New Zealand Government

MINISTRY OF HEALTH
MANATŪ HAUORA

Report of the Parliamentary Review Committee Regarding the

National Cervical Screening Programme

April 2019

Commissioned by the New Zealand Government

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Kua tawhiti kē to haerenga mai kia kore e haere tonu; he nui rawa o mahi kia kore e mahi tonu.

You have come too far not to go further; you have done too much not to do more.
Sir James Henare

Commissioned by the New Zealand Government

Submitted by the review committee:
Gail Ward PSM, Dip App Sc (Med Rad), Dip Prac Mgt, Grad Cert PSM (Australia)
Ian Hammond AM, MBBS (Lond), FRCOG, FRANZCOG
Liane Penney NZRGON, Adv. Dip Nursing, Dip Public Health, MPH (Hons) (New Zealand)

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Foreword

by the Chair of the Parliamentary Review Committee, 2018

It has been an honour and a privilege to have been invited by the Associate Minister of Health to chair the 2018 Parliamentary Review of the National Cervical Screening Programme (NCSP). On behalf of my Parliamentary Review Committee colleagues – Ms Liane Penney and Professor Ian Hammond – I am pleased to submit this report.

We have chosen the inspiring whakataukī of Sir James Henare, translated as 'You have done too much not to do more; you have come too far not to go further', as the keystone of our report. His words are representative of the findings we have made during this review. The NCSP has achieved much over the last 29 years, but there is still more to be done – and opportunities to do so – most particularly in addressing the inequities in cervical cancer incidence for the priority group women.

I wish to acknowledge the enthusiasm and commitment of my colleagues, Liane and Ian, over the many months of interviews, meetings, teleconferences, drafting and editing of our report. I thank them for their patience, kindness and wisdom as we deliberated extensively on our findings and developed our recommendations. All the recommendations set out in this report were determined unanimously, which is testament to the collegiality and collaboration of the committee. My congratulations and sincere thanks to Liane and Ian.

My gratitude also to Ms Clare Davey of the National Screening Unit who has organised us, researched for us, coordinated teleconferences across multiple time zones and consolidated our writings into a structured, cohesive document. Thank you Clare.
And so it leaves me to commend to the Minister, the Parliament, and the people of New Zealand the following 2018 Parliamentary Review Committee Report of the National Cervical Screening Programme.

Gail Ward PSM
Chair
Parliamentary Review Committee 2018

Acknowledgements

The National Cervical Screening Programme (NCSP) has been a successful public health intervention, supported by all governments since its inception in 1990, resulting in a significant reduction in the incidence of and mortality from cervical cancer in New Zealand women. The incidence of cervical cancer was at its highest in the mid-1960s, at just over 16 per 100,000 women (Lewis et al 2005). Since the introduction of the organised screening programme, there has been a steady decline, down to 6.3 cases per 100,000 women in 2016 (Ministry of Health 2019). Substantial inequities between different population groups have narrowed over the same period.

Cervical cancer generally impacts women at the busiest and most productive stage of their lives, with devastating effects on not just the women themselves but also on their families and communities. Cervical cancer can be prevented through participation in regular screening to identify and treat early changes in the cells of the cervix.

New Zealand has a well-organised cervical screening programme, with dedicated professionals committed to delivering quality services aimed at eliminating cervical cancer during this century. However, there is more work to be done and new opportunities to further reduce the number of women diagnosed with cervical cancer – particularly Māori women. Multiple international studies referenced throughout this document have shown that the current screening test (Pap smear) cannot achieve any further reductions in incidence and mortality. This evidence, in conjuction with a 2019 *Lancet Oncology* paper by Simms et al 'Impact of scaled up human papillomavirus vaccination and cervical screening and the potential for global elimination of cervical cancer in 181 countries, 2020–99: a modelling study' have shown that by moving as soon as possible to the new primary human papilloma virus (HPV) screening programme, in combination with an effective vaccination programme, cervical cancer incidence can be reduced further to ultimately reach the point where cervical cancer can be considered to be eliminated. It is entirely conceivable that New Zealand could be one of the first countries – if not *the* first – to achieve this milestone.

The Parliamentary Review Committee 2018 were honoured to be invited to undertake this review into the effectiveness of the current programme and also to advise on the strategic direction of the transition to HPV screening.

The committee thank the management and staff of the National Screening Unit (NSU) who supported us in undertaking this review. They made our work so much easier through their organisation of the review processes and willingness to engage with the committee in honest and open dialogue. We also met with many passionate and dedicated clinicians, scientists, administrators, screening service providers and community representatives who were eager to share their knowledge and answer our many questions. We thank you all for giving your time to talk with us and congratulate you on your ongoing commitment and dedication to improving the health of New Zealand women.

The committee asked two experts, Professor David Allen and Associate Professor Bridget Robson to review the contents of this report. We thank you both for your support of this important review of the National Cervical Screening Programme.

About the Parliamentary Review Committee

Ms Gail Ward is the Director of Population Screening and Cancer Prevention Services in Tasmania. She has qualifications in medical radiography, mammography, health practice management and public sector management. Ms Ward has worked both clinically and administratively in the breast, cervical and bowel screening programmes in Australia since the introduction of the respective programmes, commencing with breast screening in in the early 1990s. She has been a member of multiple national screening management, advisory and steering committees, including the BreastScreen Australia Accreditation Review Committee, the Steering Committee for the Implementation of the Renewed National Cervical Screening Programme and the National Cervical Screening Programme Quality and Safety Monitoring Committee. Ms Ward was instrumental in developing the Australian Population Based Screening Framework, the Newborn Bloodspot Screening Policy Framework, and has served as Chair of multiple BreastScreen Australia accreditation surveys. In 2018, she was awarded the Public Service Medal for outstanding public service to breast cancer screening in the Australia Day 2018 Queen's honours list. Ms Ward was also a member of the New Zealand National Cervical Screening Programme Parliamentary Review Committee 2015.

Professor Ian Hammond is a retired gynaecological oncologist, with over 30 years in clinical practice. He is a Clinical Professor in the Division of Obstetrics and Gynaecology, Faculty of Medicine, Dentistry and Health Sciences, The University of Western Australia. Professor Hammond chaired the group that developed the Australian Government's 2005 National Health and Medical Research Council (NHMRC) guidelines for managing abnormal pap smears in Australia. Since 2012, he has been involved in the renewal of the Australian National Cervical Screening Programme (NCSP) and was Chair of the Steering Committee for the Renewal Implementation Project. He chaired the Australian working party that developed the 2016 NCSP guidelines for managing screen detected abnormalities, screening in specific populations and investigation of abnormal bleeding. In 2011, he was awarded the President's Medal of The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG) for services to Women's Health. In 2018, he was appointed a Member in the General Division of the Order of Australia (AM) in the Australia Day Queen's honours list for significant service to medicine in the field of gynaecological oncology as a clinician, to cancer support and palliative care, and to professional groups.

Ms Liane Penney (Ngāpuhi) is the Director of Kiwikiwi Services Limited, a research, evaluation and change management consultancy. Liane is a public health professional with expertise in Māori health and equity development. She has extensive experience in service innovation and change management, research, evaluation and health service operational management. Liane was previously the Northland Health Services Plan Portfolio Manager and, in that role, managed the implementation of a number of strategic projects across both primary and secondary health care. In her role as the Service Planning Manager, Māori Health Directorate, Health Funding Authority, she led the design and implementation of national Māori health services. She has also been involved in women's health as a service manager for National Women's and as the inaugural Cervical Screening Programme Manager for Tairāwhiti Area Health Board. Liane has been a member of many governance groups, expert panels and research committees. She has published an extensive range of peer reviewed journal articles on New Zealand and Māori health issues.

Contents

List of tables

List of figures

Glossary of terms and abbreviations

ACC	Adenocarcinoma cervix
AIS	Adenocarcinoma in situ of the cervix
ASC-US	Atypical squamous cells of undetermined significance. A finding of abnormal cells in the tissue lining the cervix's outer part. The abnormal cells may suggest infection with certain types of HPV, a benign growth or, in menopausal women, low hormone levels.
Asian	The definition of 'Asian' by Stats NZ includes people with origins in the Asian continent, from Afghanistan in the west to Japan in the east and from China in the north to Indonesia in the south. Asian New Zealanders largely comprise Chinese and Indians, who also have long histories of settlement in New Zealand.
ASR	Age-standardised rate
BAU	Business as usual
BSA	BreastScreen Aotearoa
CAR	Corrective Action Request
CIN	Cervical intraepitheial neoplasia. The development of abnormal, pre-cancerous cells in the cervix. It is subgraded into CIN1,CIN2 and CIN3. CIN1 is not considered to be pre-cancerous but merely an expression of HPV infection. CIN2 and CIN3 are considered to be pre-cancerous.
CIN 2+ histology	A term used to cover any changes in histology that are CIN 2 (see description under CIN above) or greater (and can include squamous cancer if so defined)
COG	HPV Clinical Oversight Group
Colposcopy	The examination of the cervix and vagina using a magnifying instrument with a bright light source
C-QuIP	Cervical Quality Improvement Programme
Cytology	The examination of cells under a microsope
DHB	District health board
DNA	Deoxyribonucleic acid
e-colposcopy	The electronic transfer of colposcopy data to the NCSP-R
Equity	The absence of avoidable or remediable differences among groups of people, whether those groups are defined socially,

	economically, demographically or geographically
FWHC	Federation of Women's Health Councils
GP	General practitioner
HDANZ	Health and Disability Auditing New Zealand Limited
Histology	The study of the microscopic structure of tissue
HPV	Human papilloma virus
hrHPV	High-risk types of HPV
HSIL	High-grade squamous intraepithelial lesion
IANZ	International Accreditation New Zealand
IARC	International Agency for Research on Cancer
ISP	Independent service provider
IT	Information technology
LBC	Liquid-based cytology
LGBTQI	Lesbian, gay, bisexual, transgender, queer or questioning, intersex
LSIL	Low-grade squamous intraepithelial lesion
MDM	Multi-disciplinary meeting
MMEG	Māori Monitoring and Equity Group
NCR	National Cancer Registry
NCSP	National Cervical Screening Programme
NCSP Advisory Group	An independent group of expert advisors to the National Cervical Screening Programme
NCSP-R	National Cervical Screening Programme Register, or NCSP-Register. A database that holds details of all participants enrolled in the NCSP. It stores and maintains screening details and manages data about participants with abnormal screening tests.
NHI numbers	National Health Index numbers. The unique identifers assigned to all New Zealanders who use health and disability support services in New Zealand.
NHS	National Health Service
NKG	National Kaitiaki Group
NSAC	National Screening Advisory Committee
NSU	National Screening Unit. The national unit for all cancer screening programmes within the Ministry of Health
NSS	National Screening Solution
NZCR	New Zealand Cancer Register

NZDep Index	New Zealand Deprivation Index
OECD	Organisation for Economic Co-operation and Development
PCR	polymerase chain reaction
PHO	Primary health organisation
PMS	Practice management systems
PPV	Positive predictive value
PRC	Parliamentary Review Committee. The parliamentary or ministerial review committee established under Part 4A Section 112O of the Health Act 1956
RANZCOG	The Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCPA	The Royal College of Pathologists of Australasia
RCT	NCSP-R central team
RFP	Request for proposal
SCC	Squamous cell carcinoma
SC cytology	Morphological (structural) changes in cervical squamous cells that predict an underlying histological invasive squamous cell carcinoma
SSS	Support to Screening Services
ToC	Test of Cure
WHO	World Health Organization

Executive summary

The 2018 Parliamentary Review of the National Cervical Screening Programme (NCSP) was established in accordance with s 1120 of the Health Act 1956 by the Associate Minister for Health, the Hon Julie Anne Genter, in October 2018. The review's focus is to assess the effectiveness of the NCSP and to make recommendations for the future directions of cervical screening.

This report focuses on the continuous quality improvement of the NCSP that aims to further reduce the incidence of, and mortality from, cervical cancer in New Zealand. The scope of the NCSP review's terms of reference included, but was not limited to the following five main themes:

- Effectiveness of programme strategies to improve equity
- Effectiveness of programme monitoring and evaluation
- The current strategic direction on the change to primary human papilloma virus (HPV) screening
- Effectiveness of programme governance and advisory structures
- Progress against the recommendations from the 2015 Review.

The NCSP, which was implemented in 1990, has been successful in reducing incidence and mortality from cervical cancer. Before the introduction of the programme, cervical cancer was the eighth highest cause of cancer mortality in New Zealand women, but by 2015 it had dropped its position to 17th highest. Although there has been a reduction in overall incidence and mortality and a narrowing of inequities in incidence and mortality, there remain unacceptable inequities between different population groups.

Māori women are twice as likely to be diagnosed with cervical cancer, and 2.3 times more likely to die from cervical cancer compared with European/Other women. Cervical cancer disproportionately affects young Māori women, being the second leading cause of cancer death in Māori women aged 25–44 years.

The Parliamentary Review Committee (PRC) have made six primary recommendations for quality improvements to the programme that address:

- the introduction of primary HPV screening, including self-sampling
- the cost barrier of cervical screening for New Zealand women
- the need for an audit of invitation and follow-up processes to improve participation and timely treatment
- the need for a continuous prospective audit of all cervical cancer diagnoses to ensure continuous improvement of clinical outcomes
- appropriate resourcing for implementing primary HPV screening
- the development of communication strategies for the public and programme providers on the introduction of primary HPV screening.

There are thirty general recommendations that cover programme governance, communication, equity, the introduction of primary HPV screening, the development of the National Cervical Screening Programme Register (NCSP-R) as part of the National Screening Solution (NSS) and programme monitoring and evaluation.

It is important to note that the review occurred at a point in time between October 2018 and March 2019, with face-to-face interviews in November 2018. Ongoing work by the NCSP and service providers may have subsequently removed the need for some of the recommendations contained in this report.

The committee have identified the six primary recommendations as the highest priority issues for the NCSP, the Ministry of Health (the Ministry) and the Government in the short to medium term. The thirty general recommendations are no less important. The committee believe the NCSP should plan to incorporate these general recommendations into its ongoing business, strategic and project plans over the next 12–24 months. The majority of the recommendations are operational, and many relate to the strategic preparation for, and implementation of, primary HPV screening by the NCSP. However, some recommendations require broader Government consideration and policy decisions.

Where the committee identified areas of concern or opportunities for the future direction of the programme that were additional to the main themes of the review, in accordance with the review's terms of reference, they included these observations and opportunities in the report. In addition, where similar feedback was received from multiple interviewed sources, direct quotes from some key informant interviewees have been included to support the discussion and findings of the report.

For clarity of understanding, the terms 'review' and 'audit' are used throughout this report. Some resource documents provided by the NSU were titled 'Review', and in other instances 'Audit'. The committee's interpretation of these terms is that:

- a 'review' is the collection of data or outcomes against specific criteria
- an 'audit' is a quality improvement process that seeks to improve patient care and outcomes by reviewing the data.

The committee was pleased to note that where a review of data identified anomalies or unexpected outcomes, an audit process occurred that recommended quality improvement inititatives. The committee encourages the NCSP to continue this quality improvement approach of regular review and audit across all elements of the programme.

The committee congratulates the National Screening Unit (NSU) on their success to date in leading the delivery of the NCSP and on their ongoing commitment to continuous quality improvement for the programme with the planned strategic transition to primary HPV screening. The NSU and the health care providers who deliver the programme directly to women, together, have significantly reduced the burden of cervical cancer in New Zealand.

2018 recommendations

Primary recommendations

The Parliamentary Review Committee (PRC) makes the following primary recommendations:

1. Primary HPV screening, including self-sampling, should be funded and implemented as a matter of urgency. Delays in implementing the primary HPV screening programme will result in a significant number of otherwise preventable cervical cancers in New Zealand women and continuing inequities.
2. the cost of screening has been consistently identified as a major barrier, and all eligible women should receive fully funded cervical screening, to align cervical screening with all other New Zealand cancer screening programmes. Initially, priority for fully funded screening should be given to priority group women with a strategic objective of including all eligible women.
3. The NCSP, in their oversight and stewardship capacity, should lead district health boards (DHBs) and primary health organisations (PHOs) in monitoring, auditing and reviewing local delivery of reminder, recall and referral processes against the NCSP policy, standards and guidelines and develop a toolkit of support for providers to ensure consistent, quality practices.
4. A continuous prospective audit should be undertaken of all cervical cancer diagnoses in New Zealand, including a review of cervical screening-related tests and investigations (HPV, cytology, histopathology and colposcopy) with audit findings translated into quality improvement initiatives.
5. The NSU team should be adequately and specifically resourced (in both human and financial terms) to enable an effective and efficient transition to the new HPV screening programme, especially as the magnitude of the multiple and complex changes required should not be underestimated.
6. A comprehensive, culturally appropriate communication and education/training strategy should be developed as a key project of the primary HPV screening implementation strategy – for both the public and programme providers.

General recommendations

The PRC makes the following general recommendations:

Equity

7. A set of NCSP equity indicators should be included in the new health measures.
8. Equity analysis should be included in the routine NCSP independent monitoring reports, providing a synthesis of all NCSP equity data. This analysis should inform

strategies to improve access and remove barriers to participating in the programme.

9. Support to Screening Services (SSS) should be strengthened to ensure it is available across all DHBs and is used effectively as standard best practice by all general practices and colposcopy services. The PRC supports the planned 2019 SSS evaluation.

10. There should be more focus on investment and development of strategies to improve coverage of priority group women in metropolitan DHBs.

11. The NCSP should provide support to DHBs and PHOs to enable a standard, best-practice approach to the use of the data-matching tools to ensure optimum matching of data between the NCSP-R and general practice practice management systems (PMS).

12. The NSU should work with the relevant Ministry directorates to explore opportunities for measuring access to national screening services for disability and mental health service users as well as the lesbian, gay, bisexual, transgender, queer or questioning, intersex (LGBTQI) community.

Programme monitoring and evaluation

13. Independent monitoring should be carried out annually, and not six monthly. Interval monitoring data reports of key standards can be developed internally by the NSU.

14. The NCSP independent monitoring reports, which are provided by independent external experts, should be continued for the foreseeable future, including through the transition to and implementation of the new primary HPV screening programme. The NCSP will benefit by having continued independent, robust and transparent evaluation of the programme.

15. The NCSP should implement processes to monitor the timeliness of cytology reporting in the lead-up to HPV screening so that indications and early trends of capacity constraints might be identified. Ideally, monitoring should occur monthly.

16. The recommended timelines for 'referral to colposcopy' should be reviewed to ensure they are appropriate, realistic and safe.

17. The targets for indicators currently included in the independent monitoring reports should be reviewed for the implementation of primary HPV screening, and some new indicators for HPV testing will be required.

18. The three yearly audit of DHB-contracted colposcopy services should continue, albeit in a modified form, with particular emphasis on areas not covered by e-colposcopy data reporting, such as those noted in Section B of the Colposcopy Audit Report Tool by Health and Disability Auditing New Zealand (HDANZ) (Health and Disability Auditing New Zealand 2017). A definition of the risk matrix with identified timelines for correction should be included in any audit report. (See also Chapter 5, Governance – Colposcopy Services).

Importance of primary HPV screening

19. The PRC believes it is essential that self-sampling be included in the initial implementation of the new primary HPV programme as this will lead to improved equity for and the increased participation of priority group women.

20. A pilot programme should be developed to examine the feasibility of 'whole population self-sampling for cervical screening'.

21. The 'draft' 2017a Clinical Practice Guidelines for Cervical Screening in New Zealand should be reviewed, including the development of a clinical management pathway for women who have HPV detected in a self-sample.

22. As part of the NSU's project planning processes for transitioning to primary HPV screening, it will be important to incorporate the lead-in time required by pathology laboratories to commence HPV screening regimes.
The NSU should continue to collaborate closely with laboratories regarding the maintenance of a cytology workforce up to and after the new HPV screening programme has been implemented. This includes providing early advice regarding the confirmed date for implementing the new programme.

Programme governance

23. The NSU should support and partner with the clinical leads to clearly articulate, both within the NSU and externally to the relevant sectors, the clinical leads' responsibilites in maintaining clinical quality for the current NCSP and leading the clinical implementation of primary HPV screening to ensure quality and consistency of clinical practices across New Zealand.

24. Governance (both clinical and operational) and advisory committees should be reviewed to maximise efficiency across the committees and minimise potential duplication of work. The review should focus on the multi-disciplinary requirements of the committees that are leading this important population screening programme and the balance required between population screening and practising clinical expertise.

25. To facilitate the transition to the new screening pathway, the NSU should articulate their expectations of members of the NCSP Advisory Group in leading and disseminating advice to their relevant sectors around implementing the new screening pathway.

26. A process should be established that will ensure national quality and consistency of colposcopy performance, review processes and clinical services across DHBs. The NCSP should lead the development of a system for clinical, expert, consistent oversight of DHB's colposcopy clinical services (including benchmarking and the development of quality improvement plans) to ensure appropriate and independent monitoring of clinical practice. This system should include processes for identifying and remediating colposcopists who are not meeting the national standard and whose performance may be masked by the overall performance of the colposcopy service.

27. In addition to recommendation 31, in order to facilitate quality improvement, the NCSP is encouraged to send regular benchmarked reports (the committee suggests six monthly) on colposcopy performance to individual colposcopists, using the e-colposcopy data within the NCSP-R. The colposcopy data held in Datamart needs analysis and work to determine the best 'fit for purpose' reporting tool for quality improvement purposes. The PRC urges the NSU to make this a priority activity.

28. Work to define new standards for pathology and colposcopy should be completed well in advance of the introduction of primary HPV screening so that systems can be developed that will enable reporting against the new standards.

29. Funding for NCSP colposcopies should be reviewed to ensure pricing supports the maintenance of quality services.

30. The NCSP should review contractual arrangements with DHBs. The aim of the review would be to strengthen accountability for participation and to establish nationally consistent performance measures, reporting requirements and expected outcomes. This review should also include reporting on colposcopy performance and quality improvement initiatives implemented by DHBs.

Communication

31. In addition to recommendation 6, comprehensive communications for women and service providers should be developed to answer questions, allay fears and provide reassurance about the new HPV test, the later starting age (25 years) for screening, the five-year screening interval, the predicted transient early rise in cervical cancer diagnoses and the importance of examining and assessing symptomatic women at any age. Emphasis should be given to a co-design approach with priority group women and service providers to ensure any communications reach all intended audiences.

32. A coordinated national training and education campaign around HPV infection, cervical cancer, HPV vaccination and HPV cervical screening is needed for women and service providers (including colposcopists) before and while implementing the primary HPV screening programme. Emphasis should be given to ensuring the availability of culturally appropriate information for Māori, Pacific and Asian women.

33. The NCSP complaints management processes and reporting requirements should cover the entire clinical pathway, including at DHB and PHO level as well as those received by the NCSP-R. Complaint reviews should include actions that result in the development and implemention of quality improvement initiatives that align with best-practice consumer-focused care.

Development of the National Cervical Screening Programme Register

34. The development of the new NCSP-R, as part of the NSS, should occur in parallel with the National Bowel Screening Programme Register, if this is logistically possible, and not be delayed until after the National Bowel Screening

Programme Register has been developed. This would reduce the risk of unnecessary further delay to implementation of the new HPV screening programme.

35. Effective and appropriate integration of Practice Management Systems (PMS) must be considered as part of any design for a new technology solution for cervical screening. This will enable real-time access to cervical screening data to optimise clinical decision-making.

Introduction

Principles of cancer screening

The Ministry of Health's National Screening Unit (NSU) is responsible for delivering three cancer screening programmes:

1. BreastScreen Aotearoa (BSA)
2. National Cervical Screening Programme
3. National Bowel Screening Programme

In this chapter, we review the principles of cancer screening, the natural history of cervical cancer and the cervical screening pathway in New Zealand.

The World Health Organization (WHO) defines screening as '... the presumptive identification of unrecognized disease or defects by means of tests, examinations, or other procedures that can be applied rapidly' (WHO n.d.). Screening is intended for all people, in an identified target population, who do not have symptoms of the disease or condition being screened for. There should be an agreed policy on who should be screened: the target population. The process can identify:

- a pre-disease abnormality
- early disease
- disease risk markers.

The aim of screening for a disease or a risk marker for a disease is to reduce the burden of the disease in the community, including incidence of the disease, morbidity from the disease and mortality from the disease. This is achieved by intervening to reduce individual risk of the disease or detecting the disease earlier, on average, than is usually the case in the absence of screening, and thereby improving disease outcome.

In 1966, WHO published *The Principles and Practice of Screening for Disease* (Wilson and Jungner 1966). These principles are outlined below and form the basis when developing criteria for a specific country or screening issue.

WHO principles of early disease detection

Condition

- The condition should be an important health problem.
- There should be a recognisable latent or early symptomatic stage.
- The natural history of the condition, including development from latent to declared disease, should be adequately understood.

Test

- There should be a suitable test or examination.
- The test should be acceptable to the population.

Treatment

- There should be an accepted treatment for patients with recognised disease.

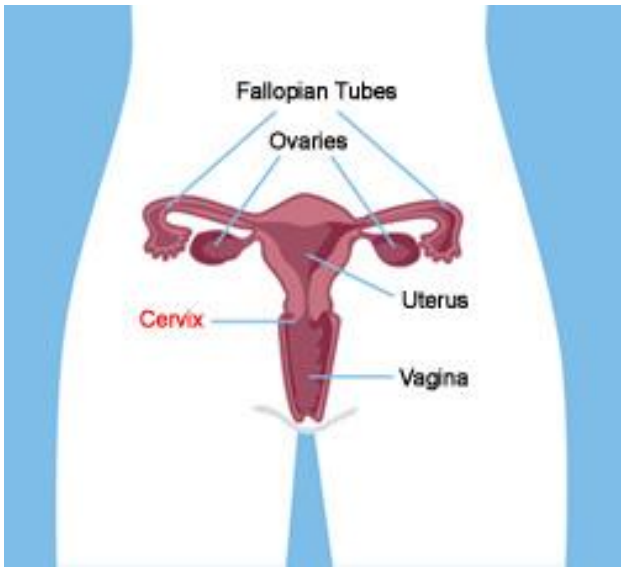
Screening programme

- There should be an agreed policy on whom to treat as patients.
- Facilities for diagnosis and treatment should be available.
- The cost of case findings (including diagnosis and treatment of diagnosed patients) should be economically balanced in relation to possible expenditure on medical care as a whole.
- Case findings should be a continuing process and not a 'once and for all' project.

What is cervical cancer?

Cervical cancer develops from the tissues of the cervix as a result of infection with high-risk oncogenic human papilloma virus (HPV). The cervix is part of the uterus, and part of the female reproductive system. It is the lowest part of the uterus that connects to the vagina and is sometimes called the 'neck' of the uterus (Figure 1). The cervix is covered by two distinct cell types: squamous and glandular. The squamous cells are flat, thin cells found in the outer layer of the cervix (ectocervix). Glandular cells are mainly found in the cervical canal (endocervix). The junction of these two cell types is called the squamo-columnar junction. The area adjacent to this junction is called the transformation zone, and it is here that most cervical cancer usually starts (see chapter 4: Strategic direction on the change to primary HPV screening for more detail).

Figure 1: Female reproductive organs



Uncontrolled growth of the squamous or glandular cells is called 'cancer' and leads to invasion and destruction of the local cervical tissue. If undetected and untreated, this invasion will lead to locally advanced cancer, with involvement of adjacent organs such as the vagina, uterine body and pelvic tissues, including the bladder and/or rectum.

In other cases, the cancer may spread (metastasise) to more distant parts of the body, including the pelvic side wall, pelvic or aortic lymph nodes, upper abdominal organs or the lungs and brain. If untreated, cervical cancer is uniformly fatal, with death most commonly caused by locally advanced disease causing ureteric obstruction and renal failure.

Cervical cancer fulfils all the WHO criteria for early disease detection.

- There is a recognised pre-cancerous phase before the development of invasive cervical cancer that may be present most commonly for 10–20 years.
- It is now understood that HPV infection is necessary for the development of cervical changes that may lead to cancer.
- There is a suitable test – currently the smear test – that detects cell changes in the cervix, and this has proved acceptable to the female population as a screening intervention.
- For women who are discovered to have a pre-cancer of the cervix, there is an accepted clinical pathway for diagnosis and treatment that, in nearly all cases, is local to the cervix and preserves fertility in younger women.
- There is an agreed policy on who should be treated, and there are facilities for diagnosis and treatment throughout the country organised by the district health boards (DHBs).
- Cost-benefit analysis has confirmed that this is a cost effective programme and case finding is ongoing.

However, screening is a complex process that is not generally well understood by professionals and the public for a range of reasons. In 2003, the National Health Committee in New Zealand published *Screening to Improve Health in New Zealand. Criteria to assess screening programmes*, with the aim of improving this understanding (National Advisory Committee on Health and Disability 2003).

Cervical cancer is a significant world health problem, and in 1988, before the introduction of the National Cervical Screening Programme (NCSP), was the eighth highest cause of cancer mortality in women in New Zealand (3.3% of all cancer deaths in women). In 2015, it had dropped to the 17th highest cause of cancer mortality in New Zealand women, responsible for only 1.2% of all cancer deaths in women in that year. Globally, mainly in low- and middle-income countries without cervical screening programmes, cervical cancer remains the fourth highest cause of death in women, and in 2018, there were an estimated 265,000 deaths that were largely preventable by HPV vaccination and cervical screening (Global Cancer Observatory n.d.).

In New Zealand, cervical cancer screening is a population-based screening programme, where a screening test is offered systematically to all individuals in the defined target group within a framework of agreed policy, protocols, quality management,

monitoring, evaluation and review. Population-based screening is an organised, integrated process where all activities along the screening pathway are planned, coordinated, monitored and evaluated through a quality improvement framework. All of these activities must be resourced adequately to ensure benefits are maximised.

Screening can reduce the risk of developing or dying from a disease, but it does not guarantee that the disease will not occur or, if it occurs, that it can be cured. A 'positive' screening test identifies people who are at increased likelihood of having the condition and who require further investigation to determine whether they have the disease or condition.

As screening has benefits, costs and harms, there is an ethical obligation to maximise benefits and minimise harm. The overall benefits should outweigh any harms that might result from screening. When community resources are used to fund screening, there should be community consensus that the benefits of screening justify the expense.

Cervical screening pathway in New Zealand

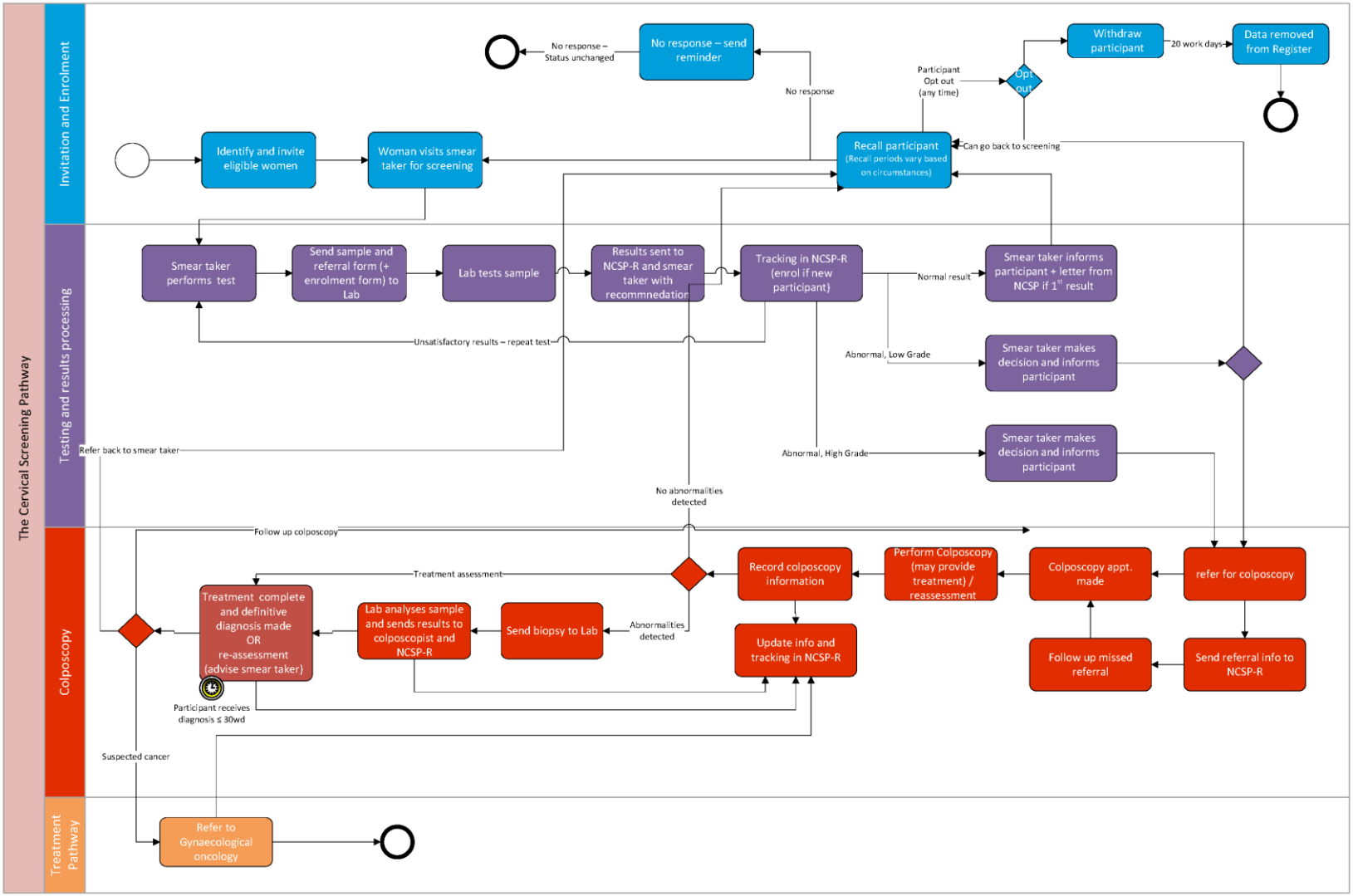
In 1990, New Zealand introduced an organised approach to cervical screening under the auspices of the NCSP.

All women who have ever been sexually active and are between 20 and 69 years of age are recommended to have a cervical screening test, taken by their health care provider, every three years.

The screening test, a liquid-based sample, is examined by a cytologist in a pathology laboratory. If no abnormal cells are discovered, then the woman is advised to have her next screen in three years time.

If any abnormality is noted, the woman enters a 'clinical management pathway' as prescribed by the NCSP in *Guidelines for Cervical Screening in New Zealand* (National Screening Unit 2008).

Figure 2: The cervical screening pathway



If a cytological high-grade abnormality is predicted, the woman is referred for colposcopy and managed according to clearly defined national guidelines. If a high-grade abnormality is confirmed on biopsy (histopathology), then the cervix is treated to remove the abnormal cells, and the woman then enters post-treatment follow-up surveillance to ensure that her cervix has returned to normal and that she can return to the normal screening programme.

If the diagnosis of high-grade abnormality is made in pregnancy and there is no colposcopic suspicion of invasive disease, it is safe, and recommended, for treatment be delayed until the pregnancy is completed.

If cytology results are inconclusive, then the woman is offered either follow-up testing within 6–12 months and managed as dictated by the test results. Alternatively, she may require a colposcopy or other diagnostic interventions to be diagnosed.

If a cytological low-grade abnormality is predicted, HPV testing may be used for women over the age of 30 years for triage to either a repeat cervical smear test in 12 months or colposcopy assessment if HPV is detected.

The results of all cytology, histopathology, colposcopy and HPV tests are recorded on the National Cervical Screening Register (NCSP-R). This information is used to invite and remind women about their cervical screening test and to ensure that appropriate follow-up occurs after an abnormal test result. The NCSP-R provides an essential 'safety net' function for women who are participating in the programme. Screening and treatment results data recorded on the register enable processes for ongoing monitoring of the safety and effectiveness of the NCSP.

Background to the Parliamentary Review

Under the Health Act 1956 (Part 4A, Section 112O), the Minister of Health (the Minister) must, at least once every three years, establish a review committee of up to three people to review the NCSP.

According to the legislation, the focus of the review committee must be the continuous quality improvement of components of the NCSP, with a view to reducing the incidence and mortality rates of cervical cancer.

Context for the parliamentary review

1. The Parliamentary Review Committee's (PRC's) remit is defined in their terms of reference (Appendix 1). The NCSP was introduced in 1990, and since then, women aged 20–69 years have been invited by their primary health care provider to be screened on a three-yearly basis. The aim of the programme is to reduce

the incidence and mortality of cervical cancer by detecting and treating cell changes that could progress to cervical cancer.

2. The current cytology-based cervical screening programme has seen significant reductions in incidence and mortality from cervical cancer since its introduction. However, in recent years, the decline in incidence and mortality from cervical cancer has plateaued for all women. Additionally, there has been no further narrowing of the gap between Māori and non-Māori women for both incidence and mortality from cervical cancer. The Acting Associate Minister of Health, the Hon James Shaw, met with the PRC before they began their review and reaffirmed the review's focus – in particular improving equity across the screening pathway.

The scope of the review

As articulated in their terms of reference (Appendix 1), the 2018 Parliamentary Review aims to review the effectiveness of the current NCSP to deliver outcomes with a focus on identifying opportunities and making recommendations for the future direction of the programme. This includes but is not limited to:

- reviewing the current effectiveness of the programme's strategies to improve equity across the screening pathway
- reviewing the effectiveness of the current system for monitoring and evaluating the programme's performance and clinical safety
- providing advice on the current strategic direction on the change to HPV screening
- reviewing the effectiveness of the programme's governance and advisory structures to support its performance and strategic direction
- reviewing the programme's progress against the recommendations from the 2015 PRC.

The scope of the review's terms of reference specifically excluded reviewing the procurement of the new register for the NCSP (the National Screening Solution, NSS) or undertaking a technical review of the current NCSP-R, as this has been completed recently. However, throughout this report, the PRC has provided some comment on the limitations of the existing register and aspects of the new register they believe are important in supporting the NCSP's strategic directions.

Where the PRC identified areas of concern or opportunities for the future direction of the programme that went beyond the main themes of the review, in accordance with its terms of reference, the PRC included these observations and opportunities in this report. In addition, where similar feedback was received from multiple interviewed sources, direct quotes from some key informant interviewees have been included to support the discussion and findings of the report.

Parliamentary Review 2018

This is the third Parliamentary Review of the NCSP.

The Associate Minister of Health appointed the PRC in October 2018. The committee developed a review plan approved by the Associate Minister of Health before it began its review in November 2018.

This report comprises six chapters, one each for the areas identified in the PRC's terms of reference. Each chapter make recommendations for the programme to work towards, with some identified as 'highest priority' primary recommendations. These are the recommendations that the committee considers most urgent. The remaining recommendations are termed 'general recommendations'. They are also important for the continuous quality improvement of the programme.

The report uses data that is publically available. The data has been taken from:

- the latest National Cervical Screening Programme annual report (produced for the year 2016), which reports on the incidence and mortality of cervical cancer in New Zealand (Ministry of Health 2019) and compares this with previous annual reports
- the latest monitoring report (48), which gives data on programme coverage and programme indicators, covering the period 1 July–31 December 2017 (Smith et al 2018c) and compares this with previous monitoring reports.

The PRC makes six primary recommendations for consideration that broadly encompass the following areas:

- the strategic directions of the NCSP in implementing primary HPV screening
- inequities in participation and outcomes
- quality improvements for programme delivery and review of cervical cancers.

The PRC makes a further 30 recommendations that have been captured under the following themes:

- Programme governance (see the definition of 'governance' under chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction)
- Communication
- Equity
- HPV
- Register
- Monitoring.

Methodology

The PRC used both quantitative and qualitative research methods to gather information and inform its findings.

The committee conducted 50 interviews with key stakeholders. The interviews were held in November 2018. Stakeholder groups included:

- Ministry of Health (Ministry) staff, NCSP staff and contractors from the programme's independent service providers (ISPs)
- primary health organisations (PHOs), DHBs, Support to Screening Services (SSS) and Māori health providers
- practitioners working in laboratories, colposcopy clinics, gynaecology services and public health
- women's advocacy groups, screening advisory groups and Māori advisory groups.

Appendix 2: Interviews conducted by the Parliamentary Review Committee provides a full list of all interviewees.

Interviews took place either in person or by teleconference. A semi-structured interview guide was used to help prioritise the content being discussed and to ensure relevant information was gathered. Additionally, all interviewees were invited to share anything they felt necessary with the committee via follow-up emails. A copy of the interview guide is provided in Appendix 3: Interview guide.

The PRC reviewed all relevant documentation provided by the Ministry, relating to the NCSP.

It also took into consideration the findings of the previous Parliamentary Reviews, the Gisborne Inquiry and the Cartwright Inquiry.

It assessed evidence from New Zealand and international sources. This evidence includes peer-reviewed scientific literature, randomised controlled trials, standards documents, and guidelines, strategic assessments, audits, health strategies and specific reports.A full bibliography is available at the end of the report. .

The PRC also requested that the NCSP provide an update of progress towards the recommendations made in the Parliamentary Review 2015. The programme's update has been included in chapter 6: Progress against the 2015 Parliamentary Review recommendations, accompanied by this committee's analysis of what progress the NCSP has made towards achieving those previous recommendations.

Equity across the screening pathway

Terms of reference

Review the current effectiveness of programme strategies to improve equity across the screening pathway.

Overview

Inequalities in cancer incidence, mortality and survival rates in New Zealand have persisted over time, despite focused cancer control strategies. These inequities impact particularly on Māori.

An international assessment of cancer inequalities between indigenous and non-indigenous populations in Australia, the United States of America, Canada and New Zealand shows that New Zealand experiences particularly significant inequalities, particularly in preventable cancers associated with persistent infection, such as cervical cancer (Moore et al 2015).

Cervical cancer is almost entirely preventable through HPV vaccination, screening and effective follow-up treatment of abnormalities.

The NSU's oversight and stewardship of the NCSP since 1990 has led to a decline in cervical cancer incidence and mortality to one of the lowest globally, and a narrowing of inequities.

However, there remains unacceptable inequity between different population groups. Māori women carry the greatest burden of cervical cancer incidence and mortality. They are twice as likely to be diagnosed with cervical cancer and 2.3 times more likely to die from cervical cancer compared with European/Other women (Ministry of Health 2019). Cervical cancer disproportionately affects young Māori women, being the second leading cause of cancer death in Māori women aged 25-44 years (Ministry of Health 2015; Atkinson et al 2014). Pacific and Asian women and those living in the most deprived quintile of the New Zealand Deprivation Index (NZDep Index) also experience higher incidence and mortality from cervical cancer than European/Other women (Ministry of Health 2019).

The NCSP recognises that current inequities throughout the screening and treatment pathway for cervical cancer are unacceptable and have prioritised strategies and resources to eliminate these inequities (Ministry of Health 2017d).

A key strategy of the NCSP is to focus investment and efforts on a prioritised group of women who carry the greatest burden of cervical cancer inequities. The NCSP definition of 'priority group women' includes:

> ... women aged 20–69 years who are Māori, Pacific or Asian and other women aged 30–69 years who have never had a cervical screening test or who have not had a test in the previous five years (Ministry of Health 2017c).

In 2005, a review of the first decade of the NCSP concluded that the key challenge for the following decade would be addressing inequities (Lewis et al 2005). More than 10 years on, the challenge remains.

The following sections in this chapter outline the current status, key issues and recommendations for achieving equity in cervical screening coverage (participation) and follow-up treatment for abnormalities. The chapter also discusses the equity opportunity arising from self-sampling as part of the future primary HPV screening programme.

Current state

Three-yearly cervical screening coverage

The overall three-yearly cervical screening coverage target of having 80 percent of eligible women screened within three years has not been met nationally, with only 74.8 percent of eligible women screened within the previous three years to December 2017. Nationally, coverage targets were met for European/Other women (80.4 percent screened within the previous three years) but were not met for Māori, Pacific or Asian women (62.0 percent, 73.4 percent and 63.4 percent respectively). Within specific five-year age groups, the coverage target was only met for women aged 45–49 years.

Nationally, the three-yearly coverage target was met within the least deprived quintile (quintile 1) of the NZDep Index (82.3 percent screened within the last three years) but was not met nationally within quintiles 2, 3, 4 or 5 (74.4 percent, 69.4 percent, 66.0 percent and 59.6 percent respectively screened within the previous three years).

Three-yearly coverage rates vary between DHBs, and the variation is most noticeable when compared by ethnicity and deprivation.

Māori

Three-yearly coverage for Māori women ranged from 50.9 percent in South Canterbury DHB to 71.9 percent in Hawke's Bay DHB. The target level of having 80 percent of Māori women screened within the previous three years was not achieved in any DHB (Smith et al 2018c).

Pacific

Three-yearly coverage for Pacific women ranged from 56.2 percent in Northland DHB to 92.4 percent in South Canterbury DHB. The target level of having 80 percent of Pacific women screened within the previous three years was achieved by two DHBs (South Canterbury and Wairarapa). (Smith et al 2018c).

Asian

Three-yearly coverage for Asian women ranged from 52.2 percent in West Coast DHB to 77.4 percent in Hutt Valley DHB. The target level of having 80 percent of Asian women screened within the previous three years was not met in any DHB (Smith et al 2018c).

European/Other women

Three-yearly coverage for European/Other women ranged from 76.5 percent in Counties Manukau and Wairarapa DHBs to 87.8 percent in Bay of Plenty DHB. The target level of 80 percent of European/Other women screened within the previous three years was achieved in 9 of the 20 DHBs (Auckland, Bay of Plenty, Tairāwhiti, Waikato, Lakes, Taranaki, Capital & Coast, Nelson Marlborough and Southern) (Smith et al 2018c).

Deprivation

In all, 14 of the 20 DHBs met the three-yearly coverage target for women living in the least deprived quintile. In these DHBs, quintile 1 (three-year coverage) rates ranged from a low of 80 percent (Wairarapa DHB) to 93.1 percent (Tairāwhiti DHB).

Two DHBs (Taranaki and Wairarapa DHBs) met the target for women living in deprivation quintile 2, and one DHB (Bay of Plenty DHB) met the target for women living in deprivation quintile 3.

No DHBs met the 80 percent three-yearly coverage target for women living in quintile 4. The rates ranged from 55.2 percent (Auckland DHB) to 75.3 percent (Bay of Plenty DHB).

No DHBs met the 80 percent three-yearly coverage target for women living in quintile 5. Rates ranged from a low of 42.1 percent (Auckland DHB) to 71.4 percent (Lakes DHB) (Smith et al 2018c).

Five-yearly cervical screening coverage

Given the pending implementation of a five-year screening interval with the introduction of the primary HPV screening programme, it is useful to note five-year coverage among women 25-69 years exceeded 80 percent in all DHBs, in Pacific and European/Other women and in women in all five-year age groups between 30-69 years. Five-year coverage exceeded 80 percent of women 25-69 years at all DHBs except Whanganui for women living in quintiles one and two of the NZ Deprivation

Index. When compared to the findings for three-year coverage, five-year coverage had broadly similar patterns of variation by DHB, ethnicity and deprivation.

Five-yearly coverage for:

- **Māori** women ranged from 64.1 percent (South Canterbury DHB) to 90.3 percent (Hawke's Bay DHB)
- **Pacific** women ranged from 68.7 percent (Northland DHB) to all women (Wairarapa DHB)
- **Asian** women ranged from 58.1 percent (West Coast DHB) to 89.7 percent (Hutt Valley DHB)
- **European/Other** women ranged from 90.5 percent (Counties Manukau DHB) to all women (Bay of Plenty and Capital & Coast DHBs)
- **By deprivation,** half of all DHBs showed an 80 percent or better five-year coverage for women living in the most deprived quintile. The coverage ranged from 56.7 percent (Auckland DHB) to 86.4 percent (Hawke's Bay DHB) (Smith et al 2018c).

Regularity of cervical screening

Timeliness of attendance is an important measure for ensuring women are not over or under screened. It is important for both women recommended to return for routine screening at three years or at an earlier interval of 12 months (eg, following a recent abnormality). The target is not defined; however, the aim is to maximise on-time attendance.

As the programme moves to a routine five-yearly screening interval, risks associated with early (programme cost-effectiveness) and late (un-detected abnormalities) screening will be more significant.

Different demographic groups display differences in timeliness of attending for screening.

Three-yearly recall

By ethnicity, the proportion of women re-attending on time in 2017 was highest in Asian women (64.1 percent) and lowest in Māori women (53.8 percent).

The proportion of women returning early for routine screening was highest in Asian women (13.8 percent) and lowest in Pacific women (10.4 percent).

The proportion of women screened who were re-attending later than recommended was highest in Pacific women (34.4 percent) and lowest in Asian women (22.1 percent)

Twelve month recall

Among women attending for screening in 2017 following a 12-month repeat recommendation, 40.5 percent attended on time; 2.4 percent were more than three months early and 57.1 percent were more than three months late.

By ethnicity, the proportion of women re-attending in 2017 who were on time was highest in European/Other women (43.2 percent) and lowest in Pacific women (30.5 percent).

The proportion of women returning for 12-month repeat screening who were re-attending early was very small in all groups but was highest in European/Other women (2.6 percent) and lowest in Pacific women (1.6 percent).

The proportion of women screened who were re-attending later than recommended was relatively high in all groups but was highest in Pacific women (67.9 percent) and lowest in European/Other women (54.2 percent) (Smith et al 2018c).

Follow-up for cervical abnormalities

Timeliness (follow-up of women with high-grade cytology, no histology)

The follow-up of women with high-grade cytology and no histology measures the completeness of follow-up for women with a prediction of high-grade disease.

The target is for 90 percent of women to have a histology report within 90 days of their cytology report date and 99 percent to have a report within 180 days of their cytology report.

Nationally, 1,451 women (83.0 percent) had a histology report within 90 days of their high-grade cytology report, and 1,544 (88.3 percent) had a histology report within 180 days.

Variation by ethnicity in the proportion of women with histological follow-up is evident. At 90 days, the proportions with histological follow-up by ethnicity were:

- Pacific 68.6 percent
- Asian 77.6 percent
- Māori 78.9 percent
- European/Other 85.7 percent

By 180 days, however, the difference had narrowed, and the proportions with histology reports were:

- Pacific 76.7 percent
- Asian 84.1 percent

- Māori 86.1 percent
- European/Other 90.2 percent

When follow-up tests of any kind (colposcopy, histology, HPV or subsequent cytology) were considered, 149 women (8.5 percent) had no record of any subsequent follow-up within 90 days and 100 women (5.7 percent) had no record of any subsequent follow-up within 180 days on the NCSP-R.

The proportion of women who had no record of any subsequent follow-up also varied by ethnicity. At 90 days:

- Pacific 17.4 percent
- Māori 13.3 percent
- Asian 9.4 percent
- European/Other 6.6 percent

At 180 days:

- Pacific 10.5 percent
- Māori 9.5 percent
- Asian 7.1 percent
- European/Other 4.3 percent

Many of the women with no follow-up histology recorded *do* have a record of some follow-up test. This provides reassurance that many women without histology have not been lost. Women who do not have a colposcopic follow-up of high-grade cytology abnormality (including microinvasive and invasive) are at highest risk, but it is reassuring to note that the NCSP portfolio managers at the DHBs are ensuring that these women are at the highest priority for strategies to ensure their follow-up.

Timeliness (follow-up of high-grade cytology, indicating suspicion of invasive disease)

For women with high-grade cytology *with suspicion of invasive disease*, the standard requires that 95 percent have a colposcopy visit within 10 working days (two weeks). Accepted referrals for colposcopy were found for 40 (54.8 percent) of the 73 women who had high-grade cytology indicating suspicion of invasive disease. Of these 40 women with a referral, 26 (65.0 percent) have a record on the NCSP-R of a colposcopy visit within 10 working days of their referral, and 33 (82.5 percent) have a visit within 20 working days. At 10 working days, variations by ethnicity are evident:

- Asian 50 percent
- Māori 62.5 percent
- Pacific 66.7 percent
- European/Other 73.7 percent

At 20 working days, the variations by ethnicity are:

- Asian 60.0 percent
- Pacific 66.7 percent
- Māori 87.5 percent
- European/Other 94.7 percent (Smith et al 2018c).

Considering all 73 women with high-grade cytology indicating suspicion of invasive disease, regardless of whether or not a referral to colposcopy was recorded, a total of 64 (87.7 percent) had a colposcopy visit before 31 December 2017, representing a follow-up period of at least 6 and up to 12 months after their high-grade cytology report.

There are two mechanisms for following up women with high-grade cytology. The primary mechanism is at the NCSP-R, which has a documented pathway for follow-up through worklist tasks. The secondary mechanism is review after the provision of each independent monitoring report.

Timeliness (follow-up of high-grade cytology, no suspicion of invasive disease)

For women with high-grade cytology *with no suspicion of invasive disease*, the standard requires that 95 percent have a colposcopy visit within 20 working days (four weeks).

Accepted referrals for colposcopy were found for 1,502 women (89.6 percent) of the 1,676 women who had high-grade cytology not indicating suspicion of invasive disease. Among the women with accepted referrals, 1,135 (75.6 percent) were seen for colposcopy within 20 working days of their referral, and 1,365 (90.9 percent) were seen within 40 working days.

The proportion of women seen within 20 and 40 working days varied by ethnicity.
At 20 days:

- Pacific 67.6 percent
- Māori 68.5 percent
- European/Other 77.6 percent
- Asian 78.0 percent

At 40 days:

- Pacific 81.7 percent
- Māori 83.1 percent
- Asian 91.5 percent
- European/Other 93.5 percent (Smith et al 2018c)

In total, 1,579 (94.2 percent) of the 1,676 women with high-grade cytology (but no suspicion of invasive disease) relating to a sample collected in the period 1 January–30 June 2017 have a record of a colposcopy visit before 31 December 2017 (representing a follow-up period of at least 6 and up to 12 months after their high-grade cytology).

Timeliness of colposcopic assessment (low-grade cytology)

For women who have persistent low-grade abnormalities, or a low-grade abnormality and positive HPV test, the standard is 95 percent of women must receive a date for a colposcopy appointment that does not exceed 26 weeks of receipt of the referral.

There were 3,523 women with either persistent low-grade cytology or low-grade cytology and a positive hrHPV test collected in the period 1 July–31 December 2016. Nationally, subsequent accepted referrals are recorded for 2,990 (84.9 percent) of these women and subsequent colposcopy for 3,207 (91.0 percent). Variation in the proportion of women for whom an accepted referral was recorded on the NCSP-R by ethnicity is as follows:

- European/Other 82.8 percent
- Asian 85.5 percent
- Pacific 91.0 percent
- Māori 93.6 percent (Smith et al 2018c).

The proportion of women by ethnicity with a subsequent colposcopy visit recorded on the NCSP-R (regardless of whether or not a referral was recorded) was:

- Māori 86.6 percent
- Pacific 86.7 percent
- Asian 91.2 percent
- European/Other 92.1 percent (Smith et al 2018c).

Timeliness of colposcopic assessment is confirmed by examining the time between when a referral was accepted for a colposcopy and when a woman attended for colposcopy. Among the 2,990 women with an accepted referral nationally, 2,543 women (85.1 percent) attended for colposcopy within 26 weeks of their accepted referral. This figure varied by ethnicity:

- Māori 73.9 percent
- Pacific 86.1 percent
- European/Other 86.6 percent
- Asian 88.9 percent (Smith et al 2018c).

Cervical Cancer Incidence

In 2016, there were 170 new diagnoses of cervical cancer, including 32 new diagnoses in Māori women (Ministry of Health 2019). This is equivalent to an age-standardised rate (ASR) of 6.3 per 100,000 new diagnoses in all women and 9.7 per 100,000 for Māori women.

Of the 170 cases, there were 106 cases (ASR 4.9 per 100,000) in 'other women' who are not Māori, Pacific or Asian (Ministry of Health 2019). Māori women had an incidence rate almost double that of the 'other women' group (ASR 9.7 versus 4.9). Rates for

Pacific and Asian women were between the rates for Māori women and 'Other women' at ASR 7.7 and 5.8 respectively. See Table 1 for more details.

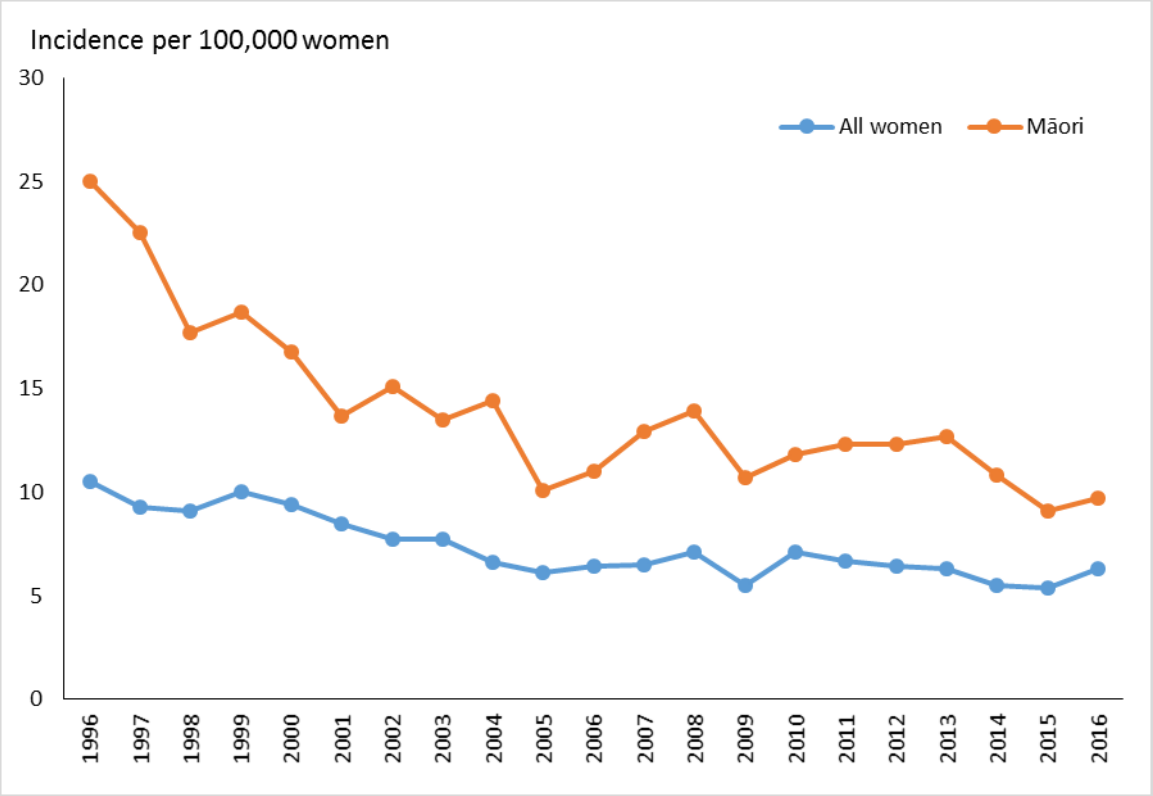
Table 1: Cervical cancer incidence, 1996 to 2016, by ethnicity

	All women		Māori women		Pacific women		Asian women		Other women	
Year	N	Rate	N	Rate	N	Rate	N	Rate	N	Rate
1996	211	10.5	47	25	n/a	n/a	n/a	n/a	164	9
1997	205	9.3	51	22.5	n/a	n/a	n/a	n/a	154	7.6
1998	200	9.1	36	17.7	n/a	n/a	n/a	n/a	164	8.3
1999	220	10	43	18.7	n/a	n/a	n/a	n/a	177	8.9
2000	204	9.4	43	16.8	n/a	n/a	n/a	n/a	161	8.3
2001	189	8.5	33	13.7	n/a	n/a	n/a	n/a	156	8
2002	181	7.7	33	15.1	n/a	n/a	n/a	n/a	148	7.2
2003	178	7.7	33	13.5	n/a	n/a	n/a	n/a	145	7.1
2004	157	6.6	33	14.4	n/a	n/a	n/a	n/a	124	5.9
2005	154	6.1	25	10.1	17	n/a	15	n/a	97	n/a
2006	158	6.4	28	11	10	8.4	15	7.6	105	6
2007	163	6.5	34	12.9	12	12.1	12	6.2	105	5.8
2008	175	7.1	39	13.9	12	10.5	13	5.6	111	6.3
2009	142	5.5	30	10.7	20	16.9	7	2.9	85	4.5
2010	180	7.1	36	11.8	14	12	12	4.6	118	6.7
2011	169	6.7	37	12.3	18	14.9	12	4.4	102	6.1
2012	168	6.4	40	12.3	11	9	13	5.1	104	5.6
2013	159	6.3	39	12.7	12	9.4	15	5	93	6
2014	144	5.5	35	10.8	12	8.7	13	4.2	84	4.8
2015	142	5.4	29	9.1	4	3	63	4.8	93	5.4
2016	170	6.3	32	9.7	11	7.7	21	5.8	106	4.9

Notes:

- Cases and rates for 1997–2004 sourced from Cancer: New Registrations and Deaths, 2007.
- Cases and rates for 1996 sourced from Cancer: New Registrations and Deaths, 2006.
- Cases and rates for 2005 sourced from previous NCSP annual reports (2008–2009).
- Counts and rates for 'Other women' 1996–2004 were combined for all non-Māori women, ie, they also include cases in Pacific and Asian women.
- Rates are per 100,000 women, age-standardised to the WHO standard population (all ages).
- n/a = not available.
- Source: NCSP Annual Report 2016 (Ministry of Health 2019)

Figure 3: Age-standardised cervical cancer incidence rates for Māori* and all women, 1996–2016†



Notes:

- Rates are per 100,000 women, age-standardised to the WHO standard population (all ages).
- * Aged-standardised rates for Māori women were not available for years before 1996.
- † Rates for 1996–2004 were sourced from Cancer: New Registrations and Deaths, 2007 and 2006 (Ministry of Health 2010b and a respectively). Rates from 2005 were sourced from previous and the current NCSP annual monitoring report.
- Source: NCSP Annual Report 2016 (Ministry of Health 2019)

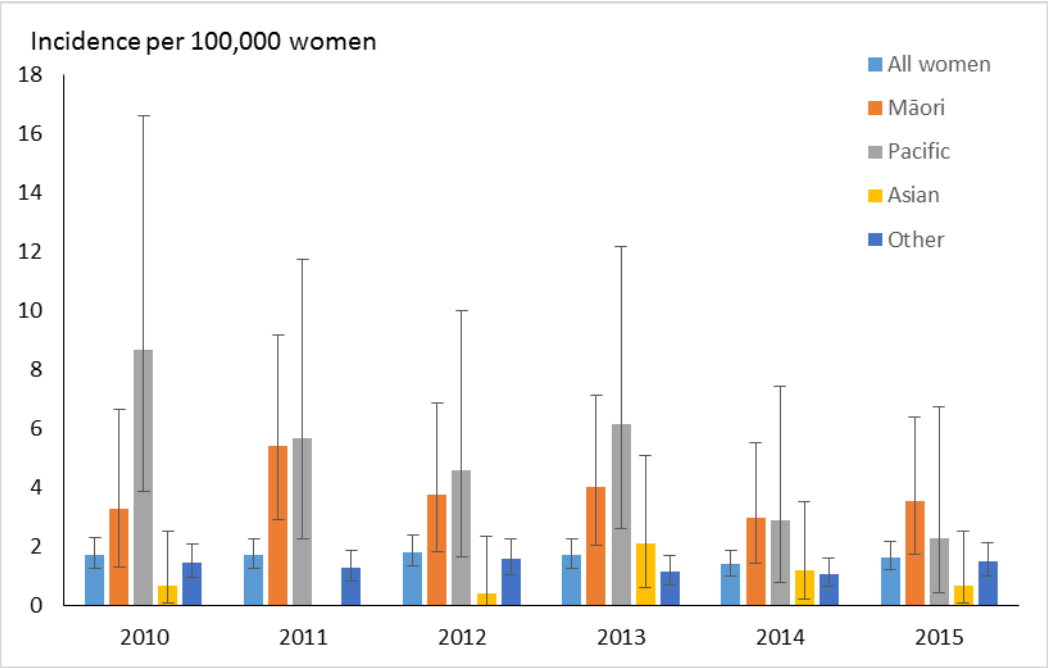
Cervical cancer mortality

The most recent available mortality data is for 2015. In 2015, there were 53 deaths due to cervical cancer, including 11 deaths in Māori women. This is equivalent to an age-standardised mortality rate of 1.6 in the general population and 3.6 for Māori women. In Pacific women, the ASR was 2.3 and in Asian women, it was 0.7, compared with 1.5 in European/Other women.

Overall, between 1998 and 2015, cervical cancer mortality declined from 3.2 to 1.6 per 100,000 women for all ethnicities and from 10.3 to 3.6 for Māori women, as shown in figures 4 and 5 below.

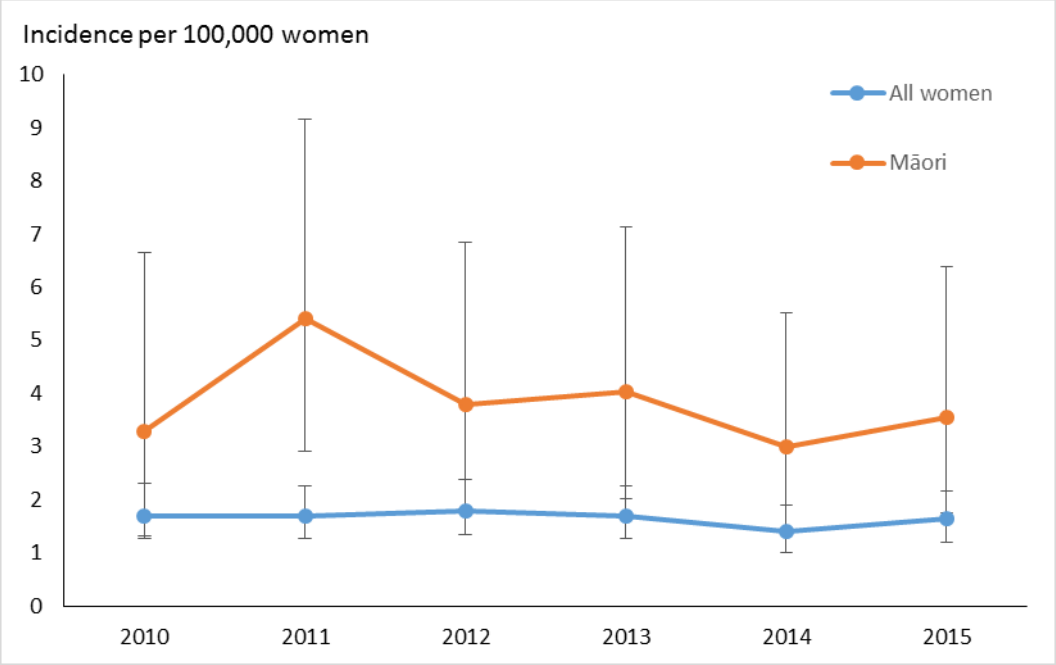
Figure 4: Age-standardised cervical cancer mortality rates, by ethnicity, 2010–2015

a. All ethnic groups



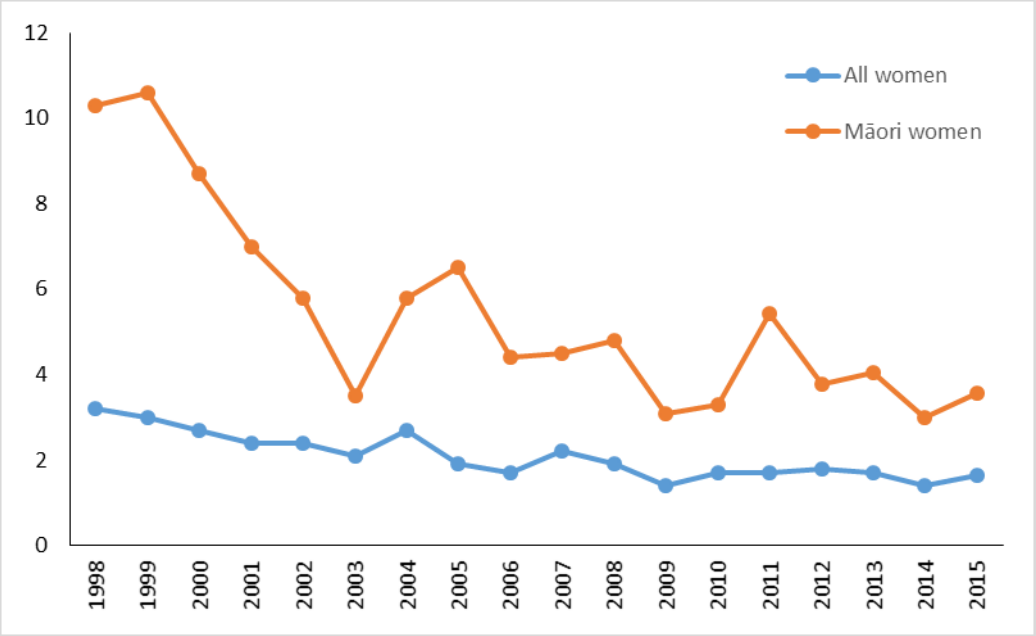
Notes:
- Vertical bars represent 95% confidence intervals.
- No deaths were recorded for Asian women in 2011.
- Source: *NCSP Annual Report 2016* (Ministry of Health 2019)

b. Māori women, compared with all women



Note:
- Vertical bars represent 95% confidence intervals.
- Source: *NCSP Annual Report 2016* (Ministry of Health 2019)

Figure 5: Age-standardised cervical cancer mortality rates for Māori* and all women, 1998–2015†



Notes:

- Rates are per 100,000 women, age-standardised to the WHO standard population (all ages).
- * Aged-standardised rates for Māori women were not available for years before 1996.
- † Rates for 1996–2004 were sourced from Cancer: New Registrations and Deaths, 2007 and 2006 (Ministry of Health 2010b and a respectively). Rates from 2005 were sourced from previous and the current NCSP annual monitoring report.
- Source: *NCSP Annual Report 2016* (Ministry of Health 2019)

Key issues

Screening coverage and follow-up treatment inequities

Cervical screening coverage (participation) rates for all population groups increased significantly for the first 15 years of the NCSP and inequities narrowed. However, there has been a plateau in screening coverage, incidence and mortality over the last decade, and inequities have persisted with a higher burden of cervical cancer incidence and mortality for priority group women, particularly Māori.

Socioeconomic deprivation is associated with lower screening coverage rates and higher cervical cancer incidence and mortality (Sykes et al 2018). Māori and Pacific populations are over-represented in the most deprived quintile of the NZ Dep Index. Ethnicity and socioeconomic deprivation are independently and jointly associated with Māori and Pacific populations carrying a high burden of cervical cancer incidence and mortality.

Comparing DHBs shows that the lowest coverage of priority group women is in the urban DHBs in the largest metropolitan centres of Auckland, Wellington, Christchurch

and Hamilton, where numbers of priority group women are highest. A focus on improving coverage in urban DHBs would have a significant impact on inequities. This will require investment in developing strategies to improve coverage of priority group women in these urban metropolitan DHBs.

There are variations in the regularity of screening by ethnicity, with a greater delay for all priority group women compared with European women, as was noted in the PRC 2015 report.

The continuing proportional over-representation of Māori, Pacific and Asian women not accessing timely follow-up for treatment and management of suspicious high-grade abnormalities is cause for concern and indicates these women face barriers to accessing treatment services as well as screening services.

Indicators have not been developed for NCSP standard 609 relating to failure or refusal to attend colposcopy appointments. This needs to be done for priority group women as we see relatively high rates of accepted referrals for colposcopy and then relatively lower rates for attendance, suggesting access issues. The access issues will relate to a range of barriers, including those that occur as a result of organisational arrangements or health professional practices, such as appointment notification, reminder and recall processes, as well as those associated with the women themselves, such as cost of transport, parking, child care and fear of treatment or a cancer diagnosis.

Unknown inequities: Disability, mental health, LGBTQI

While the review committee has been unable to access relevant NCSP data, it concurs with key stakeholders who advise it is likely that women with disabilities and mental illness and LGBTQI women will have lower screening rates than others. These population groups are known to experience poorer health status and poorer access to health services than others (Gahagan and Colpitts 2017; Te Pou n.d.; Institute of Medicine 2011). In order to understand and address cervical cancer and screening inequities in these population groups, appropriate data collection and reporting will be necessary (Counting Ourselves 2019; Statistics NZ 2015; Patterson et al 2017). These issues will likely be impacting across New Zealand's cancer screening services.

Barriers to cervical screening and follow-up

Barriers to cervical screening and follow-up across the cervical cancer prevention pathway have been well researched, particularly for Māori, Pacific and Asian women (Jameson 2010; McLeod et al 2011; Pacific Research and Policy Centre 2016; Best Practice Advocacy Centre New Zealand 2009; Gao et al 2008; Armstrong and Murphy 2008). These barriers are linked to factors at a societal/structural level associated with the organisation of service delivery and health provider actions as well as factors relating to the women themselves and their families.

As reported by the Waitangi Tribunal (2019) following stage one of the Health Services and Outcomes Kaupapa Inquiry, the severity and persistence of health inequity that Māori continue to experience indicates that the health system is institutionally racist and this, including the personal racism and stereotyping that occurs in the health care sector, particularly impacts on Māori. The Director-General of Health in his

acknowledgement of institutional racism noted we now have some good evidence that racism at a range of levels does determine access to, experience of and outcomes in the health care system. The Tribunal accepted that institutional racism is a determinant of health and wellbeing.

Key informants interviewed by the PRC raised many of the known barriers identified in the literature and summarised in Table 2 below. One group of key informants also raised concern for obese women, who they believe will be under-screened:

> 'The other population who we know from literature are not presenting for cervical screening ... is women of size, fat women, women with a high BMI – there [are] countless studies that have said that it is a major barrier to women, women have experienced fat-shaming stigma in their health care encounters quite routinely and in their desire to reduce their exposure to body shaming and fat shaming encounters from their health providers.'

This group also advocated for appropriate services to overcome the barriers that LGBTQI women face:

> '... But there is another population group that we are concerned about and come under the realm of gender diverse people and sexuality, lesbian and bisexual women and transgender men who have cervixes and people who don't identify as female or male who have cervixes. We know from international literature that it's a population of people that are significantly under-screened for cervical cancer, and we have a dearth of information in NZ about that, because we are not collecting that data. So I guess our first call to the screening programme is that we do collect data on the basis of gender identity and sexuality.'

Barriers may be categorised as sociocultural, financial, geographic,organisational and those relating to health literacy.

Table 2 summarises barriers to cervical screening and the strategies/services aimed at addressing these barriers.

Table 2: Barriers to cervical screening and related strategies

	Barriers	Demographic groups impacted	Notes	Mitigation reported to be effective	Example
Sociocultural	Whakamaa, embarrassment, shame, fear of cancer	Māori, Pacific, Asian, disabled, obese, LGBTQI		Culturally specific services and practitioners designed to support and minimise embarrassment Effective co-designed communication strategies	Group consultations
Sociocultural – provider/patient relationship	Previous negative experience with health services generally or specifically for cervical screening	Māori, Pacific, Asian, obese, LGBTQI		Primary health care workforce development in supportive service delivery & cultural competency	Facilitated sessions for health professionals to hear women's experiences and adapt their services accordingly
Health literacy / health provider communication	Misunderstood (women and health providers) need for screening, frequency of screening or follow-up	Māori, Pacific, Asian, disabled, LGBTQI		Co-designed multimedia communication campaigns	Smear Your Mea campaign
Financial	Cost of cervical screening (fee for service, time off work, child care, public transport, parking) or unpaid GP accounts	Economically disadvantaged across multiple demographic groups	Particularly affects Māori and Pacific women who are over represented in NZ Dep Q5	Free smears. GP policies that alleviate the burden of unpaid accounts Community, workplace, home, church, cultural settings for free cervical screening	Free home-based smears offered by independent Māori service providers

	Barriers	Demographic groups impacted	Notes	Mitigation reported to be effective	Example
Organisational	Women have not received any requests, recalls or reminders to be screened	Unenrolled, highly mobile, homeless and prison population groups	Particularly affects Māori but also immigrant and NZ Dep Q5 populations	Community outreach screening services GPs working with ISPs and SSS to identify and reach unscreened or under-screened women	Prison and workplace cervical screening promotion and smear testing free of charge to the women, offered by ISPs Data matching between the NCSP-R and general practice register
Organisational / geographic	General practice hours, location inaccessible	Working and rural women		As above plus out-of-business-hours GP services	General practice hours extended to enable bookable appointments outside usual business hours

Key stakeholders raised other barriers during the review process. These include barriers experienced by GPs and ISPs or SSS around:

- the mismatch of data between the NCSP-R and the GP practice management system
- variable capability in general practices and variable support to utilise the data matching tools provided by NCSP
- the lack of direct access to the NCSP-R
- being unable to access NCSP-R from within the GP practice management system
- out-of-date contact information for eligible women
- a lack of time in a busy general practice to follow up women who have not responded to recall
- a reluctance to refer women to NCSP SSS, no available NCSP SSS services or confusion around the referral process
- confusion as to NCSP eligibility – start and finish age and frequency of screening
- confusion as to NCSP eligibility related to earlier communications on the proposed start date for primary HPV screening
- a perception that the Privacy Act 1993 does not allow for referral to NSU SSS without the patient's consent
- limited funding for free smears.

Resourcing strategies to address barriers and inequities

The NCSP currently resources a range of governance and service delivery strategies focused on addressing barriers to cervical screening and reducing inequities. These include:

- Clinical Lead – Equity across NSU programmes
- NCSP National Kaitiaki Group – a Māori data advisory group
- The Māori Monitoring and Equity Governance Group across all NSU programmes
- Māori and Pacific expert advisors on the NCSP Advisory and HPV Technical Groups
- Equity data collection and reporting to monitor equity
- Māori, Pacific and Asian language cervical screening information resources
- NCSP policies, standards and guidelines for providing effective recall and reminder systems and supportive service delivery, including cultural competency and equity actions
- Funding for NCSP coordination at a DHB level
- Accountability requirements of DHBs to plan and report on service delivery to address inequities at a DHB level
- Funding for free smears for some priority group women
- Funding of and direct contracting with SSS
- National knowledge transfer on successful SSS to support priority group women

- Funding an independent evaluation of SSS
- Investment in research on self-sampling for primary HPV screening in priority group women.

The PRC acknowledges the value of these strategies and the resource committed to them. However, persistent inequities clearly indicate a need for improvements to existing strategies and the pursuit of new approaches to accelerate actions to eliminate inequities. Almost without exception, key informants raised concerns with persistent inequities and highlighted the need to invest in new approaches to address this ongoing challenge, as summarised by the following key informant:

> 'Over all …the screening programme is providing an extremely valuable service, as evidenced by the decreasing cancer rates, but that doesn't mean we can't do better. Our unscreened and under-screened women must be the target of better education and face-to-face discussions with people who understand the programme, HPV, vaccination, etc. They will require novel approaches to screening, but mostly they will require a lot of time to establish the level of trust required to accept screening. This will require money.'

Addressing inconsistent reminder, recall and referral processes

While a suite of support systems and processes are provided to DHBs, PHOs, GPs and ISPs to enable effective invitation, recall, reminder and referral so that all women are screened, followed up and treated when necessary, in a timely manner, these systems and processes are not applied consistently at a local level. The PRC heard of PHOs who had no knowledge of data matching tools to assist with reconciling information on eligible women between the NCSP-R and a GPs practice management system, while others provided practical support to every general practice in their PHO to use the tools. It also heard of variable practices with regard to referrals to SSS designed to follow up with priority group women (or others who have never been screened or are under-screened) who general practices or colposcopy services are unable to reach. The PRC believes that an audit should be undertaken of reminder, recall and referral processes against the NCSP policy, standards and guidelines. The audit should be undertaken with a view to developing a toolkit to support those PHOs, general practices and colposcopy services that are not currently following the NCSP policy, standards and guidelines.

The PRC understands and acknowledges the stewardship role of the NSU and the NCSP and the operational role of DHBs, PHOs and health care providers in delivering the programme. It acknowledges the role of DHBs and PHOs in monitoring, auditing and reviewing local delivery of the NCSP. However, in regard to oversight and stewardship capacity, the PRC recommends that the NCSP lead the establishment of a local audit of reminder, recall and referral processes against the NCSP policy, standards and guidelines and the development of a toolkit of support for providers.

The PRC concurs with the advice of a number of key informants from the primary health care sector that the full benefit of a national cervical screening register can only be achieved if it is well integrated with primary health care practice management systems (PMS).

The committee understands that the proposed NSS will help register look up, which is an important advancement. However, it is not sufficient, and the end user's experience around clinical workflow at the point of care needs to be understood and incorporated into the solution. While the committe recognises the complexity within the primary health care PMS landscape (with multiple vendors), it believes this work is essential in developing a functioning integrated care system.

An IT system that can be integrated with the PMS has the potential to better manage clinical risk, through electronic messaging from the NCSP for those at higher risk and through improving coverage with enhanced referral to SSS.

The future primary HPV screening programme and the new register provide the opportunity to make screening easier for women and for services where women attend by ensuring IT systems are well integrated.

Strengthening Support to Screening Services

A range of ISPs provide SSS in 15 of the 20 DHBs. Many have particular expertise working with priority group women, such as kaupapa Māori services or Pacific or Asian providers. They are outreach services rather than services provided solely in clinics. These services are adept at delivering cervical screening promotions and smear testing in community settings, on weekends and after hours in ways that prioritise what is important to the women and their family (eg, whānau ora services) to address many of the barriers experienced by priority group women.

These services reach out to vulnerable populations not enrolled with a general practice (eg, prison and homeless populations) as well as working closely with general practices to follow up on any women who the practices have been unable to engage in cervical screening at all or on time.

SSS is a vital support to colposcopy services to follow up on women not attending booked colposcopy appointments. SSS recognises the critical importance of building relationships with general practices and colposcopy services to facilitate smooth referral processes.

However, not all general practices or colposcopy services make the best use of SSS. The PRC noted examples of primary health care services that may inadvertently be a barrier to women accessing SSS. Not all primary health care or colposcopy services apply standard processes to SSS referral for women who have not responded to screening recalls or colposcopy appointments.

The NCSP contracts directly with these services and has held both face-to-face meetings and teleconferences with the collective of providers to showcase best practice options and address challenges. The NCSP is planning an independent evaluation of the SSS in 2019. The PRC sees this evaluation as being critical to developing an effective SSS as a key strategy to address inequities in the NCSP.

Extending free smear funding

Consultation fees charged to women attending general practices and other primary health care clinics for a smear test are widely considered to be one of the main barriers to cervical screening for priority group women. Cervical screening is different from all other NSU programmes in charging a consultation fee.

Key informants consistently referred to the barrier created by charges for a cervical smear test.

> '... if someone goes into the GP and asks for a smear, often the GP or the [nurse] practitioner will charge them a fee for ... that [actual] consultation. So regardless of whether the smear is free, they're still getting charged that consultation fee.'

Pre-existing debt at the general practice was also referred to.

> 'So, if I have some debt at the GP that I can't afford to pay because I can't afford to put food on my table, then I'm not going to turn up to the GP to get a smear done because I know that they're going to hit me with the bill. So, for me, the no-brainer is make cervical free, and then your barriers would decrease overnight.'

In response to this cost barrier, funding is allocated to DHBs to provide smear tests with no fee for a limited proportion of priority group women. However, the level of NSU funding has remained static for five years; the allocation does not cover all priority group women and it is disproportionate nationally.

Key informants referred to the limitations of the current funding model for 'free smears'.

> '... we'd like to see the programme fully funded, if possible, and also agree that the co-payment at $25.02 isn't enough to cover the cost for primary health care to deliver free smears to priority group women.'

There are substantial inconsistencies in the allocation of free smear funding and, except for MidCentral DHB, the DHBs with the lowest free smear funding per capita of priority group women rank in the bottom five DHBs for percentage coverage of Māori women for cervical screening.

Some PHOs contribute additional flexible primary health care funding to enable more priority group women to access free smear tests, however, the NCSP is not involved with this funding, and so it is unknown to what extent this contributes to reducing inequities.

The current available funding falls short of requirements to reach all priority group women, and the method of allocation creates considerable confusion for service providers. Both factors lead to priority group women not being able to access free smears.

The PRC recommends consideration be given to the level of funding and model for allocation to enable free cervical screening and progress towards eliminating cervical cancer inequities. The PRC has been advised that the allocation of funding to DHBs for free smears is being reviewed in 2019. It commends this intention.

Improving NCSP equity analysis

For a number of years, data collection and reporting on cervical screening in New Zealand has enabled analysis of coverage across the cervical screening pathway by ethnicity. Following a recommendation by the 2015 PRC, reporting now also includes coverage by deprivation quintile to enable analysis of equity by socioeconomic status. Reporting on incidence and mortality trends over time currently compares Māori with other ethnic minority groups and the 'All women' group. Because Māori women make up between 20 percent and 25 percent of all cervical cancer cases and deaths respectively, comparison with 'All women' is less informative than a comparison with non-Māori women would be. Consideration should be given to comparing Māori and non-Māori women.

Ethnicity data is presented in the six-monthly independent monitoring reports and the NCSP annual report. Quarterly DHB monitoring reports also present coverage by ethnicity. An online application gives access to coverage data by ethnicity and deprivation monthly.

The PRC has commented about the lack of data on coverage by disability and mental health service users or the LGBTQI community and made a recommendation around this (see Unknown inequities: Disability, mental health, LGBTQI above).

The PRC has found that no document provides a synthesis of all equity-relevant NCSP data, and none of the regularly published NCSP monitoring and evaluation reports draw conclusions or make recommendations for equity improvement. For an equity lens to be cast over the NCSP, a number of sources of information need to be drawn on. The PRC recommend that a synthesis of equity data and an analysis through an equity lens occur on a routine basis in a regular monitoring report. BreastScreen Aotearoa is now producing such a report, and the Māori Monitoring and Equity Group (MMEG) supports this approach.

The PRC is aware the Ministry is developing a new suite of measures and a framework for reporting population health outcomes and health system performance. These new health measures will replace the current health targets. The NSU has put forward advice for including cervical screening measures in that suite. The committee recommends that any cervical screening measures developed should be equity focused.

The opportunity to address inequities through primary HPV self-sampling

Standardising recall, reminder and referral processes, ensuring access to SSS and extending the availability of free smear tests to all priority group women are strategies

intended to address a number of known barriers. However, the embarrassment of a speculum examination or a previous poor health care experience, will remain a barrier to screening for some priority group women, irrespective of clear, culturally relevant information and other strategies to support participation.

The NCSP has recognised the opportunity presented by self-sampling as part of the implementation of the primary HPV screening programme (Ministry of Health 2017f) and supported pilot studies to investigate the feasibility of HPV self-sampling.

A recent authoritative, updated meta-analysis (Arbyn et al 2018) confirmed that self-sample testing for cervical screening is as accurate as clinician-collected cervical sampling, in terms of HPV sensitivity. It is essential that a polymerase chain reaction (PCR) HPV test be used to gain equal sensitivity. In a previous report, there was a small, but significant reduction in sensitivity of self-sampled HPV testing using hybrid capture rather than PCR-based tests. This recently updated meta-analysis is very reassuring and gives further impetus for the introduction of self-sampling as a strategy to improve participation and coverage for those women currently under-screened or never screened. The report also confirmed that offering self-sampling kits directly to women is more effective in reaching under-screened women than sending written invitations. The report noted that response rates are highly variable among different settings and recommended that pilot studies be set up before a regional or national roll-out of self-sampling strategies. These pilots are in progress, and the results are awaited with interest. In Australia, health care providers are already offering self-sampling as part of the renewed NCSP (Canfell et al 2016).

The primary HPV self-sampling pilot studies currently underway in multiple geographic locations around New Zealand are showing a high degree of acceptability amongst priority group women (Adcock et al 2018; Bartholomew et al 2018).

The Waitemata and Auckland DHBs research programme aims to determine how best to optimise HPV self-sampling technology and robustly test potential approaches to reaching all women effectively (Bartholomew et al 2018). These DHBs have recognised the potential of self-sampling for addressing the current cervical cancer inequities.

The research programme, feasibility study 1 has been completed, and study 2 – a Health Research Council funded randomised controlled trial is midway through recruitment. Study 1 involved focus group interviewing of Māori women first and then Pacific, Asian and other unscreened or under-screened women, followed by an invitation to participate in self-sampling. Women undertaking self-sampling also completed a survey questionnaire. The women recruited were all under-screened (five or more years overdue) or never screened. The under-screened or never screened women who undertook self-sampling in study 1 universally described a positive experience, for example:

> 'That was so easy!'
>
> 'I would come back every six months to do this test.'
>
> 'Why aren't all women offered to do this?'
>
> '"It was so quick and easy!"; "OMG that was so much better."

'I really liked doing the test this way – I hope I can do it this way next time.'

'Thank you for choosing me for this test – I never want to have another smear.'

'This is what women need; we are shy to do it the other way.'

'I didn't think I needed a test, now I know I have HPV, I want to make sure I'm OK.'

Amongst the 84 women were a number who had cervical abnormalities requiring a follow-up. Colposcopy was arranged for all women, and the following records a lead colposcopist's response to one case:

'... the participant we saw two weeks ago had the most extensive HSIL (high-grade squamous intraepithelial lesion) I've ever seen. She'll be having a cone biopsy, and I have no doubt we will have truly saved a life.'

The study 1 researchers have concluded that co-designing with women and key partners and taking a health literacy and kaupapa Māori approach were valuable strategies. In addition, they believe the technology offers opportunities for improving access for other groups of women, for example, disabled women, older women and obese women. They conclude, as elsewhere internationally, that the increase in uptake from self-testing is likely to be modest but important (in the order of 15–20 percent of the cohort invited) (Bartholomew et al 2018).

A second research programme funded by the Ministry and led by the Centre for Women's Health Research, Faculty of Health, Victoria University of Wellington has also completed a feasibility study and is currently recruiting into a randomised control trial.

The feasibility study survey of under-screened and unscreened women found that three in four said they were likely or very likely to take up self-sampling if they were to be offered it. Nine in ten women said that they would be likely or very likely to seek follow-up cytology or colposcopy if they had a positive high-risk HPV result.

The New Zealand researchers and other key advisors for priority group women are calling for primary HPV self-sampling to be made available to all priority group women and any women who decline a speculum examination when the primary HPV screening programme begins.

'… I think that we urgently need to implement some HPV self-testing … that would be our preference; to start with HPV self-testing.'

'Any restrictions [to the availability of the self-sampling option] will impact those currently least served and may introduce perverse outcomes (eg, waiting until [they are] more overdue, which is concerning in the context of the five-year interval for primary HPV).'

The PRC agrees that self-sampling for HPV offers the opportunity to address and reduce inequities in the cervical screening programme. Both New Zealand research programmes and the Australian evidence provide a wealth of data that should inform self-sampling implementation policy and guidelines. Recommendations concerning the

future primary HPV screening programme are made in chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction.

Recommendations

- The cost of screening has been consistently identified as a major barrier, and all eligible women should receive fully funded cervical screening, to align cervical screening with all other New Zealand cancer screening programmes. Initially, priority for fully funded screening should be given to priority group women with a strategic objective of including all eligible women.
  The NCSP, in their oversight and stewardship capacity, should lead district health boards (DHBs) and primary health organisations (PHOs) in monitoring, auditing and reviewing local delivery of reminder, recall and referral processes against the NCSP policy, standards and guidelines and develop a toolkit of support for providers to ensure consistent, quality practices.
- A set of NCSP equity indicators should be included in the new health measures.
- Equity analysis should be included in the routine NCSP independent monitoring reports, providing a synthesis of all NCSP equity data. This analysis should inform strategies to improve access and remove barriers to participating in the programme.
- Support to Screening Services (SSS) should be strengthened to ensure it is available across all DHBs and is used effectively as standard best practice by all general practices and colposcopy services. The PRC supports the planned 2019 SSS evaluation.
- There should be more focus on investment and development of strategies to improve coverage of priority group women in metropolitan DHBs.
  The NCSP should provide support to DHBs and PHOs to enable a standard, best-practice approach to the use of the data-matching tools to ensure optimum matching of data between the NCSP-R and general practice practice management systems (PMS).
- Effective and appropriate integration of Practice Management Systems (PMS) must be considered as part of any design for a new technology solution for cervical screening. This will enable real-time access to cervical screening data to optimise clinical decision-making.
- The NSU should work with the relevant Ministry directorates to explore opportunities for measuring access to national screening services for disability and mental health service users as well as the lesbian, gay, bisexual, transgender, queer or questioning, intersex (LGBTQI) community.

The effectiveness of monitoring and evaluation in informing the NCSP's performance and clinical safety

This chapter reviews all monitoring and evaluation processes involved in the NCSP. This includes overarching reports produced by external experts monitoring the indicators that measure and demonstrate the effectiveness of the programme. It also includes reviews and monitoring of the safety and effectiveness of clinical performance at DHB and pathology provider level.

Recommendations include the need for timely review and development of new indicators for the transition to primary HPV screening, a process for reviewing and auditing cervical cancers on an ongoing basis and translating the findings into quality improvement initiatives, and to closely monitor timeliness of cytology reporting in the lead-up to introducing primary HPV screening in order to be able to manage the expected attrition of the cytology workforce.

There are currently several monitoring, review and audit activities that provide a comprehensive review of all aspects of the cervical screening pathway and beyond. The six-monthly independent monitoring provides the principal programme performance report on:

- coverage
- regularity of screening
- first screen
- withdrawal rates
- colposcopy
- laboratory performance
- follow-up of women with abnormalities
- HPV testing.

It is important to note that there is an annual on-site audit of cytology, histology and HPV testing laboratories as a combined effort of International Accreditation New

Zealand (IANZ) (against ISO15189) and NSU (NCSP National Policy and Quality Standards, Section 5).

In addition, all DHB colposcopy units participate in e-colposcopy reporting to the NCSP-R, and there is the capacity to audit individuals, units and DHBs, plus the triennial (NSU commissioned) independent audit of colposcopy units. Retrospective reviews (2004, 2009 and 2017) of cervical cancer diagnoses have provided insight into the difficulties of effective cervical screening. Colposcopy audits are discussed in detail in chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction.

In this chapter, we address the monitoring, review and audit of cervical cancer.

This section is informed by monitoring report 48 (Smith et al 2018c). It will be necessary to review many of these indicators, their ongoing relevance and their positive predictive values with the transition to primary HPV screening.

Indicators

Indicator 1: Coverage

Two indicators measure cervical screening coverage in the eligible population. They are both important measures as they give insight into inequity in the target population.

Indicator 1.1 measures three-year coverage

The target is to have screened 80 percent of eligible women within the previous three years. The overall coverage target had not been met nationally, with only 74.8 percent of the eligible 1,241,159 women screened within the previous three years. Nationally, coverage targets have been met for European/Other women (80.4 percent screened within the previous three years) but have not been met for Māori, Pacific or Asian women (62.0 percent, 73.4 percent and 63.4 percent respectively screened within the previous three years). Within specific five-year age groups, the coverage target was met for women aged 45–49 years.

Three-year coverage rates vary between DHBs, and the variation is most noticeable when compared by ethnicity. Chapter 2: Equity across the screening pathway describes coverage by ethnicity in more detail.

Given the pending implementation of a five-year screening interval with the introduction of the primary HPV screening programme, it is useful to note that five-year coverage among women aged 25–69 years exceeded 80 percent in all DHBs, in Pacific and European/Other women and in women in all five-year age groups between 30–69 years. When compared with the findings for three-year coverage, five-year coverage had broadly similar patterns of variation by DHB and ethnicity. This is described more fully in chapter 2: Equity across the screening pathway.

Indicator 1.2 measures regularity of screening

The target is not defined; however, the aim is to maximise on-time attendance. This indicator reports on the timeliness of attendance, both for women returning for routine screening at three years or at an earlier interval of 12 months (for example following a recent abnormality).

As the programme moves to a routine five-yearly screening interval, risks associated with early screening (programme cost-effectiveness) and late screening (undetected abnormalities) remain, and so a target would be worth considering.

Three-year recall

Among women attending for screening in 2017, following a three-year recall recommendation, 62.5 percent attended on time; 13.4 percent more than six months early and 24.1 percent more than six months late. Differences are seen between different population groups – described more fully in chapter 2: Equity across the screening pathway.

Twelve-month recall

Among women attending for screening in 2017, following a 12-month repeat recommendation, 40.5 percent were attending on time; 2.4 percent more than three months early and 57.1 percent more than three months late. Differences between ethnic groups are discussed in chapter 2: Equity across the screening pathway.

When considering monitoring and evaluation, the 2015 PRC report noted the significance of monitoring both ethnicity and socioeconomic positions, concluding that both matter in terms of health. These two factors jointly and independently influence morbidity and mortality through multiple pathways. (Ministry of Health and University of Otago 2010). The 2015 PRC recommended regular reporting and monitoring of participation by a measure of socioeconomic status to ensure equitable access by all disadvantaged groups.

Drawing on deprivation data at an area level, the NCSP now includes coverage by DHB by deprivation quintile. This data is published to the NSU website and updated each month. This new coverage data by deprivation quintile is discussed in the equity section of this report.

A new monitoring indicator to measure coverage by deprivation quintile has not been set.

Indicator 2: First screening events

There is no target for this indicator, and its current value is uncertain. It is an 'observation' of the number of women by age, DHB and ethnicity at the time of their first recorded cervical sample (the screening event) in New Zealand. The proportion of first screening events has remained constant from the previous report (1.8 percent of the eligible population aged 20–69 years).

This indicator will be more important with the implementation of the new HPV-based programme. It will be important to assess the proportion of women who have their first screen close to their invitation to screen at their 25th birthday.

Indicator 3: Withdrawal rates

The target is nil, as it is desirable that all eligible women who have had a cervical sample should be on the NCSP-R, which provides a safety net for all women enrolled in the NCSP. This measures those women, previously enrolled and on the register, who elect to have their names removed from the register. Only 20 (0.001 percent) of 1,590,837 women withdrew from the register, and this figure is lower than the 30 women who withdrew in the previous reporting period. It is gratifying that such a small number of women choose to withdraw from the register.

Indicator 4: Early rescreening

There is no target for this cohort, which addresses the question 'What proportion of women recommended to return in three years for routine screening return at least six months early?' In some cases, early rescreening may be in response to clinical symptoms, and this is appropriate. In others, it is a failure to adhere to recommended screening intervals for reasons that are uncertain but may be logistical or driven by the woman or her doctor.

This indicator will be especially important with the change to the five-year interval for HPV screening, where some of the cost-effectiveness of the HPV-based programme relates to an extended screening interval, and measurement of compliance with the recommended interval will be important.

If there is a significant amount of 'early rescreening,' the NCSP will be alerted through regular monitoring and able to discover why this is occurring. This will enable strategies to be implemented for educating women and health care providers about the safety of the five-year interval and the potential harms of non-compliance.

Indicator 5: Laboratory indicators

There are five separate indicators, measuring different aspects of laboratory activity and performance. Monitoring laboratory performance and quality measures is essential for the governance of the NCSP and to reassure the participating women and health care providers that the NCSP is providing optimal care. Laboratories that are not performing to the required standard may require investigation and remediation where appropriate. The Royal College of Pathologists of Australasia (RCPA) has a robust quality assurance programme, and New Zealand has an excellent national cervical pathology training service for pathology service providers. Overall the results for Indicator 5 are very reassuring and provide evidence of good performance in the six laboratories providing services to the NCSP.

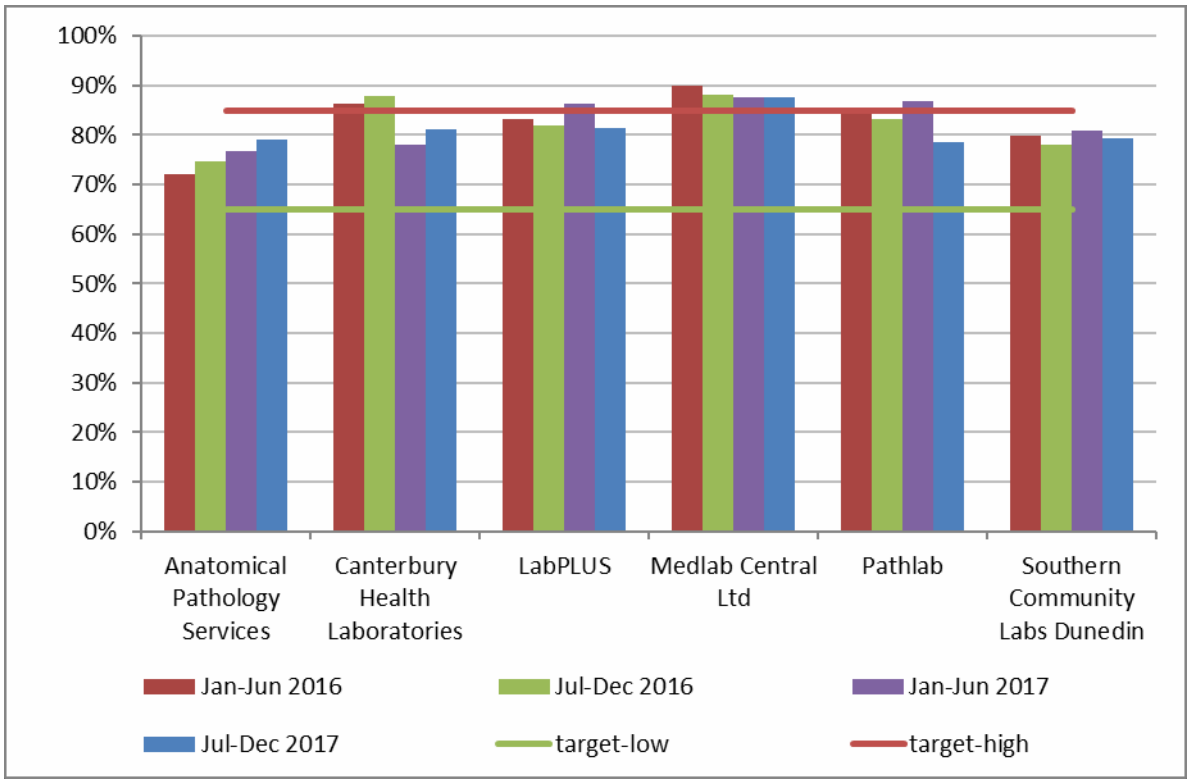
Indicator 5.1: Laboratory cytology reporting

Overall, laboratory cytology reporting for this period is reassuring. It is important to note that workload catchments for laboratories may be regional or nationwide, and it is not always easy to determine the catchment for a specific laboratory. Rates for

negative and abnormal results for individual laboratories must be interpreted with caution.

Indicator 5.2: Accuracy of cytology predicting HSIL

Figure 6: Trends in the positive predictive value for CIN 2+ in women with HSIL or SC cytology results, by laboratory



Note:

- Time period relates to monitoring report period; cytology samples were collected in the period six months previous.
- Source: Figure 58, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c).

The PPV for reporting a high-grade squamous intraepithelial lesion (HSIL) or squamous cell carcinoma (SCC) should be not less than 65 percent and not greater than 85 percent. One of the six labs exceeded the 85 percent limit by a small margin (88 percent), which is an improvement on the last report when three of the labs exceeded this upper limit. It is reassuring to note that all labs reported above the lower limit of 65 percent. This is reassuring as it indicates that the laboratories are not over-reporting high-grade abnormalities that may lead to an unnecessary investigation nor are they under-reporting high-grade abnormalities that may lead to delays in assessment and diagnosis.

Indicator 5.3: Accuracy of negative cytology reports

This indicator is a very important measure as women who are deemed to have a negative cytology report are recommended to rescreen in three years, and this is particularly important if the cytology examination missed the presence of cell abnormality predictive of possible or actual invasive cancer.

This indicator measures the ability of a laboratory to correctly identify a negative sample. It also measures, in women who have had a histological diagnosis of high-grade disease or invasive cancer, the proportion of cytology slides originally reported as negative within the previous 42 months, which on review are consistent with a high-grade or worse category. It ensures that laboratories are performing to a high standard. It is reassuring that all laboratories met the required standards, and in fact, there was some improvement in performance over the previous 12 months.

Indicator 5.4: Histology reporting

This indicator is observational and shows trends in histology reporting and the proportion of women with benign/negative pathology and those with abnormal pathology. There was no concerning change in results between this and the previous reporting period, and this is reassuring.

There was a continuing decrease in the percentage of HSIL in younger women (20–24 years), which reflects the reduced proportion of HSIL cytology in this age group and probably represents an HPV vaccine effect.

Indicator 5.5: Laboratory turnaround times

The overall turnaround times for cytology and histology reporting are similar for this and the previous reporting period. There was a noted improvement in the proportion of cytology samples with HPV triage reported within 15 working days, and two additional laboratories met the standard of 98 percent.

Note: This indicator will be of increasing importance as the transition to HPV screening approaches and can be used as a 'monitor' of the ability of a laboratory to function well in light of the potential for decreased cytology workforce as HPV screening approaches (see also chapter 6: Progress against the 2015 Parliamentary Review recommendations).

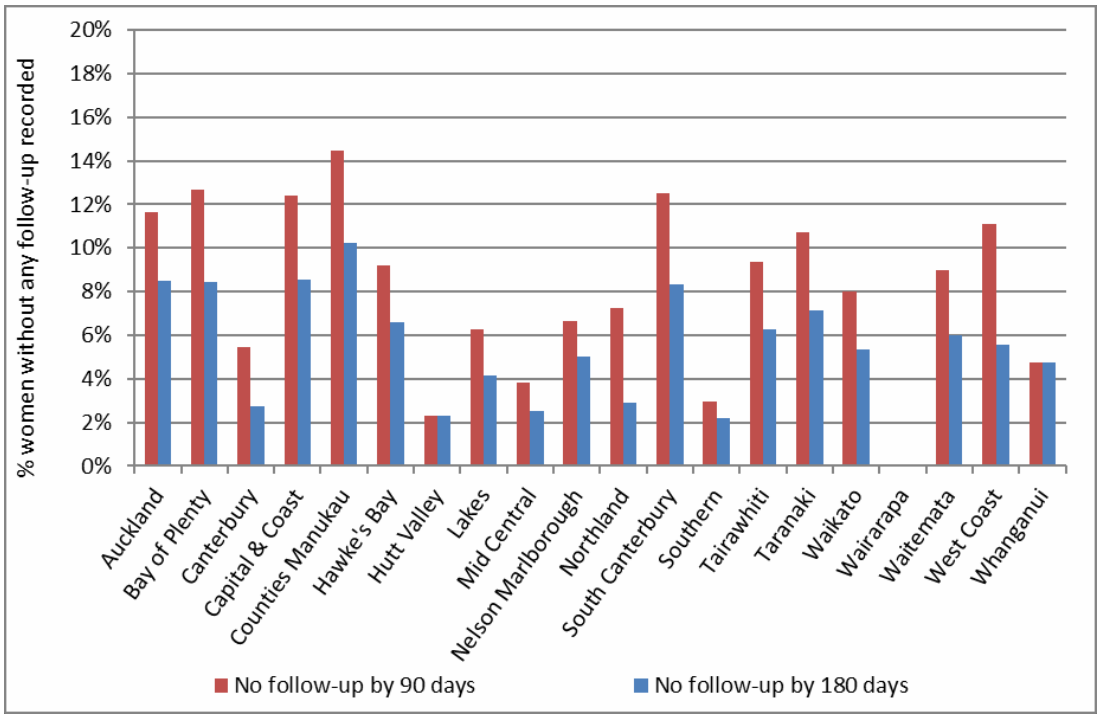
Indicator 6: Follow-up of women with high-grade cytology and no histology

This indictor measures the completeness of follow-up for women with a prediction of high-grade disease. The target is for 90 percent of women to have a histology report within 90 days of their cytology report date and for 99 percent to have a report within 180 days of their cytology report.
Note: Some women will attend for a colposcopy but will not have a biopsy taken. However, this information can be determined by Indicator 7.1: High-grade cytology and timeliness of colposcopy visit.

Nationally, 83 percent had a histology report within 90 days and 88.3 percent within 180 days in the previous three years. There was significant variation by DHB and by ethnicity, but the target was not met for any ethnic group. The proportion of women with follow-up histology at 90 days has improved for Māori women (increasing from 74.3 percent to 78.9 percent) but has decreased for Pacific women (77.8 percent to 68 .6 percent).

Figure 7: Proportion of women without any follow-up test within 90 days and within 180 days of a high-grade cytology report, by DHB

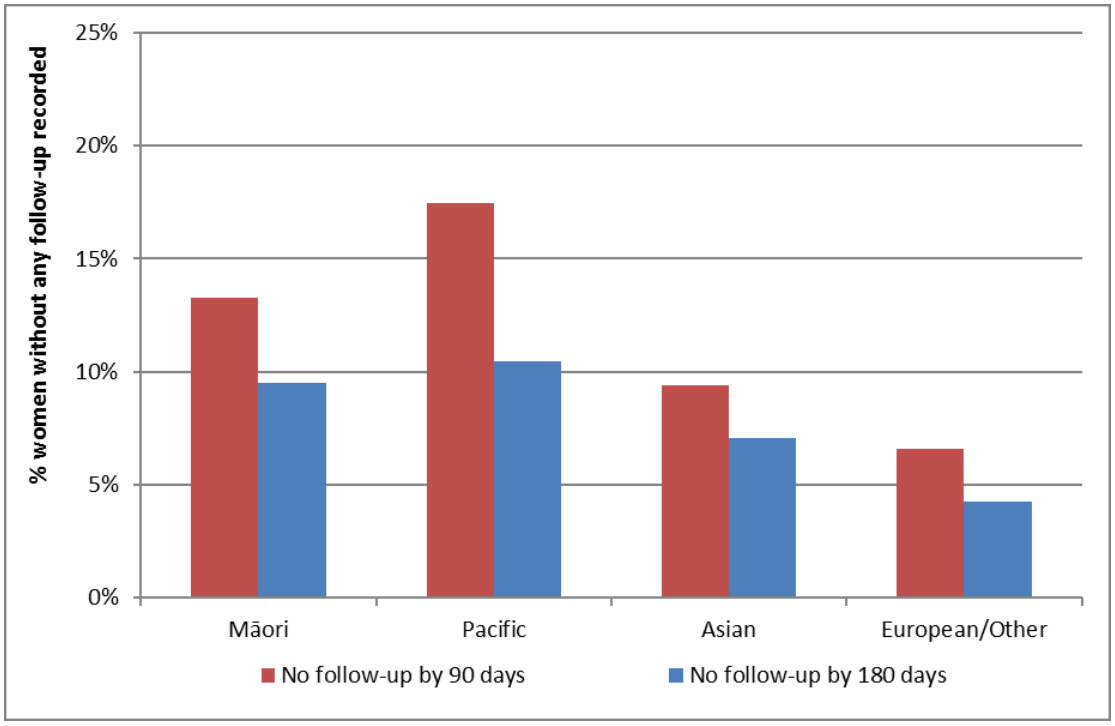
Note:



Note:

- There was no record of women not being followed up within 180 days for Lakes, Nelson Marlborough, South Canterbury, Wairarapa and Whanganui DHBs.
- Source: Figure 72, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c)

Figure 8: Proportion of women without any follow-up test within 90 days and within 180 days of a high-grade cytology report, by ethnicity



Source: Figure 73, National Cervical Screening Programme Monitoring Report Number 48 (1 July-31 December 2017) (Smith et al 2018c)

The proportion of women who do not have any kind of follow-up test is also reported under this indicator and provides additional useful information. While 17.0 percent of women with high-grade cytology reports had no record of a histology report within 90 days, the proportion without a record of a follow-up test of any kind was much lower (8.5 percent). The same was also true at 180 days, where 11.7 percent of women with high-grade cytology reports had no record of a histology report within 180 days.

Although only 5.7 percent of these women had no record of a follow-up test within 180 days, this is of concern as it suggests unwarranted delays and the potential for adverse consequences. Consistent with previous monitoring reports, many of the women with no follow-up histology recorded do have a record of some follow-up test. This provides reassurance that many women without histology have not been lost.

The risk level for women with no recorded histology (biopsy) is difficult to ascertain as there are multiple reasons for absence of histology, including:

- Examined but no biopsy taken
- Did not attend or refused to attend for follow-up
- Delayed attendance outside 'wait time'
- Died or left New Zealand.

Women who do not have a colposcopic follow-up of high-grade cytologic abnormality (including microinvasive and invasive) are at highest risk, but it is reassuring to note that the NCSP coordinators at DHBs ensure that these women are given the highest priority for strategies to ensure their follow-up.

Indicator 7: Colposcopy indicators

These indicators report on colposcopy against *NCSP Policies and Standards, Section 6: Providing a colposcopy service* (National Cervical Screening Programme 2013). There has been incomplete reporting of colposcopy data to the NCSP-R, and hence some of the results for these indicators should be interpreted with caution. However, it was considered that these indicators are an important quality measure and reporting should not be unnecessarily delayed.

This suite of indicators (7.1–7.5) monitors the timeliness of access to colposcopy and treatment and the adequacy of documentation of colposcopy assessment. Two of the indicators (7.6, 7.7) have not yet been developed. 7.7 will monitor minimum colposcopy volumes for providers to maintain competency. It will be reviewed as part of the planned transition to primary HPV screening.

It is pleasing to note that all DHBs were entering colposcopy data via e-colposcopy by August 2016, and as of August 2018, there is now a complete data set for the DHB colposcopy services. Management of this data is now being considered, especially in terms of feedback to colposcopists and DHBs (also see recommendation 14 and chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction).

7.1: High-grade cytology and timeliness of colposcopy visit

The targets for timely follow-up for women with a high-grade cytology report (for those with suspicion of invasive disease and those with no suspicion of invasive disease) from accepted referral to colposcopy visit have not been met.

For women with high-grade cytology *with suspicion of invasive disease*, the standard requires that 95 percent have a colposcopy visit within 10 working days (two weeks). Accepted referrals for colposcopy were found for 40 women with such cytology (54.8 percent). Of these 40 women with a referral, 26 (65 percent) had a recorded colposcopy visit within 10 working days, well below the standard. However, 33 (82.5 percent) have a visit within 20 working days (four weeks).

Table 3: Women with a high-grade cytology report (suspicion of invasive disease), accepted referral and colposcopy visit, by ethnicity

		Urgent referrals received	Women seen within:			
			10 working days		20 working days	
Ethnicity	**N**	**N**	**N**	**%**	**N**	**%**
Māori	13	8	5	62.5	7	87.5
Pacific	8	3	2	66.7	2	66.7
Asian	13	10	5	50.0	6	60.0
European/Other	39	19	14	73.7	18	94.7
Total	73	40	26	65.0	33	82.5

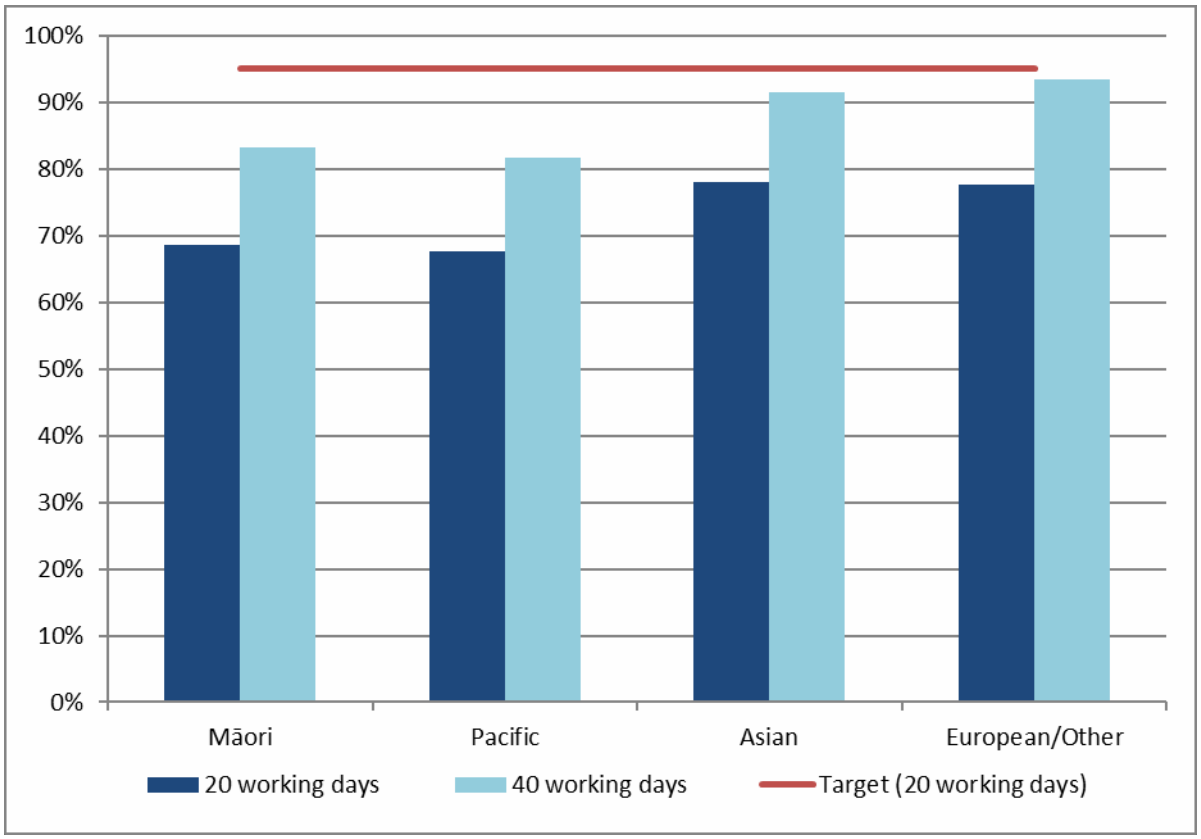
Source: Table 19, National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017) (Smith et al 2018c)

Nationally, the proportion of women with this high-grade cytology suspicious for invasion result and an accepted referral who were seen within 10 working days has decreased from 90 percent to 65 percent: and those seen within 20 working days has also decreased from 92.5 percent to 82.5 percent. Variation in timeliness by ethnicity is noted, with greater delay for all priority group women compared with European women.

It may appear alarming that a large number of women with cytology suspicious for invasive disease do not appear to have a colposcopy referral at all. However, it is likely that this is an underestimation of the actual follow-up of these extremely high-risk women. Many of these women will have been referred directly to a gynaecological oncology unit for assessment, hence by-passing colposcopy referral. For those women who have not been seen within the time period, it is not possible to determine whether this is due to clinic capacity, the woman needing to reschedule her appointment, problems with contacting the woman or her non-attendance.

For 1502 women with a high-grade cytology report *with no suspicion of invasive disease* and an accepted referral for colposcopy: 1,135 (75.6 percent) were seen at colposcopy within 20 working days (four weeks), and 1,365 (90.9 percent) were seen within 40 working days (eight weeks). There is variation by ethnicity, from 67.6 percent (Pacific women) to 78 percent (Asian women) as shown in Figure 8.

Figure 9: Percentage of women with a high-grade cytology (no suspicion of invasive disease) seen at colposcopy within 20 and 40 working days, by ethnicity

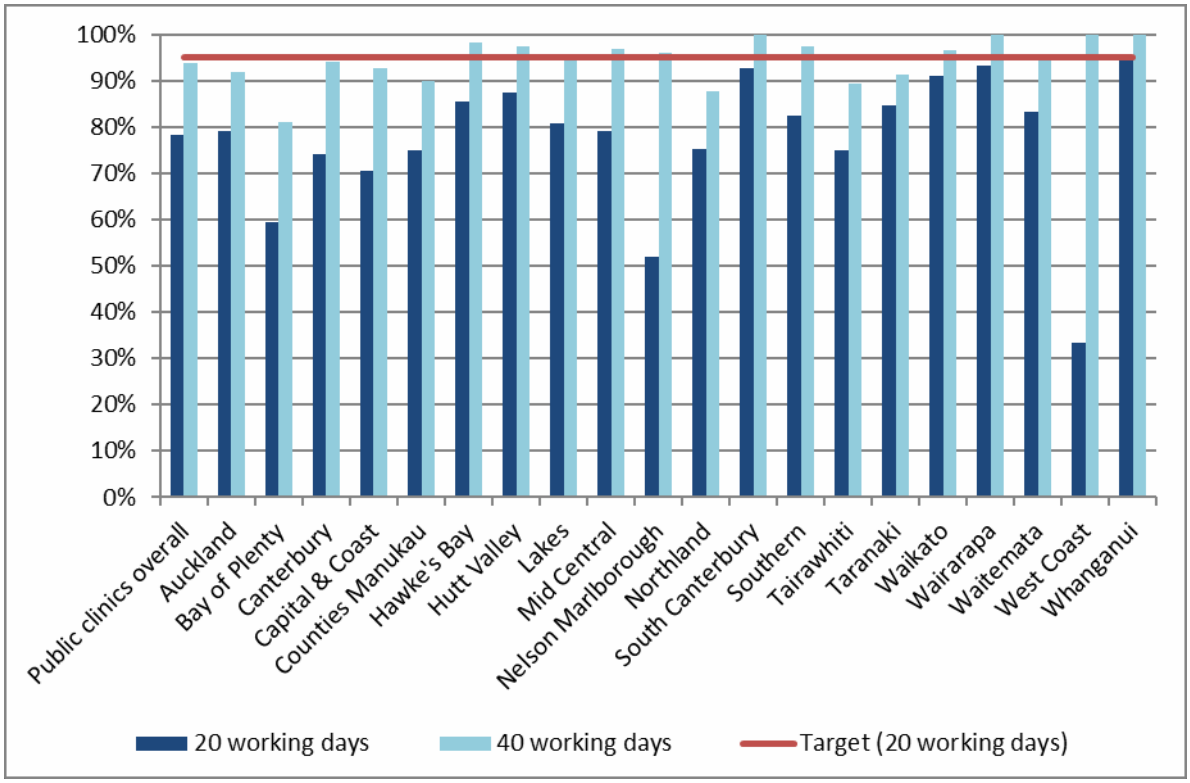


Note:

- 95% target relates to colposcopy visits within 20 working days.
- Source: Figure 78, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c)

Figures varied between DHBs, with the West Coast DHB having the lowest percentage of women with a high-grade cytology receiving a colposcopy visit within 20 working days, at 33.3 percent, while at the other extreme, Whanganui DHB had 95 percent of women with a high-grade cytology receiving a colposcopy visit within 20 working days (see Figure 9).

Figure 10: Percentage of women with a high-grade cytology (no suspicion of invasive disease) with a colposcopy visit within 20 and 40 working days, by DHB



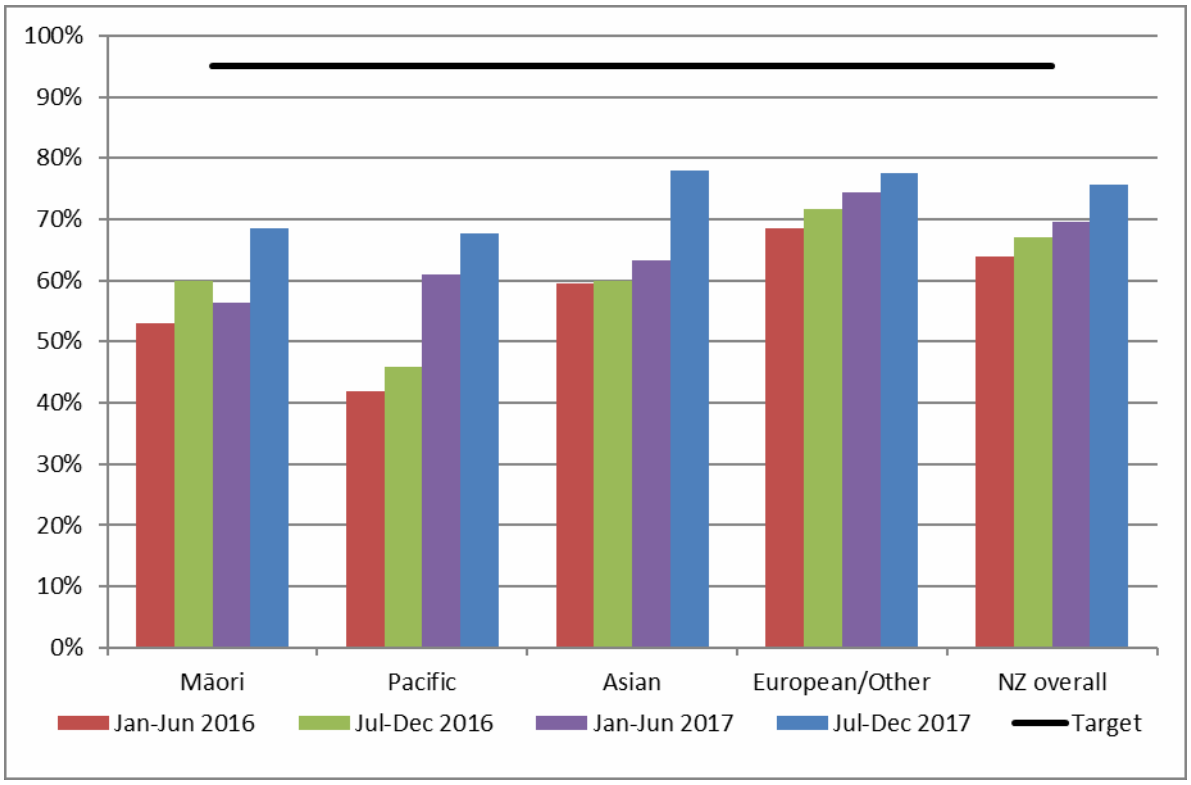
Note:

- 95% target relates to colposcopy visits within 20 working days.
- Source: Figure 79, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c)

It is reassuring to note that most DHBs met the secondary target of women receiving a colposcopy visit within 40 working days. We note that the targets are optimistic in comparison with other countries, and in Australia, it is recommended that women with high-grade cytology with no evidence of invasion, be seen within eight weeks (or 40 working days). The '20 working day' standard may be aspirational rather than realistic or achievable, and the PRC was pleased to hear that modification of this standard is being considered in a revision of Section 6 of the standards.

Figure 11 shows the trends over time of the proportion of women with a high-grade cytology report (with no suspicion of invasive disease) who are seen within 20 working days by ethnicity. There is a reassuring positive trend in all ethnic groups, though all fail to meet the 95 percent target.

Figure 11: Trends in the proportion of women with a high-grade cytology report (no suspicion of invasive disease) seen within four weeks (20 working days), by ethnicity



Note:

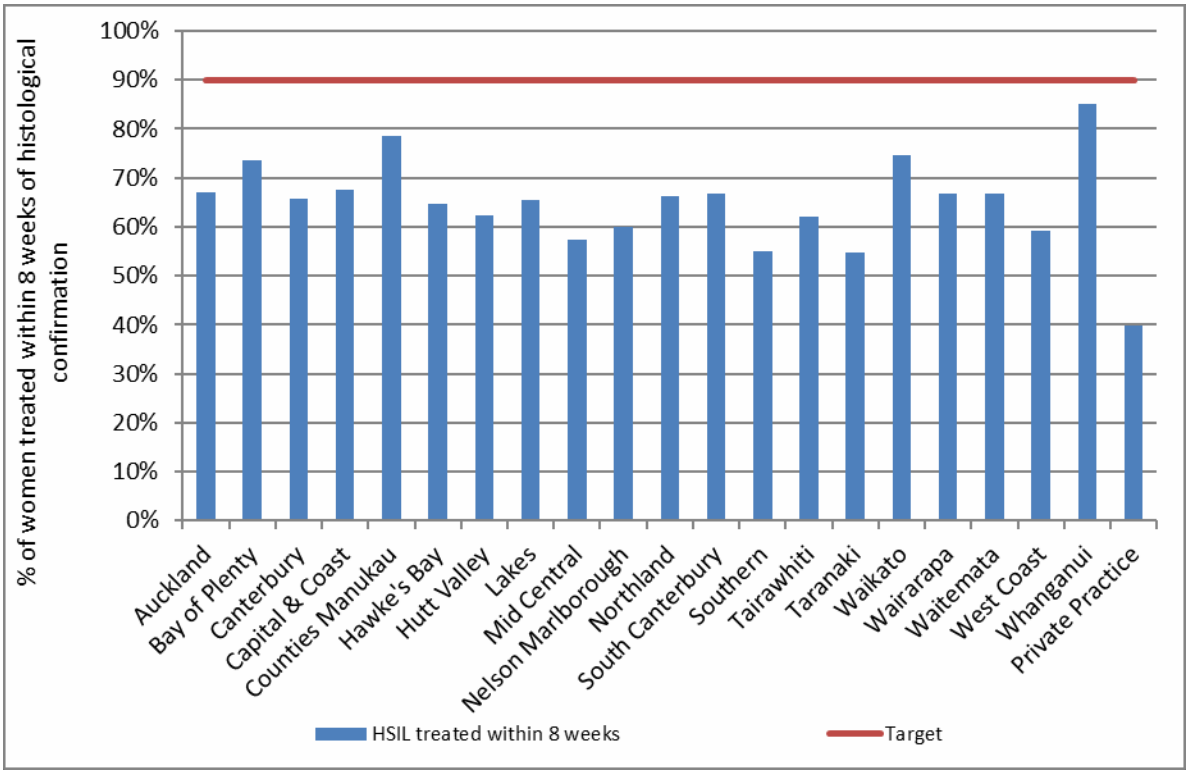
- 95% target relates to colposcopy visits within 20 working days.
- Source: Figure 80, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c)

7.2: Timeliness and appropriateness of treatment

The requisite standard is for 90 percent of women with HSIL to be treated within eight weeks of histological confirmation of CIN2/3. The proportion of women treated within eight weeks varied widely by DHB, from 54 percent (Taranaki DHB) to 85 percent (Whanganui DHB). Unfortunately, no DHB met the target, and there was wide variation across the DHBs. While this is of no major clinical concern, unless the woman are not getting treated at all, it seems likely that this target is unrealistic and could be reviewed.

The PRC was advised by several interviewees that the main problem is accessing treatment facilities, as many women are still being treated in an operating theatre or as a 'Day Stay' rather than in the more appropriate and less costly outpatient clinic setting.

Figure 12: Proportion of women treated within eight weeks of histological confirmation of HSIL, by DHB



Notes:

- The date that histology results were reported to the requesting clinician is used as the date of histological confirmation.
- The DHB is assigned based on the clinic where the original HSIL histology sample was collected, however, treatments will be included regardless of where they occurred.
- Source: Figure 90, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c)

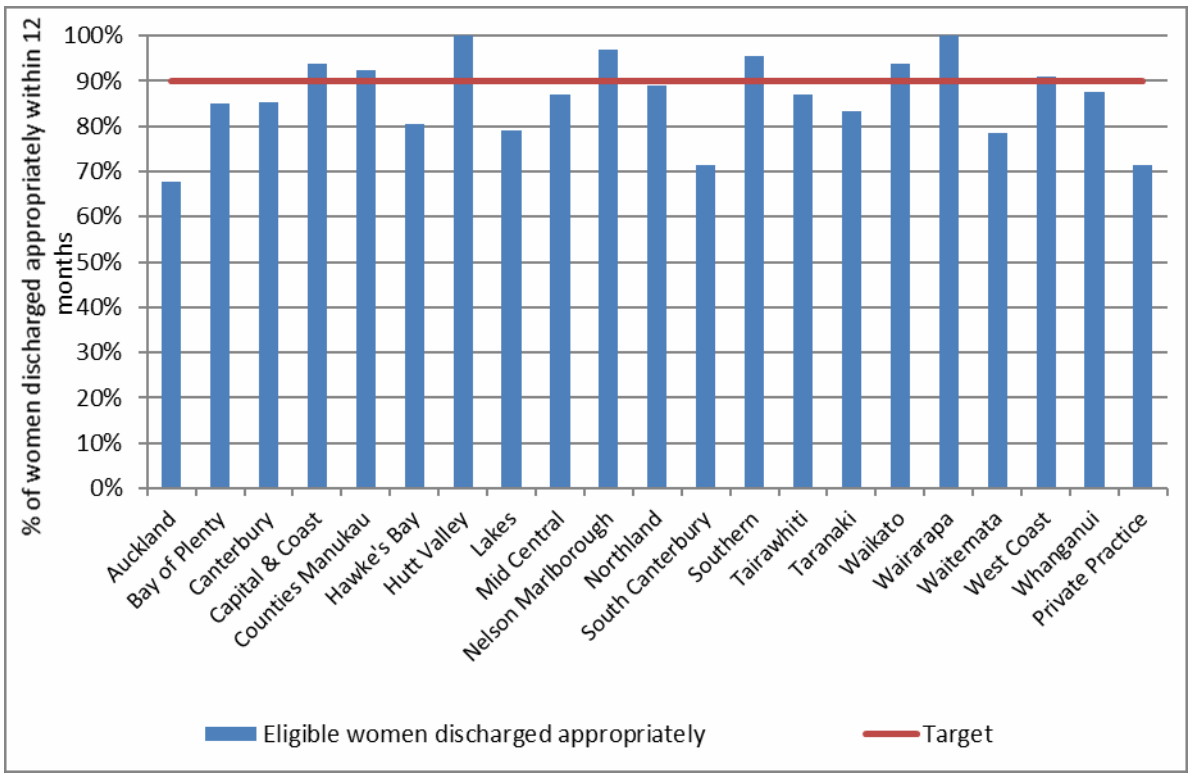
7.3: Timely discharging of women after treatment

The proportion of women with appropriate colposcopy follow-up after treatment has increased overall (from 76.4 percent to 77.5 percent for colposcopy and from 75.1 percent to 76.5 percent for both cytology and colposcopy). Two DHBs met the target of 90 percent of women having colposcopy and cytology within nine months of treatment, compared with none in the previous report.

The percentage of women discharged back to their service provider (most commonly their GP) by 12 months after treatment is shown in Figure 12.

It is possible that incomplete reporting of colposcopy visits has led to an underestimate of compliance with the standard.

Figure 13: Percentage of women discharged appropriately within 12 months of treatment, by DHB



Source: Figure 93, *National Cervical Screening Programme Monitoring Report Number 48 (1 July–31 December 2017)* (Smith et al 2018c)

7.4: Adequacy of documenting colposcopy assessment

The standard requires that 100 percent of medical notes record colposcopic findings accurately at first and any subsequent visits. This has not been achieved in any DHB. The current standard relates to the 2013 colposcopy standard, and not all DHBs and almost none of the private clinics report against this standard; instead they report against the 2008 standard.

With the completion of the transition to e-colposcopy data transfer from DHBs to the NCSP-R in August 2016 and the functional requirement to complete all fields to submit the data electronically, the adequacy of reporting should be improved. However, it is noted that only 6 of the 42 private clinics are using e-colposcopy, and further efforts should be made to encourage the remaining private clinics to move to electronic reporting in order to improve accuracy and to enable the collection of meaningful data.

Comment

The proportional over-representation of Māori, Pacific and Asian women not accessing timely follow-up for treatment and management of suspicious high-grade abnormalities indicates these women face barriers to accessing services. While this is a work in progress, strategies to identify and address these issues are essential.

The 2015 Parliamentary Review made several recommendations regarding the importance of accurate data, and it is pleasing to note all DHBs are now using e-

colposcopy, and this should be reflected in the accuracy of subsequent independent monitoring reports. The PRC understands that private practices are not contracted to the NCSP, and there is no mechanism to obligate them to report electronically. However, this is subject to an ongoing review process.

Indicator 8: HPV tests

The three indicators included under HPV tests are:

1. Triage of low-grade cytology
2. HPV test volumes (including the purpose for which the test was performed)
3. HPV tests for follow-up of women with a historical high-grade abnormality.

There are no targets set for any of the above indicators.

The indicator for triage of low-grade cytology reports showed no change since the previous report. A consistently small number of women aged under 30 years appear to have inappropriate HPV testing, and the reason is uncertain. The overall value of HPV triage is uncertain, and this was noted in the 2015 Parliamentary Review. As this 'HPV triage' will be discontinued in the new HPV screening programme, there is no plan to review the use of triage at this time.

HPV test volumes are largely unchanged since the previous independent monitoring report (47). There were no concerning trends regarding test volumes, but the report does explore the reason for some tests being outside the recommended purpose for the test, and this is of interest. (See also chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction, which discusses the need for clinical leadership and oversight of practices that fall outside the guidelines).

The use of HPV testing to provide evidence of low risk for women treated for high-grade histological abnormality before 2009, is included in the independent monitoring report. There are no unexpected changes, and variation by age, ethnicity and DHB were noted, but there are no issues of concern.

Comment

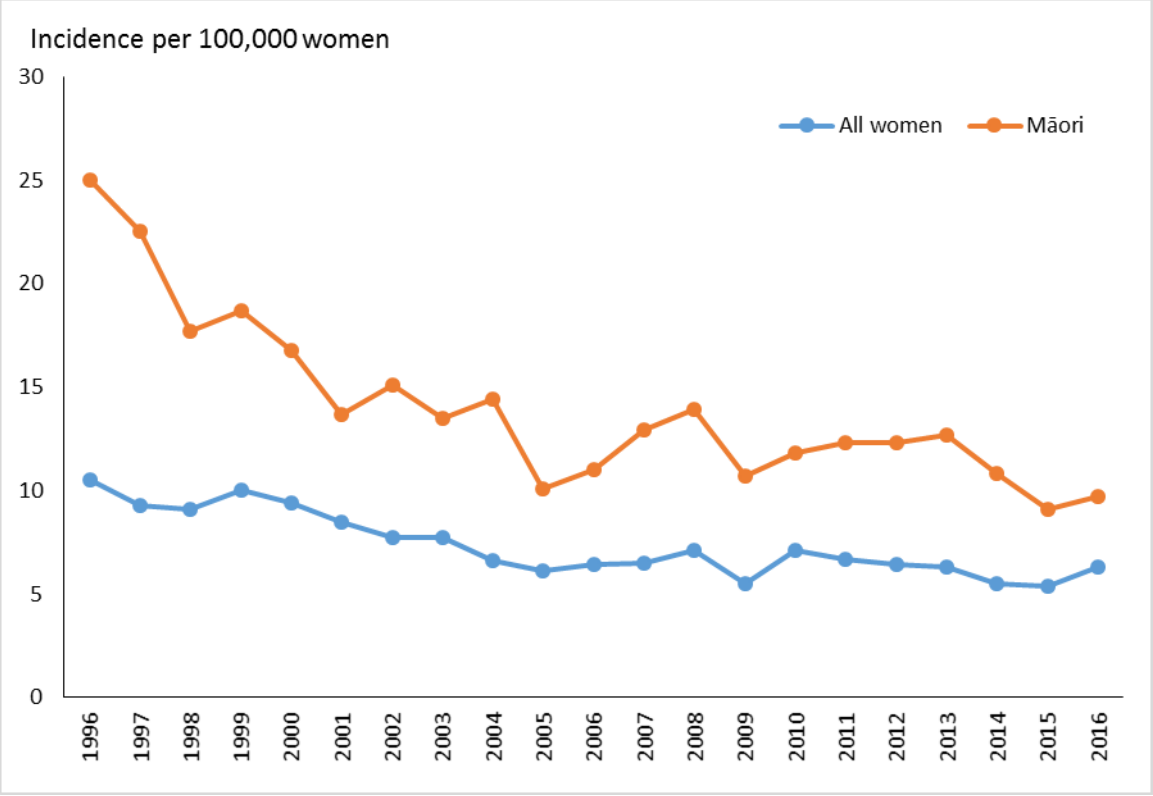
The independent monitoring reports are provided retrospectively at six-monthly intervals. The PRC believes that this could be extended to annually. In the period leading up to the transition to HPV screening, it may be useful for the NSU to regularly, in real-time, independently monitor the timeliness of cytology reporting, so that early trends of constraints in capacity can be identified and remediated wherever possible (see also chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction).

Monitoring and reviewing/auditing cervical cancer treatment in New Zealand

Cervical cancer is the fourth most common cancer worldwide with about 266,000 women dying from it each year (IARC 2016). Since the introduction of the NCSP in the early 1990s, there has been a steady decline in the incidence and mortality rates of cervical cancer in New Zealand. All cervical cancers are notified to the New Zealand Cancer Register (NZCR).

Between 1990 and 2015, incidence rates dropped from 11.5 per 100,000 to 5.4 per 100,000, a fall of over 60 percent. However, in 2016, there was an unexpected rise in incidence (with 170 new cases that year, compared with 144 cases in 2014 and 142 cases in 2015) and the incidence rate was 6.3 per 100,000, compared with 5.4 and 5.5 in the preceding two years.

Figure 14: Age-standardised cervical cancer incidence rates for Māori* and all women, 1996–2016†



Notes:

- Rates are per 100,000 women, age-standardised to the WHO standard population (all ages).
- Age-standardised rates for Māori women were not available for years before 1996.
- † Rates for 1996–2004 were sourced from *Cancer: New Registrations and Deaths, 2007* and *2006* (Ministry of Health 2010b and a respectively). Rates from 2005 are sourced from previous and the current NCSP annual monitoring report.
- Source: Figure 2, *NCSP Annual Report 2016* (Ministry of Health 2019)

Much of this appears to be due to a rise in the actual number and rate of cancers occurring in non-Māori women, as the actual number of cancers and incidence rate for Māori women has been relatively stable (though significantly higher than for non-Māori).

This data is important and is made available via the NZCR. It is also important to look carefully at individual cancers, in this case, cervical cancer, and see if there are any recurring themes relating to why New Zealand women are still suffering from this largely preventable disease. The first cervical cancer audit for 2000–2002 was reported in 2004 (Ministry of Health 2004).

The recent *Review of Cervical Cancer Occurrences in Relation to Screening History in New Zealand for the Years 2008–2012* by Professor Peter Sykes and colleagues from the University of Otago (Sykes et al 2018) builds on the work of the two previous reviews ((Ministry of Health 2004; Lewis et al 2009), one of which used the same methodology (Ministry of Health 2004). The multidisciplinary academic review team of Sykes et al provided a most informative report. They identified 772 women diagnosed with cervical cancer within the defined timeframe. They noted that the scope of the review was limited by lack of: access to clinical information, patient supplied information, a review of cytology specimens and a population-based control. Despite these difficulties, the report identified some recurring themes and made observations and recommendations that may improve future reviews and audits, one of which has recently commenced for the years 2013–2017.

Of the 772 women, 644 were eligible for cervical screening as recommended by the NCSP (aged 20–69 years). The remainder were excluded from the study proper, though some observations were made about their experiences.

Of the 644 women diagnosed with cancer aged 25–69 years, 328 had been screened in the 6–84 months before diagnosis, and of these, 127 had received an abnormal screen (92 had a high-grade screen). This represents almost 20 percent of women with cervical cancer in this age group. Their confirmed participation in the NCSP should have led to an earlier diagnosis at the very least or, more desirably, prevention of the cancer.

It appears that the majority of these women did have a colposcopy appointment or a referral for colposcopy but lack of access to clinical records made it impossible to draw any inferences regarding any shortcomings in the management pathway. In particular, the authors were unable to determine the factors that contribute to screening/diagnosis and treatment failure.

The report noted that Māori women were over-represented in this group of women, and it recommended a more detailed clinical review to identify remediable factors.

The report urged a 'review' of the smears of the 200 women who had reported 'normal' smears (of the 328 screened within 6–84 months of diagnosis). This review and audit should occur when any cervical cancer occurs, and the PRC notes that the smears that are reported as normal are regularly reviewed by all New Zealand laboratories. The rate at which possible or definite high-grade changes are detected on review of previous negative smear reports, before any high-grade or invasive histology, is regularly

monitored by the NCSP. This data is not readily available nor published, but it could give insights into the rate of false negative cytology and any modifiable factors that could influence cervical cancer incidence.

One of the prime aims of the Sykes et al study was to consider the screening history of women who developed cervical cancer in the timeframe 2008–2012. It is notable that only 13 percent of the 644 women who were eligible for cervical screening were considered to have an 'adequate' screening history, using the criteria defined in the 2002 review (Ministry of Health 2004). This is concerning and is echoed by data from Australia where 80 percent of cervical cancers have been found to occur in women who are never screened or under-screened (VCCR 2012). Regular participation in the screening programme offers the best protection against developing cervical cancer, along with the adoption of HPV vaccination.

Some of the more relevant observations from the Sykes et al 2018 report are listed below.

- Among the HPV-related cancers, SCC was the most common (72 percent), followed by adenocarcinoma (19 percent) and adeno-squamous (3 percent). HPV related cancer accounts for the overwhelming majority, 94 percent, of all cervical cancers.
- The cervical cancer incidence rates for Māori were significantly higher than for non-Māori.
- Cervical cancer occurred more commonly amongst those with higher levels of social deprivation, and there appeared to be less regular screening in women with a higher social deprivation index.
- Only 17 percent of NCSP eligible women who were diagnosed with cervical cancer had an adequate screening history.
- 44 percent of all women with SCC who had a smear in the 6–84 months before diagnosis had an abnormal smear.
  - 46 percent of Māori women who had a screen in the 6–84 months before diagnosis had an abnormal smear, compared with 26 percent of non-Māori women.
- Of the 92 women with a previous high-grade screen, 36 percent were Māori.
  - Of the 92 women, 82 percent had a colposcopy appointment registered.
  - Only 67 percent of these 92 women had a biopsy or treatment recorded on the NCSP-R, suggesting a lack/failure of follow-up.
- 24 women under the age of 25 years (3 percent) had cervical cancer.
  - 21 percent of these women were Māori.
  - 73 percent had microinvasive SCC (Stage 1a) and were likely to be diagnosed as a result of cervical screening.
  - 58 percent had a smear in the 6–42 months before diagnosis.
- Women aged 25–29 years represented 6 percent of cervical cancers.
  - 26 percent of these women were Māori.

  - 65 percent had SCC, and 58 percent of these women had microinvasive SCC (Stage 1a).
  - 24 percent of the women in this group were adequately screened.
- Women over 70 years old represent 11 percent of cervical cancer cases.
  - These were mainly non-Māori women with advanced stages of the disease.
- 39 women were over 80 years old, representing 5 percent of cervical cancer cases.
  - Only two of these women were Māori.
  - SCC was most dominant type of cancer for this group (77 percent).
  - Only three of these women had a previous screening test.
- The report endorsed the introduction of HPV-based screening.
  - Efforts should be made to ensure there is no reduction in five-year coverage.
- The report recommended prioritising improved access and quality of screening, as well as treatment of cervical cancer for Māori women and the more socially deprived.
  - Intervention strategies should consider the practical and cultural needs of these groups.
- Emphasis should continue to be placed on both enrolling and maintaining participation in the screening programme.
- With the proposed introduction of a later age (25 years) for starting screening, it is important the NCSP acknowledge the rare risk to women of upstaging screen-detected cancers and the possible increased incidence of cancer in women under 30 years old.
  - Ensure regular participation in screening from the age of commencement.
  - The programme should emphasise engaging women and getting high coverage from 25-year-old women.
- The report recommended establishing a system for ongoing audit and review of cervical cancer cases with a consistent methodology.
  - There should be pathology reviews of negative screening tests in the screening period before the diagnosis of cancer.
  - There should be case reviews of women with abnormal screening tests who subsequently were diagnosed with cervical cancer.
- The report recommended the introduction of formal clinical case reviews of women who have developed cervical cancer with previous abnormal screening tests, preferably prospectively.
  - This could be used to inform the programme, laboratories and medical practitioners of any modifiable factors that could have contributed to the outcome.

The NCSP considered all 29 recommendations made in the Sykes et al 2018 report and provided the PRC with an update on progress against the recommendations that have been actioned where feasible. The recommendations are included as Appendix 4 to this report.

The PRC notes that there is currently a further review and audit in progress (2013–2017). This includes a review of the clinical case notes where the cervical cancer diagnosis followed an abnormal screening test. There was, however, no capacity to conduct a full review of negative cytology slides from those women who subsequently developed cancer with a previous negative cytology report. Instead, there will be an assessment in the current review of the scope of 'slide review'. The PRC considers this to be an essential component of future reviews.

The PRC understands there is a proposal to develop a prospective cervical cancer review (audit) in real time and that the NCSP has suggested this be carried out 'in house' by the NCSP/NSU. The PRC believes that an independent academic review body, preferably with proven experience and demonstrated expertise in cervical screening audit and cervical cancer clinical case review, should carry out this review. Particular attention should be given to proper study design, involving multidisciplinary (including population screening expertise) input and the potential need for open disclosure of unexpected and adverse findings.

The NSU believes it would be most appropriate for the NSU to run this review with sector experts as part of the review panel.

It is also essential that this ongoing 'prospective review and audit' be adequately resourced with specific allocation of funding. The PRC anticipates that this multidisciplinary prospective review will further enhance the already robust governance and monitoring of the NCSP and provide further reassurance that the New Zealand NCSP is of the highest possible quality.

Conclusion

Several robust monitoring, review and audit activities ensure NCSP performance is effective and safe and where appropriate identify inequities and areas of concern. The independent monitoring reports, cervical cancer reviews, colposcopy audits and other activities provide a comprehensive review of the entire cervical screening pathway and beyond.

Some of the monitoring indicators will need a review with the implementation and change to primary HPV screening.

Recommendations

The PRC recommends:

- A continuous prospective audit should be undertaken of all cervical cancer diagnoses in New Zealand, including a review of cervical screening-related tests and investigations (HPV, cytology, histopathology and colposcopy) with audit findings translated into quality improvement initiatives.
- Independent monitoring should be carried out annually, and not six monthly. Interval monitoring data reports of key standards can be developed internally by the NSU.

- The NCSP independent monitoring reports, which are provided by independent external experts, should be continued for the foreseeable future, including through the transition to and implementation of the new primary HPV screening programme. The NCSP will benefit by having continued independent, robust and transparent evaluation of the programme.
- The NCSP should implement processes to monitor the timeliness of cytology reporting in the lead-up to HPV screening so that indications and early trends of capacity constraints might be identified. Ideally, monitoring should occur monthly.
- The recommended timelines for 'referral to colposcopy' should be reviewed to ensure they are appropriate, realistic and safe.
- The targets for indicators currently included in the independent monitoring reports should be reviewed for the implementation of primary HPV screening, and some new indicators for HPV testing will be required.
- The three yearly audit of DHB-contracted colposcopy services should continue, albeit in a modified form, with particular emphasis on areas not covered by e-colposcopy data reporting, such as those noted in Section B of the Colposcopy Audit Report Tool by Health and Disability Auditing New Zealand (HDANZ) (Health and Disability Auditing New Zealand 2017). A definition of the risk matrix with identified timelines for correction should be included in any audit report. (See also Chapter 5, Governance – Colposcopy Services).

Strategic direction on the change to primary HPV screening

This chapter reviews progress towards the transition to replace the current screening test (the Pap test) with primary HPV screening. Since 2005, there has been a plateau, documented internationally, in the incidence and mortality rates due to the limitations of the Pap test. This has led many countries to evaluate more effective screening methods, with most developed nations having already, or being in the process of, transitioning to primary HPV screening. Primary HPV screening is more effective and less costly than the current screening test, and combined with the opportunity for women to self-sample screening specimens, this new screening regime provides significant opportunity for improving equity outcomes.

Of particular importance is the need to appropriately resource and manage this transition as the magnitude of the multiple and complex changes to clinical practice, education and training, data collection, monitoring the effectiveness of the programme, pathology services and system and process changes required should not be underestimated.

Background

The NCSP is an organised approach to cervical screening that is implemented by a wide range of health professionals, including general practitioners (GPs), women's health nurses, colposcopists (gynaecologists, gynaecologic oncologists and nurses), cytologists, pathologists, health promoters and SSS community health workers. Underpinning this organised approach is the NCSP-R, which receives and collates data regarding cytology, histopathology, HPV tests and colposcopy to help with monitoring the NCSP's performance. The NCSP-R is responsible for sending reminder letters directly to women and issuing reports that enable women who are overdue for screening to be identified and reminded to screen. The NCSP is part of the NSU and is funded by the New Zealand Ministry of Health.

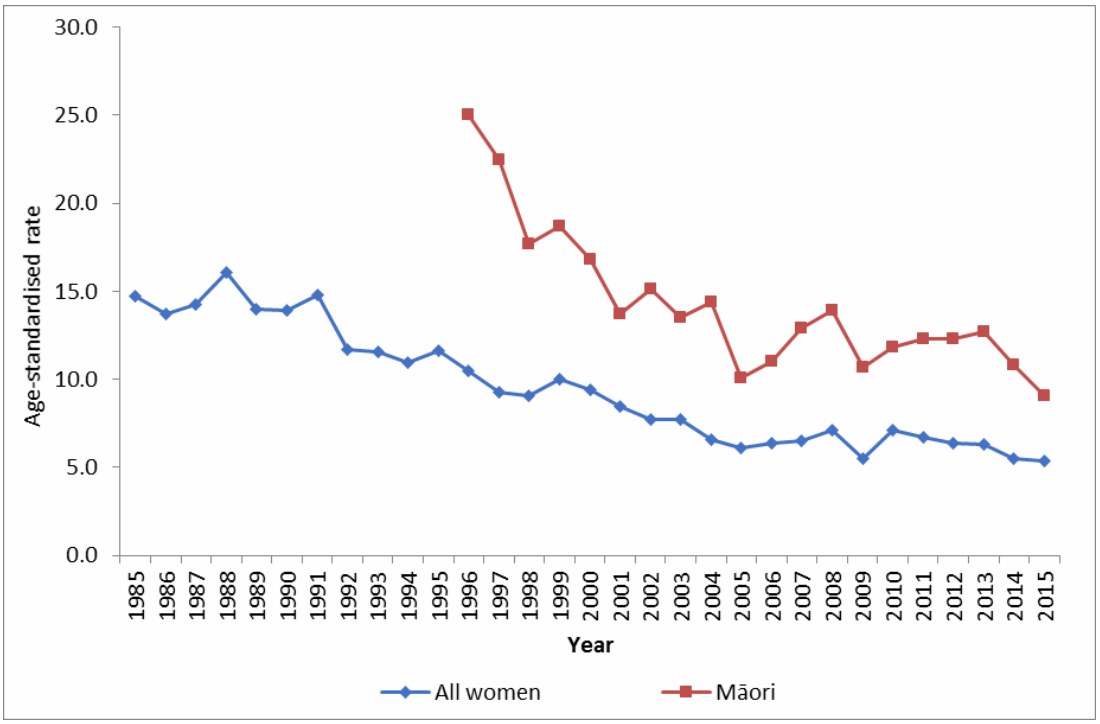
Since 2010, the NCSP has used liquid-based cervical cytology as the primary screening test. Women aged 20–69 years are recommended to have a cervical sample taken every three years. The cytology specimen is examined and, if no abnormal cells are detected, the woman is rescreened every three years. An HPV triage is performed when women over the age of 30 years have low-grade screen-detected cytologic abnormalities. If any abnormal cells are detected, further testing including colposcopy is usually recommended.

Colposcopy, the examination of the cervix using a magnifying instrument (the colposcope), is used to investigate any woman who has screen-detected abnormalities, in line with recommended management guidelines. A cervical biopsy may be taken for histopathology, and if significant pre-cancerous cervical abnormalities are detected, then the cervix is treated to remove the abnormal cells, thus preventing the development of cervical cancer.

Since 1990 New Zealand women have benefited from a highly effective cytology-based cervical screening programme that has been responsible for a 60 percent reduction in the incidence of cervical cancer and a 70 percent reduction in mortality due to cervical cancer (see Figure 15 below) (Ministry of Health 2019).

Since 2005, there has been a plateau in the incidence and mortality rates. The plateau has been documented internationally and is due to the limitations of the current Pap test. This has led many countries to consider and evaluate more effective screening methods, including primary HPV screening, which involves taking a cervical cell sample that is placed in a liquid medium for oncogenic HPV testing. If HPV is detected, then cytology is carried out on the same sample. This is very different to the existing programme, as described above, and HPV testing is reserved for triaging low-grade squamous abnormalities.

Figure 15: Age-standardised cervical cancer incidence rates for Māori* and all women, 1985–2015†



Notes

- Rates are per 100,000 women, age-standardised to the WHO standard population (all ages).
- Aged-standardised rates for Māori women were not available for years before 1996.
- † Rates for 1996–2004 were sourced from *Cancer: New Registrations and Deaths, 2007* and *2006* (Ministry of Health 2010b and a respectively). Rates from 2005 were sourced from previous and the current NCSP annual monitoring report. Other data was sourced directly from the New Zealand Ministry of Health.
- Source: Figure 2, *National Cervical Screening Programme Annual Report 2015* (Smith et al 2018c)

In 2015, the NCSP initiated a review process to consider the possible transition to primary HPV screening. A modelling and effectiveness study, funded by the Ministry, was performed by Professor Karen Canfell's group at the New South Wales Cancer Council Cancer Research Division. The study Effectiveness Modelling and Economic Evaluation of Primary HPV Screening for Cervical Cancer Prevention in New Zealand was published in May 2016. It concluded that 'primary HPV screening with partial genotyping would be more effective and less costly than the current cytology-based screening programme, in both unvaccinated and cohorts offered vaccination' (Lew et al 2016).

Primary HPV screening is more effective and less costly than current cytology screening.

In March 2016, the change to primary HPV screening was announced. In August of the same year, in preparation for HPV screening, it was announced that women would commence cervical screening at the age of 25 years instead of 20 years. The existing and current NCSP-R was investigated to see whether it could be modified to support the new NCSP, but unfortunately, it could not.

There has been a delay in the funding and subsequent development of the new NCSP-R including the NSS that will be essential to support the primary HPV screening pathway. This has delayed the commencement of the primary HPV screening programme, probably until 2020/2021. The delay has impacted the workforce and practices, creating a number of risks for the programme, and is also causing uncertainty among health care providers and consumers.

The strengths and opportunities of transitioning to primary HPV screening, as well as the adverse effects and risks are discussed further in this chapter. High-level concerns include:

- the concern that a premature loss of cytologists due to future workforce uncertainties may lead to delays in reporting results and to increased stress on the remaining cytology workforce
- health professionals and consumers losing confidence in the current programme
- early inappropriate HPV testing with subsequent difficulties in management
- a delay in improving equity for priority group women, causing distress for these women and their advocates
- some women and their health professionals delaying the scheduled screening in order to wait for the more sensitive new HPV screening test.

In December 2017, the NSU published *Strategic Assessment: National Cervical Screening Programme: Human papillomavirus primary screening*, detailing the rationale and requirements for moving from the current screening pathway and technology to primary HPV screening, seeking permission to develop a business case for funding (Ministry of Health 2017f).

The development of cervical cancers (HPV, cervical intraepithelial neoplasia and cancer)

In 1982, Harald zur Hausen demonstrated that the human papilloma virus (HPV) was the cause of cervical cancer. For his efforts, he received the Nobel Prize for Physiology or Medicine in 2008.

HPVs are DNA viruses that infect cutaneous or mucosal epithelium. There are over 130 types of HPV, of which 40 infect genital tract mucosa. They are classified into low- and high-risk (oncogenic or cancer-causing) types based on clinical outcome. Low-risk types cause benign anogenital warts, and of these HPV 6 and 11 cause over 90 percent of anogenital warts and recurrent respiratory papillomatosis. Infection with high-risk oncogenic types causes virtually 100 percent of cervical cancer, 90 percent of anal cancers, 50 percent of vulvar, vaginal and penile cancers and 12 percent of oropharyngeal cancers. Worldwide, HPV types 16 and18 cause about 70 percent of cervical cancers, and HPV types 16, 18, 45, 31, 33, 52, 58 and 35 cause approximately 95 percent of cervical cancers.

HPV is a common and usually asymptomatic, sexually transmitted infection. Almost all individuals become infected with HPV within two to five years of becoming sexually active. There is overwhelming evidence that HPV infection of the cervix is necessary for the development of cervical cancer (IARC 2012). While HPV infection is necessary for the development of cervical cancer in 99.7 percent of cases, it is not sufficient *alone,* and a variety of factors influence whether cancer will develop (Walboomers et al 1999).

Before the HPV vaccination, it was estimated that about 100 million adult women were infected with oncogenic HPV types, with approximately 528,000 new cases of cervical cancer worldwide each year (Franceschi et al 2006; Giles and Garland 2006). Several co-factors may increase the risk of developing cervix cancer, including cigarette smoking, multiparity (more than five full-term pregnancies), early age of first full-term pregnancy, use of oral contraceptives and immune deficiency. Persistent infection with certain oncogenic HPV types significantly increases the risk of developing cervical cancer (Koshiol et al 2008).

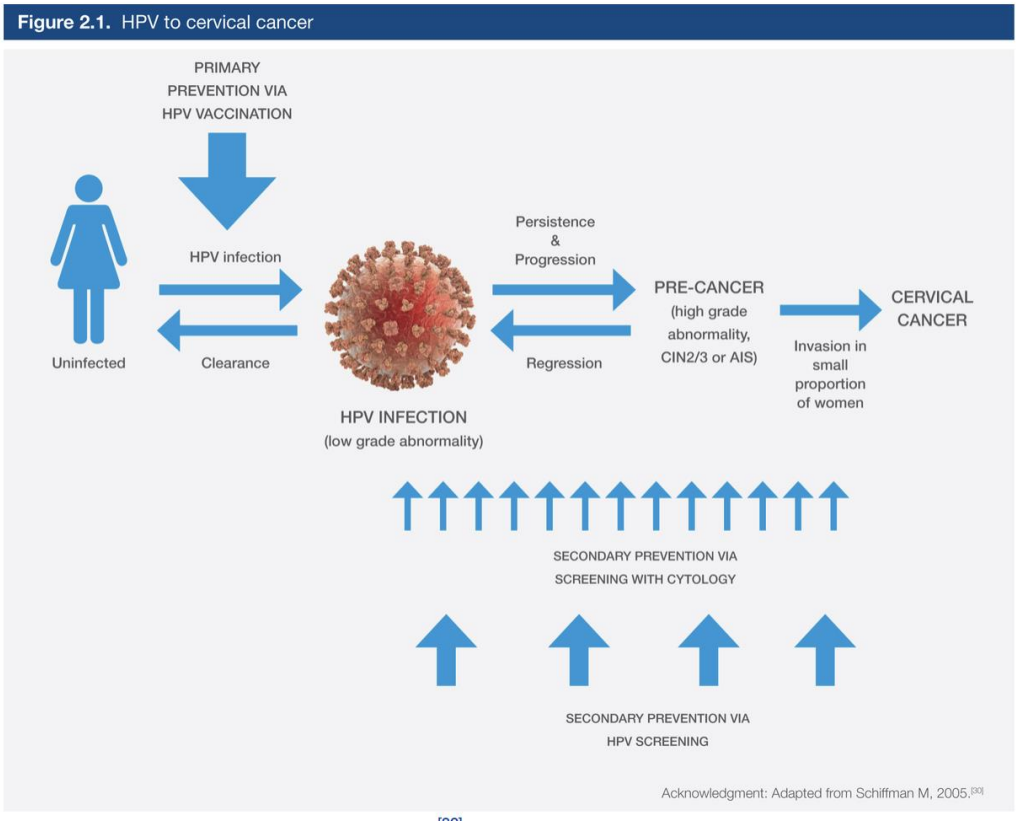
HPV infection is usually transmitted by skin to skin or mucosa to mucosa contact and is acquired during sexual activity. This includes genital skin to skin contact, vaginal sex, oral sex or anal sex. In most cases of HPV infection, the virus remains separate from the host (the woman). However, when cervical cancer develops, the DNA of the virus is integrated into the DNA of the host (the woman). The virus then inactivates the genes in the woman that suppress tumour growth. This leads to uncontrolled, abnormal cell growth that can become cancer if not detected and treated.
Preventing oncogenic HPV infection in women will prevent the development of cervical cancer. An important step was the introduction in 2008 of a primary prevention HPV vaccination programme in New Zealand for young girls and subsequent expanded age

groups as well as boys and young men. However, the benefits of HPV vaccination will take many years to realise and will not, on its own, prevent all cervical cancers.

Until recently, the HPV vaccine only contained four HPV types, two of which (16 and 18) are oncogenic. These two types are responsible for about 70 percent of cervical cancer. More recently the HPV vaccine has been improved to contain nine HPV types, seven of which are oncogenic and together are responsible for about 90 percent of cervical cancer globally. Because not all of the oncogenic HPV types are included in the HPV vaccine, there is still a risk that women will be infected by one of the HPV types not included in the vaccine, and this may lead to cervical cell abnormalities that may develop into cancer if undetected. It is essential that all women, whether vaccinated or not, continue to have cervical screening.

Primary HPV screening enables the identification of the presence of oncogenic HPV types in the cervical cells. Infection of the cervical cells can be detected before any cell changes have occurred. Cell changes can be detected by cytology (as in the Pap test), however, this occurs sometime after HPV infection. Primary HPV screening is a much more sensitive test than cytology, and using it allows for detection of the oncogenic HPV types before serious cervical cell changes have occurred, providing an earlier opportunity to diagnose and treat cervical abnormalities long before they have developed into a cervical cancer. There are four main steps in the development of cervical cancer: HPV infection, viral persistence, progression to cervical pre-cancer and finally invasion. This is shown schematically in Figure 16.

Figure 165: HPV to cervical cancer



Source: National Cervical Screening Program: Guidelines for the management of screen-detected abnormalities, screening in specific populations and investigation of abnormal vaginal bleeding (Canfell et al 2016)

HPV infection may lead to low grade squamous cervical intraepithelial neoplasia (CIN1 or atypia) that is the manifestation of a productive viral infection. The vast majority (80 percent) of these HPV infections are naturally cleared within 12 months and 95 percent within two years. However, persistent infection *may* lead to the development of high grade squamous cervical intraepithelial neoplasia (CIN2–3 / pre-cancerous cell changes). A small number of these CIN2–3 lesions may regress. If these high-grade cell changes are not detected or are untreated, a small proportion of these women will go on to develop invasive cervical cancer, usually over 10–20 years.

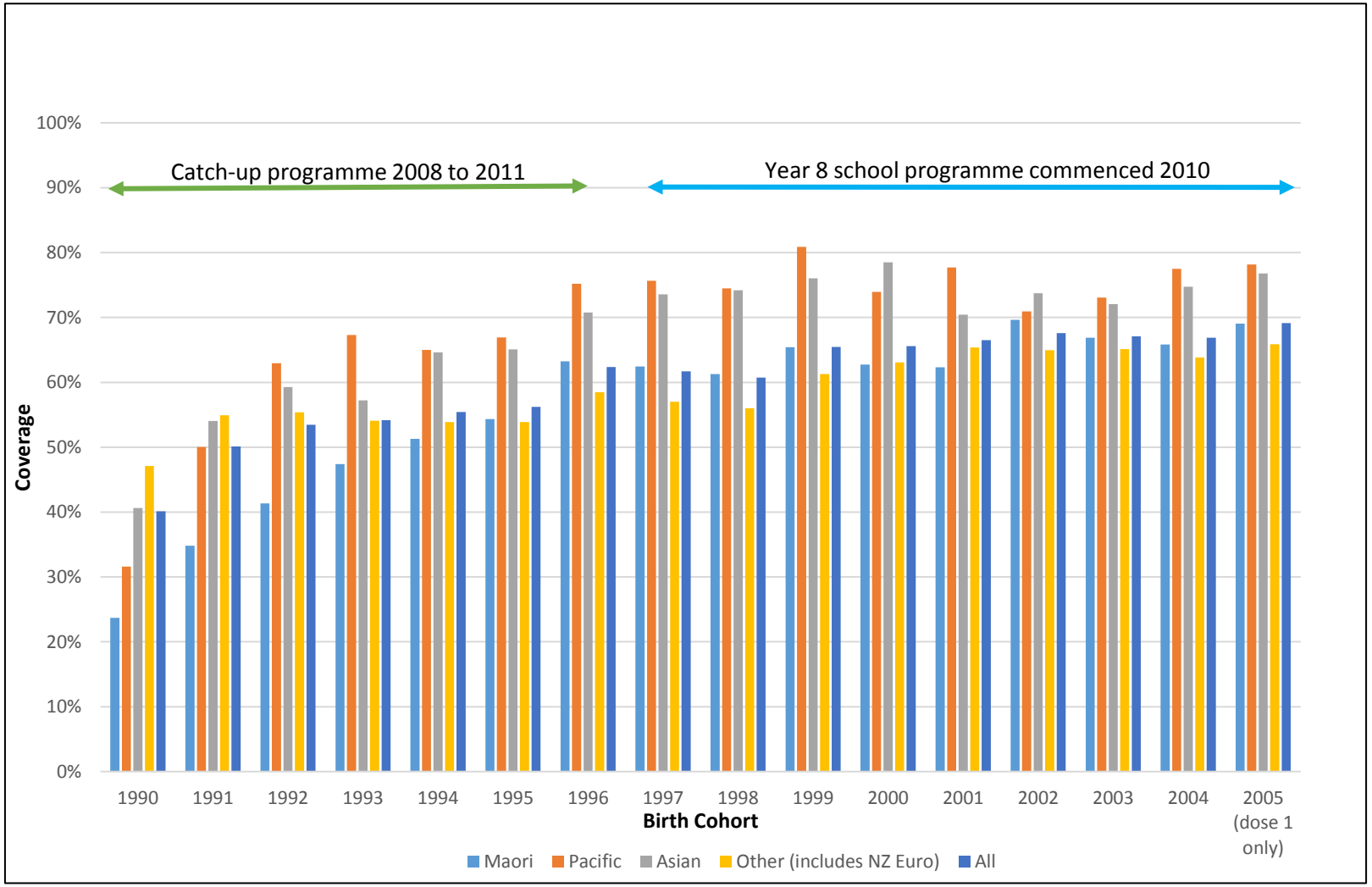
The cervical screening programme aims to detect the pre-cancerous cell changes before they develop into cancer and, by their removal or destruction, prevent the development of cervical cancer. Fortunately, most treatments are local to the cervix and in most cases do not affect cervical function and future fertility. Recent evidence has shown that using primary HPV screening is much more effective than the current cytology screening programme, especially in a population that has a national HPV vaccination programme. Not only is primary HPV screening more effective, but it will also be less costly than the current programme, in both vaccinated and unvaccinated cohorts (Lew et al 2016).

HPV vaccination in New Zealand

HPV vaccination using Gardasil® was introduced in New Zealand in 2008 for girls and young women up to the age of 20 years. Gardasil® protected against infection with HPV types 6, 11 (both of which cause genital warts) and 16 and 18, which cause 70 percent of cervical cancers globally.

From January 2017, HPV vaccination was fully funded for everyone aged 9–26 years – including boys and young men. Gardasil® 9, the new vaccine protecting against nine HPV types, has now replaced Gardasil® and offers protection against a further five oncogenic HPV types, 31, 33, 45, 52 and 58, and will eventually prevent 90 percent of cervical cancers in a fully vaccinated population. Gardasil® 9 is administered by two injections at least six months apart for those aged 14 years and under, while those aged 15 years or over need three doses to be fully protected.

Figure 17: HPV vaccination for girls, by birth cohort and ethnicity, 2008–30 June 2018

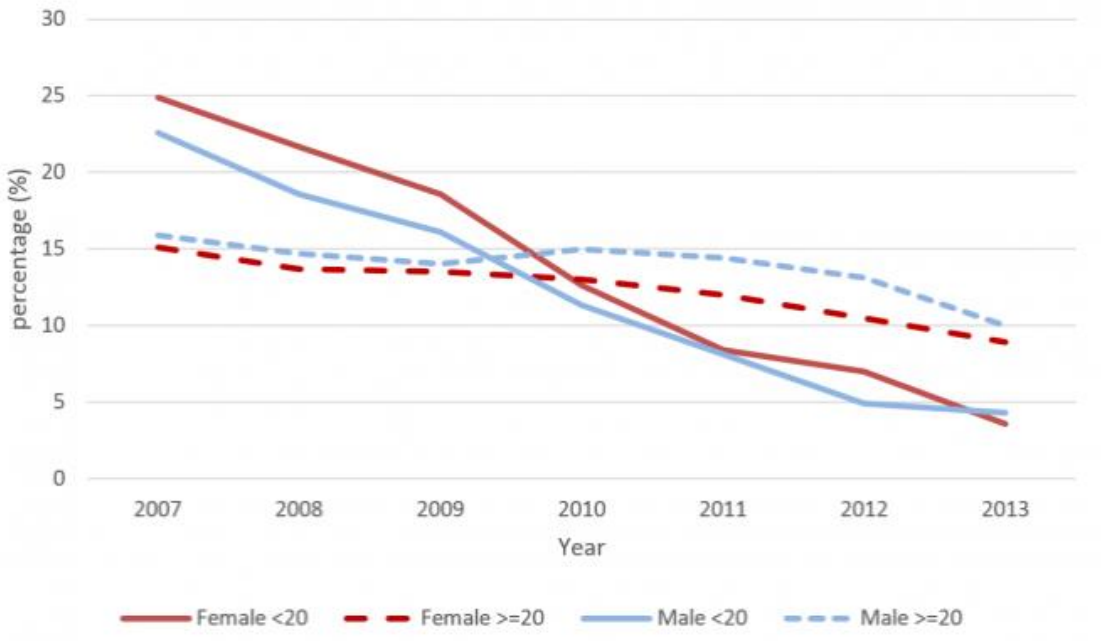


Source: Ministry of Health, 2019

Figure 17 shows the uptake of vaccination by birth cohort and ethnicity. It is clear that Asian and Pacific women have relatively high uptake in nearly all cohorts; both in the catch-up and the Year 8 school programme. Māori cohorts had less uptake, particularly in the catch-up group, but this improved significantly as the catch-up years progressed. In the Year 8 cohorts commencing in 2010, the uptake for Māori women is much improved (60–68 percent), similar to New Zealand European women but still less than Asian and Pacific women. It is possible that in the longer term, the higher rates of HPV vaccination may counteract the lower screening rates in these populations, thus reducing inequity.

There is good evidence from the Australian National HPV Vaccination Program Register and recent publications (Brotherton et al 2016) that the vaccinated cohort of younger women (under 30 years) are showing the beneficial effects of the vaccination. It has led to a reduction in the incidence of genital warts and declining incidence rates of histologically confirmed high grade squamous cervical lesions (CIN2–3). Early effects are now also being seen in the 30–34 year age group. Similar effects on genital warts are being seen in New Zealand, but at present, there is insufficient data to comment on high-grade rates.

Figure 18: Trends in genital warts diagnoses in New Zealand following the quadrivalent human papillomavirus vaccine introduction, 2007–2013



Note:

- From 2009 onwards, an increasing proportion of females presenting to the Auckland Sexual Health Service (ASHS) as ≥ 20 years old will have been less than 20 years old at the time the vaccine was introduced and so will have been eligible for funded vaccination. Over time, an increasing proportion of the group under the age of 20 years presenting to the ASHS will have been vaccinated as part of the school programme.
- Source: Figure 1, 'Trends in genital warts diagnoses in New Zealand five years following the quadrivalent human papillomavirus vaccine introduction' (Oliphant et al 2017)

HPV vaccination is leading to a reduction in oncogenic HPV infections in target populations, with a resultant decrease in the prevalence of high-grade cervical abnormalities, especially noted in younger women as these are the vaccinated cohorts and most likely to show a beneficial effect.

Optimal cervical cancer prevention can only be achieved by high HPV vaccination coverage and delivery of the best cervical screening strategy, which currently is HPV based.

Despite these demonstrable benefits, it is important to note that Gardasil® and the newer Gardasil® 9, do *not* protect against *all* oncogenic HPV types, and it is still very important for all eligible women to continue to participate in cervical screening, whether they are HPV vaccinated or not. It should be noted that overall uptake for New Zealand women is 67 percent (Ministry of Health 2017b). There is also a large number of older women who have not been offered vaccination, and they remain at increased risk of cervical cancer and should be screened. There is no room for complacency, and it remains important that New Zealand utilise the optimal technology for cervical screening. Current evidence indicates that the implementation of primary HPV screening would be more effective than the current NCSP and should not be delayed on the grounds that New Zealand has introduced HPV vaccination.

It is essential that all eligible women, whether vaccinated or not, continue to have cervical screening.

Current strategic planning for primary HPV screening in New Zealand

Following the acceptance of the NCSP HPV strategic assessment (Ministry of Health 2017f) the NSU is developing a business case to request funding for implementing primary HPV screening. It is proposed that HPV screening be implemented in 2020/2021, contingent upon appropriate resourcing for implementation. It is also dependent on the development of a NCSP-R that is fit for purpose and can manage the new programme, as the current register is not able to support the changes. The need for a new register has led to a delay in the introduction of primary HPV screening. Deloitte New Zealand has been contracted to undertake the initial planning and design for the NSS that will initially support the new National Bowel Screening Programme and subsequently the NCSP.

HPV testing in the current NCSP

In the current NCSP, HPV testing covers:

- triaging women aged 30 years or older with cytology showing low-grade cytology results
- managing women previously treated for high-grade lesions, to assess if they can return to routine three-yearly screening
- helping to manage women in whom there is discordance between cytology and colposcopy findings.

Monitoring of HPV test usage is further described in monitoring report 48 (Smith et al 2018c) and in chapter 3: Effectiveness of monitoring and evaluation in informing the NCSP's performance and clinical safety of this report. There have been no substantial or concerning changes from the previous report (number 47).

Primary HPV screening in the future NCSP

The PRC agree with three key problem areas identified by the NSU in the current NCSP:

1. The NCSP is using a less effective and more costly screening approach, and there is compelling evidence that transitioning to HPV screening will be more effective and less costly.
2. The current age range for the NCSP is no longer appropriate as the harms of screening women under 25 years outweigh the benefits. There is compelling international and regional evidence that women under the age of 25 years should not be screened (Smith and Canfell 2016; IARC 2004).
3. The existing register is inflexible, unsustainable and at the end of its useful life, and it will not be able to support the current programme for much longer.

The NSU conducted a public consultation process regarding primary HPV screening in 2015. In general, there was good engagement with positive feedback, and for some concerned groups, there was an opportunity for further engagement, which resolved their concerns (Ministry of Health 2016).

Transitioning to primary HPV screening

The PRC 2018 believes that transitioning to primary HPV screening has the following strengths and opportunities:

1. The transition will enable New Zealand women to access internationally recognised best practice in cervical screening. This will mean further reductions in both the incidence of and mortality due to cervical cancer.

   Australia, Netherlands, Finland, the United States and Italy have already implemented HPV screening. Ireland, Canada (Ontario and British Columbia) and the United Kingdom are all planning to implement HPV screening.

   The new programme will utilise five-yearly cervical screening using a primary HPV test with partial genotyping and reflex liquid-based cytology (LBC) triage for HPV vaccinated and unvaccinated women 25–69 years of age (Lew et al 2016).

   This is predicted to reduce cervical cancer incidence and mortality by a further 12–16 percent.

2. The transition presents the opportunity to introduce self-sampling to increase participation.

   In New Zealand, 80 percent of women who develop cervical cancer are under-screened or have never been screened (Lewis et al 2009). The use of HPV screening provides the opportunity to introduce self-sampling for cervical screening and increase participation by never-screened and under-screened women, including priority group women and women from deprived areas, among whom the incidence and mortality from cervical cancer is disproportionately high (Sykes et al 2018).

   It is anticipated that if self-sampling were implemented in parallel with primary HPV screening, it would be of considerable benefit to priority group women and help to reduce the equity gap.

   Several Australian publications demonstrate the acceptability and benefit of self-sampling in increasing participation for never and under-screened women, including indigenous women.(Sultana et al 2016, 2015; McLachlan et al 2018; Saville et al 2018).

3. The transition provides self-sampling research opportunities.

   There are currently two pilot studies in progress in New Zealand, and preliminary results are encouraging (Adcock et al 2018; Bartholomew et al 2018). The introduction of self-sampling would provide further opportunity for research and confirm the optimal clinical pathway.

4. The transition provides more opportunity to assess the future potential of self-sampling in New Zealand cervical screening. Self-sampling has the potential to be the universal screening method for all eligible women in New Zealand, but this will require further research.

   When HPV screening is implemented, there is an opportunity to carry out a pilot study in one geographical area to test the possible/proposed clinical pathway for a whole population 'self-sampling' approach rather than for just the priority

group women and under-screened and never screened women. See also: 2.3.5: The opportunity to address inequities through primary HPV self-sampling in chapter 2: Equity across the screening pathway

5. The transition opens the opportunity for further HPV education programmes. A recent study (Sherman et al 2018) suggests that New Zealand health professionals' levels of HPV knowledge may not be sufficient. This is consistent with conclusions the PRC reached from some interviews. The transition to a new programme provides an opportunity for HPV education programmes and reaffirming the importance of HPV vaccination and cervical screening.

   The 2015 PRC recommended ongoing education campaigns, and this remains important as, although cervical cancer is now a relatively rare disease in New Zealand European women, it remains a significant problem for priority group women, in particular, Māori and Pacific women, women living in the most deprived quintiles and unscreened and other under-screened women.

   It is especially important that information is appropriately provided in a culturally sensitive manner to priority group women and that the NCSP work collaboratively with the immunisation team to align messaging. The PRC understands that the NCSP is planning to continue to collaborate closely with the immunisation team in implementing the new programme.

6. The transition provides options for monitoring the NCSP. Current monitoring of the performance and effectiveness of the NCSP is conducted by independent external experts and detailed in the independent monitoring reports (Smith et al 2018c). This established, proven and robust process provides reassuring safeguards about the performance of the NCSP. Continued monitoring by independent external experts will be important as the programme enters the transition to HPV screening and beyond.

7. Implementing the HPV-based programme will lead to reductions in colposcopy referrals. Initially, it was predicted that the HPV programme would result in a 'steady state' increase in colposcopy referrals of about 15 percent. It was thought that a transient larger increase would probably occur in the first two to three years, similar to that predicted (and subsequently experienced) in the Australian programme (Lew et al 2016).

That study has recently been updated to take into account the combined effect of HPV vaccination and the introduction of primary HPV screening and the influence of the revised New Zealand guidelines for managing screen-detected abnormalities (Ministry of Health 2017a), which were not available at the time of the Lew et al 2016 study.

'The combined impact of implementing HPV immunisation and primary HPV screening in New Zealand: Transitional and long-term benefits, costs and resource utilisation implications' (Hall et al 2018) provides the first comprehensive long-term estimates of the cost, health outcomes, resource utilisation and test outcomes of the NCSP in New Zealand. It takes into account both the ongoing impact of HPV vaccination and the planned transition to HPV-based screening. This study predicts that the transitional colposcopy effects of the new HPV-based programme in New

Zealand will be much less than predicted and experienced in the Australian programme. This is because New Zealand currently has far more points of surveillance involving colposcopy, including triage of atypical squamous cells of undetermined significance (AS-CUS) and low-grade squamous intraepithelial lesion (LSIL) cytology, discordant cytology/histology and follow-up post treatment of HSIL. These will be significantly reduced in the new programme, including the marked dampening effect of no longer recommending follow-up colposcopy post-treatment for HSIL (CIN2–3).

It is predicted that there will be no increase in colposcopy at all, and instead there will be a steady reduction in colposcopy referrals, as shown in Table 4 below, which assumed the new programme would commence in 2019 as originally planned.

Table 4: Model estimated number of colposcopies and percentage reduction compared with 2018

Year	Model-estimated number of colposcopies	% reduction compared with the number of colposcopies in 2018 (ie, pre-transitional volume)
2018	27,527	0%
2019	24,384	11%
2020	23,329	15%
2021	22,551	18%
2022	20,650	25%
2023	18,508	33%
2024	18,670	32%
2025	20,304	26%
2026	20,960	24%
2027	19,953	28%
2028	18,658	32%

Note:

- In Australia, the actual increase in colposcopy was much greater than predicted, much of which is considered to be driven by inappropriate co-testing (HPV and LBC) by GPs and referrals outside the recommended guidelines, including a large volume of women under the age of 25 years (Australian Commonwealth Department of Health, personal communication, March 2019).
- Source: Hall et al 2018

8. The new HPV based programme presents an opportunity to further educate health professionals about the most appropriate clinical management of women with screen-detected abnormalities. There are significant changes to the existing cytology-based management algorithms as described in the *Clinical Practice Guidelines for Cervical Screening in New Zealand* (under development, last draft 30 March 2017). It is essential that these changes are well understood by all involved. It is also important that compliance with the new guidelines is formally monitored to ensure that women are having appropriate clinical management and that potential over-investigation and unnecessary treatment is avoided.

The PRC 2018 believe that any delay in implementing primary HPV screening will have significant adverse effects and risks. These are described in more detail to follow.

Unnecessary cervical cancers

The most serious threat is that the continuing delay in funding and implementing primary HPV screening will lead to approximately 25–30 women a year developing cervical cancers that could have been prevented by the new HPV-based programme. The recent prediction that there will be 190 new cervical cancers in New Zealand in 2018 (Global Cancer Observatory n.d.) is of concern, as this is higher than noted in recent years and many could be prevented by implementing this more effective programme (Ministry of Health 2019).

In the United Kingdom, a recent article posed the question 'Is a delay in the introduction of human papillomavirus-based cervical screening affordable?' (Castañon et al 2019) In the United Kingdom, a one-year delay in implementation would miss the opportunity to prevent 581 cases of cervical cancer – a loss of 1,595 quality-adjusted life years, with a monetary value of £32 million. The authors concluded, 'this was a measurable loss and should be considered in prioritising decision making in screening'. It is likely that these findings could, in principle, be translated to the New Zealand situation; however, this requires detailed modelling and this data was not available to the PRC.

In the United Kingdom, a one-year delay in implementing primary HPV screening would miss the opportunity to prevent 581 cases of cervical cancer – a loss of 1,595 quality-adjusted life years, with a monetary value of £32 million.

Further inequity for Māori women

Māori women have a higher incidence of cervical cancer, and it is predicted that the new HPV programme will reduce incidence in this population by 17 percent compared with 14 percent in European women (Smith et al 2018a).

Uncertainty about the implementation of HPV-based screening

There is a significant concern among health care providers and women regarding the uncertainty around the funding for the HPV programme and the expected date of implementation. It is crucial that the community is kept informed regarding the status of funding and implementation of the new programme.
As noted in the 2015 Parliamentary Review (recommendation 24), laboratories need certainty for effective workforce planning in order to maintain cytology staffing levels to provide efficient cytology reporting until the new programme begins.

There is concern among service providers that some women will delay their regular screening test in order to get the new test, leading to an increase in under-screened women in the approach to the transition to the new programme.

Loss of the cytology workforce

There is a very real risk that cytologists will seek alternative employment opportunities unless some certainty is confirmed regarding the start date of the new programme.

It is important to maintain an adequate cytology workforce to service the current NCSP until the new HPV-based programme is implemented and to ensure there is an adequate cytology workforce during the transition and after the new programme has been implemented.

Maintaining training opportunities for new cytologists is essential, and there is concern that the cytology training programme has been terminated in New Zealand tertiary institutions.

Potential challenges in the build-up to transitioning to primary HPV screening

The following advice should be taken into account by the NCSP as part of their implementation planning.

Development of the NCSP register

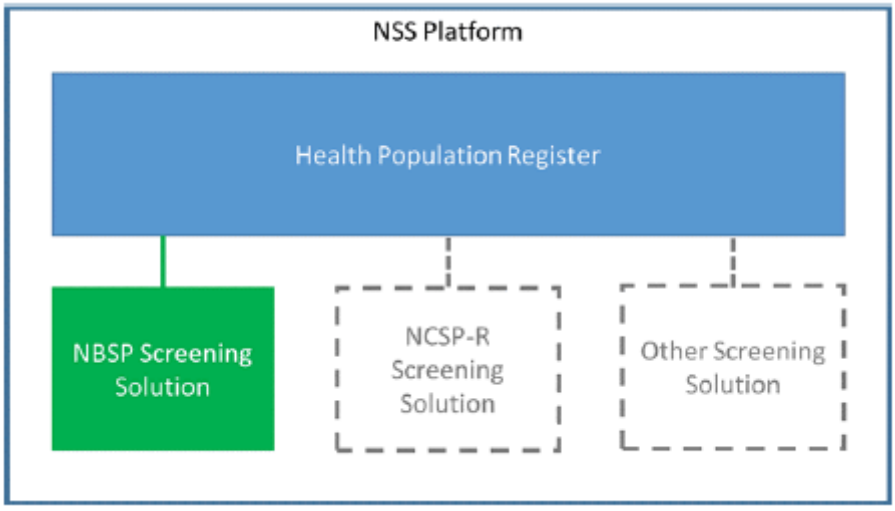
The PRC was concerned that the NSS might develop and build the National Bowel Screening Programme register first and then align the NCSP-R to that register. This risks causing a significant and unacceptable delay in developing a functioning NCSP-R, potentially leading to further delays in implementing the primary HPV screening programme.

The PRC accepts that both registers will have a common IT infrastructure. However, it is important to note that the NCSP-R has very different functional requirements to those of the bowel register. The NCSP-R is a complex data repository, clinical management and invitation/recall system and provides a safety net (reminder system) for women enrolled in the NCSP.

Following discussion with, and feedback from the NSU, the PRC is reassured that the NSS has been designed as a population health platform that is capable of supporting multiple population health initiatives (see Figure 18 below). There is a foundation platform that will be common across the National Bowel Screening Programme and the NCSP. The register for cervical screening will be built on the common platform but

will be separate with its own end-to-end process. The business rules, clinical rules, clinical functionality and algorithms for the NCSP have been subject to detailed analysis, and this analysis has been considered as part of the NSS design (NSU personal communication, February 2019).

Figure 19: National Screening Solution platform



Source: National Screening Unit 2019

The PRC has been assured by the NSU that the NSS's functionality for supporting the NCSP has been thoroughly tested. In addition, the NSS was procured through rigorous Treasury Gateway review processes, with experts providing assurance on all elements of change. It would be optimal if the NCSP-R were developed in parallel with the National Bowel Screening Programme register, but this may not be logistically possible.

The majority of interviewees involved in 'point-of-care service' emphasised the importance of 'real time' access to the NCSP-R. Effective and appropriate integration with PMSs must be considered as part of any design of a new technology solution for cervical screening.This design must consider how medical practitioners can access the information they need from their PMSs, including screening histories, to best support their patients.

Key informant:

> *'Having reliable screening history at the point of care can directly contribute to improved outcomes by enabling primary health care to correctly identify women eligible for specific interventions (eg, opportunistic screening, the offer of free screening or self-sampling for eligible women).*
>
> *'In our experience, 'at the point of care' has to go further than as a look-up function to a separate system (multiple clicks out and into). If clinicians (GPs or nurses) or receptionists (an important component of the opportunistic offer of service) have to do this, in general, they do not, and people are missed. It needs to be immediately obvious regarding eligibility and whether screening is up to date or not (eg, dashboard/alert).*

'We understand that the proposed screening solution will facilitate register look up, which is an important advancement. However, it is not sufficient, and end user experience around clinical workflow at point of care needs to be understood and designed into the solution itself.

'We understand that the primary health care PMS landscape is complex (multiple vendors) but believe this work is really important for integrated care.

'An IT system that can be integrated with the PMS has the potential to better manage clinical risk through electronic messaging from the NCSP for those at higher risk and to improve coverage through enhanced referral to support service providers.'

Information infrastructure for NCSP

The current NCSP-R team has gained considerable practical experience in the logistics and clinical functionality of the cervical register. It is vitally important that this knowledge is not lost during the development phase and implementation of the new IT solution for the NCSP. The PRC is pleased to note that during the procurement, design and build phases of the NSS, there has been – and will continue to be – a strong clinical input through the clinical reference group, led by the clinical director alongside the clinical leads, public health medicine specialists and external clinical experts. This confirms the PRC's view that the team chosen to develop the new national register should utilise the wealth of knowledge held by the current NCSP-R technical and management team in order to streamline the progress of this essential infrastructure project.

Self-sampling

The PRC believes it is essential for self-sampling to be included in the initial implementation of the new programme as this will lead to improved equity and increased participation for under-screened, never-screened women and priority group women.

The NSU strategic assessment document (Ministry of Health 2017f) mentioned the 'possibility of vaginal self-sampling for cervical screening' in the future. Since then, NSU has funded a study investigating self-sampling for Māori women to gain an understanding of how this could work in the New Zealand context (Victoria University of Wellington 2019).

Progress on draft clinical practice guidelines for cervical screening in New Zealand

The latest available version (30 March 2017) of the 'draft' clinical practice guidelines for the new primary HPV screening programme were developed in 2016 and do not include clinical management pathways for women who use a self-sampling strategy (Ministry of Health 2017a). The PRC suggests that these guidelines may benefit from

review due to the unexpected delay in implementing the new programme. The review should consider more recent international evidence and the guidelines should be updated where appropriate – particularly in the area of self-sampling.

The NSU recently informed the PRC that work has commenced on initial modelling to inform policy decisions regarding self-sampling, and the NSU will be updating the 'draft' guidelines to reflect the updated policy in due course.

Effective communication on HPV negative cervical cancers

There may be concerns among women and health professionals that some cervical cancers are negative for HPV infection and will not be detected in the new programme.

The vast majority, but not all, cervical cancers are caused by HPV infection. Some rare types of cervical cancer are not caused by HPV and have not been easily detected by the current cytology (Pap test) screening programme.

A targeted communication and education programme should proactively manage community concerns that this new HPV programme will miss cancers (see also chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction).

The increased sensitivity of the HPV test will lead to a further 12–16 percent reduction in the incidence of cervical cancer, even though a very small number of cervical cancers are HPV negative.

Increased screening interval

Some consumers and health care providers may be concerned about the safety of increasing the screening interval from three-yearly cytology to five-yearly HPV testing. This concern may lead to anxiety and early re-screening, thus reducing the effectiveness and efficiency of the new programme.

It is crucial that both women and their doctors have confidence that the five-year interval is both effective and safe.

Several studies have demonstrated the increased sensitivity of the HPV test and that the likelihood of developing cervical cancer within five to six years of a negative HPV test is remote (Cuzick et all 2006) (Arbyn et all 2006) (Dillner et al 2008).
A recent meta-analysis of four randomised controlled European trials of primary HPV testing has demonstrated that, at longer screening intervals, HPV-based screening provides 60–70 percent greater protection against invasive cervical cancers than cytology, with improved prevention of adenocarcinomas (Ronco et al 2014).

Communicating this information to women and their doctors is an essential part of implementing the new programme. This should be an important role for the NCSP clinical leaders in colposcopy and pathology.

Not screening women aged under 25 years

There may be consumer and health care provider concerns regarding the safety of not screening women under 25 years of age. This aspect of the new programme is due to commence in 2019, before the expected implementation of primary HPV screening. Community and health professional education regarding the safety of this approach is essential, emphasising the harms of screening younger women.

The new starting age of 25 years has been shown to be safe. In 2005, the International Agency for Research on Cancer (IARC) recommended that cervical screening begin at age 25 (IARC 2005).

Most countries with an organised approach to cervical screening commence screening at age 25 or 30 years, with cervical cancer incidence and mortality rates similar to New Zealand (Global Cancer Observatory n.d.). The harms of screening younger women, mainly through overtreatment, far outweigh any perceived benefits, particularly regarding reproductive outcomes in later life (Canfell et al 2016).

Adequately resourcing the National Screening Unit

The NSU is responsible for operating six screening programmes, including Breastscreen Aotearoa, National Bowel Screening Programme, NCSP, Universal Newborn Hearing Screening, Newborn Metabolic Screening Programme and Antenatal Screening for Downs syndrome and Other Conditions. This is a small unit with enthusiastic, capable and committed staff who are working to capacity.

The PRC notes that the NSU is adequately resourced to manage the 'business as usual' activity of the NCSP, including the background preparation for implementing HPV screening. However, the NSU project activity to actually implement primary HPV screening will require significant specific resourcing to support all workstreams under the project.

Planning and implementing the transition to the new NCSP will require a significant increase in workload for the NSU management and cervical screening team, including advising and testing the NSS, ensuring the NSS algorithms assign clinical pathways correctly, reminding women and providers at appropriate intervals when screening or follow-up testing is due, developing and delivering training for health care providers (including general practice, pathology and colposcopy), developing quality indicators to enable monitoring of the new programme and developing and implementing community education and messaging for women. Appropriate resourcing and staffing for the HPV implementation project must be a priority.

Potential challenges in the transition to HPV screening

Transient increase in cervical cancer diagnoses

The increased sensitivity of the HPV test compared with cytology will lead to increased numbers of cervical cancers being diagnosed in the first and second screening rounds using the new test. This will cause concern to women and health professionals and may lead to critical media reports with adverse publicity for the NCSP. This increase is predicted to occur in both Australia and New Zealand and should be explained to the public and health professionals before the new programme is implemented (Hall et al 2018).

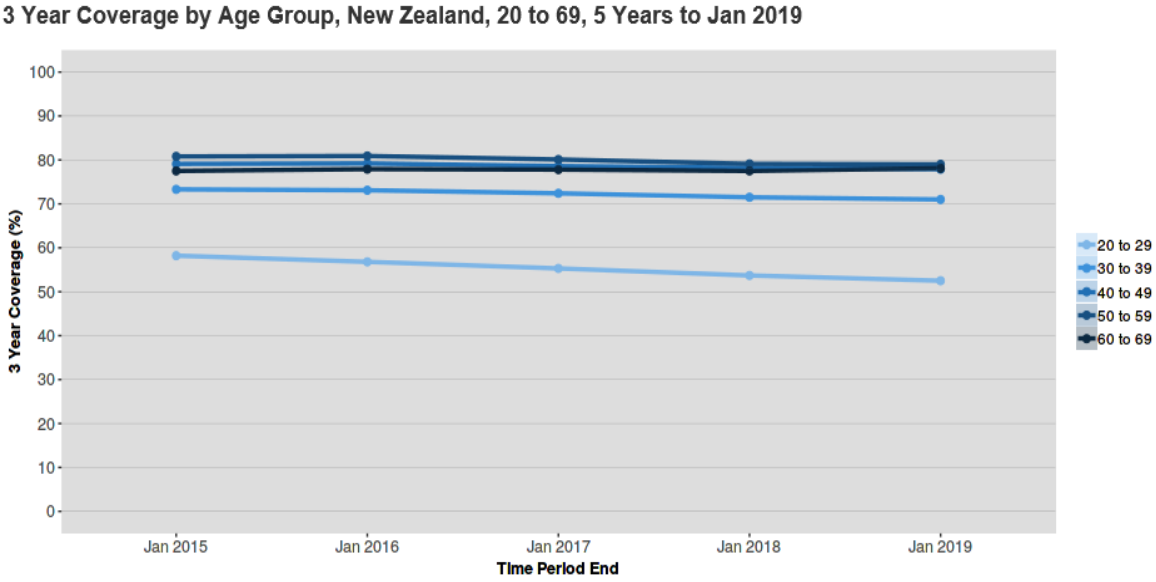
Maintaining coverage

It is important throughout the transition to maintain or improve current coverage (participation) in cervical screening to produce the predicted benefits of the new programme.

There is evidence that coverage has declined in the past three years. The cause is not certain and is probably multifactorial. It may be due to some of the HPV vaccinated cohort not participating in the programme due to the erroneous belief that they are protected and do not require screening, as has been reported in younger HPV vaccinated women in Australia (Budd et al 2014). It could be related to less focus on the promotion of cervical screening, competing priorities for priority group women and other disadvantaged women with limited financial resources, and other factors as yet unknown.

It is essential to provide community education regarding the need for HPV-vaccinated women to continue screening.

Figure 20: Three-yearly coverage by age group, New Zealand, 20–69 years, 2015–2019



Source: Ministry of Health 2019

Managing symptomatic women

Women of any age with symptoms that may be due to cervical cancer must be clinically examined. There is concern among service providers that 'symptomatic women' will not be examined or investigated appropriately, especially those under the age of 25 years.

Women of any age who have symptoms that could be attributed to cervical cancer require a physical examination, diagnostic testing (co-test with HPV test and LBC) and appropriate investigation. 'Screening' is reserved for asymptomatic women in the target age group of 25–69 years.

It is essential that all symptomatic women of any age be encouraged to present to their health care provider for examination and assessment. The PRC is reassured that the NSU has included this advice, with suggested clinical pathways, in the draft clinical practice guidelines for cervical screening in New Zealand.

Community and health care provider education is essential. (See also: Communication in chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction).

Recommendations

The PRC makes the following recommendations.

- Primary HPV screening, including self-sampling, should be funded and implemented as a matter of urgency. Delays in implementing the primary HPV screening programme will result in a significant number of otherwise preventable cervical cancers in New Zealand women and continuing inequities.

- The PRC believes it is essential that self-sampling be included in the initial implementation of the new primary HPV programme as this will lead to improved equity for and the increased participation of priority group women.
- A pilot programme should be developed to examine the feasibility of 'whole population self-sampling for cervical screening'.
- The 'draft' 2017a Clinical Practice Guidelines for Cervical Screening in New Zealand should be reviewed, including the development of a clinical management pathway for women who have HPV detected in a self-sample.
- As part of the NSU's project planning processes for transitioning to primary HPV screening, it will be important to incorporate the lead-in time required by pathology laboratories to commence HPV screening regimes.
- The NSU should continue to collaborate closely with laboratories regarding the maintenance of a cytology workforce up to and after the new HPV screening programme has been implemented. This includes providing early advice regarding the confirmed date for implementing the new programme.
- A coordinated national training and education campaign around HPV infection, cervical cancer, HPV vaccination and HPV cervical screening is needed for women and service providers (including colposcopists) before and while implementing the primary HPV screening programme. Emphasis should be given to ensuring the availability of culturally appropriate information for Māori, Pacific and Asian women.
- The development of the new NCSP-R, as part of the NSS, should occur in parallel with the National Bowel Screening Programme Register, if this is logistically possible, and not be delayed until after the National Bowel Screening Programme Register has been developed. This would reduce the risk of unnecessary further delay to implementation of the new HPV screening programme.
- The NSU and the NCSP team should be adequately and specifically resourced (both in terms of staff and financially) to enable an effective and efficient transition to the new HPV screening programme, especially as the magnitude of the multiple and complex changes required should not be underestimated..

5 The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction

The WHO document *National Cancer Control Programmes: Policies and managerial guidelines* (2002) identifies the importance of competent management in identifying priorities and resources, organising and coordinating those resources to sustain progress and continually maintain momentum, and introducing any necessary modifications through monitoring and evaluation. A quality improvement approach, systematic decision-making based on evidence, a comprehensive system with interrelated key components across different levels of the health system and partnerships with clinical disciplines are all identified as critical elements of well-managed, highly effective cancer control programmes.

These WHO guidelines articulate the essential criteria for sound operational and clinical governance of an effective and efficient population screening programme. This chapter reviews and discusses the well-managed operational governance of the NCSP, with recommendations for reviewing some committees (both internal and advisory), their roles, memberships and functions. Having clear expectations of the clinical leads' roles in meeting both their clinical discipline needs as well as their NSU function of supporting population screening principles will enhance a shared understanding and improve collaboration within the multi-disciplinary leadership team.

The PRC considered the NSU's alignment with national health strategies and initiatives and commends the management team on their strategic direction and ongoing efforts to maintain, whilst implementing changes to, a high-quality screening programme.

A well-developed communications' strategy that maps the needs of stakeholders, articulates training requirements for service providers across all sectors and engages and consults with priority groups during its development must be a priority for the primary HPV screening implementation project.

Governance

There is not one absolute definition of the term 'governance'. The Governance Institute of Australia, for example, defines it as

> '... the system by which an organisation is controlled and operates, and the mechanisms by which it, and its people, are held to account. Ethics, risk management, compliance and administration are all elements of governance' (Governance Institute of Australia 2019).

The Australian Stock Exchange Corporate Governance Council states corporate governance is 'the framework of rules, relationships, systems and processes within and by which authority is exercised and controlled' (ASX Corporate Governance Council 2019 Pg 1.).

The Canadian Institute on Governance (IOG) says 'Governance determines who has power, who makes decisions, how other players make their voice heard and how account is rendered' (Institute on Governance n.d.).

All these definitions have relevance to the governance of the NCSP.

For the purpose of this report, the term 'governance' refers to the management of the NCSP, both within the NSU and devolved to DHBs and service providers; the systems, structures and advisory bodies through which the programme receives advice and guidance and the committees and mechanisms for providing stakeholder input and feedback to the programme. Clinical governance is defined further below.

The WHO states that governance in health systems refers to a wide range of steering and rule-making-related functions carried out by governments and decision-makers in order to achieve national health policy objectives that effectively deliver universal health coverage and that effective governance systems will:

- ensure the maintenance of the strategic direction of policy development and implementation
- enable the detection and correction of undesirable trends or deviations from policy or agreed practice
- identify and advocate for any evidence-based changes or modifications in national policy or strategic direction
- establish and maintain transparent and effective accountability mechanisms (WHO 2007).

Good governance in screening programmes is forward thinking, requiring collaboration with all sectors of health service delivery, incorporating the public and private sectors, representative and interested organisations, and consumers of the services. Good governance will ensure that the screening programme promotes and maintains population health in a manner that encourages inclusion to achieve effective and equitable levels of participation and the programme's aims and objectives.

The WHO defines cancer screening as 'the systematic application of a screening test in a presumably asymptomatic population. It aims to identify individuals with an abnormality suggestive of a specific cancer' (Module 3, Page 3. WHO 2007).

Screening differs from so-called 'opportunistic testing,' which is where a test for an unsuspected disease is offered when a person presents to a health care practitioner for reasons unrelated to that disease (The Australian Population Based Screening Framework, Standing Committee on Screening 2018).

An effective and cost-effective screening programme must include core systematic components from inviting the target population to clearly defined and managed pathways to access effective treatment for individuals diagnosed with the disease or its precursors. Robust governance and clinical governance structures and arrangements that support and underpin screening programme implementation and delivery are essential to an effective and quality screening programme.

Clinical governance

The former Director of Clinical Governance for the United Kingdom's National Health Service (NHS), Professor Aidan Halligan, is credited with implementing consistent standards of care across the NHS.

He describes clinical governance as:

- systematically joining up of clinical initiatives to improve quality
- setting standards and ensuring they are met
- monitoring performance and implementing interventions where clinical quality falls short of the standards or expected outcomes (Halligan and Donaldson 2001).

Halligan and Donaldson's 2001 description is echoed throughout health system governance literature and was concisely captured in a foundation United Kingdom Department of Health document that defined clinical governance as 'A framework through which organisations are accountable for continually improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish' (Scally and Donaldson 1998).

To achieve its objective of reducing mortality and morbidity from cervical cancer, the New Zealand NCSP needs robust systems forboth corporate and clinical governance that are effective and interdependent.

Context

The PRC met with, and received submissions from, the following individuals, groups and organisations that are essential to the governance and clinical governance of the NCSP:

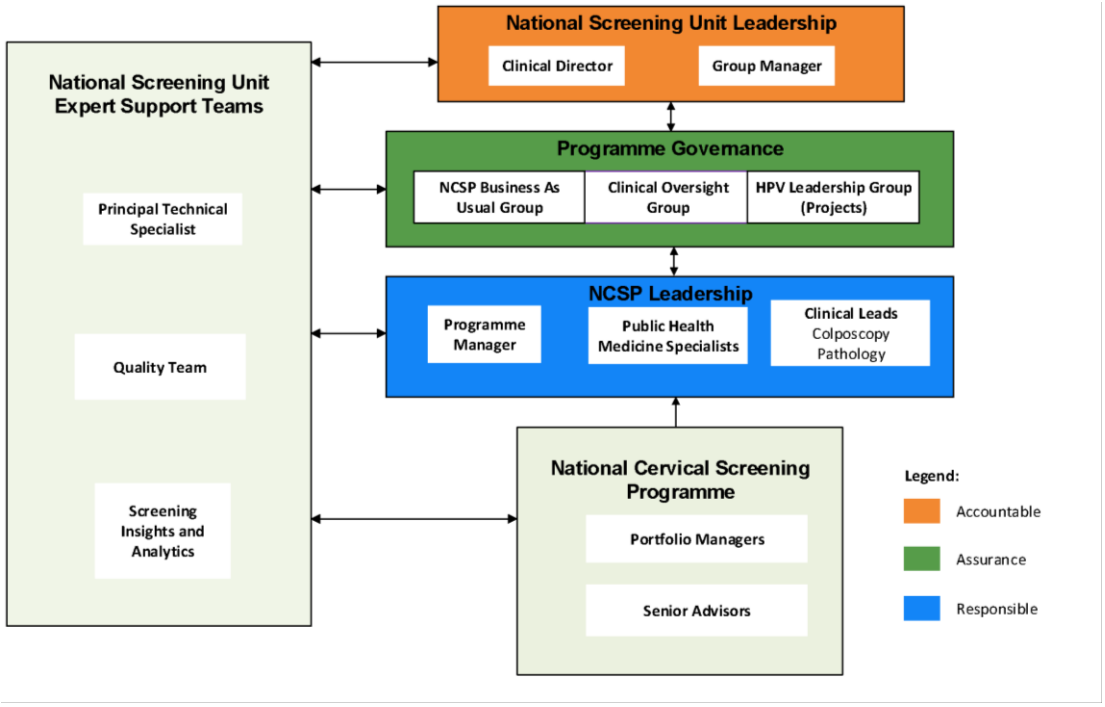
- DHBs

- PHOs
- SSSs
- Women's advocacy groups
- Ministry staff
- NCSP-R staff
- Advisory groups
- Programme governance groups.

For a full list, please see Appendix 2.

The NSU is situated within the Ministry's Population Health and Prevention directorate and is responsible for developing, managing and monitoring nationally-organised population-based screening in New Zealand. The NSU manages six screening programmes and one quality improvement programme.

Figure 21: NCSP governance structure



The NCSP was implemented in 1990 as the first of the current organised screening programmes. It has succeeded in more than halving cervical cancer incidence and mortality since its inception.

The findings and recommendations from The Cartwright Inquiry (1987–1988) were seminal in establishing this cervical screening programme, and Judge Cartwright's perceptive document has led to not just local but arguably global improvements in patient-centred health care.

Of particular relevance to this 2018 Parliamentary Review is that many of Judge Cartwright's 1988 concerns and findings are still evident today. Judge Cartwright found

that the reason women who developed invasive cancer of the cervix were not identified at the pre-invasive stage by screening was that they had not been screened, or not regularly.

Judge Cartwright warned of problems in implementing organised cervical screening and found that 'the barriers to Māori women screening are financial, cultural and questions of accessibility. Cost is a major barrier to Māori women attending a general practitioner, with many attending a doctor only when they or their children are ill …' (Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters 1988, page 202).

In 2018, 30 years after the release of The Cartwright Inquiry, multiple sources told the PRC that cost is the greatest barrier to achieving equity in participation and preventing cervical cancer in the most at-risk women.

Cartwright advised that Pacific women have similar needs to Māori women and that low-paid and older women were also at increased risk of developing cervical cancer because of barriers to screening. Judge Cartwright reported that there was a significant group in the community that were falling through the 'large holes in the opportunistic screening net', and 'It is of great concern that cost deters most of these women …' She concluded 'there is a real need to establish a screening procedure which will systematically attempt to locate and screen the entire female at-risk population' (Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters 1988, Ch. 10 Pg 200-203).

It might appear that little has changed over 30 years but this is not true. There have been significant improvements in preventing cervical cancer since the NCSP was implemented in 1990, but challenges identified in Judge Cartwright's report continue today.

The incidence of cervical cancer reached a peak of 16.7 per 100,000 women in 1979. The 2017 NCSP commissioned review of screening histories found 772 confirmed diagnoses of cervical cancer were made during the period 2008–2012, with an incidence rate of 6.9 per 100,000 women per year (Sykes et al 2018).

Only 13% of the 644 women aged 25–69 years diagnosed with cervical cancer between 2008 and 2012 had regular cervical cancer screening in accordance with the New Zealand guidelines.

This proportion was even lower among Māori and Pacific women and those living in deprived areas. Just as Judge Cartwright found in 1988: 'the large holes in screening equity and access' are just as evident today (Committee of Inquiry into Allegations Concerning the Treatment of Cervical Cancer at National Women's Hospital and into Other Related Matters 1988, Ch. 10 Pg. 203). See also chapter 4: Strategic direction on the change to primary HPV screening.

NZCR data published in August 2018 shows that cervical cancer is the fifth most common cancer in Māori women. However, cervical cancer is not in the 'top 10' of new cancer registrations for the whole population for 2016. In New Zealand's nearest neighbour, Australia, cervical cancer is the 14th most common cancer in women. Māori females had a registration rate twice that of non-Māori females (RR 2.06, CI 1.64–2.58), and the mortality rate for Māori females was about 2.5 times that of non-Māori females (RR 2.57, CI 1.70–3.90) (Ministry of Health NZCR n.d. and Tatau Kahukura: Māori Health Statistics n.d.).

According to the WHO, cervical cancer is the fourth most frequent cancer in women globally, and approximately 90 percent of deaths from cervical cancer occurr in low- and middle-income countries (WHO. *Cancer: Cervical cancer* 2018).

The 2010 report Cancer Trends: *Trends in cancer incidence by ethnic and socioeconomic group*, *New Zealand 1981–2004* jointly produced by the University of Otago and the Ministry of Health found that:

> 'Of particular policy relevance is the finding of dramatic falls in cervical cancer incidence among all ethnic and income groups, with a pronounced narrowing in inequalities; this is a notable public health success story. Much of this success is almost certainly due to screening, and (perhaps surprisingly) demonstrates that even without equivalent programme coverage across all ethnic and socioeconomic groups, a screening programme can contribute to marked reductions in absolute inequalities. Understanding trends in cancer incidence, and in social inequalities in cancer incidence, can help policy-makers to optimise cancer control programmes, as well as affording insight into patterns of distribution of risk factors, so guiding wider public health action.' (Blakely et al 2010)

It is important to note the first nine years of data in the above-mentioned 2010 report was for a period before organised cervical screening began, and it was expected there would be significant improvements in reducing cervical cancer incidence across the entire period covered by the report – nine years beforehand and the first 14 years of screening. The commentary regarding 'absolute inequalities' could be considered an academic debate and does not reflect the current need to focus on health inequities across the Māori and non-Māori population groups most at risk of developing cervical cancer. The report highlights the need to understand trends in social inequalities in cancer incidence and to use this information to guide policy and public health action. This is particularly relevant in the current environment with signs of increasing inequities in cervical cancer incidence and mortality.

Where are we now?

There is no doubt that cervical cancer prevention in New Zealand has achieved a considerable level of success. However, one of the key tenets of an effective screening programme is that governance should be strategic and forward-thinking. The planned implementation of primary HPV screening demonstrates the NSU's commitment to sound governance – looking forward and planning for reductions in the burden of cervical cancer among New Zealand women, particularly those women who are most at risk and currently disproportionately represented in incidence and mortality data.

*The PRC found an authentic and universal commitment to achieving equity in cervical cancer prevention across all clinical disciplines, regions and stakeholder groups. There are many dedicated, passionate individuals working to prevent cervical cancer, a disease that is unique among cancers as it is mostly preventable. The NCSP is, on the whole, a high-quality programme – **for those women who screen**. Unfortunately, there are too many women who do not screen, and the burden of disease is disproportionately distributed. Although the programme is generally performing well, there are impediments to improvements.*

Now is not a time for complacency. Robust and effective screening programmes require high levels of maintenance and continuous quality improvement. There are indications of some concerning trends with the NCSP, including a decline in participation in some areas, increasing percentages of screened women having delayed follow-up and a suggestion of an increase in cervical cancer incidence (see chapter 4: Strategic direction on the change to primary HPV screening).

Multiple international studies show a direct correlation between deprivation (including ethnic, cultural and socioeconomic disadvantage) and lower (and declining) screening programme coverage. New Zealand is no exception. There have been many suggestions as to the reason for this decline. However, as with all wicked[1] problems, there is neither a simple nor singular answer. Effective programme governance and progressive, innovative strategies are required if we are to halt declining participation and increasing incidence. The planned introduction of primary HPV screening is an important step in continuous quality improvement for cervical screening in New Zealand and should be implemented as soon as feasibly possible.

[1] Public services are increasingly tasked with solving very complex policy problems. Some of these issues are so complex that they have been called 'wicked' problems. 'Wicked' in this context means an issue that is highly resistant to resolution (Australian Public Service Commission 2007).

Alignment with the New Zealand Health Strategy

The PRC reviewed the New Zealand Health Strategy and considered the relevance to and alignment of the current and future delivery of cervical screening services with the strategy. The PRC found the issues identified through the independent review of health funding and the strategy were replicated within the NCSP.

The strategy identifies the need for current health investment to achieve long-term health goals. That investment needs to be wisely made, must be flexible so the system can respond to changing need and evidence and must be used appropriately to ensure systems do not contribute to inequities for groups and individuals in accessing services and improved health outcomes. The following excerpts from the strategy are particularly relevant to cervical screening and many of the findings from this review:

> **'**An investment approach takes into account the long-term impact of current government spending on people's lives ...
>
> 'An independent review of New Zealand's health funding system noted three ways in which funding arrangements sometimes prevent resources from being used to achieve the best possible outcomes.
>
> - Present arrangements may not clearly show the results that we get from health spending, making it hard to prioritise funding or take into account long-term, cross-sectoral benefits from investment.
> - When demand changes, service mix and design may not change quickly enough to deal with it. Often our funding and contracting arrangements encourage health services to keep doing things as they have always done them, instead of allowing them to work differently.
> - Some funding arrangements contribute to disparities between groups in their access to services, and sometimes they widen the gap in unmet need ...
>
> '"... tailored approaches are needed for some individuals and population groups so they can access the same level of service and enjoy the same outcomes as others ...
>
> **'Refreshed guiding principles for the system**
>
> 1. Acknowledging the special relationship between Māori and the Crown under the Treaty of Waitangi
> 2. The best health and wellbeing possible for all New Zealanders throughout their lives
> 3. An improvement in health status of those currently disadvantaged
> 4. Collaborative health promotion, rehabilitation and disease and injury prevention by all sectors

5. Timely and equitable access for all New Zealanders to a comprehensive range of health and disability services, regardless of ability to pay
6. A high-performing system in which people have confidence
7. Active partnership with people and communities at all levels
8. Thinking beyond narrow definitions of health and collaborating with others to achieve wellbeing ...' (Minister of Health 2016).

The strategy also states 'The things we need for our health and independence can vary widely. For example, we may need primary care and community services to support our wellness and prevent illness'. It recognises that the health system can struggle to give all New Zealanders equitable access to health services and that some population groups benefit less from the health system than the population as a whole. It says that health services need to achieve better outcomes for everyone, which requires new ways of working to deliver the services the population needs.

The strategy identifies five strategic themes so that all New Zealanders live well, stay well and get well. These five themes provide a focus for change and improvement across the health system. The themes (listed below) are interconnected, with people as the focus.

- People-powered (Mā te iwi hei kawe)
- Closer to home (Ka aro mai ki te kāinga)
- Value and high performance (Te whāinga hua me te tika o ngā mahi)
- One team (Kotahi te tīma)
- Smart system (He atamai te whakaraupapa).

The Ministry's Statement of Strategic Intentions 2017 to 2021 advises that:
'The Ministry funds, purchases services from and regulates national health and disability services, on behalf of the Crown, in line with Government priorities and the Ministry of Health's strategic intentions. These health and disability services include:

- public health interventions (such as immunisation or dealing with outbreaks of disease)
- disability support services
- screening services (such as cervical screening)
- maternity services
- child health
- ambulance services.

As the main funder and purchaser of services on behalf of the Crown, the Ministry makes it possible for others to provide services that support all New Zealanders to live well, stay well and get well.' (Ministry of Health 2017e)

The guiding principles for delivering the New Zealand health system successfully are also essential principles for a successful cervical screening programme. All the guiding principles are pertinent, however, in particular, with regards to this 2018 Parliamentary Review, the guiding principles identify the need for:

- An improvement in health status of those currently disadvantaged
- Timely and equitable access for all New Zealanders to a comprehensive range of health services, regardless of ability to pay.

The current programme funding arrangements sometimes prevent resources from being used to achieve the best possible outcomes; and some funding arrangements contribute to disparities between groups in their ability to access services.

The National Screening Unit strategic direction

The NSU's internal working document *National Screening for Healthier Futures 2017 to 2022* (Ministry of Health 2017d) states 'Our vision is that people can access high-quality and equitable national screening programmes that contribute to healthier futures.' The stated aim of the NSU is to have more integrated and cohesive national screening services that work in the best interests of New Zealanders.

Source: *National Screening for Healthier Futures 2017 to 2022* (Ministry of Health 2017d)

Governance and management within the NSU appear to have remained relatively stable since the 2015 Parliamentary Review. The programme manager of the NCSP has joined the NSU team since the last Parliamentary Review and is working with the leadership team on business planning for implementing primary HPV screening. This is a large and complex task, in particular while ensuring the safe and effective ongoing delivery of the current Pap-based programme.

The complexities of managing the delivery of the population-based screening programmes are perhaps not widely appreciated – it is a difficult, albeit rewarding, area to work in. The NSU has responsibility and accountability for achieving programme objectives. However, the devolvement of service delivery to DHBs has left the NSU without direct influence or control, and with very weak 'levers' to influence the quality and consistency of screening services to ensure the programme's objectives are achieved. The successes of the NCSP to date are a credit to the commitment of the NSU management, clinical advisory and leadership teams.

Effectiveness of advisory structures to support the NCSP

The NSU seeks programme delivery advice and guidance from a number of formal internal and external advisory groups as well as independent stakeholder interest groups. Some of the independent stakeholders may also hold contracts with the NSU for delivering SSSs.

Independent stakeholder interest groups

- Federation of Women's Health Councils (FWHC)
- Women's Health Action.

Formal advisory and management groups

- National Cervical Screening Advisory Group
- Māori Monitoring and Equity Group
- HPV Clincial Oversight Group
- HPV Testing for Primary Screening Project Technical Reference Group
- National Cervical Screening Programme Primary Human Papilloma Virus (HPV) Screening Implementation Leadership Group.

The PRC held discussions with each of these groups, and details from the discussions with the formal advisory and management groups are provided below.

National Cervical Screening Advisory Group

The National Cervical Screening Advisory Group comprises representatives of the clinical disciplines working within the programme as well as consumer representatives. This group's terms of reference state it will:

- review, critique and interpret the monitoring report data and make recommendations to the NSU
- provide advice on the strategic direction of the programme
- provide advice on other areas of the programme as agreed by the group and the NSU
- help build understanding and partnership with consumer and professional groups;
- be chaired either by an elected group member or by an independent chair appointed by the NSU
- receive administrative and analytical support from the NCSP team.

The PRC meeting with available members of the advisory group identified some shared concerns within the group with the organisation and conduct of meetings. Advisory group members felt that meetings were not conducted in accordance with the terms of reference and the meetings seemed to be 'more of a "show-and-tell" report by the NSU'.

It was not obvious to the PRC that the advisory group is being utilised to its full potential. It seems that currently, the group's only function is to review the monitoring reports, although it is understood some members of the group have also participated in advising on the new primary HPV screening guidelines.

It is equally important that advisory group members fulfil their roles as advocates for the screening programme, supporting the NSU in its responsibility to ensure the delivery of a safe and effective programme and building understanding and partnerships with consumer and professional groups. To facilitate the transition to the new screening pathway, it would be of benefit for members of the group to take on a leadership role in disseminating advice and informing their relevant sector about the implementation of the new screening pathway.

The advisory group made constructive suggestions as to how the NSU could benefit from the expertise of the group and improving the conduct of meetings, including:

- reviewing the terms of reference
- being chaired by an independent person
- structuring the meetings better, with agenda papers either for noting or clearly articulating what advice and recommendations are required from the group
- providing the minutes from meetings promptly so the discussions are still fresh in the attendees minds
- providing sufficient time for papers to be reviewed (and consulted on if necessary) –ideally at least two weeks before meetings.

The terms of reference for the National Cervical Screening Advisory Group are included as Appendix 6.

The PRC wish to acknowledge and thank advisory group members for their willingness to engage in frank and open dialogue.

Māori Monitoring and Evaluation Group

The group's recently reviewed terms of reference state that the objectives of the MMEG are:

- to provide Māori leadership on strategic issues related to population health screening and its impact on Māori health and inequities
- to provide Māori strategic advice on planning, implementing, monitoring and evaluating the existing screening programmes and any further screening programmes under consideration
- to monitor the NSU's progress against the aspirations and actions set out in *National Screening for Healthier Futures 2017 to 2022* (Ministry of Health 2017d).

The PRC reviewed agendas and minutes of MMEG meetings held in 2018 and attended part of the MMEG meeting on 6 November 2018. MMEG advise on all screening programmes, and from a review of meeting minutes, it appears that the group had only had a minimal focus on cervical screening over the last year. However, the group were happy to share their thoughts on the directions of cervical screening and the delivery and governance of the programme for Māori women for this report.

Understandably, much of the discussion centred around equity. The group's observations were insightful, with statements such as 'the people with the greatest burden of the disease have the most to gain as a population [from cervical screening]'. However, the consensus was that the current methods of delivering the programme seemed to be, as one member noted, 'more about mitigating the risks for the government rather than the risks for Māori women'. The group felt there were no consequences if screening targets were not met, and therefore, there were no incentives for providers to improve. They proposed there should be a strategy developed to improve performance in cervical screening delivery, in particular, educating providers around the meaning of equity to improve capability and capacity.

The group were also of the view there is little or no control or monitoring of how funding for free screens is allocated or distributed and believe that if there is a true commitment to equity and reducing the incidence of and mortality from cervical cancer, screening should be universally free.

The group noted there is an opportunity for the Ministry to make a significant difference at a local level but that this requires real commitment and strategic thinking, with greater sharing and utilisation of resources, and a 'focus on the person, not just the part of the body'.

The PRC wishes to acknowledge and thank MMEG members for their willingness to engage in frank and open dialogue. MMEG's observations were thought-provoking, constructive and most helpful to the PRC's review of cervical screening.

The Waitangi Tribunal findings at stage one of the Health Services and Outcomes Kaupapa Inquiry (Waitangi Tribunal 2019) included finding that the Crown has failed to ensure that Māori have adequate decision-making authority and influence when it comes to the design and delivery of primary health care services. The continuation of

MMEG and inclusion of Māori representation at all levels of NCSP governance would be considered a Treaty responsibility and essential to designing and implementing a programme that is effective for Māori.

Key informant:

> 'Our unscreened and under-screened women must be the target of better education and face-to-face discussions with people who understand the programme, HPV, vaccination, etc. They will require novel approaches to screening, but mostly, they will require a lot of time to establish the level of trust required to accept screening. These women are very hard to find and very hard to engage.'

The terms of reference for the Māori Monitoring and Equity Group are included as Appendix 5.

HPV Clinical Oversight Group

The HPV Clinical Oversight Group (COG) is an internal NSU group responsible for all clinical aspects of the NCSP relating to raising the screening commencement age to 25 years and introducing HPV as the primary test. The group reports to the NCSP HPV leadership group. Membership (of both individuals and roles) across both groups are very similar.

The group's objectives are:

- to support the development of and decide on the clinical guidelines
- to support the development of and decide on the policies and standards
- to support the development of and decide on the key performance indicators
- to receive monthly monitoring reports on the roll-out and act on any issues that arise
- to monitor incidents and sentinel events and act on any recommendations that arise
- to support the development of and decide the programme monitoring strategy.

These objectives are specific to introducing primary HPV screening. It is noted that the quorum requirements for the COG state that either the pathology lead or colposcopy lead must be present for decision-makingThe PRC believes that ideally, both clinicians should be present. Other members of the group, whilst having important population health expertise, are not practising clinicians within the NCSP. As this is a clinical oversight group, it is important there are decision-makers present at meetings who have the discipline-specific expert clinical knowledge to identify issues and advise on clinical decisions. The expertise of practising clinicians with intimate knowledge of cervical screening and clinical management of cervical disease will be particularly important to support the transition to HPV screening.

The PRC believes that the COG would benefit from greater contribution from, or engagement with, discipline-specific, practising clinical experts to contribute to and

advise on clinical decisions for the programme. This contribution should include advice from practising smear-takers (future cervical sample HPV test takers). As the COG is an internal committee, the NSU have advised it would be more appropriate to include a practising smear taker in the external advisory group. Clarification of the processes for decision-making and obtaining the appropriate discipline-specific clinical expertise when required would be of benefit.

HPV Testing for Primary Screening Project Technical Reference Group

The terms of reference for the HPV Testing for Primary Screening Project Technical Reference Group state that the group will provide expert advice to the NSU in its consideration of introducing HPV testing for primary screening to the NCSP. The group met regularly through 2015 but have met irregularly since – only once over the last 12 months.

It appears the group are utilised as an information-gathering resource for the NCSP as required and will be called upon when needs arise. The group's terms of reference are included as Appendix 7.

National Cervical Screening Programme Primary Human Papilloma Virus (HPV) Screening Implementation Leaders Group

The terms 'Leaders' and 'Leadership' are both used in this group's terms of reference.

The draft terms of reference state that the purpose of this group is:

- to provide leadership for implementing primary HPV screening
- to receive recommendations from sub-groups
- to provide guidance, recommendations and support
- to ensure the primary HPV screening and related projects are implemented on time, within budget and to an acceptable quality
- to provide accountability to the NCSP HPV Senior Responsible Officer for the performance of the NCSP HPV screening implementation.

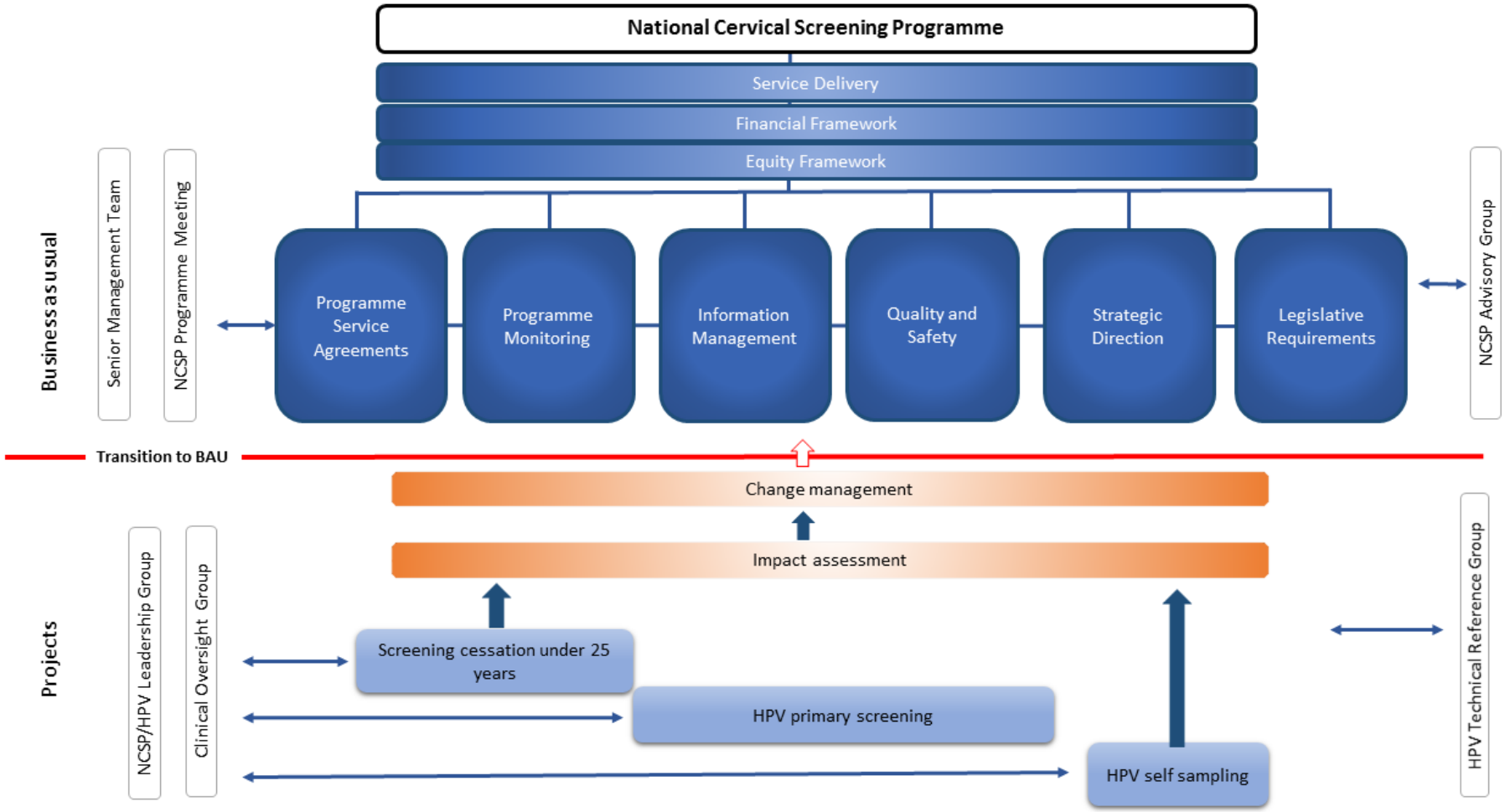
The full terms of reference for the National Cervical Screening Programme Primary Human Papilloma Virus (HPV) Screening Implementation Leaders Group are included as Appendix 8.

As well as the above-identified committees and groups, the June 2018 terms of reference for the National Cervical Screening Programme Primary Human Papilloma Virus (HPV) Screening Implementation Leaders Group (Appendix 8) includes a schematic of the NCSP Primary HPV Screening Implementation – Governance Structure and identifies another Colposcopy Q.A. Group and a Cytology Governance Group.

The PRC recommends a review of governance (both clinical and operational) and advisory committees to maximise the committees' efficiency and minimise potential duplication of work. There should be a focus on the multi-disciplinary requirements of

committees leading this important population screening programme and the balance required between population screening and practising clinical expertise. In particular, the COG would benefit from more discipline-specific, practising clinical experts to advise this group on clinical decisions for the programme.

Figure 22: NCSP clinical organisational structure



Clinical advice and leadership

The NCSP organisational structure has two clinical lead roles in the areas of pathology and colposcopy. The NSU clinical director's responsibilities encompass all screening programmes – a significant workload given the previously identified changes across the cervical and other programmes as well as the implementation of the National Bowel Screening Programme. (See also: The National Screening Unit strategic direction earlier in this chapter.)

Public health clinicians working within the NSU provide support for the NCSP through specific functions and roles. Since the 2015 PRC report, there have been two part-time positions created for clinical advisors/leads in pathology and colposcopy. The 2015 review recommendation 22 included the advice that 'Particularly important within the NSU and NCSP is the robustness of the clinical leadership structures. It is imperative that clinical leadership positions are at the forefront of the National Cervical Screening Programme and that these are sustained as its driving force'.

It is pleasing to note that discipline-specific expertise has been recruited to provide advice to the NCSP. The PRC notes that there is opportunity to provide greater clarity of the roles and responsibilities of the clinical leads/advisors. It is unfortunate that the colposcopy advisor, announced his resignation shortly before the NCSP review occurred. However, the PRC was very grateful that both clinical leads made themselves available to discuss ideas.

In considering information provided by the clinical leads/advisors, interviews with key programme providers, stakeholders and NCSP staff, it was evident to the PRC that the expectations of the relevant sectors regarding the function of the clinical leads/advisors were different and not clear, resulting in confusion for all parties. The message was unambiguous that the industry sector expects the roles to be discipline-specific experts providing clinical leadership, expertise, advice and oversight across the country. That view is supported by clinical governance frameworks, such as those in the United Kingdom National Health Service as articulated earlier in this document that clinical governance is:

- the systematic joining up of clinical initiatives to improve quality,
- setting standards and ensuring they are met, and
- monitoring performance and implementing interventions where clinical quality falls short of the standards or expected outcomes. (Halligan and Donaldson 2001)

The NSU have contracted clinical advisors/leads to provide advice to the NSU/NCSP on issues specific to their respective disciplines. Understandably, the differing perspectives, limitations and constraints on the scope of these critical positions have created frustrations. It was not clear to the PRC at the time of the review whether the two senior clinical roles were advisory or leadership roles. Subsequently the NSU has confirmed that the roles are clinical leadership roles. It is important to have clarity of expectations of the roles and the shared responsibility with the NCSP for oversight of the programme's quality.

The PRC believe the clinical leadership roles will be critical in facilitating a smooth transition to primary HPV screening. As vital members of the multi-disciplinary NSU team, these positions should be responsible for leading clinical service delivery in their respective disciplines in accordance with NCSP policies and directives. The small number of pathology providers should require one national pathology clinical leader, however, the larger number of colposcopy services may require a strategic solution to ensure the workload is achievable and initiatives can be implemented consistently across all DHBs.

Key informant:

> The clinical leads' role for the programme could and should entail more face-to-face contact with the clinical groups. There is a 'divide' between the programme/Ministry and those providing services that does not need to exist and that, if it could be bridged, would ensure continued enthusiasm and more accurate education of the providers and therefore the public.

Colposcopy services

It became evident through the PRC's interviews across the country, that the clinical governance arrangements, capacity and capability to review performance data and implement quality improvement initiatives is variable across DHB colposcopy services – from robust, quality auditing processes, data analysis and monitoring of performance in some services to limited or no processes evident in others. It is important to note that New Zealand women are generally well served by their DHB colposcopy services. The PRC did not review private colposcopy services.

The PRC was pleased to note that the e-colposcopy project (excluding private colposcopy clinics) had been completed, enabling more timely access to outcome data, and that services could access and review their performance. However, the capability within some services to access and interpret the data appeared limited.

In considering the three key clinical governance principles for delivering colposcopy services, the PRC makes the following findings:

1. **The systematic joining up of clinical initiatives to improve quality**
   The examples provided to the PRC of six-monthly and annual DHB reports submitted to the NCSP have a strong focus on coverage, equity and clinical practice for smear-takers, including cultural appropriateness education for service providers. There were no direct references in any of the example reports regarding the clinical quality of colposcopy services.
2. **Setting standards and ensuring they are met**
   The NCSP has a suite of clinical standards for colposcopy. The respective DHBs have responsibility and accountability for performing against these standards. The PRC found limited examples of how these standards are monitored and few strategies to ensure clinical standards are met. The only examples found of

systematically implementing strategies to ensure standards are met were related to the timeliness of colposcopy from date of referral.

3. **Monitoring performance and implementing interventions where clinical quality falls short of the standards or expected outcomes.**
   The monitoring of performance and implementation of interventions to improve outcomes is the DHBs' remit. In larger services, these processes seem to be well managed by the lead colposcopists. However, smaller services are disadvantaged and have limited capacity for audit and review. The diversity of arrangements for colposcopy clinical oversight risks inconsistent practice across the country. There is also variability across DHBs for approving colposcopists' credentials.

Colposcopy services will continue to play a significant role in assessing women in the new primary HPV screening programme. More complex management algorithms for colposcopists are envisaged, and service quality must be monitored and maintained at a high level. The PRC considered the current and future state of clinical governance for colposcopy services and makes the following specific observations and recommendations.

Use of NCSP-R data to provide feedback to colposcopy providers

While colposcopy service providers have been required to provide data to the NCSP-R since 2005, there have been barriers to accurate reporting, including the non-uniform acceptance of electronic reporting and the continued reporting, especially in the private sector, against the older 2008 Standards rather than the more complete 2013 Standards.

Over many years, the NCSP-R has accumulated a large repository of colposcopy data but to date has not analysed this data in a way that could provide useful feedback to individual colposcopy service providers. This is important for quality improvement activities.

PRC 2015 made several recommendations (14, 30, 34, 37, 41 and 42) regarding the need for electronic data reporting, the need for complete data, the encouragement of private clinics to adopt e-colposcopy and the urgent need to provide feedback to colposcopy providers.

The NSU has advised that the considerable amount of data, now held in the Datamart, will be used to provide feedback to colposcopy providers. This needs more analysis and work to determine the best 'fit-for-purpose' reporting tool for quality improvement purposes. The PRC urges the NSU to make this a priority activity.

Individual data audit by colposcopists

There is significant variation in the capacity and/or ability for individual clinicians in DHB colposcopy units to access performance data regarding colposcopy standards (National Cervical Screening Programme, n.d., policy and standards, 2013, Section 6). Regular and routine access to and review of performance data would allow 'real-time' review of performance against benchmarked New Zealand standards.

A mandatory colposcopy data set is collected, using Solutions Plus (a company that provides comprehensive gynaecology, maternity, surgery and anaesthesia software), and electronic transfer of this data via e-colposcopy has been in place across all DHBs since August 2016. Despite this, the PRC was informed that few clinicians have the ability or local IT support to extract meaningful data from Solutions Plus data (at source in clinic), and therefore have to rely on external agencies such as the NCSP, NCSP-R or the DHB to audit data transmitted to NCSP-R. Currently, the only feedback regarding colposcopy standards is via the independent monitoring reports (Indicator 7) that are available to all DHBs, but this is not relevant to individual colposcopists in terms of their own performance.

The ability to access this data at the source appears to be dependent on motivated, committed leaders in DHB colposcopy units, who are IT competent and have time to extract and analyse the data, providing feedback to the clinicians working in the unit. The previous NCSP clinical lead for colposcopy intended to provide assistance in this process and in other matters, by visiting the various DHBs. However, the NCSP was not able to support this.

This local 'real time' data can be used to identify 'outliers', enabling remediation/intervention to occur in a timely fashion. The PRC recommend that appropriate IT support be made available by each DHB where needed, or alternatively, the NCSP could provide direct IT support.

In order to help improve quality, the NCSP is encouraged to send regular benchmarked reports (at least six-monthly) on colposcopy performance to individual colposcopists who are using the e-colposcopy data within the NCSP-R.

A nationally coordinated process to identify and remediate colposcopists who do not meet NCSP standards

The NCSP policy and standards 2013 defines an 'External quality assurance policy'. (National Cervical Screening Programme n.d.) Reports on coverage are provided quarterly to DHB colposcopy units and are published on the NCSP website. The independent monitoring reports, based on NCSP-R data, against predefined programme indicators (Indicators 7.1–7.7 for colposcopy) are published biannually and are also published on the NCSP website. While this may show variation in performance at the DHB level, it is not useful for identifying individual clinicians who are not meeting the expected standard of practice.

The policy for 'internal quality control' is also defined. Colposcopy services must have documented internal quality control systems that will cover all their activities and:

- provide the means of identifying potential sources of error in the colposcopy service operation
- implement controls to detect and minimise errors
- identify ways of improving services to women
- provide a framework for remedial action to improve operational processes when a problem is identified.

The PRC understands that the lead colposcopist at each DHB is responsible for ensuring that internal quality controls are in place, and this would appear to be working well as evidenced by the recent Health and Disability Auditing New Zealand (HDANZ) colposcopy audit (Health and Disability Auditing New Zealand 2017).

It is not clear if all DHBs have a robust and transparent framework/process for identifying or taking remedial action against individual practitioners who are identified as 'outliers' in performance. There appeared to be variation in approach, and in many cases, it depended on the clinic nurses and other staff noting irregularities in case management (rather than audit data information) and notifying the lead colposcopist of their concerns. Subsequent management of 'outliers' who need remediation is not defined and may benefit from some nationally coordinated guidance as to procedure.

Some units (eg, Auckland DHB, Nelson Marlborough DHB) regularly audit their individual practitioners against benchmarked NCSP standards and check all cases where the discrepancy is noted, including recall/review of women where necessary and remediation where appropriate. This is to be commended and wherever possible should be applied universally to all DHB units.

Role of multi-disciplinary meetings (MDM)

Standard 603 in the NCSP Policy and Standards document states that 'colposcopists should endeavour to participate in MDMs monthly for case review, where practical'. The minimum expectation is two monthly (National Cervical Screening Programme n.d.).

The PRC noted that smaller units do not have the caseload to warrant such activity, some meeting quarterly to discuss interesting and difficult cases retrospectively. MDMs are important for retrospective case review to identify where improvements in management should occur, but they are most important for prospective discussion to assist in 'live' decision-making around the best patient care.

Perhaps smaller units could participate in the more frequent MDMs of larger DHBs, possibly by video link or similar. This sharing of information would benefit to all concerned, especially the patients.
One example of an excellent quality improvement innovation is Timaru joining with Nelson Marlborough for a joint MDM on a two-monthly basis, to discuss 'live' cases.

Implementation of initiatives such as this requires clinical leadership with approval from the NCSP.

C-QuIP in the New Zealand context

The Royal Australian and New Zealand College of Obstetricians an Gynaecologists (RANZCOG) manages the Cervical Quality Improvement Programme (C-QuIP), which has recently been updated following the implementation of the primary HPV cervical screening programme in Australia. The policy regarding colposcopy staffing in New Zealand DHBs is clearly defined in the 2013 NCSP Policy and Standards document, standards 610 and 611 (National Cervical Screening Programme n.d.). Certification by C-QuIP is essential for medical and nurse colposcopists. C-QuIP does not certify 'competency' as a colposcopist, but it does certify 'participation' in a quality improvement programme.

There have been some difficulties with C-QuIP as New Zealand demands that all colposcopists see a minimum of 50 new referred cases per annum (150 over three years): preferably 100 per annum or 300 over three years. However, C-QuIP does not specify a 'minimum number' for Australian practitioners but does recognise this discrepancy and notes that New Zealand has a different requirement. It appears that C-QuIP is now aligning with the requirements for New Zealand practitioners.

Sharing information and benchmarking across all DHB colposcopy clinics

This does not currently occur and could be considered for action in the future. This would facilitate learning across the various units, and 'lessons learned' could benefit patient care across all sites.

The future role of the NCSP colposcopy audit programme

HDANZ has been contracted to provide three-yearly colposcopy audits of the 20 DHBs across New Zealand on behalf of the NSU. There have been two previous audits, and the most recent audit for years 2015–2017 was reported in June 2017 (Health and Disability Auditing New Zealand 2017). All colposcopy service providers contracted to the NCSP are monitored using NCSP-R data against a range of indicators, most of which relate to colposcopy standards defined in the 2013 NCSP Policy and Standards document. The audit is carried out by an auditor, a colposcopist and a colposcopy nurse.

The audit tool used by HDANZ allows for Corrective Action Requests (CARs) that require action within a defined time period, according to the severity of the risk to consumer safety. The current audit did not find any critical or high-risk CARS, which is an improvement on the previous audit that had 14 areas of high-risk CARs, all of which had been rectified within the specified timeframe of six weeks. In the current audit, the total number of audit findings (across the 20 DHBs) was 110, an average of 5.5 per

audit. Of these, 79 (72 percent) were rated as low risk (to be rectified within one year), and 31 (28 percent) were rated as moderate risk (to be rectified within six months).

The NCSP advised the PRC that all but one of the CARS have been signed off. The remaining CAR relates to timeliness of women with high-grade cytology being seen within 20 working days. Two women were identified as experiencing a minor delay in being seen in the DHB, and on inquiry there was a satisfactory explanation for this delay. However, the NCSP was not satisfied that overall timeliness is satisfactory and is awaiting further confirmation before signing off.

It is very pleasing to note that, since August 2016, the DHB-contracted colposcopy services have universally adopted e-colposcopy and that this has been well supported by all colposcopy services. It seems likely that much of the audit completed by HDANZ could be done directly and more efficiently using the e-colposcopy data supplied to the NCSP-R and could possibly be done by the NSU without the need for an external contract.

Some aspects of the current audit related to 'support of women, staffing and key quality processes' including management of 'failure to attend' women may need external audit, but the majority of the areas audited (in Section A of the audit) could be audited internally, and many are included in the independent monitoring reports. This would appear to be a duplication of auditing and imposes an unnecessary burden on the colposcopy service.

The NCSP recognises that the next colposcopy audit framework needs to be improved and the PRC agrees that, at the very least, a more meaningful and relevant risk-stratified approach to corrective actions should be used.

Private colposcopy providers

There are 42 private colposcopy clinics. All report data to the NCSP-R but only six currently use e-colposcopy. There is no feedback from the NCSP-R to these practitioners and no mechanism for quality control in regard to performance against the 2013 NCSP Colposcopy Standards. The PRC recommends that private colposcopists should be subject to some regulation for the benefit of the women who are managed by them. Perhaps this can be considered for future action. At the very least, benchmarked reports should be sent to the individual colposcopists as part of a quality improvement cycle.

Funding for colposcopy

The PRC was interested to learn that DHBs receive a significantly lower payment for NCSP colposcopies than for non-NCSP colposcopies. For DHBs that are struggling to contain burgeoning deficits, this inequity in funding would suggest there is limited incentive for DHBs to prioritise NCSP colposcopies. It was suggested to the PRC during stakeholder interviews that some DHB's may choose not to continue providing NCSP

colposcopy services. The PRC recommends that funding for NCSP colposcopies be reviewed to ensure that pricing supports the maintenance of quality services.

Key informants:

> *'Clinical enquiries to the NCSP from primary care regarding the management of patients, symptoms, interpreting pathology results and referrals etc must have a colposcopist involved in formulating the response, to give greater credibility.'*
>
> *'The smear taker evenings are always very well attended, with lots of discussions, and you get a real peer sense of encouragement for people and it helps to influence practice and to improve practice. They even got the smear takers talking about peer review – voluntary peer review.'*
>
> *'Online web-based learning resources are valuable, but face-to-face learning opportunities are essential.'*
>
> *'The quality improvements to the programme that have had the most impact have been the writing and review of quality standards for colposcopy and laboratory services. In the public hospital system, this has provided the opportunity for better understanding by DHB management around the requirements of providing a colposcopy service and easier implementation of standards within a department.'*
>
> *'Mandated multi-disciplinary meetings, if used correctly, enable a more unified approach to management and early detection of management practices outside the bell-shaped curve.'*
>
> *'The most important issues the programme faces over the next 3 years is the maintenance of the current register until the change to HPV screening, increasing screening rates and maintaining laboratory staff.'*
>
> *'Improving screening requires better "engagement" with the public, smear takers, GPs and colposcopists.'*
>
> *'Re: Audit of Cervical Cancers. The most recent [audit] was of cancers between 2008 and 2012, published in 2018. There were limitations on the scope. Findings were "old" by the time they were published although they essentially confirm previous key issues. Prospective audits are a positive step forward, but they must be appropriately scoped and resourced.'*

Pathology services

With the small numbers of cervical pathology laboratories, the comprehensive performance standards that are regularly monitored, and internal robust review processes, the clinical governance arrangements within pathology services appear to be sound. (See also chapter 3: The effectiveness of monitoring and evaluation in informing the NCSP's performance and clinical safety.)

Currently, the greatest challenges for the NCSP with regards to the pathology sector will be establishing rigorous processes to monitor the quality and timeliness of cytology reporting leading up to the transition to primary HPV screening. Dr Margaret Sage informed the PRC that the cytology workforce is an older and very experienced workforce. She was concerned that there have been no trainees participating in the entry training programme for about four years. Monitoring workforce levels and the attrition rate must be a priority for the NCSP with the delay in implementing HPV screening. There are risks that without an adequate workforce to sustain the existing programme; there will be significant delays in pathology reporting.

An interesting observation made by a pathologist during discussions with the PRC was the challenge for pathologists when they are asked to review and provide comment (usually in MDMs) on slides from LBC test types with which they are not familiar. This conundrum and other similar challenges confirm that clinical governance and discipline-expert leadership is required for the pathology sector.

Of particular importance from a governance and planning perspective is the lead-up time pathology laboratories will require to start the new HPV screening regime. This includes the procurement and delivery of new equipment from international suppliers, equipment testing and validation of the tests, system development and training. Once the equipment is procured and systems tested, laboratories will want to commence the new operations promptly to ensure business sustainability. Rigorous timeline mapping will be essential to enable a smooth transition.

> Maintaining business as usual (BAU) systems whilst preparing the workforce for transition to HPV screening will require clinical leadership and stewardship across all laboratories to ensure practices fulfil programme expectations. As with colposcopy services, there is a need for clearly articulated, discipline-specific and expert clinical governance arrangements. Planning for and managing the transition to HPV screening will require high-level pathology input whilst also managing BAU. System change of this magnitude is very infrequent and has many complex facets and risks. This requires detailed planning for interim maintenance at the same time as training for, and implementing, entirely new testing methodologies, pathology reporting processes, standards and IT systems.

Key informants:

> *'Moving to primary HPV screening – it's just this transition phase we're in at the moment where the date that it's going to happen keeps moving out and out and the issue of whether or not we can hold the whole programme together in the interim until 2021 – or whenever it is they're planning on starting the new system.'*

> *'What we have is a workforce that's [ageing]. They are very efficient and do their jobs well, but they recognise that quite a number of them will not have a job when the new primary HPV screening comes in, because instead of doing their normal liquid-based cytology screening, the majority of the work will now become virology*

tests on an automated analyser with only a small number – maybe 10–20 percent of them – requiring the smear or the LBC test being done and therefore they won't need as many people. We do not know quite how many that is, and we are concerned that people might start leaving to go and do other things.'

'And the interesting thing with it as well, of course, is that there will be an ongoing requirement for cytology screeners. However, I don't think there's anyone trying to train in it anymore.'

Programme delivery

It is important to acknowledge that all DHBs are delivering services in a complex system with multiple competing priorities for limited funds and are performing well within their constraints. The greatest challenge to sustaining improvement, particularly in addressing inequities, is the devolvement of responsibility for programme delivery. The NSU holds a standard contract with each DHB that defines the service specifications and objectives/targets. There are some variations to the base contract, depending on specific regional issues or challenges, and arrangements for the funding of free smears and SSSs. The diversity in participation outcomes across DHBs as well as by ethnic groups is discussed in much greater detail in chapter 3: The effectiveness of monitoring and evaluation in informing the NCSP's performance and clinical safety.

Organisational and governance arrangements differ significantly between DHBs, and also with their arrangements with the respective PHOs. All DHBs have NCSP coordinators, while some have NCSP registry managers as well. Other DHBs combine the roles, and in some, the NCSP managers also hold other health service responsibilities. Programmatic knowledge appeared to vary greatly across the respective DHB managers. These devolved and highly variable organisational arrangements for service delivery limit the NCSP's ability to influence practice, performance or outcomes, and the NSU has is little or no ability to address underperformance.

DHBs' capacity to access and interpret their data also varies significantly varied – with some DHBs and PHOs having high-level IT capabilities and skills to utilise the data available and others having very limited capacity. This also creates challenges for the NCSP, as it cannot be assured the data it makes available is being accessed and utilised appropriately.

Portfolio managers within the NSU provide support to DHB NCSP coordinators and registry managers. However, with the significant variance in governance arrangements, there is little consistency. With more consistent governance arrangements across DHBs, lines of communication, responsibility and accountability would be much easier to navigate and enable standard, structured initiatives and improvements to be implemented.

It is appreciated that DHBs have established positions and organisational structures over time to meet their respective governance structures and service delivery arrangements.

The PRC is aware there is a national Health and Disability System Review and requested an interview with the committee of that review to contribute findings from the NCSP review to the overarching system review. At the time of writing this report, this interview has not yet occurred. Should this interview not eventuate, it is recommended that this report be shared with the Health and Disability System Review.

Some of the findings and recommendations in this report will require review and revision of some funding arrangements, with likely increases in some areas and savings in others. PRC interviews with the various sectors involved in cervical screening revealed some creative thinking for efficiencies that could offset funding being redirected to realise greater equity opportunities. The development of the NSS will ensure clinicians can access participants' screening histories directly, with the potential to realise significant efficiencies and savings as well as economies in work practices across the NCSP, DHBs, PHOs, general practice, pathology and colposcopy providers.

As identified earlier in this chapter, the New Zealand Health Strategy states that health services need to achieve better outcomes for everyone, which requires new ways of working to deliver the services the population needs. The PRC recommends the NCSP review contractual arrangements with, expected outcomes from and reporting requirements by DHBs in order to strengthen accountability for participation and mitigate inefficiencies inherent in the existing arrangements. This review should also consider colposcopy performance and quality improvement initiatives implemented by DHBs. Sector groups interviewed by the PRC offered many suggestions for creative new ways of working, and NCSP consultations with these groups may realise opportunities for greater accountability and improvements in reporting and service delivery.

The NCSP, in preparing for the transition to the NSS and primary HPV screening could generate creative solutions to many of the devolvement barriers and inefficiencies inherent in the existing structures by holding in-depth consultations with sector groups such as those interviewed by the PRC.

Managing complaints

Complaints received by the NCSP-R are recorded in JIRA (a log of IT issues, data requests and complaints). The log is shared between the NCSP-R central team (RCT) and the NSU. A complaint is allocated to a NCSP person, and that person records all relevant communication related to the complaint until it is closed.

The JIRA log is also used to log complex or serious complaints received directly by the NSU, for example, a complaint from the Health and Disability Commission or a complaint from a woman about an aspect of the clinical pathway.

The PRC understands that the respective service providers manage complaints to DHBs, GPs, pathology laboratories or colposcopy clinics. It is not clear if there is a requirement for these providers to report complaints to the NSU. This fragmentation risks the NSU being unaware of any recurring themes or emerging trends that may impact the quality of service delivery and the consequent implications for participation.

The PRC recommends the NSU review complaints management processes and reporting requirements across the screening pathway and implements quality improvement initiatives that align with best-practice consumer-focused care.

Communication

Throughout the PRC's interviews with clinicians and stakeholder organisations, a common theme emerged regarding the need for consistent national messaging around the implementation of primary HPV screening as well as the importance of women continuing to screen with the current Pap programme. Many interviewees expressed concern at the absence of national promotional campaigns to support providers in their efforts to improve participation.

Multiple sources cited the success and impact of the Smear Your Mea campaign, which was developed independent of the NSU by Talei Morrison, a woman who was diagnosed with and later died of cervical cancer. Talei was a key influencer who came from a whānau prominent in Māori performing arts. She drew on her personal experience with cervical cancer to encourage all women, particularly Māori women, to have a Pap test. As a long-time kapa haka exponent, Talei focused attention on the kapa haka community, reaching tens of thousands of whānau. Her legacy continued through the 2019 Te Matatini kappa haka competition, and national television media covered her story. Social media accounts of women having a smear as a direct result of Talei Morrison's original Smear Your Mea campaign in 2017 and the recent coverage at the 2019 Te Matatini testify to its success. In particular, the power of key influencers, personal stories and the right communication channels are important lessons for the NSU.

In situations of system-wide service delivery changes of the magnitude of those soon to occur with the implementation of primary HPV screening; clear, concise, appropriately targeted communications are imperative. A communications and education/training strategy should be undertaken as a key project of the primary HPV implementation strategy.

Communicating with service providers

The PRC became aware that, across many areas, knowledge and understanding of HPV and its role in cervical disease is not well understood (Sherman et al 2018). Consequently, the rationale for the change to primary HPV screening is being received with some degree of reticence and resistance to change. It is essential that the NSU progress, as a top priority, a communication strategy for clinical streams that includes training programmes and educational resources.

Resource materials for clinicians should detail agreed appropriate responses to consumer enquiries and concerns. Health literacy and co-design principles should be applied in the development of the communication strategy.

Communicating with the public

There are many misconceptions and myths to de-bunk for women. Many consumers do not understand HPV, its role in the treatment of cervical disease and the meaning of the change to primary HPV screening. Understandably they have some concerns about the safety and effectiveness of the new HPV screening programme.

Communication strategies that address different levels of health literacy and in particular respond to concerns regarding changes to the age range and screening interval, should be developed now, enabling adequate time for focus testing, consumer acceptability testing and modifications if required.

Co-design principles should be adopted from the outset, involving priority group women to ensure the messages and distribution channels are culturally appropriate and meaningful so that they resonate in a way that leads women to action – as we have seen with the Smear Your Mea campaign.

National Kaitiaki Group

The 2015 review made recommendations regarding the working arrangements between the NCSP and the National Kaitiaki Group (NKG), with recommendation 35 stating 'It is strongly recommended that NCSP and NKG work in partnership to identify more streamlined processes that minimize the burdens the current processes for accessing data place on both parties'. The 2018 PRC terms of reference requested the PRC assess progress against the 2015 recommendations.

The NKG's purpose is to consider applications, under the Health (Cervical Screening (Kaitiaki)) Regulations 1995, for approval to disclose, use or publish protected information, and to grant approval for such disclosure, use or publication in appropriate cases. The NKG is appointed by and is accountable to the Minister of Health and responds to applications for release of protected information as soon as reasonably practicable after receiving the application. The NKG protects Māori women's cervical screening data by ensuring that the data is not used or published inappropriately or in a way that reflects negatively on Māori. It also provides a way of

assuring Māori women that their data is protected so they will continue to participate in the screening programme.

The PRC met by teleconference with members of the NKG. Members advised they have only met twice since the formation of the new group under revised terms of reference. The group's focus is narrow – solely considering applications for access to data. Since the group's establishment, they have received three applications for data from researchers. The group feel the application forms require some refinement to ensure all necessary information is provided at the time of application, hence avoiding the need to refer questions back to researchers for further information and enabling the group to respond to applications in a more timely fashion.

NKG members feel comfortable with their remit and are of the view that the new systems will enable them to be more responsive to researchers, thus enabling the researchers to progress their research in a more timely manner. The group feel that they are working effectively and efficiently within a very narrow focus.

In a general discussion regarding the current state and future directions of cervical screening, the group expressed concern that the incidence of and mortality from cervical cancer has plateaued and observed that health literacy is a major impediment to improving participation and outcomes. The group also advised they were not really aware of the proposed change to primary HPV screening, although some members did state that their roles on other committees had provided some insight, albeit minimal.

The group found the NSU to be very helpful and responsive to its needs. The Chair noted the previous PRC report had identified some challenges in communication between the NKG and NSU; however the current group have had no issues. The PRC was very pleased to receive this feedback and wish to thank and acknowledge the NKG for their helpful and constructive responses and willingness to participate in the 2018 PRC review.

Recommendations

The PRC recommends that:

- The NSU should support and partner with the clinical leads to clearly articulate, both within the NSU and externally to the relevant sectors, the clinical leads' responsibilites in maintaining clinical quality for the current NCSP and leading the clinical implementation of primary HPV screening to ensure quality and consistency of clinical practices across New Zealand.
- Governance (both clinical and operational) and advisory committees should be reviewed to maximise efficiency across the committees and minimise potential duplication of work. The review should focus on the multi-disciplinary requirements of the committees that are leading this important population screening programme and the balance required between population screening and practising clinical expertise.

- To facilitate the transition to the new screening pathway, the NSU should articulate their expectations of members of the NCSP Advisory Group in leading and disseminating advice to their relevant sectors around implementing the new screening pathway.
- A process should be established that will ensure national quality and consistency of colposcopy performance, review processes and clinical services across DHBs. The NCSP should lead the development of a system for clinical, expert, consistent oversight of DHB's colposcopy clinical services (including benchmarking and the development of quality improvement plans) to ensure appropriate and independent monitoring of clinical practice. This system should include processes for identifying and remediating colposcopists who are not meeting the national standard and whose performance may be masked by the overall performance of the colposcopy service.
- In addition to recommendation 31, in order to facilitate quality improvement, the NCSP is encouraged to send regular benchmarked reports (the committee suggests six monthly) on colposcopy performance to individual colposcopists, using the e-colposcopy data within the NCSP-R. The colposcopy data held in Datamart needs analysis and work to determine the best 'fit for purpose' reporting tool for quality improvement purposes. The PRC urges the NSU to make this a priority activity.
- Work to define new standards for pathology and colposcopy should be completed well in advance of the introduction of primary HPV screening so that systems can be developed that will enable reporting against the new standards.
- Funding for NCSP colposcopies should be reviewed to ensure pricing supports the maintenance of quality services.
- The NCSP should review contractual arrangements with DHBs. The aim of the review would be to strengthen accountability for participation and to establish nationally consistent performance measures, reporting requirements and expected outcomes. This review should also include reporting on colposcopy performance and quality improvement initiatives implemented by DHBs.
- A comprehensive, culturally appropriate communication and education/training strategy should be developed as a key project of the primary HPV screening implementation strategy – for both the public and programme providers.
- Comprehensive communications for women and service providers should be developed to answer questions, allay fears and provide reassurance about the new HPV test, the later starting age (25 years) for screening, the five-year screening interval, the predicted transient early rise in cervical cancer diagnoses and the importance of examining and assessing symptomatic women at any age. Emphasis should be given to a co-design approach with priority group women and service providers to ensure any communications reach all intended audiences.
- A coordinated national training and education campaign around HPV infection, cervical cancer, HPV vaccination and HPV cervical screening is needed for women and service providers (including colposcopists) before and while implementing the primary HPV screening programme. Emphasis should be given to ensuring the availability of culturally appropriate information for Māori, Pacific and Asian women.

- The NCSP complaints management processes and reporting requirements should cover the entire clinical pathway, including at DHB and PHO level as well as those received by the NCSP-R. Complaint reviews should include actions that result in the development and implemention of quality improvement initiatives that align with best-practice consumer-focused care.

Progress against the 2015 Parliamentary Review recommendations

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
1. Coverage, Participation, Equity, and Access				
1	Ongoing strategies are needed to address the disparities among priority groups in terms of participation and retention in the Programme. Improved follow-up is needed after abnormal screening results.	Activities that aim to improve coverage in priority group women include: Screening Support Services The NSU funds Screening Support Services (SSS) in 15 DHBs. The aim of this service is to provide additional support to priority group womennot responding to recall for breast and cervical screening, and diagnostic and treatment services. Services include information, home visiting, and assistance with transport and childcare if required. In 2015/16 the NSU undertook a Request for Proposal (RFP) to determine new SSS providers. New providers were in place in November 2016. The new providers were funded in DHBs identified to have the greatest needs.	**Ongoing – part of operational planning**	Ongoing strategies are part of operational planning. Further observations are provided throughout the 2018 PRC report.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		Funding for free smears The NCSP provides an allocation of funding to each DHB to be passed on to PHOs for free smears in priority group women($880K). DHB Cervical Screening Action Plans Each year DHBs provide an Action Plan outlining local activities to improve cervical screening coverage. This includes activities to support screening in priority group women, and improve the follow-up of women not responding to recall, either in primary care, or at colposcopy. DHB Annual Plans As part of the Annual Planning process DHBs also submit six monthly reports to the Ministry on progress in meeting the target of 80% of women aged 25-69 years having a cervical smear within the last 3 years. Individual support to practices NCSP Coordinators and Register Coordinators work intensively with individual general practices to improve coverage, particularly practices in high needs areas.		

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		System Level Measure Framework Cervical screening as an indicator under the Amenable Mortality area of the System Level Measure Framework. In 2017/18 eight district health alliances chose cervical screening as an improvement measure. Health Measures Cervical screening is one of a suite of new health measures that are proposed for introduction. Timeliness of women being seen at colposcopy The target is 95% of women with a high grade smear (not suspicious of invasion) being seen at colposcopy within 4 weeks. Priority group womenare less likely to attend appointments to be seen. The NCSP is in the process of sending letters to DHB CEOs to show their results for this measure from Independent Monitoring Reports over a three year period, with the aim of improving compliance with this measure. Also refer to #2 - Ensuring free smears are appropriately targeted.		

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
2	The provision of funding for free smears is a commendable initiative, but the amount of funding, and consequently coverage, is limited. There need to be clear strategies to ensure that access to free smears is appropriately targeted to the women in highest need. To improve coverage for high-priority women, the cost of smears must not be a barrier.	The NCSP team continues to review options for improved management of the free smear funding. In addition to the funding for free smears in general practice, priority group womencan access a free smear through a Support to Screening Service provider. The Ministry also provides funding to NZ Family Planning which subsidises free or low cost visits, including for cervical screening. The cost to have a smear at Family Planning is free for women under 22 years, $5 for women with a Community Services Card, and $32 for other women. Low cost general practice visits to people with a Community Services Card is in the process of being implemented in PHOs. This will provide for lower cost cervical screening visits in women who are eligible.	**Ongoing – part of operational planning**	The 2018 PRC report provides further commentary on the cost barriers as an impediment to achieving equity.
3	Cultural competency is vitally important and ongoing education is needed to ensure that smear takers are attuned to cultural sensitivities. Independent Service Providers play a vital role in supporting local communities and providing access to cervical	<u>Screening Support Services</u> A new Screening Support Services (SSS) contract started on 1 November 2016. In addition to supporting priority group womenfrom within their own networks, providers receive referrals from general practices and colposcopy services for priority group womennot responding to recall. The contract has been in place nearly two years and providers are consolidating their links with primary and secondary care to	**Ongoing – part of operational planning**	The SSS initiative implemented in November 2016 appears to have made some gains in ensuring culturally appropriate service delivery. Continuing

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	screening. Any changes to funding for cervical screening for Independent Service Providers should be carefully evaluated in terms of the consequences. DHBs and primary health organisations (PHOs) should be supported to work closely with Independent Service Providers to facilitate access to screening for unscreened and under- screened women.	receive referrals. As this is a revised service, the NSU will evaluate this service in order to inform future service and contracting arrangements (refer to # 1). A review of contract performance against was undertaken in July 2018. <u>Cultural competency as part of Smear Taker Updates</u> In 2018 the NCSP developed a cultural competency model to be used in smear taker updates. <u>Community development initiatives</u> The Ministry continues to look for opportunities to collaborate on community-led initiatives to improve coverage. One example of this is the Smear Your Mea campaign. This is a Māori community development initiative that originated through a well-known member of 'kapa haka' (Māori traditional dance) who developed cervical cancer and died in June 2018. In the year before her death, she coined the slogan 'smear your mea (thing)' and actively encouraged kapa haka participants to be up-to-date with screening. A trust has been formed in her memory to continue awareness-raising of the need for cervical screening. This has proved to be an important community development initiative that has promoted cervical screening in Māori women. All SSS		commitment to ensuring all providers are culturally competent should be a priority.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		providers are collaborating locally on this initiative.		
4	Ongoing HPV education campaigns are important to increase awareness and knowledge among the general population and among health care providers. Such campaigns are of particular importance prior to any introduction of primary HPV screening.	In 2016, communications to support the Year 7/8 school-based immunisation programme (which includes HPV immunisation) began. These included radio advertising and digital advertising in the form of google ad words. In 2017, there was a large 8 week campaign at the beginning of the school year which included advertisements at bus stops and a youtube video about the importance of the immunisation for boys and young men. The NCSP and immunisation teams continue to work together to align messaging across HPV.	**Ongoing**	The 2018 PRC report provides further recommendations on the need for HPV education campaigns for the public and health care providers.
5	It is recommended that NCSP and NKG work closely together to facilitate more timely and ongoing access to Māori data. See also Chapter 8: NCSP-Register and Chapter 9: Ethnicity data.	See also#35 Access to Māori women's data for NSU monitoring was clarified in 2016, and allowed the NCSP to access routine monitoring data without the need to seek approval from NKG. However, subsequently, with recent activities to change the NCSP legislation in preparation for HPV primary screening, the Health Committee is proposing a change which if passed would mean that the NCSP will need to apply to the NKG for routine use of monitoring data. The impact of this change is in the process of being	**Closed**	The NSU and NKG have worked collaboratively to ensure timely and ongoing access to Māori data – Closed.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		assessed. The Ministry is currently initiating work to develop an overarching Māori data governance framework which will include operational policies around the use of Māori data.		
6	The NSU and NCSP must continue to work to meet the priorities of the New Zealand Cancer Strategy and achieve 80% coverage for all women of all ethnic groups.	The NCSP has a number of strategies in place with the aim of reaching 80% coverage across all ethnic groups. This includes: the Ministry: • funding independent service providers to provide screening support services to priority group women • provides PHOs with a monthly report which matches data between the NCSP and PHO Registers, for PHOs to identify priority group womenwho need to be (re-) invited for screening • provides monthly and quarterly coverage information by DHB and by ethnicity • funds DHBs for free smears in priority group women. All DHBs: • have regular intersectoral regional stakeholder meetings involving DHB Planning and Funding, NCSP staff, DHB colposcopy staff, PHOs and independent service providers	**Ongoing – part of operational planning**	It is concerning there has been little change in achieving targets, and evidence of declining participation.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		• regularly monitor and track progress on cervical screening coverage rates, and provide this information to key stakeholders • collate, analyse and produce coverage reports for their local Cervical Screening Steering Groups • have an allocation of free smears for priority group women(ie, for Māori, Pacific and Asian women aged 20 - 69 years, and women aged 30-70 years who are unscreened, or >5 years since their last smear) • submit, monitor and report against an annual Cervical Screening Action Plan for activities to increase coverage • report to the Ministry on coverage in each ethnic group as part of the Annual Planning process. They are required to provide additional information on activities to increase coverage if the 80% target has not been met. • undertake cervical screening awareness-raising activities		

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
2. Monitoring and Evaluation				
7	There should be more stringent monitoring of the quality of colposcopy.	See also #34 <u>Colposcopy Audits</u> The NCSP has a regular colposcopy audit programme in place. Using external auditors, the performance of all DHB colposcopy units is assessed against the NCSP Policies and Standards for providing a colposcopy service, and contractual requirements. The latest round of audits of all 20 DHB colposcopy units was completed in June 2017. The NSU worked alongside DHBs to resolve the corrective actions identified. The Ministry is in the process of considering procurement options for the next round of colposcopy audits. <u>Independent Monitoring of colposcopy data</u> The NSU contracts the Cancer Council of NSW to undertake independent monitoring of the programme, and this includes the timeliness of women being seen at colposcopy. The NCSP is in the process of sending trend data to each DHB on their timeliness, and to support their improvement initiatives and reporting.	**Closed**	Further commentary and recommendations are provided in the 2018 PRC report. Colposcopy audits have been implemented, colposcopy data can be accessed by DHBs and the e-colposcopy project has been implemented across DHBs – but not private providers. There is more work to be done in this area.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		Electronic-reporting of colposcopy data Electronic reporting of colposcopy data was introduced in all DHB by the end of August 2016. This allows for improved reporting and monitoring against the current colposcopy standards. A letter has been sent to private colposcopy providers to encourage e-reporting.		
8	Regular reporting and monitoring of participation by a measure of socio-economic status should be considered as an additional monitoring indicator to ensure equitable access by all disadvantaged groups.	This is now included in the NCSP coverage data published to the NSU website updated each month	**Closed**	Reporting by socioeconomic status is published on the NSU website. It would be beneficial to have this data also monitored as an indicator in the regular independent monitoring reports.
9	Monitoring Indicator 2 (first screening events) has no monitoring target at this time. The NCSP should review whether targets could be implemented for this indicator to enable closer monitoring of the distribution of first screening events by ethnicity	Data on first screening events by ethnicity and age is available in the six-monthly Independent Monitoring Reports. As part of implementing the change in cervical screening start age (to 25 years), this indicator is will be reviewed to ensure it is fit-for-purpose, and consideration of targets for having a first screen within a defined period. This is	**Closed**	Noted – this indicator is to be reviewed with the implementation of cervical screening commencement at age 25 years.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	and socio-economic status.	included in the project plan.		
10	Early re-screen rates vary significantly by DHB. The NCSP should investigate to understand whether these are chance anomalies or whether training or interventions are required to ensure clinical compliance with NCSP screening guidelines.	Early re-screening rates are reported by DHB in the NCSP Independent Monitoring Report. The NCSP will progress a process of informing DHBs as part of operational activity. The NCSP has developed an electronic PHO Cervical Screening Data Match Report. This provides the screening status of all women enrolled in the PHO, including their due date, and can assist PHOs with more timely screening.	**Ongoing – part of operational planning**	Ongoing monitoring and development of strategies to improve compliance with this indicator are recommended.
11	It will be important for the NCSP to determine if the decline in the proportion of samples reported as high-grade squamous intraepithelial lesions (HSIL) for women in the age cohorts of < 20 and 20–24 years is consistent with an effect of HPV vaccination. The ability to match data or record women's HPV vaccination status on the NCSP-R is an essential body of work for the programme.	See also # 36 and #49 The NCSP is working towards reviewing women <30 years diagnosed with cervical cancer and their HPV immunisation status. This will be part of the ongoing monitoring of implementation of the increase in the starting age for cervical screening to 25 years and is included in the project plan.	**To be progressed within u25 project requirements**	Matching cervical screening results with HPV immunisation status will be important to enable the effectiveness of vaccination and primary HPV screening to be monitored.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
12	There is significant variance across laboratories for Indicator 5.3, which monitors the accuracy of negative cytology. Close monitoring of this indicator is essential. It would be highly appropriate to review and discuss these findings with pathology experts to determine whether a quality intervention is required.	Minimum requirements for case review are specified in the NCSP Policies and Standards but there is currently no specific protocol for conducting prior negative smear reviews. Consequently, laboratories use their own processes for this. Combined with population variances in abnormalities and differing case mixes of laboratories, this will contribute to some of the observed variance. The Ministry is in the process of developing a prospective cancer case audit which will include reviewing prior negative smears, and this will involve the development of a specific protocol for this. Note – the laboratories that the NCSP contracts with include community and diagnostic laboratories. This may account for some of the variance in this indicator.	**Ongoing – part of operational planning**	Ongoing audit and case review of cervical cancer cases is an important element of the quality of the programme. Reviewing the accuracy of negative cytology is an essential element of quality assurance.
13	The proportion of women who did not have a follow-up test reported within 90 days after a high-grade cytological abnormality varied significantly across DHBs. It also varied by ethnicity, with 24.4% of Pacific women and 14.8% of Māori women not having a follow-up test within an appropriate	<u>Monitoring of women with a high grade smear who are not followed up</u> Timeliness of women with a high grade smear is monitored by the NCSP Register. Following a high grade smear result the Register expects to receive a colposcopy referral. If this does not occur a work list task is sent to the DHB Register Coordinator to follow up. The NCSP Register staff will set a further tracking event to allow the required action to occur. If there is still not event	**Ongoing – part of operational planning**	Ongoing work is essential to ensure women receive timely follow-up of an abnormal test result.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	timeframe. The NCSP should investigate the barriers to attendance that are preventing timely investigations and treatment and develop strategies to improve outcomes for these women.	recorded on the NCSP Register within the timeframe set, another work list task is generated for the NCSP Register staff to resolve. In 2016 the NCSP established an ongoing process to review women with high grade cytology and no follow-up cytology on the Register. <u>Referral to Screening Support Services</u> The NSU funds Screening Support Services (SSS) in 15 DHBs. The aim of this service is to provide additional support to priority group womennot responding to recall for breast and cervical screening and mammography or colposcopy services, with the aim of supporting them to attend. Services include home visiting, and assistance with transport and childcare if required. All Screening Support Services providers have linkages with their local colposcopy unit to receive referrals for priority group womenwho are not contactable or who do not attend appointments.		

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
3. Quality Assurance				
14	A comprehensive national intervention to resolve the barriers for the successful implementation of the e-colposcopy project is essential to ensure complete data for women referred for colposcopy is captured on the Register.	See also #30, #37, #41, #42 All DHBs are reporting using e-colposcopy.	**Closed**	The e-colposcopy project is complete for DHB colposcopy clinics. Private clinics should also be encouraged to participate to ensure outcomes are monitored for all New Zealand women.
15	Regular, ongoing meetings for monitoring and quality improvement should be scheduled shortly after the release of each of the biannual monitoring reports. The agendas for these meetings should be informed by the monitoring report indicators in particular areas where targets have not been achieved. The actions and outcomes from the meetings	The NSU has an overarching Quality Framework that is used by the NCSP. The Independent Bi-annual Reports and the NCSP Datamart is able to provide timely information on key programme indicators which are presented to the NCSP Advisory Group for endorsement of the recommendations and actions. The programme has established a Business as Usual (BAU) meeting with the role of reviewing monitoring and quality improvement activity. Key issues raised are escalated to the Senior Management Team.	**Closed**	It was not apparent during the 2018 PRC review how quality improvement required through monitoring is implemented at the service delivery level.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	would inform the development of a Quality Improvement Plan for the NCSP.	In addition, a Clinical Oversight Group (COG) and HPV Leaders Group has been established to provide governance over project activity being undertaken by the Programme.		
16	The development of specific Quality Improvement Plans must be a collaborative process between the NCSP and the relevant partners in the screening programme - DHBs, primary health care providers, laboratories, the Register - so that strategies are implemented consistently across the country.	The NCSP has a multi-pronged approach to quality improvement: • Following audits of laboratories and colposcopy services, the NCSP works with providers to ensure corrective actions are identified. • The NCSP has developed nationally-consistent training modules for use at DHB smear-taker updates. Relevant information is provided as an opportunity for improving the quality of services provided. • Communications are sent to PHOs to provide information on relevant issues when required. • Relevant information for smear takers is posted on the NSU website using the 'Screening Matters' publication. • The NCSP holds quarterly teleconferences with NCSP providers to discuss relevant issues related to cervical screening and colposcopy.	**Closed**	See response to recommendation 15.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
17	Regular, ongoing audit of the screening histories of all women who develop cervical cancer is essential. The knowledge gained from these audits must be used to inform quality improvement of the programme.	In late 2017, Dr Peter Sykes completed Cancer Case Reviews for 2008-12, and the NCSP is contracting Dr Sykes to review the 2013 - 17 cases.	**Closed**	Implementation of regular, ongoing audit and case review is essential in order to identify areas requiring remedial action.
18	Complaints and feedback from consumers of the screening programme received by the Health and Disability Commissioner, the Register and the NSU must be reviewed regularly and also be used to inform quality improvement strategies. A process for the NCSP to review complaints received at the provider level should be developed so the NCSP has an understanding of issues for the programme at the point of service delivery.	See also #33 All complaints received by the NCSP and Register Central Team are logged, reviewed and responded to. Any complaints about health care provision at a local level are sent to the provider to address. A summary of complaints received is tabled at the NCSP Advisory Group on an annual basis. Note - the NCSP has no visibility of complaints at a provider level unless they are sent to the NCSP.	**Ongoing – part of operational planning**	Also addressed in the PRC report under chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
4. Organisational and structural issues				
19	The NCSP must address the variable achievement of the target rate of 80% for Māori, Pacific and Asian women by producing Action Plans for each of the priority groups that can demonstrate progressive reduction in disparities for each of these groups.	See also #27, and #40. DHBs write an annual action plan for the NCSP identifying their activities, plans and how they will improve coverage in their DHB. This has consistently included activities to increase coverage in Māori women, and also coverage in Pacific and Asian women in DHBs with larger numbers of Pacific and Asian women living in the district. In addition, as part of annual planning and the proposed new Health Measure process, each DHB reports six monthly on activities they are undertaking to improve coverage.	**Ongoing – part of operational planning**	Also addressed in the PRC report under chapter 2: Equity across the screening pathway.
20	NCSP regional portfolio managers must continue to demonstrate improvements in coordination with providers through at least one planned national meeting each year and through ongoing, regional face-to-face meetings with local service leaders for the cervical screening programme in the	The NCSP makes the best use of technology to meet with DHBs and independent service providers, with quarterly teleconferences held to discuss current issues. The NSU held a National equity hui for providers in August 2016 and a further hui is planned for early 2019. In August DHB NCSP services met for a meeting of South Island providers, and a meeting of North Island providers is planned in 2019.	**Ongoing – part of operational planning**	Noted – ongoing.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	regions.			
21	High-quality screening programmes need to be supported by high-quality organisational structures, systems and processes. The NCSP has been stable for a good part of the past three years but it experienced significant change previously, and over recent months has again seen major senior management change with the resignation of personnel from the three most senior positions impacting the NCSP.	Clinical leads with extensive experience in colposcopy and pathology have been in place for three years. The programme has experienced some staff turnover within normal limits and is considered a stable team. The team is supported through the NSU Senior Leadership Team that has the appropriate skills to provide leadership and support to the NCSP team, and there is a positive clinical / management relationship.	**Closed**	Also addressed in the PRC report under chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction..
22	Particularly important within the NSU and the NCSP is the robustness of the clinical leadership structures. It is imperative that clinical leadership positions are at the forefront of the National Cervical Screening Programme and that these are sustained as its driving	The NSU has a multi-disciplinary approach. • The Clinical Director and the Group Manager of the NSU supports decision-making across all screening programmes. • The Ministry employs two part-time clinical leads – a clinical lead for pathology, and a clinical lead for colposcopy. The clinical lead for colposcopy has	**Closed**	Also addressed in the PRC report under chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	force.	recently resigned and recruitment is underway for a new 0.4FTE clinical lead. • The model involves a collaboration of the Clinical Director of the NSU, clinical staff within the NCSP, public health medicine specialists, programme staff and staff involved in monitoring, evaluation and equity across the screening pathway. The multi-disciplinary approach is supported by the Clinical Oversight Group (COG) and the BAU meetings.		direction.
23	Information about HPV must be appropriately provided to the NCSP priority groups: Māori, Pacific and Asian people. The NCSP must work collaboratively with the HPV Immunisation team within the Ministry of Health to ensure consistent and supportive messaging for both HPV vaccination and primary screening/testing programmes is achieved for these groups.	The NCSP works collaboratively with the MoH Immunisation Team to align messaging. HPV immunisation updates are regularly tabled with the NCSP Advisory Group and the HPV Technical Reference Group. As part of the implementation of HPV primary screening there will be continued opportunities to work collaboratively on supportive messaging on the importance of HPV immunisation and cervical screening.	**Closed**	Noted – further work required. Also covered in the 2018 PRC report.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
5. Workforce issues				
24	In light of momentous changes in cervical screening in other countries, it is likely that New Zealand's NCSP will also move towards primary HPV screening. It is therefore advised that a planned process be developed over the next two years (2015 to 2017) to support the laboratory workforce to identify pathways and/or professional development programmes that assist staff to transition into other areas of work and future career pathways. This process will need to be supported by a specific communication and consultation plan that is appropriately developed with the laboratory workforce.	As part of the implementation of HPV primary screening the NCSP will work closely with laboratories and other providers to manage the workforce impacts of the transition to primary HPV screening. Regular communication with laboratories continues. In May 2017, NCSP held a series of workshops with the laboratory sector to understand the workflow and workforce impacts of implementing HPV primary screening. In June 2018 the sector was advised of the updated timelines for implementation of HPV primary screening. Engagement with the laboratory managers and Health Workforce NZ is ongoing.	**Ongoing – part of operational planning**	Also addressed in the PRC report under chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
25	The NCSP must ensure online courses are regularly updated and access is improved to online training for primary care workers, including practice nurses, midwives, registered nurses, enrolled nurses and general practitioners. It is noted that District Health Board contracts also require DHBs to provide annual smear taker updates.	All DHBs are required to ensure regular updates to smear takers. These are usually held face-to-face with guest speakers. The NCSP has regularly supported these updates as a guest speaker, but has recently moved to a range of nationally-consistent modules to be used by DHBs with the support of local champions in the areas of primary care, colposcopy and equity / cultural competency. The NCSP will continue attend smear taker updates in areas of greatest need. One DHB has posted their smear taker update online so nurses who are unable to attend the sessions could view it online and receive a certificate of attendance if they answered a range of questions. In 2015, the MoH set up an on-line HPV training module. http://learnonline.health.nz/course/category.php?id=83 In future, the NCSP will investigate the opportunity for e-learning, but in the foreseeable future this is likely to be supplementary, rather than instead of face-to-face sessions.	**Ongoing – part of operational planning**	Noted – ongoing.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
26	The NCSP can learn much from the many successful examples of reducing disparities across the health sector. This learning must be continually demonstrated and supported by actions the NCSP takes to ensure the flexible but targeted use of funds in future contracts, such as those for services to support screening, and the Very Low Cost Access funds.	See also #1, #2, #6 The NSCP has a multi-faceted approach to reducing inequalities: • The NCSP undertook an RFP to refresh screening support services. These providers provide targeted follow-up of priority group womennot responding to recall. • The NSCP provides an allocation of free cervical smears to each DHB, and is working with the primary care team of the MoH to scope alternative ways of funding this. • There is a planned review of the NCSP funding model and service provision requirements as part of working toward implementing HPV primary screening which will commence in 2019.	**Ongoing – part of operational planning**	Noted – also covered throughout the 2018 PRC report.
27	The NCSP must ensure, for those District Health Boards that are not achieving the target rate of 80% for each of the NCSP's priority groups, the DHBs have well planned programmes to avoid increasing their inequalities. See also Chapter 6:	See also #16, #19, #27, and #40. DHBs write an annual action plan for the NCSP identifying their activities and plans and how they will improve coverage in their DHB. This has consistently included activities to increase coverage all priority groups. The NCSP requires that plans are 'SMART' – specific, measurable, achievable, realistic and have a timeframe.	**Ongoing – part of operational planning**	Review of data shows that there is more work to be done to support DHBs to achieve their targets.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	Organisational and structural issues.	In addition, each DHB is involved in reporting on cervical screening coverage as part of the DHB annual planning and the proposed new Health Measure process.		
6. NCSP register				
28	Strong strategic governance and IT expertise within the Ministry are needed to enable informed decisions regarding future HPV screening, data linkage with the National Immunisation Register, and the subsequent redesign of the NCSP-R and its functions that will be required.	The MoH has commenced work to transition to HPV primary screening. This is dependent on the development of a fit-for-purpose IT solution (Register) and requires appropriation of funding to support implementation. Several independent groups are advising the NSU as the project to implement HPV primary screening test progresses: • An HPV Technical Reference Group has been formed to provide expert advice to the NSU as it considers introducing HPV primary screening; • the NCSP Advisory Group advises the NSU on the programme direction, with focus on reducing the incidence and mortality from cervical cancer; • the National Screening Advisory Committee provides high level strategic governance and leadership to the NSU for its screening programmes.	**In progress and to be actioned as part of the HPV primary screening project**	Noted and also discussed in the PRC report under chapter 4: Strategic direction on the change to primary HPV screening and chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		In 2017 an assessment identified that the current NCSP Register technology is inflexible, lacks integration and is not able to support a new HPV clinical pathway. Procurement of the National Screening Solution (NSS), a common information technology platform for screening programmes within the NSU, included NCSP requirements and will provide opportunities for greater integration of data sources.		
29	Decisions regarding the future directions of cervical screening must be strategically planned. Realistic and achievable timeframes and resourcing are needed so that robust registry systems can be developed to support any revised screening pathway.	The MoH has commenced work to transition to HPV primary screening and the development of a new NCSP Register. A range of work streams to inform the changes for primary HPV screening have been established. This includes work streams to develop the IT requirements /new Register, development of new Guidelines, Policies and Standards, and Laboratory workforce transition planning. In preparation for HPV primary screening a strategic assessment has been developed, and a business case to support the IT solution and funding for the new programme is in the process of being written. The updated timeline for implementation of HPV primary screening is from 2021. This is contingent on appropriation of funding.	**To be progressed as part of the HPV primary screening project**	Noted – part of NSS development.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
30	Issues impeding the successful completion of the e-colposcopy project to enable electronic uploading of colposcopy data must be resolved as a priority. This must include working with providers who are responsible for uploading colposcopy reports to ensure the colposcopy forms are user- friendly and able to be transmitted in a timely manner. A comprehensive national intervention to resolve the barriers to the successful completion of the e- colposcopy project is essential to ensure complete data for women referred for colposcopy is captured on the NCSP-R. It is recommended that an audit across all DHBs is undertaken by December 2015 to ensure colposcopy data is successfully being uploaded to the NCSP-R.	See al.so #14, #37, #41, #42 Electronic reporting of colposcopy by DHBs was achieved in August 2016, and since 31 August 2018 the NCSP has two years of data for monitoring key colposcopy indicators against the current standards.	**Closed**	Noted – some DHBs require support to access, understand the data and improve performance.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
31	Achieving the ability to populate the NCSP-R with population data and issue invitations to all eligible women to screen should be a strategic priority for the NCSP to investigate.	Refer to #28.	**To be progressed as part of the HPV primary screening project**	Noted – to be done.
32	It is noted the NCSP-R audit in 2014 did not include a random audit of coding on the NCSP-R and correlation with laboratory records. This quality assurance intervention should be considered for future audits.	The NCSP has a system of work list tasks that identify when information doesn't load and where the information received does not align with the clinical pathway.	**For possible future development**	Noted – data quality assurance will be an important body of work for the implementation of the NSS.
33	The issue, action and outcome of complaints, regarding either the NCSP-R or the programme as a whole, need to be regularly reviewed and monitored, and a summary report provided to the NCSP Advisory Group, so that any trends can be identified and addressed.	See also #18 NCSP Register complaints and general complaints are logged. A summary of complaints received by the NCSP is an annual item on the agenda of the NCSP Advisory Group.	**Closed**	See also the PRC report, chapter 5: The effectiveness of governance and advisory structures in supporting the NCSP's performance and strategic direction for gaps in complaint

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
				management.
34	A focus for the NCSP into the future should be reporting back to providers and reviewing the data and outcomes in collaboration with lead clinical providers from DHBs, as part of a continuous feedback cycle for quality improvement.	See also #43 Newsletters are sent out to primary care when the NCSP is aware of service issues and gaps and this information is also bought up at smear taker updates. NCSP providers are advised by email when quarterly coverage reports and other relevant reports are loaded on the NCSP website. A laboratory audit report from the Datamart is provided to auditors prior to a laboratory audit. The NCSP will progress plans to use the Datamart to review colposcopy indicators and reporting to DHBs, in particular the timeliness of women being seen at colposcopy. Work is being undertaken to ensure the correlation of data in the Datamart with the Independent Monitoring Report.	**Ongoing – part of operational planning**	Noted – ongoing.
35	It is strongly recommended the NCSP and NKG work in partnership to identify more streamlined processes that minimise the burdens the current processes for accessing data	Refer to #5	**Closed**	Noted – partnership with NKG is working well.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	place on both parties.			
36	Any future planning for the NCSP-R must include options for linking the HPV Immunisation Register data with women's cervical screening history on the NCSP-R, so that a woman's vaccination status forms part of her cervical screening history.	See also #11 and #49 As part of the development of the National Screening Information Technology Solution (NSS) required for HPV primary screening the NCSP will explore including HPV immunisation status on the Register.	**To be progressed as part of the primary HPV screening project**	Noted and as per recommendation 11.
37	The NCSP must ensure processes are in place to monitor compliance with the legislative requirement for all colposcopy clinics, including the private clinics, to send their colposcopy data to the NCSP-R.	See also #14, #30, #41, #42 From July 2017 all DHBs are electronically reporting colposcopy data, and also six private colposcopy clinics. A letter was sent to private colposcopy clinics in July 2018 to encourage electronic reporting.	**In progress (private colposcopy clinics only)**	Noted – further work with private colposcopy clinics required to ensure compliance with monitoring indicators.
7. Ethnicity data				
38	The PRC is encouraged by the progress made between the NCSP and the NKG in order to provide timely and accurate reporting information on Māori women. There is further room for	Following a review of the NKG, the secretariat function is now managed by the NSU, and new members have been appointed. The first face-to-face meeting was held in December 2017, and the NCSP has established a positive working	**Closed**	Noted – see also recommendation 35.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	NCSP and NKG to continue to strive to improve relationships. Also see recommendation 35.	relationship with the group. Regular meetings have been established, with the most recent being in October 2018 to discuss the proposed changes to the legislation and Māori data governance.		
39	The NSU, NCSP portfolio managers and DHB managers need to collaborate with Independent Service Providers and PHOs (general practices) regarding data sharing between the agencies to identify unscreened women in the regions. It is emphasised that this issue is related to reducing disparities for priority women and Māori women in particular. It is recommended that, as a result of this collaboration, NCSP and NSU should issue clear guidelines on sharing client data between agencies.	A range of data sharing activities are underway: • The monthly PHO Cervical Screening Data Match report is provided to PHOs to share with practices in order to support recall. This identifies women who are unscreened (not on the NCSP Register), overdue and due for screening. • As part of the Screening Support Services (SSS) contract a referral pathway is in place for primary care to refer women who are hard to reach / not responding to an independent service provider for follow-up. • All SSS's are working in an ongoing way with PHOs and general practices to receive referrals for women not responding to recall. It has taken time to develop trust with some general practices to refer to SSS. • The NSU is working towards a legislative change to allow direct access to the register for health care professionals (and associated administration staff) providing services along the cervical screening	**Ongoing – part of operational planning**	Noted – ongoing.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		pathway for the purposes of undertaking their work. This has gone through health select committee and the next stage will be the Second Reading in Parliament.		
40	The NCSP should ensure that DHBs provide Action Plans for each of the priority groups. In particular, DHBs should develop an annual Pacific Action Plan and an annual Asian Action Plan to address inequities and disparities in cervical screening for each of these priority groups. Also, see recommendation 19.	See also #19, and #27 Each year DHBs write an action plan for the NCSP identifying their activities and plans and how they will improve coverage in their DHB. This has consistently included activities to increase coverage in Māori women, and also coverage in Pacific and Asian women in DHBs with larger numbers of Pacific and Asian women living in the district. In addition, as part of the Annual Plan and the proposed new Health Measure process DHBs need to advise the Ministry of their plans for improvement if they have not met the coverage target of 80%.	**Ongoing – part of operational planning**	Noted – ongoing.
8. Colposcopy				
41	There is an urgent need to ensure that colposcopy data in the NCSP-R is complete. The NCSP can facilitate this process by making available e-colposcopy to all DHB	See also #14, #30, #37, #42 Completed July 2017	**Closed**	Noted – closed.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	colposcopy clinics. Also see recommendation 30.			
42	The NCSP should ensure that colposcopy data submitted from the private sector fully complies with the Health Act 1956. Also see recommendation 37.	See also #37 The Ministry has no authority to require the private sector to adapt their reporting method. The NCSP is working in collaboration with private colposcopy clinics to move from manual reporting to electronic reporting. A letter was sent to private colposcopy clinics in July 2018 to encourage electronic reporting. As at October 2018, six private colposcopy clinics are reporting electronically.	**Closed**	Noted – private clinics not yet compliant.
43	Data held on the NCSP-R that is received from colposcopy services should be analysed annually to support practitioners in their quality improvement. Also see recommendation 34.	See also #7 The NCSP now has two years of datamart information able to be used to monitor key indicators. Work is progressing to review the structure of the information in the datamart to provide for fit-for-purpose reporting.	**Ongoing – part of operational planning**	Noted – ongoing (see also recommendation 30).
44	The NCSP and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists will need to address the discrepancy between	Individual DHBs are accountable for ensuring the credentialing of individual clinicians. The Ministry is in the process of updating the National Policy and Quality Standards for colposcopy in the area of	**In progress**	Noted – ongoing.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	the C-QuiP and NCSP colposcopy standards. This recommendation is to ensure New Zealand colposcopists accredited by C-QuiP meet the same standards as those required by the NCSP.	credentialing. RANZCOG certifies colposcopists as meeting the C- QuiP criteria, but it is still up to the individual DHBs to take responsibility for credentialing, and meeting the C-QuiP requirements is part of the credentialing process. Note: C-QuiP is less rigorous than the colposcopy standards in New Zealand. Locally, there is a view that New Zealand should not be lowering standards to be equivalent to C-QuiP.		
9. Human papilloma virus and cervical cancer				
45	New Zealand must give priority to reviewing international evidence and developing a process for the introduction and implementation of a revised contemporary best practice screening programme that will realise further improvements in reducing morbidity and mortality attributable to cervical cancer and its precursors. Evidence shows that a screening protocol	In February 2016, the then Minister of Health signed off the plan to implement primary HPV screening by 2018. A steering group is in place, and also a range of work streams to plan the transition. A business case was developed to support the appropriation of funds. In 2017 an assessment identified that the current NCSP Register technology is inflexible, lacks integration and is not able to support a new HPV clinical pathway. Procurement of the National Screening Solution (NSS), a common information technology platform for screening programmes within the NSU, included NCSP requirements and will provide opportunities for greater integration of	**To be progressed as part of the HPV primary screening project**	Noted – also covered comprehensively throughout the 2018 PRC report.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	employing primary HPV screening with partial HPV genotyping will result in the greatest reductions in incidence and mortality from cervical cancer.	data sources. A business case for the change to HPV primary screening is in the process of being developed.		
46	It is recommended the Ministry of Health requests the engagement of the National Health Committee to support the National Screening Unit in developing the business plan and recommendations for the design and implementation of the new model of care for cervical screening in New Zealand. This process must be appropriately resourced and funded.	This recommended action cannot be progressed as the NHC no longer exists. Strategic decisions are considered by the National Screening Advisory Committee who endorse all major changes related to existing screening programmes, including the decision to transition to HPV primary screening.	**Closed**	Noted – also covered throughout the 2018 PRC report.
47	Within the existing programme, the benefits of HPV triage for LSIL cytology should be reviewed.	The NCSP plans to implement Primary HPV screening and HPV triage will no longer be used for women with LSIL cytology - the decision to refer will be based on the presence of HPV, and if high risk types are present.	**Not being progressed at this time**	Noted – not being progressed as a result of planned transition to HPV screening.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		As the current pathway will be discontinued in the future, there is limited value in prioritising resource to this piece of work. Also, for such a short period, it would also be very confusing to stop HPV testing for LSIL and still do it for ASC-US. Using the Independent Monitoring Report 40 the PRC report identified that in women over 30 years with valid HPV triage test results, 26.2% of women with ASC-US results and 60% of LSIL samples test positive for HPV. The Committee identified the need to determine whether there is any benefit in continuing HPV triage in women with LSIL results. Ceasing HPV triage of LSIL samples would mean that the remaining 40% of women with LSIL who are HPV negative would be referred to colposcopy. Currently, these women avoid colposcopy, and there are risks with unnecessary referral of women to colposcopy which may expose women to unecacary procedures.		
48	Within current screening guidelines, the use of HPV tests by clinicians should be monitored. Feedback from this monitoring should be provided to non-compliant clinicians to	The biannual monitoring report provides overall information on HPV tests including the reason for requesting an HPV test. The NSU can obtain NHIs and therefore who asked for HPV tests where the test is 'other' ie, not consistent with the NCSP Guidelines. A number of these requests are from private gynaecologists and sexual	**For review as part of the HPV primary screening project**	Noted – part of work for transition to HPV screening.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	improve practice.	health clinics / family planning. Using the current pathway, for women over 30 years, HPV testing following an LSIL/ASC-US result is not normally requested by clinicians as this is a 'reflex' test undertaken by the laboratory. Monitoring this would add little value and has not been progressed. HPV tests performed as part of a Test of Cure (ToC) need to be requested by clinicians, but it would currently be complicated to identify women in the ToC pathway and check that the guidelines for offering an HPV test are being followed. At smear taker updates, the NCSP is reminding smear takers of the ToC and historical testing guidelines to encourage compliance. With the approach of HPV primary screening the NCSP is assessing the number of isolated HPV tests being ordered that don't meet the NCSP Guidelines. In January 2018 communication was sent to PHOs and laboratories to advise that HPV tests outside of the NCSP Guidelines are not funded by the NCSP should not be accepted by the laboratory. The rationale is that: • There are no NCSP management guidelines for determining further follow up for women if they have		

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
		an HPV test outside the current guidelines for cervical screening which are based on a cytology screening pathway. The NCSP Register is not able to take the results of isolated HPV tests into account when determining future recall. • HPV tests outside of the current guidelines could result in clinical risk by inappropriate recall. Should isolated tests outside of the clinical guidelines be reported the laboratory, the recall or referral advice recommended by the laboratory will be based on the cytology result and the NCSP Register screening history.		
49	As per recommendations in Chapter 8: NCSP-Register, to enable monitoring and evaluation of the effectiveness and cost-effectiveness of the HPV Immunisation Programme, it is necessary to develop strategies to capture and record a woman's HPV vaccination status with her screening history, or data linkage with the National Immunisation	See also #11 and #36 It is planned to include women's HPV vaccination history in a woman's screening history as part of the development of the National Screening Solution.	**To be progressed as part of the HPV primary screening project**	Noted – see also recommendation 11.

No.	2015 Parliamentary Review Committee Recommendation	NSU Update October 2018	Comment from NCSP	2018 PRC's view of effectiveness of progress against 2015 recommendations
	Register.			
50	In reviewing evidence for a revised screening protocol, consideration should be given to screening options that would encourage participation by unscreened and under-screened women. Self-sampling has been identified as a strategy to reduce inequities and barriers for women at highest risk who are not screening, or not screening regularly.	Support to screening services Screening Support Services are in place in a number of DHBs. Providers are funded to provide targeted follow-up of priority group who are unscreened, under-screened, or for follow-up of an abnormal result. Self-sampling Currently three self-sampling feasibility studies are underway, the findings of which will inform any new pathway development for primary HPV screening in the future.	**Ongoing – part of operational planning**	Noted – ongoing. Further recommendations regarding the evidence for self-sampling are incorporated in the 2018 PRC report.

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Appendix 1: Terms of reference

National Cervical Screening Programme - Parliamentary Review Committee - Terms of Reference

Terms of Reference – Parliamentary Review Committee for National Cervical Screening Programme

Background

The National Cervical Screening Programme (NCSP) was introduced in 1990 to reduce the number of women who develop and die from cervical cancer.

Women aged 20 to 69 years are invited by their primary health care provider to be screened on a three-yearly basis. The aim of the programme is to reduce the incidence and mortality of cervical cancer by detecting cell changes which could progress to cervical cancer.

The current cytology-based cervical screening programme is working well and has seen significant reductions in incidence and mortality from cervical cancer since its introduction in 1990. In recent years however, the decline in incidence and mortality from cervical cancer has plateaued for all women. Additionally there has been no further narrowing of the gap between Māori and non-Māori women for both incidence and mortality from cervical cancer.

The Review

The NCSP Parliamentary Review Committee is a ministerial review committee established under s 1220 of the Health Act 1956 (the Act).

Under s 1120(1) of the Act, the Minister must at least once every three years establish a review committee of up to three persons to review:

- the operation of the NCSP;
- evaluation activities of the kind described in section 112T that have been carried out or are proposed to be carried out

Under s 1120(2), the focus of the Review Committee must be the continuous quality improvement of components of the NCSP, with a view to reducing the incidence and mortality rates of cervical cancer.

Scope

The primary focus is to review the effectiveness of the current programme to deliver outcomes with a focus on identifying opportunity and making recommendations of the future direction of the programme. This includes but is not limited to:

- Review the current effectiveness of programme strategies to improve equity across the screening pathway
- Review the effectiveness of programme monitoring and evaluation to inform programme performance and clinical safety
- Review and provide advice on the current strategic direction on the change to HPV screening
- Review effectiveness of programme governance and advisory structures to support programme performance and strategic direction

- Review the effectiveness of progress against the recommendations from the 2015 Parliamentary Review Committee

Scope exclusion

- The procurement of the National Screening Solution because this is already subject to Gateway Review as part of the assurance process.
- Technical review of the current NCSP register because this has already been completed as part of due diligence for Budget '18.

Review personnel

The committee is appointed by and accountable to the Associate Minister of Health.

Under s 112O(3) of the Act, no person appointed to an NCSP review committee may be:

- A Member of Parliament.
- An officer or employee of the Ministry of Health.
- A person who is, or has been, designated under section 112U of the Act as a screening programme evaluator.
- A person who would have a material conflict of interest if appointed.

The National Screening Unit will provide project management, secretariat and report writing support to the review committee.

The skills and experience required to undertake a review of the NCSP include:

- clinical experience in cervical screening, e.g. smear-taking, pathology or colposcopy
- cervical screening programme management experience
- health programme evaluation experience
- understanding of the New Zealand context, in particular equity issues

Review process

The reviewers will review relevant documentation, held by the Ministry or providers, relating to the Programme. Where possible the NSU will provide these in advance to the Committee.

For the purposes of carrying out the Review, the Committee may request any information held by the NCSP that is directly relevant to the subject matter of the Review.

The reviewers may interview former and current Ministry and DHB staff and any other persons as required.

The confidentially obligations set out in section 112J of the Health Amendment Act 2004 apply to the members of the Review Committee.

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

Engagement and communications strategy

A communications strategy will be developed by the Ministry of Health, in consultation with the Minister's office to support the review.

Deliverables

As required by s 112R(1) of the Act, the Committee will set out in a Report -

1. the details of its review; and
2. the conclusions it has reached; and
3. the recommendations that it makes as a result of that review.

The report must be submitted to the Associate Minister of Health as soon as reasonably practicable after it is completed. In consultation with the Minister of Health, the Associate Minister of Health will present the Report to the House of Representatives within 10 sitting days of receiving it and after this it will be made publically available (as required by s 112R(2) of the Act).

The lead reviewer will provide a written report to the Associate Minister of Health, setting out their evidence based findings, and recommend any actions or improvements to policies, processes and practices as a result of the findings of the review.

Issues, conflicts and risk resolution

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

Fees

Committee members are paid daily fees for their Committee work and these are decided by using the Department of the Prime Minister and Cabinet fee framework (CO (12) 6). [redacted]

Travel and expenses

Remuneration will be according to the guidelines set out by the Department of the Prime Minister and Cabinet. Travel and accommodation will be reimbursed, including travel to New Zealand (where necessary) and around New Zealand for interviews.

Signed:

Hon James Shaw
Associate Minister for Health Date:

Appendix 2: Interviews conducted by the Parliamentary Review Committee

Organisation	
Ministry of Health	Director-General of Health Acting Deputy Director-General, Population Health and Prevention Clinical Director, NSU Group Manager, NSU Manager, NCSP Māori Leadership HPV School-based Immunisation Programme Senior Portfolio Manager, NCSP Senior Service Development Analyst, NCSP Senior Service Development Advisor, NCSP Public Health Physician – Equity Public Health Physician – Monitoring and Evaluation Clinical Leader NCSP - Pathology Team Leader, Information, Quality & Equity (IQ&E), Monitoring and Reporting, NSU Deputy Director, Service Commissioning
(Acting) Associate Minister of Health	Hon James Shaw
NCSP-R	
Mana Wahine Collective (SSS)	
Māori Monitoring and Equity Group (MMEG)	
NCSP managers/coordinators	Waikato DHB Bay of Plenty DHB

Organisation	
(at DHBs)	Tairāwhiti DHB Taranaki DHB Hawke's Bay DHB MidCentral DHB Nelson Marlborough DHB Coast DHB Southern DHB
Victoria University of Wellington	Researchers, self-sampling study
Hutt Valley NCSP services	NCSP Service Manager NCSP Coordinator Practice Nurse
National Kaitiaki Group	
National Hauora Coalition	
Waitemata and Auckland DHBs (WDHB and ADHB respectively) NCSP services	Portfolio Manager, Planning & Funding, ADHB/Waitemata NCSP Coordinator, ADHB/Waitemata DHB ADHB Portfolio Manager Public health medicine specialist
Te Pou Matakana (SSS)	
Well Woman & Family Trust	
Counties Manakau DHB NCSP services (including SSS)	Portfolio Manager, Planning & Funding, CMDHB NCSP coordinator, CMDHB (and SSS) BreastScreen Counties Manukau SSS coordinator Programme Manager, Primary and Community team
	Previous clinical lead, colposcopy, NCSP, NSU
Women's Health Action group	Women's Health Action Director Northland-based health promoter Senior policy analyst
Federation of Women's Health Councils Aotearoa	
Auckland DHB (ADHB) colposcopy services	Lead colposcopist, ADHB Colposcopy Service Manager, ADHB Lead colposcopy nurse, ADHB

Organisation	
	Colposcopist
Anatomic Pathology Service	Lead cytoscientist Histo-cyto pathologist Lab manager at LabPlus Head of Cytology, LabPlus AP laboratory manager
ProCare (PHO)	
Tairāwhiti DHB (TDHB) NCSP Services	Clinical Care Manager Women, Child and Youth Services, Portfolio Manager (NCSP and colposcopy services) NCSP coordinator (including register coordinator) Lead colposcopist Lead colposcopy nurse
Turanga Health (SSS)	
NCSP Advisory Group	
He Waka Tapu (SSS)	Manager, Hauora & Alcohol and Other Drug Services Operations manager Registered nurse smear taker
Canterbury NCSP Services	NCSP Lead Provider Manager (also BSA Lead Provider Manager), and Manager of SSS for BreastScreen Otago-Southland NCSP coordinator (including Register Coordinator) GP and Director of ScreenSouth
Laboratory managers	CEO Southern Community Laboratory Manager Pathlab Tauranga Manager Medlab Central
NCSP DHB Portfolio Managers / Service Managers	Northland DHB Portfolio Manager Lakes DHB Portfolio Manager Hawke's Bay DHB Programme Manager Hutt Valley DHB Portfolio Manager Nelson Marlborough DHB Portfolio Manager Nelson Marlborough DHB Service Manager Southern DHB Portfolio Manager (Southland)
Christchurch DHB Colposcopy Services	Lead colposcopist Colposcopy Service Manager Lead colposcopy nurse
Christchurch DHB Laboratory Services	

Organisation	
Otago University	Research, Gynaecology Oncology
Cancer Council of NSW	
Christchurch DHB Planning & Funding	
Christchurch PHO	Service Development Facilitator
Pegasus PHO	Operations Manager, Pegasus PHO

Appendix 3: Interview guide

Review Committee
of the
New Zealand Cervical Screening Programme 2018

Introduction

The National Cervical Screening Programme (NCSP) Review Committee is a ministerial review committee established under Part 4A section 112O of the Health Act 1956 ("the Act").

The NCSP Review Committee's statutory functions are to review:

- the operation of the NCSP
- evaluation activities of the kind described in section 112T of the Act that have been carried out or are proposed to be carried out.

The focus of the Review Committee is the continuous quality improvement of components of the NCSP, with a view to reducing the incidence and mortality rates of cervical cancer.

The Review Committee members are:

- Ms Gail Ward (Chair)
- Ms Liane Penney
- Prof Ian Hammond.

One way the Committee wishes to elicit feedback is by semi-structured interviews. This will involve a series of questions with emphasis on your expertise in the NCSP and that will be followed by an opportunity for you to offer your own comments, feedback and concerns.

The Review Committee is most appreciative of the time that you have taken to be involved in this process.

1. Can you tell us how you are involved in cervical cancer screening?
(Please check all that apply – please number each in order of priority.)

☐ Laboratory ____ ☐ Nurse Practitioner ____ ☐ Health Promotion ____
☐ Public Health ____ ☐ Scientist ____ ☐ Screening Participant ____
☐ Other (please specify) _____
☐ Advisory Committee ___ Please specify Committee Name _____
Physicians: ☐ General Practice ____ ☐ OB/GYN ____ ☐ Colposcopy ____

2. What are the most important matters for the Review Committee to understand about cervical screening in New Zealand?

3. What do you know about quality improvements that have been underway within the Screening Programme?

4. What is your opinion as to the success of these efforts?

5. At an overall level, do you believe that the Screening Programme is providing a valuable and high-quality service for New Zealand women?

   ☐ Yes
   ☐ No

   Please explain your reasons.

6. In your opinion, what has been the biggest single challenge that the Screening Programme faces?

7. In your opinion, what has been the most significant accomplishment of the Screening Programme?

8. In your opinion, what is the most important issue that the Screening Programme must address and resolve in the next three years?

9. Please identify what, if any, other issues the Review Committee should be aware of.

10. Is there any other information that you wish to share with the Review Committee for their consideration?

Thank you so much for your time and contribution.

If you later have anything else that you wish to share with the Review Committee, please feel free to notify us by contacting:

Ms Gail Ward
gail.h.ward56@gmail.com

Appendix 4: Recommendations of the Cancer Case Review 2008–2012

The following recommendations are not listed in order of importance.

Recommendation
The NCR may form the basis of future NCSP-R cervical cancer audits and reviews
The NCR inform the NCSP-R of any cervical cancer diagnosis
The NCR use the date of histological diagnosis of cancer
The NCSP-R enable data management to support future cervical cancer audits and reviews
For future reviews consideration should be given to recording at the time of diagnosis (i.e. in "real time") identification, verification, and classification of the diagnosis and staging of cervical cancer cases for the NCSP-R and NCR
For future audits and reviews, a case control methodology from a population based registry should be used to estimate the protective effect of cervical screening
A consistent definition of regular screening that can be applied to both monitoring of the screened population and to the group of women with cancer should be agreed upon
Emphasis should continue to be placed on both enrolling and maintaining participation in the screening programme
To prioritise improved access and quality of screening, and treatment of cervical cancer for Māori women and the more socially deprived
Intervention strategies should take into consideration both the practical and cultural needs of these groups
Improve collection and recording of ethnicity data on the NCSP-R, including the recording of more than one ethnic group
"Real time" data collection may enable improved collection of ethnicity data
The protective effects of screening in relation to age continue to be monitored
That steps should be taken to ensure the regular participation in screening from the

Recommendation
recommended age of commencement
For the purpose of cervical cancer review that micro-invasive tumours continue to be distinguished from other cancers
The NCSP should continue to aim to reduce the incidence of all cervical cancers, including micro-invasive tumours
Formal review of normal screening tests in women who develop cervical cancer should be undertaken and reported on for educational and quality improvement purposes
We endorse the introduction of HPV based screening, efforts should be made to ensure that there is no reduction in 5 year cervical screening coverage rates
A formal clinical case review for patients who have developed cervical cancer following previous screen detected abnormalities should be performed. This should be used to inform the programme, laboratories and medical practitioners of any modifiable factors that have contributed to the outcome
In view of the proposed changes to the age of commencement of screening it is important the NCSP acknowledge the rare risk to young women including the upstaging of screen detectable cancers and the possibility of increased incidence of cancer in women under 30
That the NCSP should continue to monitor cancer incidence trends in women under 30
An emphasis is made on engaging women with a high coverage rate at age 25
That a system for ongoing audit and review of cervical cancer cases is established which utilises a consistent methodology. In doing so, the following points should be taken in consideration
Matching the NCSP-R with a population based registry to allow the selection of control groups for case control studies. This will allow estimation of the protective effect of screening within different populations
Including clinical data, this will confirm diagnosis, stage, method of diagnosis, residency status and ethnicity
Clinical data would best be collected prospectively in conjunction with the 3 national gynaecological cancer treatment units
HPV type status of cervical tumours should be recorded
Review of negative screening tests in the screening period prior to the diagnosis of cancer
Case review of patients with prior abnormal screening tests

Appendix 5: Māori Monitoring and Equity Group Terms of Reference

TERMS OF REFERENCE

MĀORI MONITORING AND EQUITY GROUP

To

THE NATIONAL SCREENING UNIT

2018

National Screening Unit

MĀORI MONITORING AND EQUITY GROUP

Terms of Reference

COMMITTEE NAME
The full name of the committee will be the "Māori Monitoring and Equity Group". For the purposes of this document the:

- Māori Monitoring and Equity Group shall be referred to as 'MMEG'
- Ministry of Health shall be referred to as the National Screening Unit (NSU)

RATIONALE
The NZ Health and Disability Act 2000 specifies the Government's commitment to Māori participation in health and pae ora through a framework of partnership, participation and protection. Strengthening Māori participation in planning and decision making is also a key pathway of the Māori Health Strategy; He Korowai Oranga 2014.

The Māori Monitoring and Equity Group operates under the korowai (cloak) of partnership, participation and protection. The group applies Tikanga and Whakaaro Māori to the activities of the NSU with the intent of protecting Māori health and wellbeing.

ROLE OF THE GROUP
The group will provide independent advice to the NSU to achieve its vision, namely:

> *"that people can access high-quality and equitable national screening programmes that contribute to healthier futures".*

OBJECTIVES

The objectives of the Group include:

- Providing Māori leadership on strategic issues related to population health screening and its impact on Māori health and inequities
- Providing Māori strategic advice on planning, implementation, monitoring and evaluation of the existing screening programmes and any further screening programmes under consideration
- Monitor the NSU's progress against the aspirations and actions set out in *National Screening for Healthier Futures*

MMEG will take a population health perspective.

MMEG will seek input from stakeholders to any key decisions. Input can include whānau, hapū, iwi, Māori communities, Māori providers, Māori consumers, and others as required.

MEMBERSHIP

MMEG will comprise up to ten independent (non-Ministry) members who have been appointed for their experience and knowledge in the areas of:
the health sector, particularly population based screening programmes, improving Māori health outcomes and reducing Māori health inequalities; tikanga and whakaaro Māori; strategic thinking and leadership; and their linkages to other groups.

MMEG membership may include representation from a variety of Māori health professionals or other relevant sectors, including:

- Kaimahi
- Health management
- Academia
- Clinicians
- Māori Women's Welfare League representative
- Tumu Whakarae representative

The NSU Clinical Director will appoint members, in consultation with MMEG, after discussion with relevant stakeholders including providers, consumer groups and professional groups. The appointment process may include a call for nominations/applications. If vacancies occur, the NSU will seek input from the MMEG on specific skills and knowledge required.

MMEG may co-opt other member(s) as required for specific pieces of work to address any gaps in expertise and/or involve key stakeholders. With the permission of the NSU Clinical Director, MMEG may create working groups to address key areas of screening, which may include co-opted members.

The Clinical Director, in partnership with the members, will appoint and chairperson who is independent of the Ministry of Health. A deputy chair will be appointed by the Clinical Director, in partnership with the group. The independence of the Group members will be respected.

HONORARY MEMBERS

The NSU Clinical Director, in partnership with the Chair, may appoint honorary members to MMEG in recognition of their longstanding service the group. Honorary members will not attend regular meetings.

TERM, REVIEW PROCESS AND END DATE

Members will be appointed to the Group for up to a two-year period and may be re-appointed for further term(s).

The Ministry may, at any time and entirely at the Ministry's discretion, remove any member from the Committee. MMEG members may also, at any time, resign by providing notice in writing to NSU Clinical Director.

In line with Ministry requirements the terms of reference will be reviewed annually.

IN ATTENDANCE
NSU staff in attendance will comprise the NSU Clinical Director, NSU Group Manager and Public Health Physician – Equity. Others may be invited to attend at the discretion of the Chair and NSU Clinical Director.

MEETINGS
Face to face meetings will be held three times per year, or as required by the Clinical Director, with teleconferences in between depending on requirements.

Meeting agendas items will reflect current NSU priorities and strategic issues identified by MMEG members. The agenda will be developed in consultation between the NSU and the chair.

A meeting quorum will consist of five members and can include members joining by teleconference

REPORTING
MMEG reports to the NSU Clinical Director.

REPORTING REQUIREMENTS

- Minutes of all meetings are correct and include a clear record of any decisions taken, duties decided or recommendations made.
- Where the NSU note any matters are confidential, that members do not divulge details of the group matters or discussion with the group to persons who are not group members.
- The NSU will report back on recommendations made by the MMEG
- The NSU will report on all matters and activities that are relevant to the objectives in these terms of reference.

CONFLICT OF INTEREST
Members will complete a Conflict of Interest Declaration form at the commencement of their term on the NSAC. Any changes to a member's actual, potential or perceived conflicts of interest during their membership of the NSAC will be notified to the Clinical Director, NSU or the Committee Chair. The NSU will maintain a register of interest for NSAC members which will be updated as required. Further guidance, Managing conflicts of interest: guidance for public entities, can be found on the Office of the Auditor-General web site; http//www.oag.govt.nz/2007/conflicts-public-entities.

When members believe they have a conflict of interest on a subject that will prevent them from reaching an impartial decision or undertaking an activity consistent with the NSAC functions, then they must declare a conflict of interest or absent themselves from the discussion and/or activity.

ADMINISTRATIVE SUPPORT
The NSU will provide administrative support to the MMEG and working groups including secretarial assistance.

FEES AND ALLOWANCES

The NSU will arrange and pay for travel to and from the meetings. The Ministry will pay fees for attendance at meetings to those members who are not Ministry or state sector employees, or working under contract to the Ministry, in accordance with the State Services Commission's framework for fees for statutory bodies.

LIABILITY

Members are not liable for any act or omission done or omitted in their capacity as a member, if they acted in good faith, and with reasonable care, in pursuance of the functions of the Committee.

Appendix 6: National Cervical Screening Advisory Group Terms of Reference

NCSP Advisory Group

Terms of Reference

Background

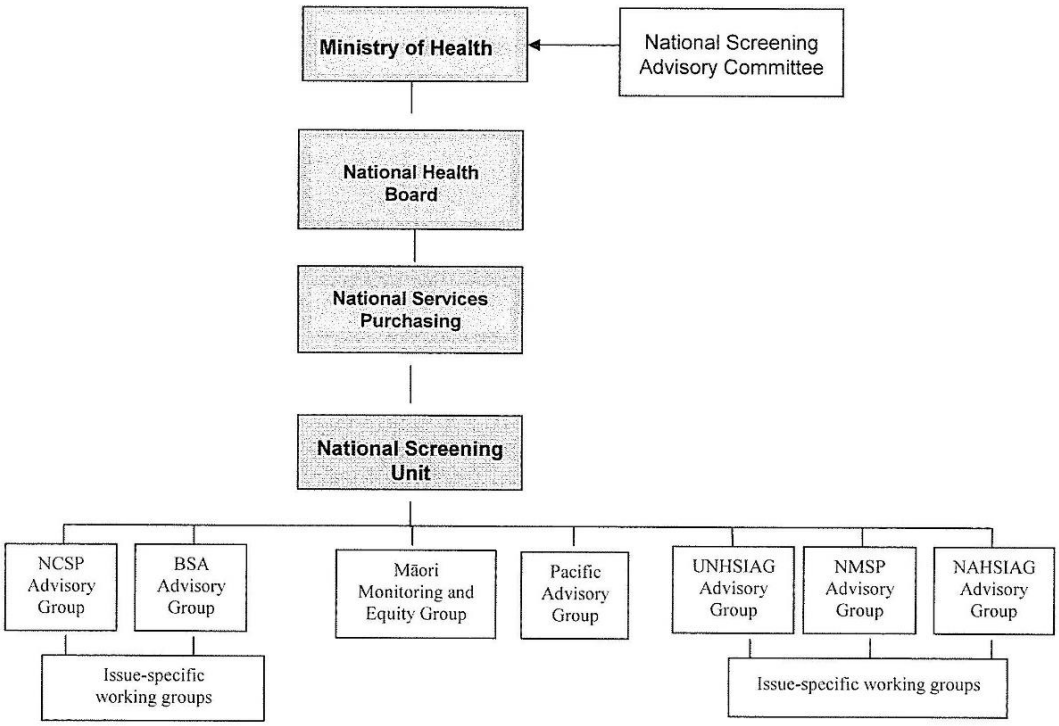
The National Screening Unit (NSU) in the Ministry of Health has a stewardship role for the National Cervical Screening Programme (NCSP), BreastScreen Aotearoa (BSA), the Newborn Hearing Screening Programme (UNHSP), the Universal Newborn Metabolic Screening Programme (NMSP) and the Antenatal HIV Screening Programme (AHSP).

The National Screening Unit is responsible for:

- Providing leadership and strategic direction for the cancer, antenatal and newborn screening programmes
- Providing advice to Government regarding new screening programmes
- Ensuring nationally consistent policy and quality standards for screening programmes
- Providing national monitoring, audit, evaluation and quality improvement processes for screening programmes
- Providing educational resources for health care practitioners and consumers in relation to screening programmes
- Funding the provision of services along the screening pathways.

The NSU seeks external advice from a range of sources to support its work. Advisory groups for each screening programme were established in 2002 as well as a national screening advisory body to provide oversight of and advice on screening activities throughout the health sector. Māori, Pacific and consumer advisory groups have also provided advice to the screening programmes. Advisory groups for the NSU were further reviewed in 2008.

NSU Advisory Group Structure



Purpose of the Advisory Group

The aim of the National Cervical Screening Programme is to reduce the incidence and mortality of cervical cancer among all New Zealand women by the detection and treatment of precancerous squamous cell changes, and where possible other abnormal cervical/vaginal cell changes, through the coordination of a high quality, population based screening programme.

The NCSP Advisory Group (the Group) supports the NSU to achieve this aim and to continuously improve the quality of the NCSP by providing advice on Programme monitoring and strategic direction.

Role of the Group

The NCSP Advisory Group understands the context of the Programme and operates 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 as agreed by the Group and the NSU
- Help build understanding and partnership with consumer and professional groups.

In turn, the group will expect that its advice will be appropriately published and implemented as far as practicable.

It is expected that members will consult widely within their own groups.

Principles

The Group will:

- Work in accordance with the Treaty of Waitangi principles of partnership, participation and protection
- Have a commitment to equity of outcome for priority and under-screened groups within the programme
- Have a well-women focus
- Use the best available evidence to inform its work
- Have a population perspective with an understanding of the principles of screening programmes
- Operate in a way that is consistent with government policies for the NCSP.

Composition

The Group will be comprised of members who collectively will have wide knowledge and experience of the NCSP.

The membership will consist of representation from:

- Royal Australia and New Zealand College of Obstetricians & Gynaecologists
- Royal College of Pathologists of Australasia
- Royal New Zealand College of General Practitioners
- New Zealand College of Primary Health Care Nurses
- The New Zealand College of Public Health Medicine
- New Zealand Society of Cytology

- New Zealand Institute Medical Laboratory Science
- Pacific Advisory Group
- The Maori community
- Consumers

The NCSP may co-opt other members from time to time as required, to address gaps in knowledge and/or expertise, or to contribute to deliberations on specific agenda items.

The NSU membership will be ex officio and will comprise of the NCSP Manager and NCSP Clinical Leader, with input from NSU team members as required.

The Group will report to the NCSP Manager and NCSP Clinical Leader. The Group will be informed of the outcome of their advice. The Group will be responsible for advising the NCSP, but will not carry the responsibility for whether that advice is accepted and acted upon.

Term of Office

The term of office will be for two years with the right of consideration for re-appointment for one further consecutive term.

When vacancies occur, the NSU will be responsible for seeking nominations from the relevant group or organisation.

Working Arrangements of the Group

The Group will be chaired either by an elected Group member or by an independent chair selected by the NSU.

The NCSP team will provide administrative and analytical support.

Meetings are expected to be held twice a year, with teleconferences in between depending on requirements.

The terms of reference will be reviewed annually.

Conflicts of Interest

Members should formally document their conflicts of interest and identify any conflict of interest prior to a discussion of a particular issue. The Group will determine what part the member may take in any discussion relating to this issue. Further guidance can be found in the document *Conflict of Interest Protocol for Statutory Bodies and Other Committees.*

Appendix 7: HPV Testing for Primary Screening Project Technical Reference Group Terms of Reference

HPV Testing for Primary Screening Project
Technical Reference Group Terms of Reference

Purpose

The HPV Testing for Primary Screening Technical Reference Group (the Group) will provide expert advice to the National Screening Unit in its consideration of introducing Human Papillomavirus (HPV) testing for primary screening to the National Cervical Screening Programme.

Background

The National Screening Unit is considering introducing Human Papillomavirus (HPV) testing for primary screening to the National Cervical Screening Programme. HPV testing is for a subset of high risk HPV (hrHPV) types that have known oncogenic potential.

On the basis of the worldwide evidence for the effectiveness and safety of HPV-based screening, several countries have recently considered revising existing cervical screening programs to implement primary HPV screening. The Ministry of Health, Welfare and Sport of the Netherlands announced review of the existing screening program to adopt primary HPV testing for primary screening from 1 January 2016 (National Institute for Public Health and the Environment, 2014). The National Cervical Screening Program Renewal in Australia has also made a recommendation for five-yearly cervical screening using a primary HPV test with second tier partial HPV genotyping and reflex liquid-based cytology (LBC) triage from April 2017 (Australian Government Department of Health, 2014).

Timeframes and estimated time commitment

The Group will meet at least once per month between April 2015 and December 2015. The Group may continue meeting past this point to provide technical advice in the development of clinical guidelines and other aspects of implementation. Aside from attendance at meetings, Group members should expect to spend between 1-4 hours per week providing feedback on material provided to them for consideration and comment.

The Group's Terms of Reference will be reviewed each year alongside the Ministry's annual stocktake of Ministerial and Ministry committees.

The table below outlines key project milestones throughout 2015. Each meeting of the Group is likely to focus on key decisions and advice related to these key milestones.

Policy question finalisation	5 June 2015
UNSW options advice received	12 June 2015
Rapid assessment draft agreed for NCSP Advisory Group meeting	30 June 2015
Sector consultation	Mid-August 2015
Consider sector feedback and update Rapid assessment draft	End-September 2015
Rapid assessment finalised for NCSP Advisory Group meeting	Late-October 2015

Membership

Membership on the Group is by invitation from the Project Sponsor. It is possible that new members with particular areas of expertise will be invited to join the Group as required. Sub-groups of the Group may be formed as required to focus on specific tasks within a particular area of expertise.

Members of the Group will:

- Have a commitment to work for the public of New Zealand.
- Be subject matter experts in a range of subjects relevant to cervical screening

- Act in their professional capacity as experts on areas relevant to cervical screening
- Provide the National Screening Unit with their own views on HPV testing for primary screening without requiring consensus or an agreed position amongst the Group
- Attend meetings and undertake activities as independent persons responsible to the Group as a whole and are not representatives of professional organisations or communities. This issue is particularly important when Group members may, at times, be required to be party to decisions which conflict with the views of other organisations with which they are involved

Group members may leave at any point. However, any Group member who leaves should discuss their reasons with the Group Chair and, where possible, help arrange for a replacement member with similar skills and knowledge to theirs.

The Group Chair will run the Group to ensure its effectiveness in all aspects of its role.

Expert advice from the Australian NCSP programme renewal perspective and modelling work for the NCSP will be available to the Group from Associate Professor Karen Canfell, Director, Cancer Research Division, Cancer Council NSW.

An illustration of the Group's role in the HPV Testing for Primary Screening Project is attached as Appendix A.

Organisation	Name	Role
Ministry of Health	Jane O'Hallahan	Clinical Director, National Screening Unit Project Sponsor
	Harold Neal	Principle Scientific Advisor
	Stephanie Chapman	Project Manager (in attendance)
Māori Monitoring Equity Group	TBC	
	Bev Lawton	Associate Professor, Director Women's Health Research Centre, University of Otago
NCSP Advisory Group	Gaye Tozer (Chair)	Bowel Screening Pilot Programme Manager, Waitemata DHB
	Richard Massey	Clinical Director, Medlab Bay of Plenty
	Josephine Samuelu	Pacific advisor
Nelson Marlborough DHB	Gary Fentiman	Consultant, Obstetrics and Gynaecology
Canterbury Health Laboratories	Lance Jennings	Clinical Virologist
Massey University (formerly Aotea Pathology)	Collette Bromhead	Molecular Scientist
Anatomical Pathology Services Mount Wellington (formerly Diagnostic MedLab – DML)	Liz Pringle	Laboratory Manager, Cytology/HPV testing
Cancer Research Division, Cancer Council NSW	Karen Canfell	Associate Professor, Director Advisor to the TRG

Expectations for meetings and communication	Most of the Group's work will be done via email, teleconference or video conference, with the potential of meetings if considered necessary. A quorum will consist of five of the nine members.
	Meetings, where required, will generally be scheduled for one day per month.
	Agendas and papers will be distributed to members as early as practicably possible prior to each meeting. Meeting minutes will be circulated to members within two weeks of each meeting. Group members may request items for inclusion on the agenda, via the Project Manager.
Reporting and accountability	The Group is not expected to produce a report or any other documentation or to make any formal recommendations.
	The Group will not formally report to any person or area.
	Any formal requests or concerns should be raised in the first instance with the Group Chair. The next point of escalation is the Project Sponsor.
Liability	Members are not liable for any act or omission done or omitted in their capacity as a member, if they acted in good faith, and with reasonable care, in pursuance of the functions of the Group.
Confidentiality	Throughout the life of the project, members of the Group will be privy to confidential and commercially sensitive information. It is expected that all information shared and discussed will be treated as confidential. Members must ensure that documents are kept securely to ensure that confidentiality is maintained. Release of correspondence or papers can only be made with the approval of the Ministry. At the end of a member's term, all Group information must be returned to the Ministry.
	Members are free, and are expected, to express their own views within the context of meetings, or the general business of the Group. Members must publicly support a course of action decided by the Group, or if unable to do that, must not publicly comment on decisions.
	Expert members are expected to justify the position and decisions from the project to their peers based on evidence used to inform decisions and outcomes.
	Decisions from meetings may require discussion and ratification by other groups within the project e.g. Steering Group.
	At no time shall members divulge details of Group matters or decisions to people who are not members, or Ministry employees. Disclosure of material to anyone outside of the Group or the Ministry can only be made following approval from the Group Chair and/or the Project Sponsor.
Official information requests	All agendas, minutes, emails and other written communication are subject to release under the Official Information Act unless otherwise excluded for release under the provisions of that Act.
	All requests for information related to the HPV Testing for Primary Screening Project made by any person from outside of the Group should be referred to the Project Manager.
Conflicts of interest	All Group members (or their delegates) will complete conflict of interest forms, and declare any perceived or potential conflicts of interest.
	If Group members believe that they have a potential or actual conflict of interest on any matter before the group, they must declare that conflict of interest to the Group Chair and/or Project Sponsor. They must exclude themselves from reviewing any material or participating or being present for any discussions or decisions on those matters and ensure that actions taken to exclude themselves are recorded on meeting minutes or elsewhere as appropriate.

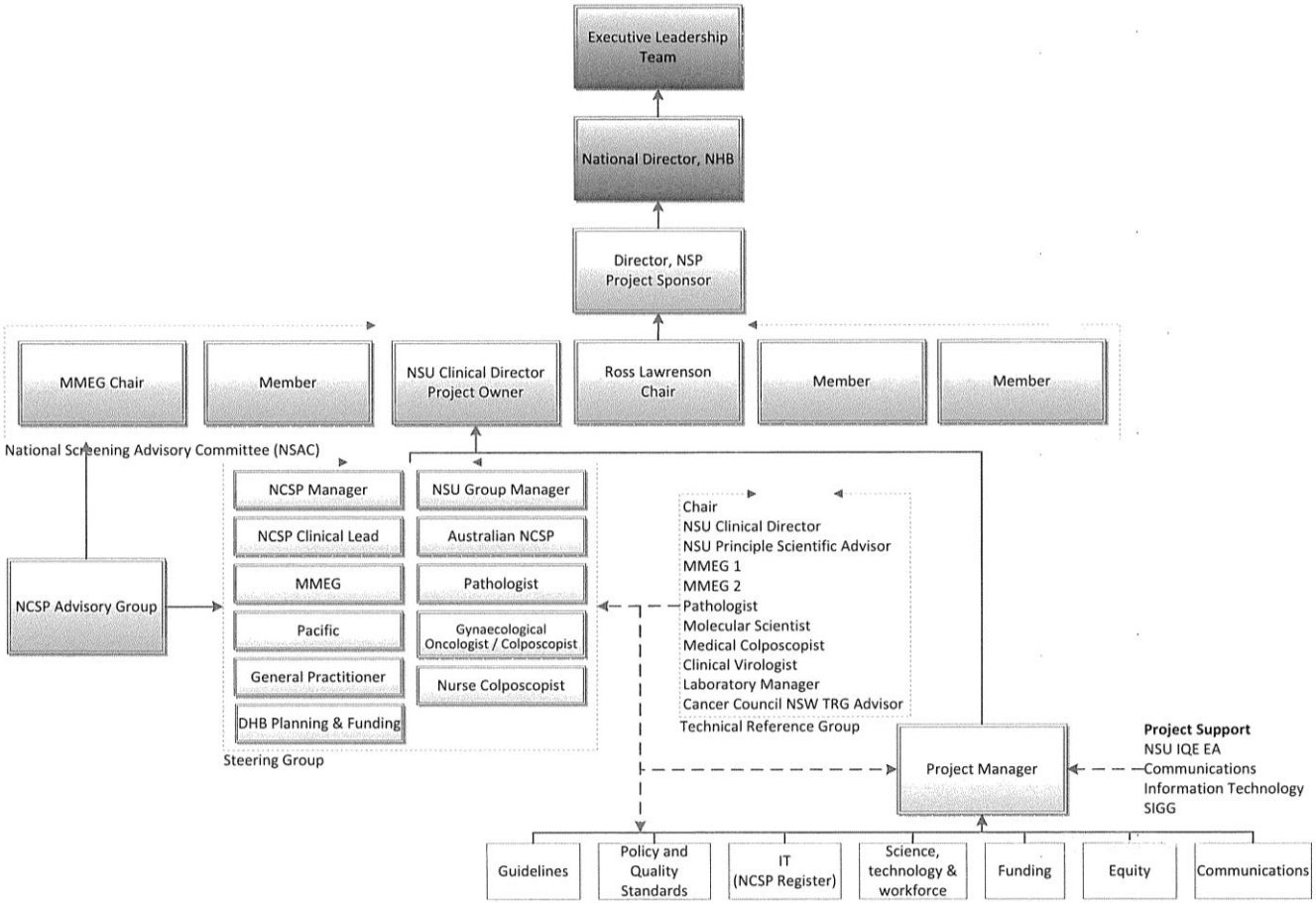
Attendance and nominees	When members of the Group are absent they may nominate an authorised delegate to attend meetings who shall participate with the same rights and responsibilities as the Group member. Absent members of the Group should take all practicable steps to ensure that any nominee is briefed on upcoming meetings and is able to fully participate in discussions.
Remuneration	Members of the Group are paid fees for attendance at meetings, in accordance with the Cabinet Office Circular CO (12) 6 *Fees framework for members appointed to bodies in which the Crown has an interest* (or its successor circular). Members will also be paid actual and reasonable document review / meeting preparation time at the daily fee and pro rata. Members who are employees of the wider State sector are not entitled to be paid fees for Group business if this is conducted during regular paid work time (ie, members cannot be paid twice by the Crown for the same hours). The Ministry will be responsible for booking any necessary travel and accommodation.
Secretariat	The Project Manager will ensure that the Group is provided with adequate secretarial support for the Group to carry out its functions efficiently and effectively.

Approved by

Jane O'Hallahan

Date: 17/6/2015

Appendix A: HPV Testing for Primary Screening Project Structure



Appendix 8: National Cervical Screening Programme Primary Human Papilloma Virus (HPV) Screening Implementation Leaders Group Terms of Reference

MINISTRY OF HEALTH
MANATŪ HAUORA

National Cervical Screening Programme (NCSP)
Primary Human Papilloma Virus (HPV) Screening Implementation
Leaders Group

Terms of Reference

1 Purpose

1.1 The purpose of the NCSP HPV Leadership Group (the Group) is to:

1.1.1 provide leadership for the implementation of primary HPV screening for the National Cervical Screening Programme (NBSP), plus selected projects (see Appendix), and

1.1.2 receive and agree or note recommendations from the sub-groups shown in the Appendix, and

1.1.3 provide the NBSP HPV Governance Group with guidance, recommendations and support to enable them to make the best decisions for the implementation of HPV primary screening, and

1.1.4 ensure that the implementation of HPV primary screening and related projects are completed on time, within budget, to an acceptable quality, and

1.1.5 provide accountability to the NCSP HPV SRO for the performance of the NCSP HPV screening implementation.

2 Term

2.1 The Group is expected to be in place for the duration of the NCSP HPV screening implementation (Implementation) that is forecast to occur by December 2021.

2.2 Membership and Terms of Reference for the Group will be reviewed annually.

3 Document Location

3.1 When viewed electronically, these terms of reference can be found in Lotus Notes

4 Background

4.1 Primary HPV cervical screening aims to reduce the incidence and mortality from cervical cancer in New Zealand.

4.2 In 2016 the Minister agreed to the recommendation to implement primary HPV screening in New Zealand, based on international evidence and the recommendations of the Ministry's advisory groups.

4.3 In early 2019 a Better Business Case will be submitted to Treasury requesting funding in Budget 2019 to implement primary HPV screening by 2021.

5 Population Based Screening Programme Objectives

5.1 The objectives of population based Screening programmes are:[1]

5.1.1 achieve a greater mortality reduction,

5.1.2 delivered in a manner that is acceptable and encourages participation,

5.1.3 promote equity between population groups,

5.1.4 minimise risk of adverse events, maximising benefits versus harm,

[1] Investment Objectives taken from the National Bowel Screening Programme Better Business Case

5.1.5 deliver a safe, high quality programme which is consistent nationally.

6 Membership on the Group

6.1 The governance structure is shown in the Appendix.

6.2 The table below lists members of the Group, all of whom are Ministry of Health staff.

Name	Role
Astrid Koornneef	Chair (NSU Group Manager)
Jane O'Hallahan	Deputy Chair (NSU Clinical Director)
Nicki Martin	NCSP Manager
Dr Gary Fentiman	NCSP Clinical Lead (Colposcopy)
Dr Margaret Sage	NCSP Clinical Lead (Pathology)
Toby Regan	NSU IQE Manager
Peter Young	NCSP HPV Project Manager
Eddie Gray	Technology Project Manager

6.3 Membership of the Group is by invitation from the Chair. New members with particular areas of expertise may be invited to join the Group as required.

6.4 Group members may leave the Group at any time. Any member who leaves should discuss their reasons with the Chair and where possible, help arrange for a replacement member with similar skills and knowledge.

6.5 All members will commit to:

6.5.1 Full attendance.

6.5.2 Agreed work outside meetings.

6.5.3 Work collaboratively with others in the Group.

6.5.4 Work in an open and transparent manner.

6.5.5 Share specific knowledge and expertise.

6.5.6 Take into account the principles of the Treaty of Waitangi.

6.5.7 Adhere to privacy codes, confidentiality protocols and policies on media statements.

6.5.8 Secretariat for the Group will be provided by the NCSP team.

7 Role of the Chair

7.1 The role of the Chair is to run the Group and to ensure its effectiveness in all aspects of its role.

7.2 Appoint and remove members, at the sole discretion of the Chair.

7.3 Approve changes to these terms of reference.

8 Role of the Senior Responsible Owner (SRO)

8.1 The SRO does not attend the Group meetings but has overall responsibility for implementation of primary HPV screening for NCSP.

9 Roles and Responsibilities of the Group

9.1 Provide leadership to the NCSP HPV Screening, direct the implementation and technology planning and sign off on key documents pertaining to these.

9.2 Note decisions from the HPV Clinical Oversight Group (HPV COG) and refer clinical matters for consideration to HPV COG.

9.3 Note and consider advice and updates received from the:

9.3.1 Technical Reference Group;

9.3.2 National Screening Advisory Committee;

9.3.3 Interim Register Governance Group;

9.3.4 Pathway partners (Sample takers, DHBs, Māori and Pacific networks, NCC, Labs);

9.3.5 Related projects such as Raise the first invitation age to 25 years; Transition the Register services to a new provider; Extend the Cytology Lab agreements.

9.4 Review and approve the work programme, monitor progress and review/approve proposed changes to the programme of work.

9.5 Resolve issues escalated to the Group for resolution, in a timely manner to minimise impact on the programme progress.

9.6 Be responsible for timely resolution of resourcing conflicts, to ensure the Programme has adequate resource to deliver its objectives within scope, time and budget.

9.7 Ensure organisational and stakeholder impacts are taken into consideration and understood.

9.8 Ensure that proper risk assessment is performed and mitigation strategies are developed. Review programme risks and approve mitigation strategies on a monthly basis or as required.

9.9 Approve programme deliverables at the relevant milestones.

9.10 Communication and engagement with relevant stakeholder organisations.

10 Timeframes and commitment

10.1 Meetings will generally be scheduled for 60 minutes per meeting.

11 Meetings

11.1 The Group will meet every two weeks or as required during the programme.

11.2 A meeting quorum will consist of three of the members.

11.3 Those participating in the meeting via teleconference or video conference shall participate with the same rights and responsibilities as those physically present.

12 Agenda and Minutes

12.1 Minutes are the responsibility of the Secretariat.

12.2 The minutes will be permanently retained on file in a secure location within Lotus Notes. No hard copies will be maintained.

12.3 The minutes of each meeting will be submitted by the Chair to the next meeting of the Group for their certification as a correct record of the proceedings.

12.4 Agenda and papers will be distributed to members no less than one day prior to each meeting.

12.5 Minutes of meetings will be circulated to members as soon as possible and no later than three days after that meeting.

12.6 Group members may request items for inclusion on the agenda via the Secretariat.

13 Reporting and accountability

13.1 The Group is responsible to the NBSP HPV Governance Group through the Chair.

13.2 Any formal requests or concerns should be raised in the first instance with the Chair. The next point of escalation is the Senior Responsible Officer.

13.3 The Senior Responsible Officer has accountability to the Director General for programme performance and to the Minister, Treasury and GCDO for programme assurance as required for each project.

14 Confidentiality

14.1 Meetings, including agenda material and minutes, are confidential. Members must ensure that the confidentiality of Group business is maintained.

14.2 Members are free, and are expected, to express their own views within the context of meetings, or the general business of the Group. Members must publicly support a course of action decided by the Group, or if unable to do that, must not publicly comment on decisions.

15 Official Information Act Requests

15.1 All agendas, minutes, emails and other written communication are subject to release under the Official Information Act unless otherwise excluded for release under the provisions of that Act.

15.2 All requests for information related to the NCSP HPV implementation made by any person from outside of the Group should be referred to the NCSP Manager.

16 Declaration of Interest

16.1 If members believe they have a potential or actual conflict of interest on any matter before the Group, they must declare that conflict to the Group and accept the Group's decision, which may include withdrawal from that discussion or task.

17 Secretariat

17.1 Secretariat for the Group will be provided by the NCSP team.

17.2 The Chair will ensure adequate Secretariat support and such other support as may be required from time to time, for the Group to carry out their mandate efficiently and effectively.

NCSP HPV Leaders Group ToR – Approved by the group on 7 June 2018

18 Appendix – Governance Structure