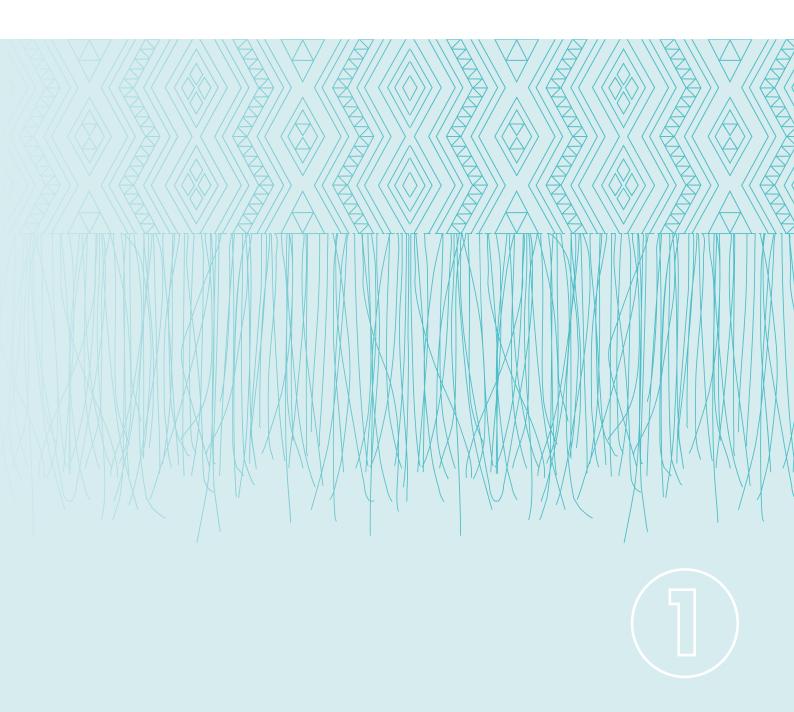




NCSP Policies and Standards Section 1: Tiro Whānui Overview Interim v1.0

National Cervical Screening Programme, 2023



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NCSP Policies and Standards

The National Cervical Screening Programme (NCSP) Policies and Standards document the agreed policies, guidelines, and standards of practice for providers of National Cervical Screening Programme services.

Their purpose is to support all those involved in the NCSP to achieve the programme's aims and objectives by ensuring a high standard and national consistency of service at each step of the screening pathway.

In this section

This section of the NCSP Policies and Standards contains an overview of the National Cervical Screening Programme and is relevant to all provider groups.

Te Tīmatanga – Introduction

The National Cervical Screening Programme (NCSP) was established as a national, centrally coordinated screening programme in 1990. Recommendations arising from the Cartwright Inquiry 1988 were an important factor in its establishment.

The NCSP is coordinated and led from within Te Whatu Ora – National Public Health Service. We acknowledge all those who suffered as a result of the "Unfortunate Experiment" at National Women's Hospital which led to the Cartwright Report 1988, and also those who were affected by the events prior to March 1996 that resulted in the Ministerial Inquiry into the Underreporting of Cervical Smear Abnormalities in the Gisborne Region, which led to the Health Amendment Act 2004.

Nā koutou i tangi, nā tātau katoa – when you cry, your tears are shed by us all

We honour the passionate voices both past and current who have been relentless in the expectations of the NCSP. Waireti Walters is one such Māori advocate who famously commented:

Know my face before you know my Cervix – Waireti Walters We acknowledge the hard work over many years of the Māori Monitoring and Equity Rōpū, the NCSP Advisory and Action Rōpū, the National Kaitiaki Group, the Parliamentary Review Committees and the numerous community advocacy groups who have also made a major contribution.

We also acknowledge the dedicated cervical sample takers, Support to Screening Services, NCSP Register central team, regional coordinators, primary healthcare, laboratory and colposcopy service providers, and others in the cervical screening programme who have worked hard over many years to foster and develop NCSP services. Many individuals have built on and upheld the mana passed from those who have gone before.

Ko te pae tawhiti, whāia kia tata, ko te pae tata, whakamāua kia tīna – seek out distant horizons and cherish those you attain

Te Tiriti and Equity

The National Screening Unit (NSU) has a responsibility to uphold the Articles of Te Tiriti o Waitangi. The Pae Ora (Healthy Futures) Act 2022 sets out the health sector principles in Section 7. Adhering to the principles of tino rangatiratanga, partnership, active protection, options and equity, and upholding the Articles of Te Tiriti is fundamental to the rights of Māori. (For more information see health.govt. nz/our-work/populations/maori-health/ whakamaua-maori-health-actionplan-2020-2025)

The Ministry of Health (2019) defines equity as follows: "In New Zealand, people have differences in health that are avoidable, unfair, and unjust. Equity recognises that people with different levels of advantage require different approaches and resources to achieve equitable health outcomes". The Aotearoa New Zealand Cancer Action Plan 2019-2029 advocates responding to Māori models that are holistic and whānau-centric, addressing racism and discrimination and achieving equity by design (MOH, 2019). Screening providers must recognise and respect Māori views relating to reproductive health, including the importance of te whare tangata, whakapapa, whānau, and wellbeing.

Achieving equitable access to cervical screening is essential to the overall success of the HPV primary screening programme. Currently, around 85% of participants who develop cervical cancer in Aotearoa New Zealand have either never been screened or have been screened infrequently. People of European/other ethnicity have been privileged by the way screening programmes have been designed , while Māori and Pacific people have lower rates of screening and higher rates of cancer. Other groups whose needs are not met by a 'one size fits all' approach include the rainbow community, people with disabilities, people living with mental illness, and people living in rural areas. (For up-to-date screening coverage data, please visit: nsu.govt.nz/ health-professionals/national-cervicalscreening-programme/cervicalscreening-coverage/monthly)

HPV primary screening, effectively implemented, is expected to improve access to screening for participants who are currently unscreened or underscreened, and to reduce inequitable outcomes. However, changing the primary test from cytology to HPV will not achieve equity on its own. The NCSP and providers of screening need to take deliberate steps to progress the goal of achieving equity in all aspects of the programme.

The equity goals are as follows.

- All ethnic groups have reached the target for participation in cervical screening.
- The incidence of cervical cancer has reduced to below the WHO elimination target of <4/100,000 for Māori, Pacific, Asian and 'Other' in Aotearoa.
- There are no differences in mortality rates for cervical cancer between ethnic groups.

- Research and evaluation show that the NCSP vision is achieved for all groups including the rainbow community, disabled people, people living in rural areas and people with experience of mental illness or trauma.
- Māori have mana motuhake over screening design and outcomes, and tino rangatiratanga is embedded throughout the process.

Mahia te mahi hei painga mo te iwi – Do work for the betterment of the people – Te Puea Herangi

The aim of the NCSP

The aim of the NCSP is to reduce the incidence and mortality of cervical cancer among all eligible people in Aotearoa New Zealand by the detection and treatment of HPV and precancerous squamous cell changes and, where possible, other abnormal cervical/vaginal cell changes through the coordination of a high-quality, population-based screening programme.¹

For all providers, the NCSP encourages processes that contribute to a positive experience for participants and that foster their commitment to having regular cervical screening.

A participant's journey within the screening programme is influenced by the support they receive from health professionals providing the screening service. Amohia ake te ora o te iwi ka putaki te whei ao – To protect the wellbeing of people is paramount

Objectives of the NCSP

The objectives of the NCSP as set out in the Health (National Cervical Screening Programme) Amendment Act 2004 Section 112D are to:

- promote high quality cervical screening, assessment, and treatment services, while recognising and managing the differences between the various types of cervical cancer, with a view to reducing the incidence and mortality rate of cervical cancer
- inform participants and the community of the risks, benefits and expected health gains from participation in the NCSP
- promote the regular recall of participants who are enrolled in the NCSP for cervical screening tests
- facilitate continuous quality improvement by allowing and performing regular evaluations of the NCSP
- ensure that information that is collected for the purposes of the NCSP is:
 - available in a reliable, accurate and timely manner to persons authorised to have access to it
 - safely stored, including on the NCSP Register
- provide information to participants about the quality and effectiveness of the NCSP including, if it is appropriate, information based on the results of evaluations.

Transition to HPV primary screening

The National Cervical Screening Programme (NCSP) has saved thousands of lives in Aotearoa New Zealand with the help of the current cytology test by identifying those at a higher risk of cervical cancer.

The NCSP, which started a pap smearbased population-level cervical screening programme in 1990, will begin using an HPV DNA-based test with the option of selftesting from 2023 onwards (NSU, 2022).

This is in response to the World Health Organization's (WHO) new global strategy for cervical cancer elimination, of which the organisation calls for a shift in the recommended approaches for cervical screening from visual inspection with acetic acid or cytology using a smear test to a human papillomavirus (HPV) DNAbased test (WHO, 2021). The rationale for the change in testing strategy is because there is growing evidence that HPV testing is more sensitive than cytology (cytology: 55%-79% vs. HPV testing 94%-100%) for detecting high-grade cervical intraepithelial neoplasia (CIN grade 2 and above), and also offers a longer screening interval after a negative test compared to a negative cytology test (Gilham et al., 2019; Gravitt et al., 2010; Kripke, 2008).

In addition to these benefits, there is evidence to show that the change in testing strategy has the potential to increase the coverage of cervical screening, especially among people with a cervix who experience barriers to healthcare and those without healthcare (Gravitt et al., 2011; Schmeink et al., 2011). Cytology will continue to be used to determine whether cell changes have occurred. This is because cytology is more specific and it works well as a second test for those who have HPV detected, to identify who needs further investigation. An HPV primary screening programme can identify those at a higher risk much earlier than cytology only.

The new screening method will test for the presence of HPV. There will be several changes when the new primary screening test is introduced:

- Self-testing will be an option.
- Routine cervical screening will only be needed once every five years. Screening was previously three yearly.
- The HPV test is highly sensitive:
 - About 10% of people screened will have HPV detected. This will need follow-up as it means there is a risk of already having or developing precancerous cell changes on the cervix.
- The NCSP Register is populationbased, so people who are not enrolled in primary care will be invited for screening.
- The Register will send centralised notifications (invitation, reminder and recall).
- The Register will not send result letters to participants.
- The Register can store and action participants' communications preferences.

Tikanga a Iwi – Cultural context

POLICY

Culturally safe practices

NCSP providers must employ culturally appropriate practices and procedures that provide a culturally safe service and promote equity of access to cervical screening across all population groups.

Providers should be aware of the component groups and rationale for NCSP 'priority group participants'.

Achieving equity in cervical screening

A key priority of the NCSP is achieving equity in access to the benefits of cervical screening across all population groups, with the overall aim of eliminating inequity in cervical cancer incidence and mortality, and eliminating cervical cancer overall.

Māori participants continue to experience higher incidence and mortality from cervical cancer than non-Māori (or all New Zealand participants). The incidence rate of cervical cancer among Pacific participants is also higher than that of the general population.

Māori, Pacific and Asian people all have lower rates of screening than 'other' groups. Cervical cancer incidence among the 'Asian' group is lower than that of other groups.

Research has also shown that around 85% of participants who develop cervical cancer in New Zealand have either never been screened or have been screened infrequently. It is recognised that, to be successful for Māori participants, the NCSP must offer screening in ways that Māori feel are acceptable, accessible, affordable, and culturally safe. The programme must also actively promote the benefits of screening for Māori participants.

NCSP priority group participants

To reduce health inequities, different approaches are needed to support priority group participants to be screened, and to access assessment and treatment services. Certain groups of participants, because of their greater burden of cervical cancer, are identified as 'priority' for the NCSP, attracting additional resources and targeting of invitation strategies with the aim of increasing screening rates.

Providers are expected to use evidencebased and culturally responsive strategies to support equitable access and outcomes for priority group participants. This will include monitoring access and adjusting approaches where required.

Free screening is available to participants who:

- are Māori or Pacific
- hold a community services card
- are 30 years or over and have never been screened
- are 30 years or over and have not had regular screening (have not had a cervical screen in the past 5 years).

Free follow-up testing, including Test of Cure, is available to all participants.

Māori participants

Health promoters, cervical sample takers and colposcopy providers must have culturally safe processes for communication with wāhine/whānau Māori to encourage their participation in the NCSP.

Initiatives that providers can take to reduce inequalities in screening coverage and follow-up for Māori participants include:

- better collaboration with Whānau Ora collectives, Māori health providers, lwi and Localities
- building and maintaining linkages and relationships with Māori communities
- working more closely with Māori providers, lwi and Localities to strengthen networks and raise awareness within Māori communities.

- New Zealand Health Strategy
- New Zealand Disability Strategy
- He Korowai Oranga: Māori Health Strategy (MoH 2002 /updated 2013/2014) sets the direction for Māori health development in the health and disability sector and has as its vision the achievement of whānau ora, or healthy families health.govt.nz/our-work/ populations/maori-health/he-korowai-oranga
- Whānau Ora puts whānau and families in control of services and supports they need to build on their strengths and achieve their aspirations. Whānau Ora uses a kaupapa Māori approach to improve the wellbeing of whānau as a group, addressing individual needs within the context of whānau or families and their culture tpk.govt.nz/en/nga-putea-me-ngaratonga/whanau-ora
- NCSP biannual and annual monitoring reports https://www.nsu.govt.nz/health-professionals/ national-cervical-screening-programme/hpvprimary-screening/hpv-primary-0-6
- Pae Ora Healthy Futures https://www.health. govt.nz/new-zealand-health-system/pae-orahealthy-futures-all-new-zealanders
- Models of Māori dimensions of health can provide guidance for providers in developing policies and service expectations for Māori participants, for example: Whare Tapa Whā, Te Wheke and Te Pae Māhutonga health.govt. nz/our-work/populations/maori-health/ maori-health-models
- NCSP Te Tiriti and Equity Strategy
 (in development)

Pacific participants

Pacific people are identified as priority group participants and are actively involved in the development and implementation of the NCSP at the national policy level as well as delivering the NCSP at a local level.

Initiatives that providers can take to reduce inequalities in screening coverage and follow-up for Pacific people include:

- strong collaboration with Pacific providers and communities
- building and maintaining linkages and relationships with Pacific communities
- working closely with Pacific providers and Pacific health managers
- knowing the different Pacific communities in their region.

There are more than 22 different Pacific communities in New Zealand, each with its own distinctive culture, language, belief systems and challenges. The biggest Pacific groups in New Zealand are the Samoan, Cook Islands Māori, Tongan, Niuean, Fijian, Tokelauan, and Tuvaluan communities.

- NCSP monitoring reports https://www.nsu. govt.nz/health-professionals/nationalcervical-screening-programme/hpv-primaryscreening/hpv-primary-0-6 publications and report
- Overcoming barriers to cervical screening in Pacific participants bpac.org.nz/bpj/2010/ november/cervicalscreening.aspx
- Ola Manuia: Pacific Health and Wellbeing Action Plan 2020–2025 https://www.health.govt.nz/ publication/ola-manuia-pacific-health-andwellbeing-action-plan-2020-2025

Whakatureture - Legislation

POLICY

All NCSP providers must be aware of and comply with the detail and principles of all relevant codes and legislation.

Legislation sets out:

- duties of cervical sample takers
- duties of colposcopy providers
- duties of laboratories where specimens are analysed
- obligations to Māori data sovereignty.

The NCSP is governed by legislation as follows:

The Health (National Cervical Screening Programme) Amendment Act 2021

The Health (National Cervical Screening Programme) Amendment Bill passed on 23 June 2021 and amends Part 4A of the Health Act 1956 (the Act). It will enable the National Cervical Screening Programme (NCSP) to take advantage of modern information technology by providing direct look-up access to health providers providing screening services.

The changes will enable cervical screening to be more efficient as health providers will be able to access participants' screening histories in a wider range of settings.

The requirements in the Kaitiaki Regulations are unchanged, however a new clause 6A provides clarity on when approval of the National Kaitiaki Group is required for Ministry use of data that identifies participants as being Māori.

Other changes are that the Act:

- provides changes as to who can authorise access to the NCSP Register for specific functions
- introduces minor technical definition changes, including:
 - amendments to the definitions of 'screening test', 'diagnostic test' and 'specimen''
 - a change to the new section 112J

 (4) (d) relating to the disclosure
 of information for the purpose
 of enabling the compilation and
 publication of non-identifiable
 statistics from the NCSP Register.
 The change is to use the phrase
 "unless the disclosure is prohibited
 by" instead of "in accordance with"
 - a change to the definition of the NCSP Register to ensure that it captures any data that was on a previous register that has been replaced
 - a consequential change to the Health (Cervical Screening (Kaitiaki)) Regulations 1995 so they are consistent with the new definition of the NCSP Register in the principal Act.
- introduces a penalty for amending information on the NCSP Register without the authorisation of the NCSP Manager
- allows the NCSP Manager to put conditions on access to the NCSP Register for the purpose of ensuring privacy and security of the material or information.

The Health (National Cervical Screening Programme) Amendment Act 2004

The NCSP is governed by the Health (National Cervical Screening Programme) Amendment Act 2004 (the Act), which became effective from March 2005.

The purpose of the Act is to:

- reduce the incidence and mortality rate of cervical cancer by providing for the continuation of the NCSP
- facilitate the operation and evaluation of the NCSP by enabling:
 - access to information and specimens by persons operating the NCSP
 - access to information and specimens by screening programme evaluators, appointed to evaluate the programme (Section 112A).

The Act sets out:

- the objectives of the NCSP
- responsibilities of the NCSP Manager, cervical sample takers, laboratories and colposcopists
- procedures for enrolment of participants and enrolment cancellation
- recording of cervical screening results
- who has access to NCSP Register data, and
- provides for the appointment of experts to assess the performance and safety of the programme by ensuring they have access to key information.

The Act ensures that:

- responsibilities to inform participants are clearly outlined
- all cervical test results are sent to the NCSP
- all participants are enrolled unless a participant withdraws from the programme in writing
- data held on the NCSP Register is confidential
- programme standards may be enforced if required.

- The Health (National Cervical Screening) Amendment Act 2004 legislation.govt.nz/act/ public/2004/0003/latest/DLM238121.html
- Changes to NCSP Legislation https://www.nsu. govt.nz/health-professionals/national-cervicalscreening-programme/legislation/changesncsp-legislation
- The Report of the Cervical Cancer Inquiry 1988
 nsu.govt.nz/current-nsu-programmes/3233.aspx
- Report of the Ministerial Inquiry into the Underreporting of Cervical Smear Abnormalities in the Gisborne Region (2001) https://www. moh.govt.nz/notebook/nbbooks.nsf/0/ a79b9e52f04d57e5cc256a9f006f1687/\$FILE/ csireport.pdf
- Report of the Parliamentary Review Committee regarding the New Zealand Cervical Screening Programme June 2021 https://www.nsu.govt. nz/health-professionals/national-cervicalscreening-programme/legislation/ncspreview/parliamentary-0

The Health (Cervical Screening (Kaitiaki)) Regulations 1995

Māori participants' aggregate data stored on the NCSP Register is protected under the Health (Cervical Screening (Kaitiaki)) Regulations 1995.

The National Kaitiaki Group (NKG) is appointed by the Minister of Health to oversee the release of this data.

Persons planning to undertake an analysis of aggregate Māori data held on the NCSP Register are required to complete an application to the National Kaitiaki Group following a data request application to the NCSP.

See also:

- The Health (Cervical Screening (Kaitiaki)) Regulations 1995 legislation.govt.nz/regulation/ public/1995/0029/latest/DLM198873.html
- The National Kaitiaki Group https://www. tewhatuora.govt.nz/our-health-system/ national-kaitiaki-group/

The Cancer Registry Act 1993

The Cancer Registry Act 1993 requires laboratories to report any new tissue diagnosis of cervical cancer to the New Zealand Cancer Registry, a population-based register of all primary malignant diseases diagnosed in New Zealand.

- The Cancer Registry Act 1993 https://www. legislation.govt.nz/act/public/1993/0102/latest/ DLM318888.html
- The Health Information Privacy Code 1994 (revised 2008) – sets specific rules for agencies in the health sector to better ensure the protection of individual privacy, addressing health information collected, used, held, and disclosed by health agencies https://privacy. org.nz/assets/Files/Codes-of-Practicematerials/HIPC-1994-incl.-amendmentsrevised-commentary-edit.pdf
- The Health and Disability Commissioner Code of Health and Disability Services Consumers' Rights Regulations 1996 hdc.org.nz/your-rights/ about-the-code/code-of-health-and-disabilityservices-consumers-rights Note that complaints can be made to the Health and Disability Commissioner
- Medicines Act 1981
- Privacy Act 2020
- Human Rights Act 1993

Ngā Painga me ngā Kōpiringa – Benefits and limitations of screening

POLICY

All NCSP providers must have an understanding of the benefits and limitations of the NCSP and where appropriate, communicate these to participants.

Benefits of a national HPV primary screening programme

Well-organised cervical cancer screening programmes can significantly reduce the incidence and mortality from the disease. High screening uptake, with regular participation, is essential.

The shift to HPV primary screening is expected to lead to increased uptake in cervical screening as people now have the option of self-testing. This option has been found to be highly acceptable to participants. Other options are cliniciantaken HPV swab, or clinician taken LBC. Moving to HPV primary screening means that the regular screening interval can be safely extended to five years. HPV is a better primary screening test. Other general benefits of an organised national screening programme include:

- availability and provision of appropriate and consistent health information
- screening and follow-up services are available and coordinated
- explicit and nationally consistent quality standards
- ongoing monitoring and evaluation of the programme
- participant notification of results, including:
 - use of preferred methods of contact (text/email/letter)
 - an initial communication that a participant's information has been added to the NCSP Register, with options for withdrawal
 - a reminder that the next cervical screen test is due/overdue
 - reminders if a required clinical step is overdue
 - worklist tasks to clinical and other support services to support follow-up
 - a record of a participant's screening history, including name and location of previous sample takers.
- provision of a participant's screening history on request
- enabling participants to be contacted by the NCSP if required.

Limitations of HPV primary screening

All screening programmes have limitations and the potential to cause harm. The potential for harm needs to be understood so it can be minimised.

HPV primary screening is a highly sensitive test. This means that it is unlikely to 'miss' cases of cervical abnormality. However, it is less specific than cytology, which means that the 'net' is cast wider, and there will be more 'false positives'. Approximately 10% of people screened will have a test result of HPV detected. They will need further investigation, either a return to see their screening provider for an LBC sample to check cytology, or (if HPV 16 Detected or HPV 18 Detected) direct referral to colposcopy.

Participants who have a test result of HPV detected may feel anxious about this finding and the need to return for further testing. Providers need to clearly explain, before HPV testing is undertaken, that:

- approximately 10% of participants will have a HPV detected test result and will need follow-up
- HPV detected does not necessarily mean that there is a significant cervical abnormality
- HPV infections can resolve over time.

An important risk for any screening programme is if people identified as requiring follow-up do not receive this. This can result in significant clinical abnormalities being missed, as well as anxiety and stress for the participant. All people who need follow-up need to be supported to get their required clinical follow-up.

No screening test is 100% accurate. High quality services with comprehensive quality assurance processes are essential to ensure that laboratory and clinical services all operate to a very high standard. A high quality, well-organised cervical screening programme, in which a high proportion of eligible participant participate regularly, will prevent many cases of invasive cervical cancer by early detection and treatment of cervical cell changes.

Te Whānui o ngā Pakeketanga – Age range

POLICY

Anyone with a cervix or vagina who has ever been sexually active should be offered an HPV primary screening test from age 25 to age 69.

If the HPV screening test result is HPV Not Detected, the next screening test should occur in five years, or in three years for those who are immune deficient.

All participants should have an HPV Not Detected result before exiting screening.

Those aged between 70 and 74 years who were unscreened or under-screened prior to age 70 should have an HPV Not Detected result before ceasing screening.

The recommended screening interval after HPV Not Detected is five years (three years for people who are immune deficient).

Symptomatic participants

Screening programmes are for asymptomatic or well participants.

The aim of the cervical screen test is to detect precancerous lesions in asymptomatic participants. However, in some situations participants with symptoms and signs suggestive of cervical cancer have a cervical screen as part of a diagnostic work-up and these cervical screens are also subject to the NCSP Policies and Standards. A cervical screening test alone must not be used as a diagnostic test.

Any participant with symptoms and signs which may indicate cervical cancer must be referred to a gynaecologist, regardless of the results of the cervical screen. The results of the cervical screen test should be noted on the referral form to the colposcopy service as well as the presenting symptoms and signs.

Minimising inappropriate screening

Providers should work to minimise inappropriate early re-screening and screening of participants under 25 years.

Minimising early re-screening

The NCSP policy is for a five-yearly interval for routine cervical screening. More frequent screening without clinical basis, termed 'early re-screening', is discouraged by the NCSP.

Early re-screening is defined as the proportion of participants who are recommended to return at the regular interval of five years, who return for a cervical screen within four years. This measure excludes participants for whom an earlier screening visit is appropriate due to previous abnormality or urgent referral due to clinical history.

Cervical screening need only be taken more often if required on clinical grounds determined by the cervical sample taker or if the specialist (and sometimes laboratory) recommends a shorter interval.

Early re-screening without clinical basis can lead to undue anxiety and inappropriate medical intervention, and represents inappropriate use of limited NCSP resources.

Starting age for screening

Key messages

- There is no evidence to show that routine screening should start earlier than 25 years.
- The risk of cervical cancer is extremely low in this age group (despite high rates of transient HPV infections).
- Screening of participants under 25 years is discouraged by the NCSP and can cause more harm than benefit (studies show a small increased risk of some pregnancy complications following treatment).

The appropriate age at which to start cervical screening depends on the agerelated risk of cervical cancer in the population and must take into account the costs of screening and the risk of harm from screening and consequential treatment, alongside the potential benefits. The NCSP reviews the starting age and screening intervals on a regular basis.

See also:

 https://www.nsu.govt.nz/health-professionals/ national-cervical-screening-programme/ age-range-change-cervical-screening-0#whychange

Ngā Karere Matua – Cervical screening and HPV key messages

POLICY

All NCSP providers must be aware of NCSP key messages regarding cervical screening, HPV, HPV testing and HPV immunisation.

Clear, consistent messaging throughout the screening programme is important.

Public facing messages and messages for health professionals are available at: nsu.govt.nz/health-professionals/ national-cervical-screening-programme/ hpv-primary-screening

HPV immunisation

Achieving high rates of HPV immunisation is essential to achieving the goal of cervical cancer elimination. Gardasil is the 9-valent HPV vaccine available in Aotearoa New Zealand, and is highly effective in preventing infection with the most common high risk HPV types.

For key messages about HPV immunisation, see: https://www. immunise.health.nz/about-vaccines/ nz-immunisations/hpv-humanpapillomavirus-vaccine/?gclid=CjwKCAjw q4imBhBQEiwA9Nx1Bha8VIGOCOOVMtEaS VGKN220iJ0HbgN6N1KxD912AbO6bjwGzx-VzBoCvJAQAvD_BwE

Te Whakaurunga Whai Mana – Mana enhancing participation in cervical screening

Improving participation in the NCSP

All NCSP providers must ensure open and transparent communications with participants. Health professionals undertaking the service are to ensure participants are fully informed.

Health promoters, cervical sample takers and colposcopy providers will have a range of processes for communicating with participants to encourage their participation in the NCSP.

NCSP providers need to be conscious of barriers and enablers to participants having a cervical screen or colposcopy and work collaboratively with other services to encourage participation.

Informed consent policy

Full information must be provided to ensure participants are able to make an informed choice about participating in cervical screening.

Information about screening, the NCSP and enrolment in the NCSP must be presented to participants in a language and manner that is culturally appropriate and easy for them to understand.

The NCSP has developed a list of key messages for providers to use when discussing cervical screening with participants. Key messages to provide to participants on cervical screening include:

 risk factors for developing cervical cancer (ie, the sample taker and/ or provider can provide a clear explanation of the role of HPV infection in the development of cervical cancer)

- the HPV vaccine and its role in preventing cervical cancer
- the need for participants to be screened every five (or three years if immune deficient) years even if they have been vaccinated against HPV
- HPV testing the options participants have about how their test is done
- the importance of reporting any abnormal symptoms to a health professional immediately.

- Informed consent in screening https://www. nsu.govt.nz/about-us-national-screening-unit/ informed-consent
- Code of Disability Services Consumers' Rights Regulation 1996 (see Your rights – Health and Disability Commissioner (hdc.org.nz)). The code includes three rights that together form the elements of informed consent: the right to effective communication (Right 5); the right to be fully informed (Right 6); and the right to consent freely given by a competent person (Right 7)
- Under the HDC, consumers must also be informed on how to make a complaint or provide feedback to the provider hdc.org.nz/ making-a-complaint/how-to-raise-yourconcerns-directly
- NSU Open Communications and Complaints policies:
 - NSU Open Communications Policy https:// www.nsu.govt.nz/publications/nationalscreening-unit-policy-framework-opencommunication-policy-nsu-03
 - NSU Complaints policy https://www.nsu. govt.nz/publications/national-screeningunit-policy-framework-complaintsmanagement-policy-nsu-02
- NCSP Policies and Standards Section 3: Cervical Screening Services.

Te Hanganga Whakahaere – Organisational structure of the NCSP

Successful cervical screening requires a high standard of quality at each step in the screening pathway, from invitation and recall, through to cervical screening, laboratory testing, colposcopy, and the management and information systems that support these processes.

The NCSP screening pathway

The Health Amendment Act, which came into effect in 2004, underpins the NCSP's operations to ensure the coordination of a high-quality cervical screening programme in New Zealand. A full description of the NCSP is available on the website under the Service Delivery Model.

Scope of the NCSP

The scope of the NCSP service provision includes:

- national services:
 - management, coordination and monitoring
 - information management through the NCSP Register.
- regional/local services
 - programme coordination, health promotion and supporting invitation and recall services
 - screen-taking services
 - laboratory services, including interpretation and reporting of all cervical cytology, histology and HPV testing samples relating to the cervix

- colposcopy services including biopsy and treatment of pre cancerous lesions
- NCSP Register support services

For further information see the NCSP Service Delivery Model (in progress).

National coordination and leadership of the NCSP

National coordination and leadership of the NCSP is the responsibility of Te Whatu Ora. This responsibility includes:

- setting the strategic direction of programmes and overseeing the introduction of new technologies
- developing and maintaining policies and standards for all providers
- national monitoring, audit, evaluation and quality improvement
- funding and contract management
- providing educational resources
- reviewing evidence on new technologies aimed at improving the accuracy and efficiency of cervical screening.

Monitoring the NCSP

Regular monitoring using NCSP Register data takes place across a range of performance indicators which are relevant to cervical sample takers, laboratories and colposcopy services and overall programme performance. A range of reports are published monthly, quarterly, six monthly, and annually.

The NCSP follows up any issues arising from the reports. Providers are also expected to use the reports as part of their own quality control processes.

NCSP monitoring reports: nsu.govt.nz/ health-professionals/national-cervicalscreening-programme/hpv-primaryscreening/hpv-primary-0-6 NCSP publications and report.

Advisory and partnership groups

The NSU seeks external advice from a range of sources to support its work.

National Kaitiaki Group

The National Kaitiaki Group considers applications for approval to disclose, use, or publish 'protected information', being information that is on or from the NCSP Register and that identifies the participant or participants to whom the information relates as being Māori. The National Kaitiaki Group protects Māori cervical screening data by ensuring that this data is:

- not used or published inappropriately or in a way that reflects negatively on Māori
- used to benefit Māori.

It also provides a way of reassuring Māori that their data is protected so they continue to participate in the screening programme.

Applications for data

Any person wanting to access, use or disclose Māori cervical screening data on the NCSP Register must first make an application to the National Kaitiaki Group. You can also apply in writing to the NCSP Programme Manager to request data from the NCSP Register and will be advised if the request needs to be forwarded to the National Kaitiaki Group.

The National Kaitiaki Group meets as required up to four times a year. Applications for data are required at least three weeks prior to a meeting: nsu.govt.nz/health-professionals/toolsand-resources/information-requests

National Screening Advisory Committee

The role of NSAC is to:

- provide leadership and strategic direction for national populationbased screening programmes
- make evidence-based recommendations about the case for implementing new population screening programmes, including consideration of their effectiveness, feasibility, likely harms and benefits, value for money, and impact on the health system
- identify screening technologies of proven effectiveness which require central agency led and well-managed implementation as national screening or quality improvement programmes
- advise whether to continue, modify or withdraw existing population screening programmes, particularly those programmes inadequately evaluated or of doubtful effectiveness, quality, or value
- consider and endorse major changes within current screening programmes as raised by NSU advisory groups
- consult and liaise with clinical leaders and experts on screening to obtain sound advice, referring appropriate issues for further research and commissioning evidence-based review as NSU resources allow
- undertake a horizon scanning function to provide guidance on emerging and future technologies suitable for population screening programmes

NSAC terms of reference https://www.nsu. govt.nz/system/files/page/nsac-termsof-reference-november-2020.pdf

Māori Monitoring and Equity Group

The National Screening Unit (NSU) established the Māori Monitoring and Equity Group (MMEG) to provide independent advice to the NSU to achieve its vision, namely:

"Saving lives, reducing inequalities, and building the Nation's health by leading the delivery of screening programmes, uncompromising in their quality and trusted by the communities we serve".

The objectives of the Group include the following.

- Provide Māori leadership on the strategic issues in the planning, implementation, monitoring and evaluation of the existing screening programmes and any further screening programmes under consideration.
- Provide Māori leadership on strategic issues related to population health screening and its impact on Māori health and inequalities.
- Develop a collective equity assessment framework improving equity (reducing inequalities) in health for Māori and therefore for all.
- Provide Māori leadership that is clinically and technically sound.
- Review new technological advances that may impact Māori Health.

The MMEG will take a population health perspective and an evidence-based approach in the provision of Māori leadership. All decisions of the MMEG will be by consensus. The MMEG will seek input from stakeholders to any key decisions. Such input will include whānau, hapū, iwi, Māori communities, Māori providers, Māori consumers, and others as required.

https://www.nsu.govt.nz/about-usnational-screening-unit/nsu-advisorygroups/m%C4%81ori-monitoring-andequity-group

NCSP Advisory and Action Rōpū

The NCSP Advisory and Action Rōpū will provide leadership to deliver high quality cervical screening outcomes for whānau Māori and Pacific Peoples, and highrisk participants through developing knowledge around ways to effectively deliver, monitor, and improve health outcomes with a Māori and Pacific focus.

The NCSP Advisory and Action Rōpū is multidisciplinary, with representation from professional bodies, Māori, Pacific and consumer groups. Its role is to:

- review, critique and interpret the NCSP monitoring report data and make recommendations to the NSU
- provide advice on the strategic direction of the programme
- provide advice from time to time on other areas of the programme
- help build understanding and partnership with professional and consumer groups.

The NCSP Advisory and Action Rōpu is committed to continuous improvement of the programme and services. Therefore, other groups and individuals are occasionally invited to provide specialist advice and support.

https:www.nsu.govt.nz/healthprofessionals/national-cervicalscreening-programme/ncsp-advisoryand-action-r%C5%8Dp%C5%AB

- Six-monthly and annual monitoring reports at nsu.govt.nz/health-professionals/nationalcervical-screening-programme/hpv-primaryscreening/hpv-primary-0-6 NCSP publications and report
- Report of the Ministerial Inquiry into the Under-reporting of Cervical Smear Abnormalities in the Gisborne Region (2001) moh.govt.nz/notebook/nbbooks.nsf/0/ a79b9e52f04d57e5cc256a9f006f1687/ \$FILE/csireport.pdf
- Report of the Parliamentary Review Committee regarding the New Zealand Cervical Screening Programme June 2021 https://www.nsu.govt.nz/ system/files/page/2021-prc-report-into-thencsp.pdf

The NCSP Register

Key functions of the NCSP Register

The NCSP Register is the national database that stores the cervical screening histories of participants enrolled in the NCSP. It is a key tool for both clinical management and monitoring of the programme.

Collection of information on the NCSP Register is authorised by the Health (National Cervical Screening Programme) Amendment Act, 2004. Every result reported to the NCSP from a screening test, or from a diagnostic test, must be accurately recorded on the NCSP Register, if that result relates to a participant who is enrolled in the NCSP.

The Register is a key tool for the NCSP to:

- maintain a master record of all cervical screening performed in Aotearoa New Zealand
- track progress of participants through the screening journey
- record statistical information to monitor and evaluate the safety and efficacy of the Programme
- monitor operational activities and information to ensure quality
- undertake future planning

Overview of NCSP Register functions

The NCSP Register:

 contains personal, demographic and contact details for all² individuals eligible for, or participating in (current or historical), the NCSP

- contains all³ cervical screening test results processed by New Zealand laboratories, including gynaecological cytology, histology, human papillomavirus (HPV) tests, and colposcopy information
- receives information on any additional specialist treatment required
- calculates next event type and due dates based on clinical pathway rules for programme participants
- is the source-of-truth for screening history reports used by health professionals
- flags and communicates data issues or actions required to Register Services teams
- enables correspondence to be sent to participants in the programme
- enables correspondence to be sent to participants who wish to withdraw from the programme
- records statistical data for monitoring and evaluation of the programme
- records and provides data used in operational reporting.

The NCSP Register has been programmed against the *Clinical Practice Guidelines for Cervical Screening in Aotearoa New Zealand* and the NCSP Policies and Standards, enabling reports to be generated against specific standards. Further detail regarding the NCSP Register can be found in NCSP Policies and Standards **Section 2 – Register Services**.

3. Unless the individual has withdrawn from the NCSP programme

Note that if the individual has withdrawn from the NCSP programme, their basic demographic data will be retained in the Register

NCSP providers

NCSP providers should aim to improve participants' awareness of and access to services along the NCSP screening pathway, and encourage them to participate in regular cervical screening and any follow-up assessment and treatment that may be required. Their role includes:

- planning and implementing awareness raising/education and strategies that promote the importance of cervical screening
- encouraging informed participation in the NCSP by providing information about the programme and promoting cervical screening opportunities
- engaging with primary care providers and colposcopy services to encourage collaborative approaches to engaging participants in the NCSP
- working with other NCSP providers to support participants to attend cervical screening and colposcopy services
- working with the NCSP Register teams and the NSU to support/undertake data matching with primary care and Support to Screening Services teams to enable targeting of under-screened and unscreened individuals.

Cervical screening services

Cervical sample takers and cervical screening services hold a pivotal role in supporting people to participate in the NCSP and in ensuring the quality and safety of the NCSP.

In addition to ensuring the quality of the clinical environment and procedures, ensuring that participants have a culturally and physically safe experience of screening that supports lifelong participation is essential for equitable health outcomes.

Cervical screening services are any service provider, business or organisation that provides any type of cervical screening or employs persons who provide cervical screening services.

Settings include Primary Care clinics, Support to Screening Services, Family Planning clinics, sexual health centres, outreach and independent services that provide screening in the home, marae, or community settings, and colposcopy and other specialist clinics.

Cervical screening services are responsible for ensuring:

- health practitioners performing cervical screening hold a current New Zealand practising certificate
- appropriate training for all staff providing cervical screening services
- a culturally and physically safe environment

- the service complies with relevant legislation including:
 - Part 4A Section 112 of the Health Act 1956
 - Health Practitioners
 Competence Assurance
 Act 2003
 - Privacy Act 2020
 - Health and Disability Services (Safety) Act 2001
- compliance with:
 - infection control standards, as outlined in Standards New Zealand NZS 8134:2021
 - Code of Health and Disability Services Consumers' Rights Regulation 1996.

Cervical sample takers

Cervical sample takers are registered health practitioners, such as a medical practitioner, nurse practitioner, registered nurse, enrolled nurse, or registered midwife who holds a current New Zealand practising certificate and has completed cervical screening training either through:

- training as part of a medical degree or midwifery training programme, or
- an NZQA accredited course to conduct cervical screening.

Cervical sample takers:

- are responsible clinicians and take clinical responsibility for the tests they request
- provide information about the NCSP and options for cervical screening
- obtain informed consent
- offer self-testing to participants
- obtain a vaginal swab to test for HPV
- obtain an LBC sample from the cervix
- take responsibility for cervical screening results
- provide results to participants
- refer to Support to Screening Services
- refer to colposcopy.

Some of the above tasks may be able to be undertaken by people working under the delegation of the responsible clinician. The roles and responsibilities for people working in cervical screening services, including delegations are further outlined in National Cervical Screening Programme Policies and Standards Section 3: Cervical Screening Services.

Laboratory services

Role of laboratory services

NCSP cytology, histology and HPV testing laboratory services are provided by contracted community and hospital laboratories.

Laboratories contracted to provide NCSP services have the following key functions:

- Ensure correct labelling of samples and request forms to ensure that the participant is correctly and unequivocally identified.
- Processing and reporting on gynaecological cytology, hrHPV testing, cervical/vaginal cytology and histology.
- Consulting with and providing advice and results to sample takers/requestors and specialists who are managing cervical disease.
- Forwarding results to the NCSP Register and collaborate with NCSP Register staff.
- Forwarding relevant results to the New Zealand Cancer Registry (NZCR).

It is expected that laboratories will develop cooperative working relationships with the wider NCSP workforce, such as by providing training/support for sample takers and specialists and collaborating with NCSP Register teams. Laboratory staff are required to participate in multidisciplinary meetings.

The roles and responsibilities for laboratories are further outlined in National Cervical Screening Programme Policies and Standards Section 5: Providing a Laboratory Service.

Colposcopy services

Role of colposcopy services

Colposcopy is central to the successful diagnosis and treatment of cervical abnormalities.

The primary objective of colposcopy is to undertake a comprehensive visual examination of the cervix in participants with any of the following (see Clinical Guidelines for more information):

- Human Papilloma Virus (HPV) 16 or 18
- cytological abnormalities detected on cervical sampling
- persistent HPV Other detected
- visible abnormalities of the cervix
- signs and symptoms of cervical cancer
- location of a possible lesion requiring treatment.

Te Whatu Ora hospital sites provide colposcopy services for the NCSP. Some participants will choose to attend private colposcopy services provided by some obstetrician and gynaecology services.

Providers of colposcopy services are responsible for:

- providing information to participants on the NCSP and colposcopy pathway and what to expect when having an examination or procedure
- providing a culturally safe environment for assessment and treatment ensuring services are sensitive to each participant's needs
- ensuring participants are appropriately informed of the result of their test and a system is in place to provide appropriate surveillance

 ensuring the participants are seen for specialist assessment and investigation when required and coordinating their ongoing care following discharge.

Colposcopy services should develop close working relationships with their regional NCSP team for access to the NCSP Register, support through the pathway and link into screening and support providers.

Colposcopy services should develop close relationships and arrangements with Support to Screening Services and other local services (e.g. Kaupapa Māori services, Pacific Health services) which can support participants into screening and through the pathway of follow-up, assessment, and treatment.

The roles and responsibilities for providers of colposcopy services are further outlined in NCSP Policies and Standards Section 6: Providing a Colposcopy Service.

GENERAL REQUIREMENTS OF PROVIDERS

NCSP Policies and Standards

While most provider groups have direct contractual obligations to meet the NCSP Policies and Standards, the NCSP has a mandate to ensure they apply to all providers.

NCSP Policies and Standards form the basis of provider audits and other monitoring of the NCSP.

NCSP Policies and Standards are published on the web as independent sections relating to provider groups as follows:

- Section 1: NCSP Overview
- Section 2: Register Services
- Section 3: Cervical Screening Services
- Section 5: Providing a Laboratory Service
- Section 6: Providing a Colposcopy Service.

Where an NCSP provider is prevented from working within these policies and quality standards in any substantial manner, they must bring the matter to the attention of the National Screening Unit.

No product endorsements policy

NCSP providers will not endorse or promote products.

Complaints policy

NCSP providers are required to:

- provide all participants with access to information advising them:
 - how to make a complaint
 - of their rights under the Code of Health and Disability Services Consumers' Rights.
- Have in place a complaints management and reporting process which meets the requirements of the Code of Health and Disability Services Consumers' Rights.

See also:

- NSU Complaints policy https://www.nsu. govt.nz/publications/national-screeningunit-policy-framework-complaintsmanagement-policy-nsu-02
- NSU Open Communications Policy https:// www.nsu.govt.nz/publications/nationalscreening-unit-policy-framework-opencommunication-policy-nsu-03

Telephone communication policy

NCSP providers are to have guidelines for telephone contacts with participants that take into consideration the principles of honesty, sensitivity, and the reduction of any anxiety that may be felt by participants.

It is important that information is given only to the participant concerned, unless otherwise arranged by the participant. When making telephone contact the provider representative must:

- identify the participant by first and surnames
- identify themselves to the participant (full name and role)
- if asked by a third party advise that the call is "personal"
- not leave messages on answering machines or with friends or relatives of the participant, unless the participant has given consent and instructions to do so (such instructions must be documented)
- offer the participant a contact phone number.

Communication with the media policy

Communication with the media about the NCSP that is initiated by providers, such as press releases, must be checked with the National Screening Unit.

The National Screening Unit will review material and return it to the provider, where possible, within 48 hours. Providers are requested to give as much lead-in time as possible.

Media issues management should also be discussed with the National Screening Unit.

It is recognised providers may also be required to work with their own organisation's staff and media policies.

Te Tuku Raraunga – Release of data from the NCSP Register

POLICY

All providers must be aware of the policies and processes concerning release of participants' information from the NCSP Register.

Legislative framework governing access to data

A legislative framework governs the principles and procedures for accessing data maintained by the NCSP Register. Access to information on the NCSP Register is governed by the provisions of the:

- Health (National Cervical Screening Programme) Amendment Act 2004
- Health (Cervical Screening (Kaitiaki)) Regulations 1995.

Applications for data from the NCSP Register can be made for a variety of purposes.

Principles covering the collection and release of data

The principles covering the collection and release of data mean that:

 a sample taker must inform a participant that, unless their objection is made in writing, their cervical results will be stored on the NCSP Register (Health (National Cervical Screening Programme) Amendment Act 2004).

Information is to be used in a way that:

- is consistent with the NCSP's overall purpose and goals
- protects the interests and privacy of participants involved in the programme, and
- complies with appropriate legislation.

Participants' access to their data

A participant is able to access any data specific to them from the NCSP Register.

Procedures for participants seeking access to their own personal information on the NCSP Register must be consistent with the requirements of the Official Information Act 1982 and the Health Information Privacy Code 1994.

Prior to accessing their information they should be authenticated by the NCSP Register staff member by asking their name and two or more of the following:

- NHI number
- date of last cervical screen and the name of the cervical sample taker (this may be the medical centre/ practice name)
- date of birth
- address and phone number.

Accessing NCSP Register data

All requests for data from the NCSP Register must be sent to the NCSP Manager, National Screening Unit, Te Whatu Ora.

The application for NCSP Register data form is available at: https://www.nsu.govt. nz/system/files/page/ncsp-and-ncspregister-request-for-data-applicationform-nov19.pdf

Accessing Māori participants' aggregate data

The provisions of the Health (Cervical Screening (Kaitiaki)) Regulations 1995 govern approval from the National Kaitiaki Group for release of Māori participants' summary data from the NCSP Register. The group is currently serviced by the Māori Health Directorate of the Ministry of Health and meets quarterly to consider applications.

The criteria used to approve applications are:

- the principle of the sanctity of Te Whare Tangata
- the need for culturally appropriate protection for the taonga of protected information
- the need to ensure that protected information is used for the benefit of Māori participants.

- NCSP Policy and Standards Section 2: Register Services
- National Kaitiaki Group https://www.tewhatuora. govt.nz/our-health-system/national-kaitiakigroup/

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