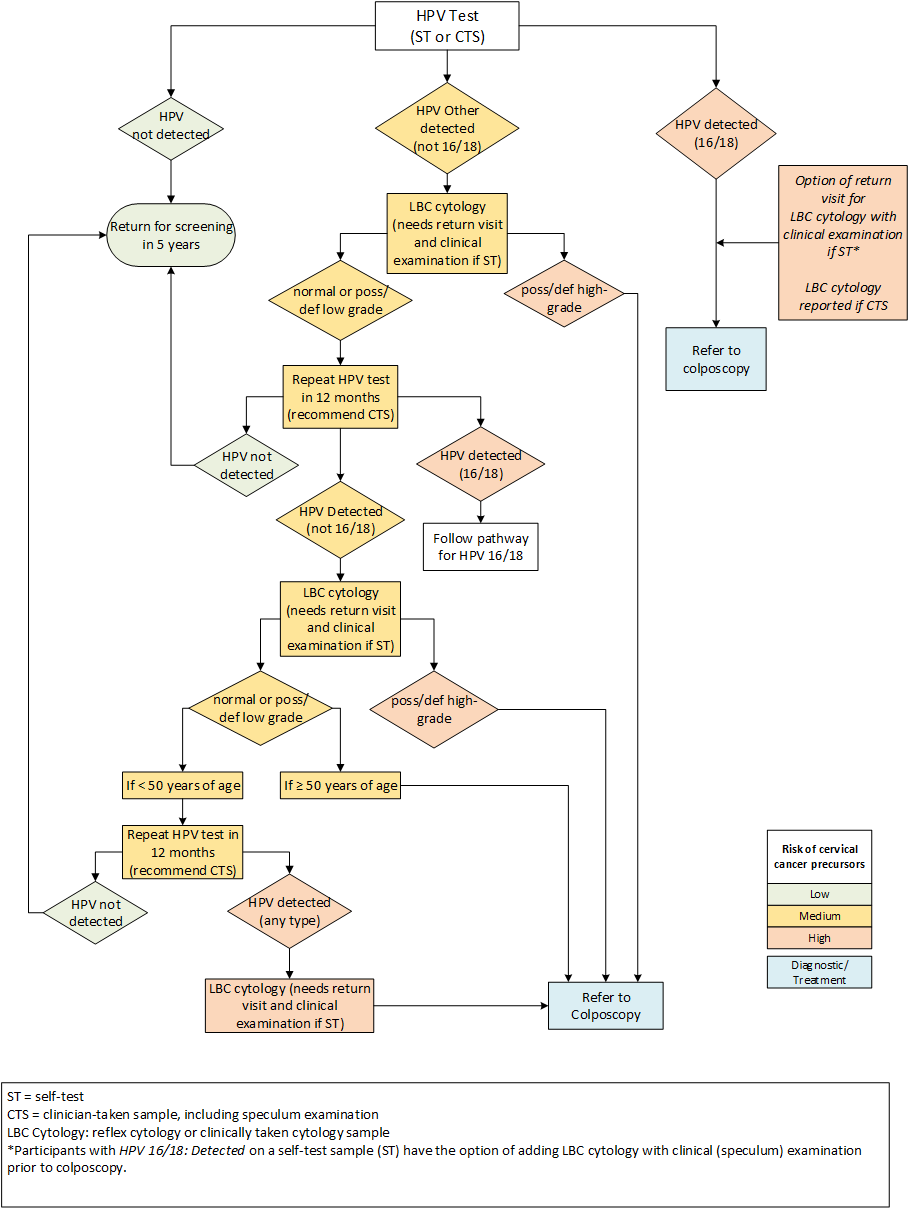
### 9. Pathway terminology and logic

A few recommendations related to ensuring the clinical pathway is logical and easy to follow. These include: needing clarification about the difference between self-testing, clinician-taken samples and speculum examination and when a return visit would be required to collect cytology.

The screening sector also recommended a clear definition of the timeframes for participants to attend cytology and colposcopy after testing positive for HPV (any type), including maximum timeframes for referring participants to secondary health care services.

# Revised HPV screening clinical pathway for asymptomatic participants

Over May and June 2021, the NCSP undertook a public consultation on the HPV primary screening clinical pathway to introduce self-testing. The following diagram is the revised HPV primary screening clinical pathway for asymptomatic participants, updated to include screening sector feedback and recommendations.



## Changes made to the clinical pathway

* The changes clarified that a return visit for cytology and speculum examination is required if a participant tests positive for HPV-other (not HPV 16/18) on a self-test.
* The changes clarified that a clinician-taken sample is preferred for repeat HPV tests at the 12-month interval on the pathway, so that cytology can also be performed if the HPV test result is positive.
* The changes clarified the type of HPV detected at the repeat intervals within the clinical pathway.
* The changes added a pathway for direct referral to colposcopy if HPV type 16/18 is detected. Participants with HPV 16/18 on a self-test sample (ST) will have the option of adding cytology with clinical (speculum) examination before colposcopy.

# General feedback on HPV primary screening and self-testing

## General key points raised

There is consensus and feedback that the proposed pathway is clinically sound and evidence based overall. There is international evidence that HPV self-testing achieves the same sensitivity to clinician-collected samples as long as PCR DNA-based tests are used for HPV testing.[[7]](#footnote-7) [[8]](#footnote-8) [[9]](#footnote-9) [[10]](#footnote-10) Modelling in Australia to assess the impact of self-testing concluded that offering HPV self-testing has considerable potential to improve outcomes for under-screened participants.[[11]](#footnote-11) Accordingly, there is strong support for giving people the option of self-testing in addition to offering a clinician-taken HPV sample.

## Equity and access

* The increased acceptability of self-testing, especially in the un- and under-screened populations, will increase uptake for people who have been reluctant to screen. This will likely result in a more equitable screening programme and reduce the number of cervical cancers.
* Self-testing empowers people to take more control of their own health. There is strong support for New Zealand to move toward self-testing for convenience, privacy, empowerment and autonomy over whare tangata[[12]](#footnote-12).
* Mana motuhake[[13]](#footnote-13) must be a foundational value in empowering wāhine Māori to access health services. Self-testing will help to achieve this by reinforcing autonomy.
* Self-testing is an important opportunity to mitigate the barriers whānau experience when visiting primary care facilities.
* The use of HPV self-testing as a health promoter will support more wāhine Māori to self-test in the community. It is much more empowering than a speculum examination as it does not require professional scrutiny, which can feel violating. This will take away the whakamā[[14]](#footnote-14) experienced by many wāhine.
* Self-testing will increase access for population groups with lower screening rates, including Māori and Pacific peoples, those who have suffered past physical and sexual abuse and more marginalised groups, such as transgender, intersex and those who identify as non-binary.

## Demand on primary care services

* The longer timeframes between negative tests are more convenient and place less burden on the health system. They reduce the number of appointments, freeing up space in medical centres and reduce costs for participants. The health system can focus more resources on those with a positive test result.
* Streamlining cervical screening will help free up general and nurse practitioners and nurse consultations to cope with an increasingly demanding general health workload.

## Demand on colposcopy services

* The screening pathways aim to provide a balanced approach to triage to colposcopy while limiting the potential for overtreatment. Pairing positive tests for HPV (other) with cytology, then having the option to repeat this 12 and 24 months later will reduce the load on colposcopy services as some participants will resolve their HPV infection naturally avoiding the need for colposcopy.
* Providing the option for direct referral to colposcopy (without cytology) for wāhine who test HPV 16/18 positive is a pragmatic solution designed particularly for high-risk and priority groups for whom paying or returning to primary/community care for a liquid-based sample for cytology first will be a barrier to follow-up.
* It is recommended that those who are HPV 16/18 positive on a self-test sample see a primary health care clinician before going for colposcopy to receive education and reassurance. A liquid-based sample taken at this visit will allow a cytology sample to be reported before the colposcopy is undertaken. This may help with the colposcopic examination but is not essential.

# Theme 1: Equity

The HPV self-test is only the first step in identifying and treating cervical cancer. Many other issues, such as access to services and community outreach, must be addressed to promote equitable health outcomes.

## Key points from feedback

* Organisations such as Auckland Women’s Health Council, Pegasus Health in Canterbury and district health board (DHB) regional coordinators note that the clinical pathway document lacks focus on the principles of Te Tiriti o Waitangi and must align with the transformations called for by Wai 2575, the Waitangi Tribunal Health Services and Outcomes Kaupapa Inquiry[[15]](#footnote-15). The principle of equity in terms of both access and outcomes, specifically related to the principle of options to enable equity, must be built into the screening pathway.
* As identified in the Hauora report, the Waitangi Tribunal proposes the following framework of Te Tiriti o Waitangi principles be adopted for the primary health care system:
* the guarantee of **tino rangatiratanga**, which provides for Māori self-determination and mana motuhake in the design, delivery and monitoring of primary health care
* the principle of **equity**, which requires the Crown to commit to achieving equitable health outcomes for Māori
* the principle of **active protection**, which requires the Crown to act, to the fullest extent practicable, to achieve equitable health outcomes for Māori. This includes ensuring that the Crown, its agents and its Treaty partner are well informed on the extent, and nature, of both Māori health outcomes and efforts to achieve Māori health equity
* the principle of **options**, which requires the Crown to provide for and properly resource kaupapa Māori primary health care services. Furthermore, the Crown is obliged to ensure that all primary health care services are provided in a culturally appropriate way that recognises and supports the expression of hauora Māori models of care
* the principle of **partnership**, which requires the Crown and Māori to work in partnership in the governance, design, delivery and monitoring of primary health care services. Māori must be co-designers, with the Crown, of the primary health system for Māori.
* It is imperative that the screening pathway centres on equity from the start in order to achieve the desired reduction of morbidity and mortality outcomes gaps for priority populations and to reduce the effects of a ‘one-size-fits-all’ clinical pathway and approach.
* There is New Zealand evidence of HPV self-testing addressing access inequities, including through the use of mailed samples and the appropriate use of non-clinical staff under delegation. This should be considered by the NCSP.
* Implementation of the new pathway should focus on higher-risk populations, specifically Māori, Pacific peoples, those living in quintile 5 deprivation areas, culturally and linguistically diverse populations, gender-diverse populations and those with serious mental illness and addictions. Implementation of the new pathway should also focus on improving access for those who are un- or under-screened within the current NCSP.
* The language used to communicate screening requirements need to be more inclusive as the use of the term ‘women’ leaves out certain groups in the community.

## Sector recommendations

| **Theme** | **Recommendation** | **NCSP response** |
| --- | --- | --- |
| **Equity** | Implement the Government’s commitment to health equity for Māori (as informed by *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa* *Inquiry[[16]](#footnote-16)* and outlined in the Health and Disability System Review report[[17]](#footnote-17)) into the HPV clinical pathway and across all NCSP activities. | This is ongoing and supported as part of programme planning. |
| Establish Māori partnership across all clinical pathways and implementation activities to work in partnership with Māori. Ensure Māori representation at a governance level, screening programme development, implementation and analysis (including collection of data and monitoring). | This will be supported as part of NCSP planning and change. |
| Ensure widespread understanding of a mana wāhine world view, the continued engagement of whānau and whakawhanaungatanga[[18]](#footnote-18) in care and the proper implementation of te reo Māori me ōna tikanga[[19]](#footnote-19) across all levels of the programme. | This will be supported as part of NCSP planning and change. |
| Consider priority access services for non-Māori minority populations, such as Asian communities, migrants and refugees who may struggle to understand the New Zealand health system, as well as people with disabilities, all of whom may have lower screening rates. | Investigate this recommendation as part of an evidence-based rationale. |
| Adapt the pathway and programme to empower participants to administer the HPV self-test in an environment that they feel comfortable in and that they can access in a shared decision-making approach. | The programme will develop options as part of NCSP planning and change. |
| Include Māori health providers and Māori outreach programmes to identify gaps in the proposed screening programme, potential solutions and opportunity for face-to-face feedback. | Further consultation is planned to support this recommendation as part of ongoing screening programme changes. |
| Develop a pro-equity implementation plan that includes options for people who are not currently enrolled in the programme nor accessing primary health care services and for priority populations, such as Māori, Pacific peoples, those living in quintile 5 deprivation areas, culturally and linguistically diverse populations, gender-diverse populations and those with serious mental illness and addictions. | Further consultation is planned to support this recommendation as part of ongoing screening programme changes. |
| Undertake an approach that is informed by the end users (particularly Māori and Pacific communities), as well as local pilots and consultation with tangata whenua[[20]](#footnote-20) to ensure the resulting framework is patient centred and culturally safe. | Further consultation is planned to support this recommendation as part of ongoing screening programme changes. |
| Ensure support services and systems cater to a variety of different needs and groups, and specify the requirements of culturally competent and safe providers to enable kaupapa Māori options that align with Te Tiriti o Waitangi principles. | Further consultation is planned to support this recommendation as part of ongoing screening programme changes. |
| Use more inclusive language in all resources and implementation activities. | This is included in resource development. |
| Support active campaigns to screen, such as *Smear Your Mea,* which have had a positive response from whānau. | The NCSP will investigate opportunities for funding approaches to support active campaigns. |
| Design IT systems that enable equitable client access to electronic records and screening history. | The NCSP will investigate capability during the IT system design. |
| Consider interim measures for at-risk groups for implementing self-testing as the programme currently has a lead time out to 2023. | The NCSP will investigate opportunities for interim options as part of the planning approach. |

## NCSP next steps

Implementing HPV primary screening would enable HPV self-testing to be offered to participants as an alternative screening method. The mortality reduction predicted by changing to HPV primary screening would be augmented with the addition of self-testing as an option, with a greater relative reduction in disease incidence and mortality predicted for Māori.

The NCSP will undertake service delivery reviews, looking at opportunities to focus existing funding for support services and to ensure services are appropriate, accessible and acceptable to Māori and Pacific peoples.

The NCSP intends to explore administration of self-testing in the community by non-clinical people (such as kaiāwhina[[21]](#footnote-21)) under clinical supervision. This will include training opportunities for community workers to understand and educate participants who are on the clinical pathway.

The NCSP is also considering opportunities for early implementation of HPV primary screening for people who are most at risk (that is, those who are un- and under-screened) as soon as the new IT build is complete.

The NCSP will investigate IT capability to include participant access to electronic records and screening history in the future.

The National Screening Unit (NSU) has also started to build a co-design framework that supports partnership models in developing changes to services.

# Theme 2: Barriers to accessing primary and other health care services

Like the current cervical screening programme, this proposed pathway plans to offer the HPV screening test in a clinical setting. Replacing the test within the current delivery system presents a significant risk of replicating the inequities known to exist around access and outcomes for Māori and Pacific participants. There are concerns for priority populations, transient people and others not enrolled with a primary health care provider.

## Key points from feedback

* As the HPV screening test will initially be carried out in health centres, it may continue to create barriers to care, resulting in poor equity and access. The NSU should consider including a self-test mail-out process so people can undertake the process at home.
* With general practices already overloaded, there is a potential barrier if more than one visit is required when HPV is detected.
* As part of implementation, the NCSP should include guidelines on how staff can convince participants to come back for a more invasive test should it be required.
* If participants are still required to attend a clinical setting, this will likely see lower numbers of Māori uptake due to Māori people living in more socioeconomically deprived areas and being less likely to be able to afford transport and prescriptions.
* Consideration should be given to those living in rural settings and those who find it difficult to access a clinical space. The programme should aspire to be as permissive and trusting as possible and should make it as simple as possible for people to enrol in the screening programme.

### Follow up and recall

* The follow-up of participants must be implemented in an equitable way as this will be especially important in reducing adverse outcomes (cervical cancer incidence and mortality) among priority populations.
* There is a risk of losing follow-up participants between the primary health care service and colposcopy. Primary care organisations (such as The Royal New Zealand College of General Practitioners, RNZCGP) have expressed concern around managing follow-up participants safely and placing the right supports around them.
* Follow-up processes are an issue in some regions due to difficulties in accessing primary health care services in some regions (where general practitioners are not always able to take on new clients) and for participants who are transient. It is imperative that there are processes for following up with and providing support for all participants.
* Modelling suggests there will be an increase in demand for colposcopy services over the next four to five years, in which case the screening programme will need to implement higher levels of support for colposcopy services.
* It is recommended that the NCSP take responsibility for managing and following up on HPV self-tests via a ‘safety-net’ function. This will ensure appropriate information is provided at the time of screening, participants and their whānau are informed of their results in a safe and appropriate way and service providers have the necessary support to provide appropriate follow-up, all based on local and international evidence.

### IT design for the National Screening Solution

* There is a critical need to integrate the IT platform with primary health care services. It will be important to learn from the significant failings of the current system, where participants with abnormal screening histories are tracked but minimal action is taken by the NCSP to ensure follow-up (that is, two letters mailed out).
* The new programme continues to rely on clinician accountability for results and recall, which in the past has resulted in participants with a history of a high-grade screen to be incompletely followed up.[[22]](#footnote-22) Participants move locations and between providers, and this should be recognised and enabled, particularly in the IT solution where accountability would need to formally shift to an outreach/follow-up approach, such as that followed with immunisation, facilitated by a different way of providing support for service provision.

## Sector recommendations

| **Theme** | **Recommendation** | **NCSP response** |
| --- | --- | --- |
| **Barriers to accessing primary health care** | Manage routine invitation, recall and results to eligible participants at a national programme level and through a robust IT system. | HPV primary screening will be managed by a centralised invitation and recall strategy, including fail-safe monitoring and reporting. Active invitation follow-up and support for increasing participation will be managed through locality networking, which will include outreach services, screening support services and primary health care. |
| Utilise cultural networks, support groups and community health workers to advocate and work alongside people to access services and self-testing. | This will be supported as part of NCSP planning and change. |
| Utilise groups beyond community health centres, such as churches, libraries, hairdressers, supermarkets, gyms, swimming pools, door knocking, etc to bridge the gap between people and services. | The NCSP will work with screening providers to understand opportunities at a regional level. |
| Ensure clinical spaces are welcoming for Māori and Pacific whānau to access. Set the tone on their arrival with appropriate greetings and welcoming whānau to the space, ensuring they are looked after with manaaki[[23]](#footnote-23) and aroha[[24]](#footnote-24). | The NCSP will work with screening providers to ensure appropriate opportunities are supported at the regional level. |
| Make services available after hours. | The NCSP will work with screening providers to ensure appropriate opportunities are supported at the regional level. |
| Provide strong support for priority groups and under-screened and unscreened participants to attend colposcopy. | This will be supported as part of NCSP planning and change. |
| Implement a notification system for participants who are turning 25 years old to enrol in the programme. | This will be supported as part of NCSP planning and change. |
| **Follow-up and recall processes** | Develop robust systems of recall to ensure those who need follow-up cytology and colposcopy are not lost in the new system or the transition. | This will be supported as part of NCSP planning and change. Participants will be mapped across the transition for safe management. |
| Equip screening support services with outreach capabilities to strengthen follow-up processes for transient and priority groups. | This will be supported as part of NCSP planning and change. |
| Develop a collaborative approach between nurses within primary health care services to undertake follow-up processes with an enhanced outreach service where extra support is needed, including help with transport to services. | Regional services will be encouraged to explore opportunities to improve access. |
| **IT design** | Strengthen screening support services to ensure equitable outcomes, supported by appropriate IT infrastructure, safety-nets, missed event management and appropriately skilled staff. | This will be supported as part of NCSP planning and change. |
| Develop an intuitive IT system with the capacity for end-user testing and feedback from screening support services, gynaecology, general practice and colposcopy. | This will be supported as part of NCSP planning and change. Direct look-up access by providers is included in the IT requirements. |
| Consider a means to capture data and test results from overseas. | This will be supported as part of NCSP planning and change. |
| Consider an IT solution to link the NCSP Register with the New Zealand Cancer Register. | This will be supported as part of NCSP planning and change. |
| Consider a mobile option for the NCSP Register that could offer better accessibility for community workers. | This will be supported as part of NCSP planning and change. |
| Consider the NCSP Register’s capability to generate real-time results promptly from the laboratories. | This will be supported as part of NCSP planning and change. |
| Consider the capability for the NCSP Register to capture gender data to improve accessibility for the LGBTQIA+ community[[25]](#footnote-25). | This will be supported as part of NCSP planning and change. |
| Consider the possibility to interface Gynae+ and the NCSP Register to ease reporting and support automation. | This will be supported as part of NCSP planning and change. |

## NCSP next steps

The NCSP is undertaking a new IT build for the National Screening Solution[[26]](#footnote-26). This will have enhanced capabilities, and the NCSP plans to consult with the screening sector throughout the development of the new NCSP Register. A data repository will link across screening programmes to consolidate participant information.

The NCSP will build a fit-for-purpose ICT solution that would support:

* clinical pathway changes to enable HPV primary screening and HPV self-testing
* centralised identification of the eligible patient population and enable implementation of robust active recall and support campaign management
* direct look-up access to the screening histories of eligible participants for sample takers (this would increase efficiency and support harm reduction by ensuring full relevant clinical information is available to the people screening, diagnosing and treating participants in the NCSP)
* long-term suitability and sustainability – flexibility, adaptability and cost-effectiveness
* a shared technological approach across multiple screening programmes, in line with the NSU strategic vision
* HPV primary screening with capacity to enable further configurations to support increased efficiency of the screening programme.

Colposcopy services will continue to have fee-for-service allocation funding, which supports funding of the short-term increased demand for services. The NCSP will undertake a readiness assessment for colposcopy units before the programme goes live.

The NCSP will provide guidance to health providers to support culturally appropriate and accessible options for priority groups and encourage outreach services.

# Theme 3: Cost barriers

The cervical programme is an anomaly for cancer screening in New Zealand with the co-payment cost to participants and the inconsistent and changeable ‘free smear’ criteria. The cost implications for participants of the new clinical pathway (initial test and follow-up) must be considered.

## Key points from feedback

* Careful consideration is needed to ensure participants do not experience stigma or perceived punishment by having to pay for follow-up testing. Other unintended consequences should also be considered, such as high follow-up consultation costs that may be introduced to mitigate reduced revenue from charging for cervical screening in primary health care services.
* Cost is still a potential barrier, particularly if the programme relies largely on primary health care services. There is risk that someone who already owes money to their practice won’t want to present for their screening test due to shame around the money already owing.
* The NCSP should consider whether the proposed pathway may increase inequities in that participants with private insurance will likely request a self-swab and access colposcopy privately if they are HPV positive.
* Proper funding for the full cost of colposcopy services is imperative moving forward. The challenge to fully resource colposcopy services should not drive the design of appropriate clinical pathways for the screening programme.

## Sector recommendations

| **Theme** | **Recommendation** | **NCSP response** |
| --- | --- | --- |
| **Cost barriers** | Fully fund HPV screening and follow-up for all, particularly Māori, Pacific peoples and others living in quintile 5 deprivation areas. | The NCSP is investigating funding requirements to implement. |
| Fully fund all follow-up investigations, supports and procedures for participants where HPV is detected. | The NCSP is investigating capacity to implement. |
| Allocate proper funding for the full cost of colposcopy services. | Increased funding was provided to colposcopy services as part of current contract arrangements. |
| Allocate primary health care funding for incentivisation measures that meet the needs of enrolled populations, for example, financial incentives, such as payments at a practice level based on the results for people screened. | This is out of scope of the screening programme. |
| Fund general practices for adequate practitioner time to discuss options with participants who are detected for HPV, as well as the need to action test results, make referrals and organise recalls. | This is out of scope of the screening programme. |

## NCSP next steps

The NCSP continues to look for opportunities to reduce the cost of screening for participants and is exploring the feasibility of funding follow-up processes for people with HPV, including re-directing funding to where there is greatest need, such as those living in quintile 5 high-deprivation areas.

# Theme 4: Clinical pathway for HPV type 16/18

A cytology test performed before colposcopy is in line with the Australian model and is considered feasible and best practice. Organisations such as RNZCGP, the National Hauora Coalition, the Federation of Women’s Health Councils (FWHC) and The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) agree that it is best practice for participants who test positive for HPV type 16/18 to return for a speculum examination and cytology. This reduces the risk of overtreatment and better informs colposcopists at the time of treatment (as agreed by RANZCOG).

If a participant self-tests positive for HPV type 16/18, a follow-up visit with a primary health care service is a good opportunity to provide education and reassurance, even if cytology testing is not taken up. The algorithm allows a pathway for direct referral to colposcopy to mitigate high-risk participants being lost for follow-up, with the option of adding cytology if the participant chooses.

## Key points from feedback

* Adding a cytology visit before colposcopy will create barriers as there is already reluctance to undergo cytology among priority groups, especially among Māori and Pacific peoples, where there is a cultural aversion to a speculum examination. Requiring a person to return for cytology adds the very barrier that self-testing is designed to overcome. It may, however, be appropriate to give participants the choice of having a cytology test or direct referral for colposcopy after a positive self-test.
* People who are at risk of being lost to follow-up should be empowered to go directly to colposcopy. This referral should be accepted regardless of capacity issues with colposcopy services if it has been identified that the participant is already reluctant to have a speculum examination for cytology.
* However, having a cytology test first should be offered. Cytology gives more information at the time of colposcopy and reduces unnecessary biopsies. In addition, a cytology test in a primary health care service enables people who have visible cervical abnormalities or high-grade abnormalities to be fast tracked. A few organisations, such as the National Hauora Coalition, FWHC and RNZCGP, agree that this is a safe pathway to take to avoid the risk of overtreatment.
* A few organisations, such as the New Zealand Medical Association (NZMA), Auckland’s Procare Health, Centre for Women’s Health Research | Te Tātai Hauora o Hine (Victoria University of Wellington) and Alliance Health Plus (the Pacific-led primary health organisation) have disputed the clinical evidence that a cytology sample should be taken before colposcopy to assist with prioritisation and assessment. Although this mitigates overwhelming colposcopy services, it may risk participants at the highest clinical risk of getting lost and not getting to colposcopy. This barrier may also promote inequities. This links to some feedback that the pathway is service centred rather than patient centred.
* The NCSP should consider the unintended consequences that may arise from allowing colposcopy clinics to act as gatekeepers to equitable access to diagnosis and treatment and consider varying how colposcopists exercise this power and the development and measurement of standards and guidelines.
* Clinicians must have the understanding and knowledge that underpins their advice to accelerate colposcopy based on participant risk. Participants should be informed of the risks and benefits. There are times when colposcopists consider a ‘see and treat’ approach to be necessary, and this approach should be followed with the consent of and after fully informing the participant.

## Sector recommendations

| **Theme** | **Recommendation** | **NCSP response** |
| --- | --- | --- |
| **Direct referral of HPV type 16/18 to colposcopy** | Define waitlist criteria for colposcopy to prioritise those with increased risks, such as mortality, morbidity, ethnicity and socioeconomic status. | This will be supported as part of NCSP planning and change. |
| Offer direct referral to colposcopy services for participants who are detected for HPV16/18 on a self-test and are previously un- or under-screened. | This has been implemented in the clinical pathway. |
| Offer direct referral to colposcopy services for all participants who are detected for HPV16/18. | This has been implemented in the clinical pathway. |
| As an alternative to the above, define clear guidelines to support clinician discretion for direct referral to colposcopy, such as prioritising those with an increased risk of mortality and morbidity and those with increased risk associated with ethnicity and socioeconomic status. | Clinicians’ discretion to directly refer to colposcopy has been removed from the clinical pathway. All participants with HPV 16/18 will be referred to colposcopy, and the option of cytology will be offered as a choice. |
| Provide clear evidence and positive predictive values to support the approach of requiring a cytology test for colposcopy quality or for prioritising referrals. | All participants will be referred to colposcopy, and the option of cytology will be offered as a choice. This is underpinned by evidence. |
| Provide education to ensure clinicians have the understanding and knowledge to refer a participant to colposcopy without cytology. | This will be supported as part of NCSP planning and change. |
| Develop systems to aid colposcopists in treating those without cytology, such as a risk assessment based on patient data and screening history. | This will be supported as part of NCSP planning and change. |
| Provide education and systems to ensure participants are informed of the risks and benefits on the screening journey. | This will be supported as part of NCSP planning and change. |

## NCSP next steps

The NCSP will be monitoring the roll-out of the new programme, including follow-up to colposcopy. As we transition across to the new programme and new evidence emerges, the NCSP will undertake a programme review.

The algorithm has been revised to add a pathway for direct referral to colposcopy for all participants if HPV type 16/18 is detected. This will mitigate high-risk participants being lost for follow-up. The option of adding cytology before colposcopy will be offered as the participant’s choice.

# Theme 5: Pathway education and communication strategy

The transition process from one testing programme to another will need to be well managed and include a comprehensive information campaign. There will need to be clear, accessible information to support participants to understand how the programme has changed and what steps are involved.

## Key points from feedback

* The key to making the programme work is provision of good information and education and destigmatisation of HPV.
* There should be good education resources for participants. These should explain the pros and cons of different pathway options (including that there is no loss in efficacy between a self-test or clinician-taken sample), next steps in how results will be shared and what will be required if the test is positive or negative. Time taken by clinicians providing a speculum examination for cervical screening can be utilised to ensure good education and informed consent is provided to participants.
* It is vital that the participants are well informed about the clinical pathway, and the risks and benefits of the options available to them. Informed decision-making will be key so that participants understand that if they are non-symptomatic a self-test is an appropriate option.
* Participants need to know how to do the test correctly. For a test that is carried out so infrequently, it is important that the sample is not compromised.
* Participants should be followed up promptly no matter what test is used. All clinicians involved need to be on board and not undermining self-testing in any way.
* Resources must be available to enable clinicians to support participants with HPV to get to the next step in the pathway, decrease barriers and ensure follow-up investigations occur as appropriate.
* Regarding the five-year screening cycle, there should be general understanding that any clinical symptoms warrant a rescreen. There is experience in the screening sector of participants who weren't screened despite being symptomatic because they weren't due for routine screening.

## Sector recommendations

| **Theme** | **Recommendation** | **NCSP response** |
| --- | --- | --- |
| **Clinical pathway and self-testing education** | Provide education for participants on whether a self-test is the clinically appropriate option for them so that they are making an informed decision through an informed consent process, including how to self-test properly and that a return cytology visit will be required if HPV is detected. | This will be supported as part of NCSP planning and change. |
| Facilitate full understanding of the clinical pathway, including that participants may need to return for further tests and a speculum examination if they self-test positive for HPV, the reason colposcopy is the next step for HPV 16/18 participants, the supports provided to mitigate barriers and the 12-month recall process, with available supports to ensure attendance. | This will be supported as part of NCSP planning and change. |
| Provide robust training to ensure all clinicians are well educated about the new guidelines and pathways. | The NCSP is investigating capacity to implement. |
| Provide education on what is expected of clinicians in helping people to self-test and provide the right supports to move participants with HPV along the screening pathway without barriers or being lost to follow-up. | This will be supported as part of NCSP planning and change. |
| Provide culturally sensitive support lines and online information for whānau to ensure they feel comfortable with self-testing. | The NCSP will support regional services to explore approaches to meet the needs of priority groups. |
| Provide assurance and clarity around the confidentiality and privacy factors that encompass the HPV screening programme, including self-testing. | This will be supported as part of NCSP planning and change. |
| Develop messaging on the frequency of screening as per best practice and the rationale behind a five-year screening period as the most effective to mitigate over-screening. | This will be supported as part of NCSP planning and change. |
| **General communication to the public** | Ensure the public understands they should continue screening in the current programme and not delay until self-testing is made universally available in July 2023. | This will be supported as part of NCSP planning and change. |
| Undertake a public campaign to destigmatise HPV and provide education around what symptoms may warrant a rescreen. | This will be supported as part of NCSP planning and change. |
| Build public understanding that self-taken swabs are equally effective as clinician-taken swabs and that health professionals should not be pushing one option over the other as the gold standard. | This will be supported as part of NCSP planning and change. |
| Utilise social media platforms, television and poster displays to promote the self-test. | Campaign approaches are being developed as part of implementation. |
| Create culturally and linguistically appropriate support materials and ensure all informational resources are accessible to those with visual and hearing impairments and learning-disabled participants. | This will be supported as part of NCSP planning and change. |
| Streamline communications so that cervical screening, HPV self-testing and HPV vaccination are all linked and not separated into various disjointed campaigns. | This will be supported as part of NCSP planning and change. |

## NCSP next steps

The NCSP will facilitate a comprehensive stakeholder engagement and communications strategy. The NCSP aims to provide clear, accessible information to help participants transition through the screening programmes safely and support both the health providers’ and participants’ understanding of screening programme changes and of the clinical pathway to make people-centred informed decisions.

# Theme 6: Self-testing in a clinical setting

Although self-testing will not offer holistic care, it will be a vital tool for participants who experience barriers to service access. It is important that self-testing and clinician-taken sample are offered universally, to all people, without preference of one over the other.

However, concerns have been expressed about whether a self-test is clinically appropriate for everyone.

## Key points from feedback

* Self-testing is an important option for promoting access to cervical sampling, however, a full consultation with a health practitioner that includes a physical exam should still be promoted as good clinical care and a way to comprehensively address health issues and concerns.
* Organisations such as New Zealand Family Planning (Family Planning), regional public health services, screening support services, Talk Peach Gynaecological Foundation, the Sexually Transmitted Infections Education Foundation (STIEF), Cancer Society New Zealand and general practitioners agree that there are benefits to a clinician-taken sample over a self-test. The risk of self-testing is that some issues that may have previously been picked up during a speculum examination may be go unchecked.
* Often participants are never seen except when they come for screening. Primary health care services will have fewer opportunities to do the additional opportunistic checking that generally takes place at the same time.
* An HPV vaginal swab does not detect cervical abnormalities and runs the risk of missing participants who test negative for HPV but have abnormal cytology.
* Doing cervical screening with a speculum examination is an opportunity to investigate other aspects of the participant's health, such as sighting any physical abnormalities, checking blood pressure, weight, test recalls, immunisations, screening for family violence, alcohol and smoking, discussing mammograms, breast health and sexual health. This is especially important among older participants. Often it is also a good time to ask about other family members and is a good opportunity to assess a participant's mental health status.
* It is important for clinicians to be able to distinguish which participants would benefit more from a clinician-collected sample and full speculum examination. In particular, older participants or those with abnormal cytology tests results may indicate that they wouldn't be comfortable testing themselves as they might miss something important.

## Sector recommendations

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| --- | --- | --- |
| **Theme** | **Recommendation** | **NCSP response** |
| **Self-testing in a clinical setting** | Develop guidelines to help sample takers identify when a participant might benefit from a clinician-taken sample and speculum examination rather than a self-test. | This is included as part of education and training to support screening service providers. |
| Consider completing a questionnaire at the time of the visit to screen for other health issues or conditions. | Further consultation will be undertaken to explore requirements. |
| Develop processes to mitigate the potential risk of missing incidental findings or other health issues if participants choose to self-test. | This will be supported as part of NCSP planning and change. |
| Provide education / develop guidelines for clinicians that will help them discuss options with participants and allow the participants to make informed decisions. | This will be supported as part of NCSP planning and change. |

## NCSP next steps

The NCSP encourages discussion between participants and primary health care practitioners before HPV testing to facilitate understanding of the clinical pathway, including risks and benefits of different options. The NCSP will provide guidance to practitioners to help them empower participants to make an informed decision about which screening option might be best for them.

The NCSP will develop training for health care workers and clinicians on conducting holistic discussions at time of HPV tests. The NSCP will be supportive of how clinicians and community health workers reach participants. Training packages will emphasise the need for holistic care and discussion at the time of the HPV test.

# Theme 7: Considerations related to implementing HPV testing mail-out kits

Some organisations recommended that the HPV primary screening pathway include home-based self-sampling as well as the option for self-sampling in a clinical setting. This will be the most effective way of increasing participation, particularly for participants most at risk of cervical cancer.

Organisations such as RNZCGP, the National Hauora Coalition, ScreenSouth Ltd (the breast screening provider for the South Island) and DHB regional coordinators support the transition to home self-testing and recommend that the programme be designed to enable home self-testing in the future. However, others (such as screening support services and Family Planning) are wary of home self-testing being rolled out without considering the limitations faced in the mail-out bowel screening programme, as well as the loss of communication and education that can occur through clinicians discussing options face to face if HPV is detected.

The opportunity to provide education is crucial, particularly for priority groups, as confirmed by organisations such as Te Puna Waiora, in Kerikeri, and Kauri Health Care, in Palmerston North, who feel that this opportunity would be lost if the screening programme moved to a mail-out option.

## Key points from feedback

* The HPV primary screening pathway should include home-based self-sampling as well as the option for self-sampling in a clinical setting as the most effective way of increasing participation, particularly for participants most at risk of cervical cancer.
* A mail-out option could improve access in remote places eventually. Reducing inequities and increasing accessibility is key, so removing the need for a clinician-collected sample offers more options.
* Leading up to implementation in 2023, the screening sector requests that self-administered HPV tests be made available via mail-out and delivery through delegated authority among non-clinical staff.
* The option to screen at home may be able to reach a group of non-responders who are currently not being seen in clinic for many reasons, including feelings of vulnerability. Benefits for participants who choose self-testing in a home or clinical setting include: timeliness, privacy and comfort. Participants who have been sexually abused may find this particularly helpful.
* However, it was noted that a mail-out process may introduce the risk of participants being lost to follow-up and lack of education and clarification of process and issues with a clinician.
* Any mail-out programme needs to be entirely community driven and should consider engagement with local and regional community leaders who have strong connections with wāhine.

## Sector recommendations

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| --- | --- | --- |
| **Theme** | **Recommendation** | **NCSP response** |
| **Mail-out kits** | Include funding and resourcing of mail-out kits so these are available by 2023. | The new screening programme will require a self-test to be administered with clinical oversight. However, a mail-out option could be considered in the future. |
| Strengthen outreach services to take test kits to participants and deliver them to the laboratories. | The NCSP is considering approaches to this as part of the programme change. |
| Enable non-clinical staff to support increased access to the test within an appropriate clinical safety framework and through a delegation function with appropriate training to ensure that participants are informed and have their questions answered appropriately and accurately. | The NCSP is considering approaches to this as part of the programme change. |
| Provide instructions in a range of languages and account for poor health literacy. | This will be a component of NCSP resource developments. |

## NCSP next steps

The NCSP will continue to monitor the possibility of a centralised mail-out programme to reach those who are unenrolled in the screening programme.

# Theme 8: Workforce impacts

Feedback consistently identified a risk of this programme relying too heavily on a primary health care system that is already overloaded.

## Key points from feedback

* Offering self-tests may deskill the workforce that is able to assess a cervix and abnormalities. Currently, many nurses perform cervical screening.
* The cervical screening workforce may shrink as demand for cytology tests drops, and this could impact on the quality of cytology testing. Experts in this area may require extra support and re-training in the future.
* A few technical problems of self-testing need to be considered to maintain the quality of the test. These include: testing properly, labelling swab tests correctly, quality assurance, following the correct lab form process, delivering tests to laboratories in a prompt manner and temperature regulation.
* The requirement for clinicians to meet 30 smears per year will need to be reviewed if there will be a decreased demand for cytology due to self-testing.
* Primary health care nurses need to be sufficiently trained and funded to support participants through this process (that is, trained to have conversations with participants about colposcopy and to follow up with participants who are referred to ensure they are seen by colposcopy). Registered nurses and nurse practitioners could be trained to carry out colposcopy.
* Significant nurse colposcopy training must be planned and implemented. Investment in nurse-led services is necessary to ensure acceptability and accessibility for all those who will be offered ongoing and repeat cytology tests. Nurses can be trained and are the best resource for investment to ensure there is an increased workforce with colposcopy skills.
* Although a health practitioner needs to be responsible for any self-test requested, it is possible that the practitioner could generate a laboratory form and a kaiāwhina could explain the process to participants in the community. Online training should be provided to the kaiāwhina workforce to enable them to reach those who are un- or under-screened.

## Sector recommendations

|  |  |  |
| --- | --- | --- |
| **Theme** | **Recommendation** | **NCSP response** |
| **Workforce** | Develop strong processes to align self-tests with a dedicated sample taker and lab form to receive and follow up on results, particularly when given out in the community by kaiāwhina or support workers. | This will be supported as part of NCSP planning and change. |
| Strengthen communication between primary health care and colposcopy services. | This will be included as part of the change process and education on the new referral pathway. |
| Develop a workforce plan to adequately resource colposcopy services and safely manage the increased colposcopy demand, such as increased funding for colposcopy services and training of new colposcopists. | District health boards received an increase in colposcopy funding in June 2021. Colposcopies are funded as a fee-for-service, and this has been incorporated into the funding for the programme change. A readiness assessment will be undertaken as part of pre-implementation planning. |
| Improve access and equity and reposition existing staff into the requirements of the new clinical pathway rather than employing new people who do not have experience in cervical screening, including advisors, educators and promoters. | Change requirements across existing providers is included in the NCSP change planning. |

## NCSP next steps

The NCSP aims to design and implement a robust safety and monitoring framework for HPV primary screening that would support management of workforce challenges.

Before the transition to HPV primary screening, the NCSP will consult further with existing providers to support the development of workforce management plans and ensure there is a stable and sustainable workforce in a low cytology volume environment. The NCSP supports the ongoing training of nurse-led colposcopists and is looking at introduce accreditation criteria for all colposcopists.

# Theme 9: Pathway terminology and logic

The clinical pathway lacks clarity about what constitutes a ‘clinician-taken sample’, and a few suggestions were made to clarify some of the terminology used.

## Key points from feedback

* The clinical pathway does not make it clear whether a clinician-taken sample will be routinely used for cytology or whether a participant with a positive result will be required to return for a cytology sample. If a return visit is required, it should be made explicit in the flowchart.
* If a self-test could be administered by the clinician, the clinical pathway should clarify when a clinician performs a speculum examination (to which cytology could be added if the HPV test is positive).
* The language used when describing self-testing promotes clinician-sampling due to the ability to reflex test a positive HPV sample. Some participants may be encouraged to have a more invasive clinician-sample. The co-benefit of viewing the cervix for polyps is not an appropriate reason for continuing invasive clinician sampling given that the primary purpose of screening is to detect pre-cancerous lesions.
* There is concern that those with a financial interest in maintaining the status quo will continue to promote clinician testing. Stakeholders noted anecdotes of this already happening, particularly in Auckland where services have actively misinformed participants about the rationale for continuing with clinician testing.

## Sector recommendations

| **Theme** | **Recommendation** | **NCSP response** |
| --- | --- | --- |
| **HPV primary screening clinical pathway** | Clarify self-test, clinician-taken sample, vaginal swab and speculum examinations as these are, at times, being used interchangeably. | This has been implemented in the revised clinical pathway. |
| Clarify whether a clinician-taken sample is preferred for repeat HPV tests at the 12-month interval on the screening pathway. | This has been implemented in the revised clinical pathway. |
| Clarify which type of HPV was detected at the repeat intervals within the clinical pathway. | This has been implemented in the revised clinical pathway. |
| Define the protocol of the timeframes for participants to attend cytology and colposcopy after testing positive for HPV (any), including maximum timeframes to refer participants to secondary health care services. | This will be included in the clinical practice guidelines. |
| Clarify whether cytology can be automatically added to a clinician-taken sample if the participant tests positive, or if a return visit will be required to collect cytology. | This has been implemented in the revised clinical pathway. |
| Provide the evidence to support the approach taken for participants over 50 years old having a different screening pathway than those under 50 years old. | This will be included in the clinical practice guidelines. |
| Define strategies for cervical cancers that are not caused by HPV infection, which will not be detected with an HPV primary screening test. | The NCSP will assess requirements and evidence. |

## NCSP next steps

Changes to the clinical pathway based on the above recommendations have been implemented in the revised HPV screening clinical pathway outlined on page 12 of this document. The NCSP is developing standards for referral to colposcopy after abnormal findings, and these standards will be sent for peer review to colposcopists, cancer specialists and pathologists.

# Acknowledgements

The National Cervical Screening Programme (NCSP) is grateful to all who submitted feedback and engaged with the NCSP throughout this consultation.

The NCSP would like to acknowledge the following organisations for providing feedback and participating in productive kōrero[[27]](#footnote-27) on HPV primary screening to inform the next steps in the NCSP implementation:

* Centre for Women’s Health Research | Te Tātai Hauora o Hine, Victoria University of Wellington
* District health board (DHB) regional coordinators
* Federation of Women’s Health Councils (FWHC)
* General Practice New Zealand (GPNZ)
* National Hauora Coalition
* New Zealand College of Midwives
* New Zealand College of Primary Health Care Nurses
* New Zealand Family Planning (Family Planning)
* New Zealand Medical Association (NZMA)
* New Zealand Nurses Organisation (NZNO)
* The Royal Australasian College of Physicians (RACP)
* The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
* The Royal College of Pathologists of Australasia (RCPA).
* The Royal New Zealand College of General Practitioners (RNZCGP)
* Screening support services
* Te ORA (Te Ohu Rata o Aotearoa, Māori Medical Practitioners Association).

# Appendix 1: Consultation Stakeholder Meetings

#### Feedback on HPV primary screening clinical pathway to introduce self-testing

|  |  |  |  |
| --- | --- | --- | --- |
| **Meeting number** | **Date** | **Audience** | **Lead** |
| 1 | 26 May 2021 | The Royal New Zealand College of General Practitioners and Te ORA (Te Ohu Rata o Aotearoa, Māori Medical Practitioners Association) | Margot McLean |
| 2 | 26 May 2021 | New Zealand College of Primary Health Care Nurses | Margot McLean |
| 3 | 27 May 2021 | National Hauora Coalition | Margot McLean |
| 4 | 27 May 2021 | District health board regional coordinators | Nicki Martin |
| 5 | 2 June 2021 | Screening support services | Nicki Martin |
| 6 | 2 June 2021 | New Zealand Family Planning | Margot McLean |
| 7 | 3 June 2021 | General Practice New Zealand | Pamela Edmondson |
| 8 | 8 June 2021 | The Royal Australian and New Zealand College of Obstetricians and Gynaecologists | Margot McLean |
| 9 | 9 June 2021 | The Royal Australian and New Zealand College of Obstetricians and Gynaecologists | Howard Clentworth |
| 10 | 16 June 2021 | National Cervical Screening Programme Advisory Group | Jane O’Hallahan |
| 11 | 27 August 2021 | Federation of Women’s Health Councils | Margot McLean |

### Meeting 1: The Royal New Zealand College of General Practitioners and Te ORA (Te Ohu Rata o Aotearoa, Māori Medical Practitioners Association)

**26 May 2021 10:00am**

Feedback was generally positive about the introduction of self-testing. Research has shown acceptability of self-testing in Māori populations, and this is considered a step toward a more equitable screening programme.

There was agreement that if a participant tests for HPV type 16/18, they should return for a speculum examination and cytology. It was noted that there is a pathway for direct referral to colposcopy if the participant is at risk of being lost for follow-up, and this will be negotiated with the local colposcopy service.

#### Feedback and recommendations

* The consultation document mentions equity outcomes for all population groups but needs a stronger equity focus, particularly on equitable outcomes for tangata whenua. Guiding principles should comply with the new principles as identified in the WAI 2575 report[[28]](#footnote-28), to ensure equity is highlighted, keeping in mind that Māori groups have a higher mortality rate for cervical cancer.
* Consideration should be given to those living in rural settings and who experience challenges in accessing a clinical space. The programme should aspire to be as permissive and trusting as possible and should make it fairly simple for people to enrol.
* A health practitioner needs to be responsible for any self-test requested. Although this responsibility can’t be shifted, it is possible that a laboratory form could be generated by sample takers and then signed by the practitioner. Online training could be provided to the kaiāwhina workforce to help them learn how to explain this process to patients. This will enable them to reach patients that haven’t been on a register previously or have been late for screening.
* Provided many people will opt for a self-test, the cost of coming back for the speculum exam should be considered as this may become a barrier. It may be difficult to decide between a self-test or a speculum exam if a general practitioner (GP) knows that the participant may face barriers in returning for follow-up.
* It is critical that there’s education that if a participant chooses a self-test and is detected for HPV, they will need to return for cytology for further testing.
* The clinical pathway needs to clarify that cytology cannot be performed on a self-test. Cytology can only be added to clinician-taken samples.
* It was recommended that higher mortality risk criteria be added for participants with high-risk HPV to prioritise populations with worse outcomes (such as particular age groups, Māori and Pacific peoples, and those from socioeconomically deprived areas).
* It should be considered that, for self-testing in a clinical setting, the same barriers will exist in access, such as location, appointments, attendance, cost, etc. Both GPs and participants need to understand that there is no preference whether a self-test or a clinician-taken sample is collected. Messaging should empower participants so they understand the difference between one option and the other and that they may need to return for further testing.
* Systems need to be in place to safely manage those who don’t follow this guideline and fall off the algorithm. There is a need for GP discretion and placing the right support systems around participants, such as Screening and Assessment Support Services.
* The need was identified to engage and have robust conversations with Hauora Māori organisations to make sure the algorithm fits with best models of care and what is already working for these populations.

### Meeting 2: New Zealand College of Primary Health Care Nurses

**26 May 2021 12:00pm**

There is generally positive feedback about the introduction of self-testing in the national cervical screening programme, which has been modelled to improve equity and enrolment.

The option of implementing a mail-out programme was raised as a potential solution to improve equity. Currently, the programme will require a self-test to be administered in a clinical setting in the introductory phases of the programme, but a mail-out option could be considered as a pilot in the future.

#### Feedback and recommendations

* It should be made clear that cytology cannot be added to a self-test. If a participant tests for HPV, education around the clinical pathway will be very important for health care providers, participants and kaiāwhina who can assist participants.
* There’s a need for further guidance on how to bring participants into a practice to become enrolled in the screening programme. Because people need to present at a clinic, many of the same barriers will be faced (such as access and cost barriers).
* Due to potential increases in colposcopy referrals, funds need to be redistributed to Screening and Assessment Support Services for participants who may face barriers in attending colposcopy.
* It was recommended that further guidelines specify maximum timeframes to get participants referred to secondary health care services.
* It was recommended the language be updated to include both primary and community health care settings within the programme to specify options beyond general practice.
* There’s need for an equity strategy to target high-risk participants, and this strategy should be developed in partnership with groups who have experience in rural settings, as well as Māori and Pacific organisations and health care professionals.
* There should be succinct messaging to the wider population that it will be participants’ choice whether to choose a self-test or a clinician-taken sample, and the need to return for follow up if HPV is detected. Errors in messaging from the media should be mitigated: the programme is not being entirely replaced with self-testing; the key change is moving from cytology-based screening to HPV primary screening.

### Meeting 3: National Hauora Coalition

**27 May 2021, 1:00pm**

A key point noted was that the new programme, along with the proposed clinical pathway, will place much of the responsibility on primary health care services, which are already overwhelmed and have a history of delivering inequitably. The discussion focused on different models that have potential to decrease the equity gap, such as community outreach.

The option of self-testing will potentially make a big difference in improving coverage. Screening services that are not led by general practitioners are better placed to provide support for participants.

#### Feedback and recommendations

* Although laboratories need a health practitioner to sign off on request forms that come with a sample, community workers may be able to deliver the test to those who are harder to reach (such as in a rural location) and return it to the clinic to mitigate access barriers.
* It was highly recommended that, if someone tests for HPV, they should not have to pay for any follow-up procedures. A shift in resources and funding may be required to implement this recommendation.
* It was agreed that collecting cytology before referring to colposcopy is the best way to proceed to avoid a large number of participants being sent to colposcopy unnecessarily. There are different categories of risk: those who test for HPV type 16/18 are at higher risk than those who test HPV-other. Some infections will resolve without treatment, and the risk of overtreatment comes at great expense and little gain. Overwhelming colposcopy services may dilute those who are truly high-risk.
* More evidence is needed, including positive predictive values, to bring confidence that this is the right approach for pathways to cytology and colposcopy.
* Education should be provided for participants to understand risks and benefits along the pathway to cytology and colposcopy and make informed choices.
* Colposcopy is a more invasive procedure so participants should go to cytology first, and there should be an exception for direct referral to colposcopy if there are significant barriers for the participant to return.
* Better communication should be released for the general public that a clinician-taken sample and a self-test are equally effective. It needs to be made clear to health professionals that a self-test is not considered the gold standard, it is merely an option for those who prefer it.

### Meeting 4: District health board regional coordinators

**27 May 2021, 3:00pm**

District health board (DHB) regional coordinators proposed adding mail-out self-testing kits as a good option for reaching vulnerable groups and improving equity. However, the new programme will roll out self-testing to be administered in a clinical setting with upgraded IT systems in the first instance. The addition of a mail-out programme may be considered in the future.

Largely in a clinical setting, there will be an option for community workers to be conduits to accessing participants not enrolled in the programme. The programme is considering options to expand a workforce to go into the community to administer self-tests. The final design isn’t yet complete. The test result will always be a heath professional’s responsibility, but that doesn’t mean they can’t delegate a support person with the appropriate skillset to place supports around participants.

#### Feedback and recommendations

* It was agreed that there should be an option to directly refer those who test for HPV type 16/18 to colposcopy, but this guideline should be more clearly defined. Consideration should be given as to whether this should be based on clinical history, previous screening history, ethnicity, age, socioeconomic background and other circumstances that may act as barriers, such as sexual abuse. Health professionals should be discussing the clinical history and barriers with the participant and help guide that decision.
* The group requests clear clinical evidence for why it’s safer to request cytology for participants who test for HPV type 16/18 before referring to colposcopy.
* Terms such as ‘self-test or clinician-taken sample’ are confusing. We should clarify what counts as a speculum exam or vaginal swab and where cytology can be added.
* For repeat HPV tests at the 12-month interval, it should be clarified whether a clinician-taken sample is preferred. Some may opt for a self-test, and the pathway should reflect that.
* Modelling suggests there will be an increase in demand to colposcopy services over the next four to five years, in which case the programme will need to implement higher levels of support services and education to ensure participants attend. This is a core workstream in the programme change and will be further consulted on in the near future.
* The programme aims to work with the immunisation team to increase HPV vaccine uptake.
* The programme should have a stronger equity focus and guiding principles for empowering participants and making cervical screening a simple and positive experience.
* Vulnerable groups should be prioritised, especially to reach those outside primary health care.
* More consideration should be given to mail-out options and targeted outreach mechanisms. The programme should not be limited to primary health care. There are many barriers for people to accessing general practice, and general practice is at capacity in many areas, particularly if participants are asked to return for cytology.
* The group recommends more consultations on how to educate and communicate with participants so they understand the clinical pathway and to ensure access and participation.
* The new IT solution should consider an acceptable method of entering test results from overseas and link with the New Zealand Cancer Register (NZCR).
* The programme should communicate with DHBs that are already pushing forward with HPV primary screening to clarify that this is not ready to be implemented as part of a national screening programme. The Ministry of Health is developing communications that the current screening programme is safe and that participants need to continue to screen and not wait until self-testing is ready in 2023.

### Meeting 5: Screening support services

**2 June 2021, 11:00am**

The National Cervical Screening Programme (NCSP) has published a list of literature on the National Screening Unit (NSU) website that informs the changes in the revised pathway. This includes evidence that a clinician-taken sample and a self-test are equivalent in efficacy, although the advantage of a clinician-taken sample is its ability to conduct a visual exam and add cytology if necessary without the need for a follow up exam.

At the moment, the pathway of delivery remains with primary health care and screening support services. The programme is looking at other options for accessibility, which may include the option to mail out self-test kits, but this won’t happen in the first phase of the transition.

Participants currently in the programme will transition across into the new programme at the time of their next screening test. For others (unscreened or under-screened), a strategy will be developed with wider consultation from stakeholders within the next six months to plan how to reach vulnerable groups.

Clinician-taken samples and self-tests will not be free, but the NCSP is looking at low-cost options. Education and focus groups will be a significant workstream as part of implementation over the next 18 months.

#### Feedback and recommendations

* Options on the capabilities of the new NCSP Register were discussed, including the accessibility of real-time results.
* It’s important that kaiāwhina and support staff have the means to support HPV self-testing and that there are clear processes for managing test results. There should be trust between community workers and clinicians to deliver an equity-focused programme.
* Any mail-out programme needs to be entirely community-driven and should consider engagement with local and regional community leaders who have strong connections with wāhine. This needs to consider what worked well and what didn’t in the bowel screening programme.
* The clinical pathway should clarify timeframes after a participant tests for HPV. The pathway should also clarify the type of HPV detected at the repeat intervals, as the current pathway doesn’t specify.
* Participants, support workers and clinical workers all need to understand that the participant will be required to return for cytology if HPV is detected.
* Guidelines should clarify when to directly refer a participant to colposcopy.
* Messaging needs to clarify that the effectiveness of the testing regime is five years – testing participants more frequently is not a good use of time or resources. Education on sexual health and frequency of screening per best practice is crucial, including education for community workers who can pass on this information to participants.
* The IT solution needs to ensure a system supports participants over 70 years old to remain in the programme if HPV is detected.
* Guidance around frequency of screening for immunosuppressed people and those with atypical glandular cells should be clarified.
* The programme will develop education to the general public that participants should continue to screen and that the current screening programme is safe and effective. The NCSP will seek advice on the best way of communicating this and take guidance from the sector based on arising issues or concerns.

### Meeting 6: New Zealand Family Planning

**2 June 2021, 4:00pm**

New Zealand Family Planning (Family Planning) works with many who are not enrolled in a general practice. It was proposed to utilise Family Planning as a good mechanism for reaching unenrolled people and running screening initiatives.

Work is ongoing at the National Cervical Screening Programme (NCSP) to better enable organisations such as Family Planning to access New Zealand Cancer Register data, such as client demographics and screening histories.

#### Feedback and recommendations

* The pathway needs to clarify whether a clinician-collected sample is a swab, a speculum examination or a cytology sample.
* There is concern about missing glandular abnormalities: a small number of atypical endometrial cells may be missed, which would have been picked up in cytology. This makes it more important for people who are symptomatic to be followed up on.
* The NCSP needs to consider a good system of counselling for vulnerable people who might go from a self-test straight to colposcopy if HPV type 16/18 is detected.

### Meeting 7: General Practice New Zealand

**3 June 2021, 6:00pm**

The introduction of self-testing is a welcome change as the programme transitions from liquid-based cytology screening to HPV primary screening. However, there are concerns around participants continuing to face access and cost barriers as self-testing will be administered in a clinical setting, particularly if the programme relies on participants to be enrolled with a general practice.

#### Feedback and recommendations

* The group requests that the National Cervical Screening Programme (NCSP) provide the evidence of safety that all who test for HPV type 16/18 will require cytology and a speculum examination before they can attend colposcopy. Reassurance is needed that the NCSP aims to be participant-centred rather than service-centred to manage demand.
* In the meantime, communication will be important as there is a potential risk that people may choose to delay screening in favour of waiting for the roll-out of self-tests.
* Guidelines and evidence should be specified for a safe clinical pathway for those who are no longer sexually active and have had a negative HPV result. These participants often no longer feel the need to come back for screening, and there’s a need for guidelines on how to safely manage these participants.
* Smear takers are required to complete 30 smears/year for competency. Consideration may need to be given to how this requirement will change with the introduction of self-testing.

### Meeting 8: The Royal Australian and New Zealand College of Obstetricians and Gynaecologists

**8 June 2021, 12:00pm**

The group agrees that the new programme is a step forward in addressing equity issues. However, effort should go toward finding an approach that works for vulnerable groups when they have previously struggled to access services. The National Cervical Screening Programme (NCSP) will explore different models to approach this issue.

There was general agreement that the clinical pathway is clinically sound and in line with Australian and United Kingdom models. A five-year screening period is considered clinically safe due to the increased sensitivity of the new HPV screening test. Further guidance will be provided in the clinical guidelines on screening for high-risk participants who may need more frequent screening.

The clinical pathway will be reviewed after the first screening round, five years post-implementation, as more data becomes available for safety and efficacy.

#### Feedback and recommendations

* The NCSP should mitigate misinformation in the media and develop robust communications around HPV primary screening and the universal option of self-testing.
* Cost is a barrier for people to attend their smears; many fall off the pathway after results are referred to primary health care due to cost. It was agreed that the NCSP’s intent with the new programme is to fully fund all follow-up procedures if a participant tests for HPV, including the cost of support from screening support services.
* Access continues to be a barrier for people living in remote areas. The programme will need to roll out a thorough education campaign, especially on how to access self-testing in community settings. The NCSP will undertake education across the workforce, including clinicians and the potential use of kaiāwhina.

### Meeting 9: The Royal Australian and New Zealand College of Obstetricians and Gynaecologists

**9 June 2021, 5:00pm**

Colposcopists agree that, for those who test for HPV type 16/18, direct referral to colposcopy is not necessary and runs the risk of overtreatment. Requesting cytology first is the right approach to prioritise those with high-grade cell changes and better informs the colposcopist at the time of treatment.

#### Feedback and recommendations

* The National Cervical Screening Programme (NCSP) should develop guidelines on how to safely manage participants who decline returning for a speculum examination or cytology sample.
* Colposcopists expressed concern about the increase in demand when most district health boards (DHBs) are already underfunded. The NCSP will consider an approach for additional funding, including a workforce plan, to improve current services and ensure coloscopy services are not overwhelmed. There may also be a gradual decrease of abnormalities over time due to vaccinations.
* Guidelines should consider how to manage post-menopausal people who may be resistant to HPV primary screening.
* A pilot in Auckland identified that unscreened and under-screened people prefer to have only one clinician visit. Therefore, the clinical pathway should specify that those who have not had any screening in the last five years, are over 30 years old and test for HPV type 16/18, should be referred directly to colposcopy. Although this will be at the general practitioner’s discretion, education should make these guidelines clear to safely manage high-risk people.

### Meeting 10: National Cervical Screening Programme Advisory Group

**16 June 2021 10:00am**

The roll-out of HPV primary screening is a welcome announcement and the introduction of self-testing is a positive step toward achieving more equitable outcomes and reaching vulnerable groups not previously enrolled in the screening programme.

#### Feedback and recommendations

* All National Cervical Screening Programme (NCSP) clinical documents should clarify the meaning of the terms ‘triage’ and ‘prioritisation’ as they are not the same. It needs to be clear that cytology helps prioritise (not triage) patients to colposcopy. Cytology is a tool to prioritise colposcopy, which can be delayed if the cytology sample is negative/low-grade.
* The NCSP should have clear guidelines on when to send people to colposcopy without cytology, prioritised based on age and screening history.
* The NCSP Advisory Group requests to see the data and clinical evidence that this approach is safe and best practice.
* The option of a self-test or a clinician-taken sample is a choice, without NCSP preference of one over the other. But if the clinician believes there will be barriers for the participant to return for cytology, the clinician can request to collect a clinician-taken sample in order to be able to add cytology in the case of HPV detection. This comes down to developing a positive and trusting relationship between the wāhine and the clinician. Discussion needs to occur with a trusted person on risks, benefits and next steps in the pathway.
* The NCSP should develop systems to aid colposcopists in treating those without cytology, such as a risk assessment based on patient data and screening history.
* Screening support services should be adequately funded and empowered to provide support for wāhine along the pathway and ensure they attend colposcopy.
* Cytology pathways within the algorithm should include ‘and cervical examination’ to distinguish from a self-test.
* It was recommended to include extended genotyping to guide positive HPV tests, especially for high-risk HPV (Other) types at 12-month intervals.

### Meeting 11: Federation of Women’s Health Councils

**27 August 2021 1:00pm**

The Federation of Women’s Health Councils provided feedback on the operational detail of the new screening programme. It was agreed that equity should be the programme’s top priority. The National Cervical Screening Programme (NCSP) will continue to work to identify opportunities that support free and accessible screening for participants.

Development of a monitoring and reporting framework is a core workstream of HPV primary screening implementation. The NCSP will be reviewing the independent monitoring reports as part of the programme change. The new NCSP register will enable timely and focused monitoring, and the NCSP will be working with stakeholders to ensure the register build enables this. All indicators will be reviewed, including transition indicators, ongoing monitoring and reporting indicators from a programme perspective, and any others based on requirements from the sector.

There will be further workshops to support the NCSP change leading up to implementation in 2023. The NCSP will continue to include the Federation of Women’s Health Councils in any further sector consultations.

#### Feedback and recommendations

* Free screening should be provided for all participants, and funding should be made available for this screening. Moving forward, community health cards should be considered to bring under-screened and unscreened participants into the programme.
* Co-design based on the evidence in the Support, Assessment and Screening Services evaluation will inform the system and service-level changes required across the breast and cervical screening pathways and inform procurement for future screening support services.
* The 2018 parliamentary review recommended that comprehensive pathway support be provided to everyone. This is a key issue and fundamental in reducing inequities. It will involve providers wider than the primary health care sector.
* The parliamentary review also recommended quality improvement for colposcopy services. Colposcopy pressures and demand will need to be part of the NCSP monitoring plan.
* Mail-out self-testing kits were recommended to reach priority groups. Although this cannot be offered currently at the national level, it is something to be considered in the future. The NCSP will ensure that participants can continue to have traditional testing of a screen and speculum examination if they choose.
* It should be made clear that self-testing poses a risk of missing those with cell abnormalities, which will be picked up in cytology. This makes it all the more important for people who are symptomatic to be followed up.

1. HPV screening is done by vaginal swab, which can be taken by either the patient or a clinician and is then tested for HPV. The cytology screening approach involves a clinician using a speculum to take a cervical sample, from which both an HPV test and cytology triage can be taken. HPV self-testing is a significantly less invasive experience. [↑](#footnote-ref-1)
2. Adcock A, Cram F, Lawton B, et al. 2019. Acceptability of self-taken vaginal HPV sample for cervical screening among an under-screened indigenous population. *Australian and New Zealand Journal of Obstetrics and Gynaecology* 59: 301–7. [↑](#footnote-ref-2)
3. Smith M, Lew JB, Simms K, et al. 2016. Impact of HPV sample self-collection for under-screened women in the renewed cervical screening programme. *MJA* 204(5): epub 21 March. [↑](#footnote-ref-3)
4. Waitangi Tribunal. 2019. Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry. Wellington: Waitangi Tribunal. URL: <https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_152801817/Hauora%20W.pdf> (accessed 1 December 2021), page 163. [↑](#footnote-ref-4)
5. Whare tangata: The house of humanity, where life is created – the womb or uterus. [↑](#footnote-ref-5)
6. Waitangi Tribunal. 2019. Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry. Wellington: Waitangi Tribunal. URL: <https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_152801817/Hauora%20W.pdf> (accessed 1 December 2021). [↑](#footnote-ref-6)
7. Arbyn M, Smith S, Temin S, et al. 2018. Detecting cervical pre-cancer and reaching underscreened women by using HPV testing on self-samples: updated meta-analyses. *BMJ* 363: k4823. [↑](#footnote-ref-7)
8. Polman N, Ebisch R, Heideman D, et al. 2019. Performance of human papilloma virus testing on self-collected versus clinician–collected samples for the detection of cervical intraepithelial neoplasia of grade 2 or worse: a randomised, paired screen positive, non-inferiority trial. Lancet Oncology 20(2): 229–238. [↑](#footnote-ref-8)
9. Arbyn M, Verdoodt F, Snijiders P, et al. 2014. Accuracy of the human papilloma virus testing on self-collected versus clinic-collected samples: a meta analysis. *Lancet Oncology* 15: 172–83. [↑](#footnote-ref-9)
10. UK National Screening Committee (Costello Medical Consulting Ltd). 2017. *Cervical l cancer screening – HPV self-sampling*. Version date 14 March 2017. [↑](#footnote-ref-10)
11. Smith M, Lew JB, Simms K, et al. 2016. Impact of HPV sample self-collection for under-screened women in the renewed cervical screening programme. *MJA* 204(5): epub 21 March. [↑](#footnote-ref-11)
12. Whare tangata: The house of humanity, where life is created – the womb or uterus. [↑](#footnote-ref-12)
13. Mana motuhake: Autonomy or self-determination over one’s own body, health and destiny. [↑](#footnote-ref-13)
14. Whakamā: Shame or embarrassment. [↑](#footnote-ref-14)
15. Waitangi Tribunal. 2019. Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry. Wellington: Waitangi Tribunal. URL: <https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_152801817/Hauora%20W.pdf> (accessed 1 December 2021). [↑](#footnote-ref-15)
16. Waitangi Tribunal. 2019*. Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*. Wellington: Waitangi Tribunal. URL: <https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_152801817/Hauora%20W.pdf> (accessed 1 December 2021). [↑](#footnote-ref-16)
17. HDSR. 2020. *Health and Disability System Review: Final report. Pūrongo Whakamutunga.* Wellington: Health and Disability System Review (HDSR). URL: <https://systemreview.health.govt.nz/assets/Uploads/hdsr/health-disability-system-review-final-report.pdf> (accessed 2 December 2021). [↑](#footnote-ref-17)
18. Whakawhanaungatanga: The process of establishing genuine and caring relationships. [↑](#footnote-ref-18)
19. Tikanga: Māori customs, values and practices in the social context. [↑](#footnote-ref-19)
20. Tangata whenua: The local people, indigenous people; people born of the land where their ancestors have lived before them. [↑](#footnote-ref-20)
21. Kaiāwhina: community support workers [↑](#footnote-ref-21)
22. The NCSP Register monitors participants across the screening pathway through a number of fail-safes. There are many manual processes, and this impacts on the quality of reporting data as the coding of outcomes is not standardised. A monitoring framework is in place to manually review participants in these groups. [↑](#footnote-ref-22)
23. Manaaki: The concept of support, hospitality or caring for someone. [↑](#footnote-ref-23)
24. Aroha: Care through compassion and empathy. [↑](#footnote-ref-24)
25. LGBTQIA+ community: Lesbian, gay, bisexual, transgender, queer, intersex, asexual and other identities that make up the diverse group of people with varying sexual orientations and identities. [↑](#footnote-ref-25)
26. The National Screening Solution (NSS) is an IT infrastructure that supports the National Bowel Screening Programme and was designed to be extensible to other screening programmes. [↑](#footnote-ref-26)
27. Kōrero: discussion or conversation [↑](#footnote-ref-27)
28. Waitangi Tribunal Health Services and Outcomes Inquiry initiated in November 2016 to hear all claims around grievances relating to health services and outcomes of national significance for Māori. The initial *Hauora* report was released in 2019. (Waitangi Tribunal. 2019. *Hauora: Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry.* Wellington: Waitangi Tribunal. URL: <https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_152801817/Hauora%20W.pdf> (accessed 1 December 2021).) [↑](#footnote-ref-28)